

Family Caregiving, Home Medical Devices, and the Sociotechnical System:  
Bringing the Biomedical Sciences into the Bioethics Discourse

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## **Abstract**

Informal caregiving by family members has been a substantial, cost-effective resource for the medical system. More recently, complex devices have made it possible to sustain patient's lives at home in more acute situations for longer periods of time. The arguments supporting the use of home care devices have been predicated on improving patients' quality of life since patients want to live out their life in their home. Ethically, this has been advocated as a means by which medicine can support patient-autonomy. This assumes the patient had a choice in using these devices and, more broadly, that the family caregiver had any choice. Autonomy fails to distinguish that a patient's autonomous choice is based on the expectation of use and that family will provide care. I will argue that neither the care recipient nor caregiver has autonomy and that the relationship they share is far more important. This usual deference to patient-autonomy overlooks the caregiver, the true user, on whom the patient and the system is reliant. Pushing this cultural objective of sustaining autonomy are the home care technologies themselves through the force of the technological imperative. While we often conceive of technologies as neutral objects, I argue they are cultural artifacts reflecting social values and practices. These values are imbued in these technologies' development and design by biomedical scientists and engineers who create them. These same people, though, are separated from the values and needs of family caregivers, challenging the goals of home care. I will argue they should not be separated since they are not neutral but rather moral actors within the larger context of the medical sociotechnical system.

## Table of Contents

<b>Introduction</b> .....	<b>1</b>
<b>Part 1: A Review of Caregiving</b> .....	<b>8</b>
An Aging Population, A need for Family Care .....	8
Caregiving Burden.....	15
Issues with Going Home.....	18
Gender and Care Work .....	17
Shifting Cultures .....	19
<b>Part 2: Autonomy in Home Care—Feminist Bioethics and Relational Autonomy</b> .....	<b>21</b>
Autonomy in Home Care? .....	21
Technology Changes the Home .....	23
Technologic Isolation .....	25
Quality of Life and Autonomy.....	28
The Forgotten Caregiver.....	30
Autonomy Overlooks Gendered Care Work.....	34
Relationships and Relational Autonomy .....	36
Summary .....	40
<b>Part 3: Technology in Caregiving and the Sociotechnical System</b> .....	<b>45</b>
The Place of Medicine and Medical Knowledge.....	45
Medicine and the Body—Biomechanization, Routinization, and Normalization.....	48
From Technological Optimism to the Technological Imperative .....	50
Design Issues in Home Medical Devices.....	54
Caregiving and the Sociotechnical System.....	58
Caregivers: The User .....	63
The Sociotechnical System of Medicine and Gender .....	65
Cultural Shifts via the Sociotechnical System .....	69
<b>Conclusions</b> .....	<b>75</b>
<b>Works Cited</b> .....	<b>85</b>

## **Introduction**

I was in my junior year of my undergraduate biomedical engineering study. In my bioelectronics and instrumentations class we had just had an extremely interesting lecture regarding future products within cardiology, especially concerning pacemakers. Improvements in materials, battery life, drug elution, and lead flexion would all combine to bring about pacemakers that could last for many years, even over a decade supposedly, preventing heart attacks from causing a person's death during that time. As I was walking out with one of my friends, a classmate friend, we discussed the topics of the lecture. "Isn't this really awesome?" he thought. Isn't it awesome that we can design these things that can improve a person's life? Isn't our power of and with technology spectacular? This is when I stopped and asked him the question that had irked me throughout the lecture and made me feel unique among my peers,

"What about the person at the end of the line. Doesn't it matter that what we do here affects someone on the other side? I mean, the guy just told us we could potentially prevent someone's failing heart from failing for ten years. Does that person want to live that way for ten years? Does his wife want to deal with whatever else comes his way over those ten years? How many shocks will he have to endure before he decides enough is enough. Then what?"

The response I received was a blank stare. The questions I had asked did not fit neatly into formulas with specified variables. I was challenging the lack of distinction we, as engineering students, had between length of life and improvement of life. I was

acknowledging that we would not just be treating and manipulating *a* heart but *someone's* heart; someone such as my grandfather. The more I learned about biology and medicine, throughout my BME degree, the more I realized how misguided my Grandpa's surgery, precipitating his death, had been and how unfortunately lucky, in some ways, my family was that he died from that surgery. He was 88, frail, diabetic, in kidney failure, and suffering heart failure. The last two were likely exacerbated by his non-compliance with a diabetic's dietary needs.<sup>a</sup> I now realize I have no idea how his care would have been successful had he lived and returned home.

The cardiologists seemed too willing to perform open-heart surgery on him, knowing it was quite risky and the complications could be severe. As was predicted, after the surgery, his blood pressure was extremely low—so low that the fragile vessels in his feet collapsed. Though the physicians tried blood thinners and pressers to raise the pressure and force the vessels open, they could only do so much for fear of causing the surgical incisions to bleed. His feet were lost. Amputation and rehabilitation were the new plan. We knew he'd rather die than deal with that. He did a few days later.

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<sup>a</sup>To his credit, this was a Jewish man who had come to the USA in 1936 in order to escape what was coming in Eastern Europe. He had established himself from nothing, built a career and became a well-respected engineer, brought his wife over from Europe, and raised a family. Having meals with his grandchildren, including my Grandmother's old-style French baking, was one of the joys of his life. At 81 when he was diagnosed with diabetes, his attitude was: I've lived long and well, and will keep doing so as I always have.

My grandmother would have been left to care for him. He would have needed an onslaught of medications. Neither would have been able to keep track of these medications. My grandfather could not have because of his post-surgery condition. My grandmother would not have as she was suffering early stages of dementia. Was she supposed to give him his insulin injections, something she abhorred even watching? He would not be able to drive. She could not drive. Who was going to refill his prescriptions and go grocery shopping, take him to the clinic for needed check-ups, to rehabilitation appointment, and who was going to take him to the dialysis center? Perhaps to make it easier, he could have used a home hemodialysis machine. I cannot imagine my Grandmother ever using one of those competently. What issues would she, the family caregiver, have faced with such medical technology at home?

Unfortunately we did not receive any formal ethics education within my undergraduate degree in which such questions could be presented to the class at large. This seemed odd to me considering that as future biomedical engineers, no matter where we went from here whether it be medicine, graduate school, or industry, what we would do would have profound effects on medicine and the public. Biomedical engineering, much like most of medicine, has fallen into the grasp of specialization that allows us to focus only on a narrow problem description without attending to larger consequences<sup>1</sup>. Though biomedical engineering (BME) has many areas of study and concerns unique to engineering, it parallels and contributes to medicine in trying to preserve life, prevent or diminish disability, and even to reverse the aging process.

There are many kinds of devices designed by engineers and used by people in a health care context; from tubing, hearing aids, and mechanized wheelchairs to ventilators, hemodialysis machines, infusion devices, and ECMO (extracorporeal membrane oxygenation) machines. Like medicine, biomedical engineering deals with the well-being of people and their health. Unlike other branches of engineering, the stakes among BMEs often seem higher since problems involve life, death, and varying degrees of disability and incapacity. For these reasons, values are an inherent part of the profession in how it approaches life and death problems. Also like medicine, the profession is most commonly concerned with the preservation of life without regard to what kind of life it will be.

In this work, I am concerned with life-sustaining technologies, specifically, ventilators, hemodialysis machines, artificial nutrition, and cardiac devices, such as pacemakers and LVADs. Will a biomedically engineered device simply ‘save’ or ‘maintain’ a life, or will it actually improve the way in which that *particular* life is lived? Should biomedical engineers be concerned with such a question? I argue, yes. This work is an argument for expanding the social discourses between biomedical engineering and bioethics that would allow for greater ethical reflection on the use of technologies in medicine. I draw on three literatures—caregiving as impacted by technologic devices, the conceptualization of autonomy, and science and technology studies—interpreted through a feminist ethics viewpoint, to make the argument.

I begin by identifying the problem with a focus on family caregiving. My interest in caregiving stems from larger interest in end-of-life issues. Many medical drugs and devices are developed in order to extend lives. However, when that life is extended, the

person is not then placed into an isolated black box. The person is placed back in society and back into a family with care being required. The consequences of this practice have will be explored in the first part of this in a literature review. This review will focus not only on what is known regarding caregiving but also how technologies have contributed to the expansion and continuation of what appears to be a problematic system.

In the second part of this work, I shall then pursue the question which I presented to my colleague a few years ago, “Doesn’t it matter that what we do here affects someone on the other side?” I contend that it does. I start by exploring one of the main themes seen throughout the literature to support further technologic informal home care: patient autonomy. Autonomy, as I will show, is a poor ideal to achieve in home care as it acts as a reducing agent which neglects the greater needs and expectations of family caregivers. I show this by delving into the relational aspects of caregiving and show that the feminist concept of “relational autonomy” is a far more fitting ideal to support in home caregiving. Further, I argue that the idea of patient autonomy and the use of technology are interrelated. Autonomy shares concepts with the technologies which are supposed to support it. Autonomy, I argue, is a construct of a larger science and technology system which has been continuously supported by another problematic concept, the technological imperative.

In the last section, I go after the question of “doesn’t it matter” even further by looking specifically at the devices themselves which created the ability to “support patient’s autonomy” and move patients home sooner. In doing this, I explore the broader system within science and medicine which supports the continued use of technologies

despite the issues which arise from that use. I discuss the naturalization of use, the routinization, of medical devices which continues due to the technological imperative. With the technological imperative, I am focusing on a difference between ‘can’ and ‘should’ that is often overlooked. In this analysis, the technological consequences will align very well with technological determinism. This idea describes a view of technologic effects in which technology acts like its own decision maker and nearly as an autonomous entity. This is a rather strong approach to the effects of technology on society, as opposed to a social essentialism (determinism)<sup>2</sup> which states technologies’ uses are socially defined and determined as they are implemented. While neither view is completely correct, the separation between development and implementation in medical technologies and their acceptance has given medical technologies a certain degree of power.

Because of this separation, I will go further back in the system to the research, design, and engineering phase of medical devices. In doing so, I will rely heavily on the Social and Technology Studies (STS, also found as SST) literature to show that biomedical scientists and engineers, though seen as separate from medical decisions, are in fact ethical actors in medical decision making. Technologies are created with certain expectations from certain viewpoints which have certain values, such as extending life, but ignore other values, such as the social needs of family caregivers. Using feminism, within STS, I will show that such reduced paradigms are indoctrinated in the culture and learning of engineering. From this, I will show that technology carries social values, including gender concepts, which have implications in view of caregivers from the early

design phases of medical devices. This is a result of a broader dynamic of a “Sociotechnical System” which bioethics has not yet explored.

## **Part 1: A Review of Caregiving**

### *An Aging Population, A need for Family Care*

The population of the United States is growing older and is doing so more quickly. The fastest expanding segment of the U.S. population is the over 65 segment. This segment of the population grew, between 2000 and 2010, at a rate of 15.1%, faster than the United States' overall population growth rate of 9.7%<sup>3</sup>. Within the aging 65 and over segment, the rates of growth were the greatest among the age groups of 65-69, 90-94, and 85-90 at rates of 30.4%, 30.2%, and 29.8% respectively<sup>3</sup>. In 2010, the 65 and older population grew to its greatest ever proportion of the U.S. population, reaching 40.3 million persons or 13% of the population. This number is projected to increase to 18% by the year 2025<sup>4</sup>. Compared with other countries, this percentage is relatively small. For example, Japan's population is already nearly one-quarter over the age of 65 and has a life expectancy greater than the U.S. by about five years<sup>5</sup>.

Public health measures have increased average life expectancy by twenty-five years in the United States<sup>6</sup>. The increasing ability of medicine to sustain individuals using ever improving medical technologies<sup>b</sup> has contributed to an additional few years near the end of life. Medicine has focused quite effectively on extending human life via powerful

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<sup>b</sup> Technology in medicine can be generalized to mean drugs, devices, and innovative procedures. In this work I intend to focus on devices though the analysis will be applicable to the other areas.

technology<sup>2,9,10</sup>. However, this extension does not come without certain costs. In fact, the monetary costs alone for caring for an aging person for months to years using devices such as ventilators, dialyzers, and nutrition pumps are extraordinarily high<sup>7-12</sup>. Using Japan again as an example, the U.S. spends nearly \$8000 per person-year after 65, which is nearly \$5000 per person-year (after 65) more than Japan<sup>13</sup>. Due to these costs, the standard of medical care has transformed from curing to stabilizing patients<sup>7,14-18</sup> to the degree that they may be taken care of at home, passing off the costs of their care. With greater disease acuity being considered stable and the decreasing average lengths of stay<sup>5</sup>, patients are thought to be going home “quicker and sicker”<sup>14,18,19</sup>. Because the costs are still rising and technologies’ continue to improve, the meaning of ‘stable’ continuously undergoes changes<sup>20</sup> and patients can be sent home even more quickly, more sickly, and in more complex disease situations<sup>15,21,22</sup>. These patients are not left on their own. Rather, they are left in the care of informal caregivers, almost all of which are family members especially spouses and children<sup>12</sup>. These people have become a substantially vital resource of the medical system<sup>18,23-25</sup>.

Home health care has been promoted as a means to support the integral desire of aging-in-place for patients while also presenting itself as a cost-effective system of care<sup>9,15,26,27</sup>. With advances in the abilities of devices able to maintain complex older patients at home, such an ideal can be realized more readily than before<sup>28,29</sup>. This move allays much of the institutional cost of caring for patients with long-term conditions. While these cost savings are substantial, they are made possible by placing the patient in the hands of a family member<sup>30</sup>. As a result, family caregivers are a huge asset to the

medical system<sup>18,31</sup>. Nearly two-thirds of older care recipients rely on informal care alone, mainly from daughters and wives<sup>32</sup>. It was estimated in 2009 that family care work saved the medical system approximately \$450 billion in costs<sup>8</sup>, a figure which is expected to keep increasing as the population ages. Long-term care is unsustainable, and not desired, within hospitals as hospitals encounter a monetary loss when caring for these patients<sup>7</sup>.

Medicare also cannot sustainably pay for the amount of home care nursing which would otherwise be needed, creating the necessity to limit the time and type of services which may be reimbursed<sup>33,c</sup>. Though, Medicare will reimburse families for skilled nursing and necessary durable medical equipment (DME)<sup>15,33</sup>, the families are left to fill in the gaps between skilled care and general maintenance care by taking on the greatest portion of care work<sup>18,36</sup>. While support for general daily care may not be guaranteed, caregivers are assured to have the necessary device technologies to make sure patients can be cared for in the home despite the lack of nursing provided<sup>11</sup>. Families become not just passive consumers of care work, but rather, through their contributions, they unwittingly allow healthcare to maintain the standard, problematic, and accepted care

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<sup>c</sup> Medicaid is the main source of funding for long-term care services; however, this is mostly used for institutional services such as nursing homes. States are able to designate funds toward home and community care services through the Social Security Act. State spending in these areas has been increasing, but spending per individual, with inflation, decreased and access is highly varied across states<sup>34</sup>. Medicaid funds are spread across low-income, children, and disabled and elderly citizens. This limits the funds available to increased home care without further replacement of institutional care. Expanding the long-term care services of Medicare, especially for DME, may have also allowed states to shift the responsibility for some services away from Medicaid as a cost savings measure<sup>35</sup>.

infrastructure<sup>36</sup>. Life-sustaining devices have become a new part of this infrastructure. Medically-complex elderly patients can be sustained in the home in ever expanding numbers with the advancing abilities and increased availability of home medical devices<sup>11,15,27</sup>. Much like the counterparts seen in children<sup>37,38</sup>, complex and technology dependent elderly patients have lost most to all of the function of one or multiple organ systems which requires equipment, such as mechanical ventilators, hemodialysis, and enteral food pumps to sustain their lives. Also required is ongoing care<sup>16,27,28</sup> for months to years<sup>23,39-41</sup> on top of complex medication regimens<sup>14,42,43</sup>. Such technology based caregiving adds new demands and dimensions to the nature of home care.

Though patient's and caregivers are able to stay in their home, they do so with diminishing professional support<sup>44</sup>. The U.S. increased spending on healthcare from 13.7% to 18.1% of GDP between 2000 and 2011, but the percentage of these expenditures on long-term nursing care, which includes long-term home nursing care<sup>45</sup>, decreased from 6.3% to 5.6%<sup>5,d</sup>. Compare again to Japan, whose healthcare expenditures increased from 7.6% to 9.5% of GDP and the percentage of healthcare spent on long-term nursing care *increased* from 6.4% to 9.0%<sup>5</sup>. Cost incentives via Medicare policy and the

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<sup>d</sup> Long-term nursing care is OECD health care outcome HC.3. Long-term home nursing care is included in this as HC.3.3<sup>45</sup>. Unfortunately, this separate data is not available for the U.S. and represents only 0.5% of healthcare spending for Japan. Both Japan and the U.S. increased healthcare spending on curative and rehabilitative home care services, from 2.0-2.4% and 2.4-2.7%, respectively. Also of note is that Japan, relative to the U.S., spends over twice as much of their healthcare resources, 39% versus 18.5%, on inpatient, long-term care (HC.3.1)<sup>5</sup>.

prospective payment system (PPS) have also led to decreased financing of home health nursing or physician services while the need for their services rises<sup>46</sup>. Furthermore, limitations in access to professional care and the expectations of family involvement lead to direct and indirect devolvement of the costs, as well as non-monetary responsibilities, to caring for elderly and declining patients<sup>21</sup>. Family caregiving, rather, is accepted as an essential—a family required—element of the health system<sup>21,24,47</sup> nearly forcing people into the role<sup>48</sup>.

### *Caregiving Burden*

The demands of caregiving for complex patients require caregivers to take on numerous tasks. Caregivers perform a substantial amount of “invisible work”—work which is not included in studies tracking caregiving hours per week—such as anticipation, prevention, and supervision of the care recipients needs<sup>23,42</sup>. On top of these tasks, caregivers also must learn about the care recipient’s illness(es) and the medication regimens which are required<sup>14,27</sup>. They must learn to manage the patient’s illness, including the management and proper care of the devices the patient uses<sup>30,49</sup>. They must act as a support or management system for the patient in order to sustain them emotionally<sup>44</sup>, financially<sup>30</sup>, and professionally via communication with nurses and physicians<sup>21</sup>. To do this can require care givers to take on new and unfamiliar family roles<sup>17,19,48</sup>. Caregivers must also handle the care receivers daily needs such as bathing, dressing, and using the restroom<sup>27,42</sup>. Caregivers take on a considerable number of roles and demands<sup>14,44</sup> in a complex environment for which they often are not prepared<sup>16,48,50</sup>.

Yet, they are expected to act nearly at the level of a professional clinician<sup>22,44</sup> and provide care for “things that make nursing students tremble”<sup>51</sup>. With the systems needs to discharge patients quickly, support and time for education of caregivers can be lacking<sup>10,42,50</sup>. Caregivers describe feeling poorly educated for their role, poorly informed to the demands, and poorly supported in the care<sup>21,25,27,50,52</sup>. Some feel unrecognized and unappreciated in their caregiving role<sup>43,53</sup>.

Family caregivers have a number of reasons to do this care work. Many are the same as described earlier since these caregivers are generally spouses who want the patient to be at home and also desire themselves to stay at home<sup>22</sup>. They carry on this work for reasons such as familial obligation<sup>21,54</sup>, love, and companionship<sup>22,23,36</sup>. Many also find this work to be fulfilling and rewarding<sup>23,52,55</sup> and can even contribute to bringing their relationship with the care receiver closer than it previously was<sup>56</sup>. However, the work of giving care places many burdens on caregivers. Numerous studies have shown that caregivers are under large amounts of stress<sup>16,43,57</sup> and fatigue<sup>43,55,58</sup> which can contribute to the findings that caregivers are often suffering from greater amounts of many mental health issues such as depression<sup>59,60</sup>, anxiety<sup>61</sup>, chronic stress syndrome<sup>62</sup>, and generally being overwhelmed<sup>48,53,54</sup>. Further, it has been shown that caregiving can result in a greater risk of mortality among caregivers<sup>63</sup>. Increased caregiver burdens can also negatively impact the outcomes of those receiving care<sup>16,60</sup>. Many of these burdens are lessened when the patient is able to take part in their caregiving<sup>64</sup> however, this is not typically the case with complex patients<sup>30</sup>. These burdens also compound over time<sup>53</sup> and increase in intensity<sup>39</sup> especially as patients

decline at home. Beyond these issues, many caregivers for the elderly, such as spouses, are older themselves and have their own chronic conditions which may be aggravated, and which they often ignore, because of their caregiving demands<sup>23,43,52,55</sup>.

Family caregivers can receive respite care services in which family caregivers are given a break from their work while someone else, such as a nurse aide, takes over for a short period. Many family caregivers do not use respite care services though because they cannot easily navigate the health system<sup>21,36,65</sup> or because they do not feel comfortable leaving the patient in someone else's care<sup>36,66</sup>. Many caregivers refuse to use respite services until they reach their breaking point because they feel they are otherwise admitting to failure of their obligations<sup>21</sup>. Family caregivers may also receive professional care services from nurses or home-care aides, though this is only covered in Medicare for certain amounts of time during certain points of the day<sup>33</sup>. Medicare reimburses for intermittent "skilled care" for sixty days after a hospitalization with the requirement that one is home-bound<sup>33,67</sup>. This allocation of services is also predicated on an initial acute event and hospitalization leading to the need for home care services<sup>33,68</sup>.

Many times, paid care is abandoned due to the constant turnover of workers which places even more stress on the family caregiver<sup>21,36,69</sup>. Formal care service, in the form of home nurse aides, has the highest turnover rate of any service industry<sup>18</sup>.

To replace this, some families will turn to private services<sup>e</sup>. As Medicare beneficiaries, these patients and caregivers are fixed income, and often low income, households<sup>27</sup>. As such, when Medicare coverage of home care services does not cover their needs, expires, or if supplemental help is required, many of these families do not have the necessary means to cover more expensive private formal care services<sup>f</sup>. Such expenses create huge inequity in access to care services for the elderly, depending on their resources. This leaves many to most families taking on the brunt of all the care work<sup>24</sup>.

### *Issues with Going Home*

Beyond physiological burdens on the family, the work demands described place social strains on family caregivers. Caregivers who are still working have to reduce their hours or leave their job completely in order to maintain the caregiving duties<sup>48,58,59</sup>. The

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<sup>e</sup> Most states may allow families to be paid for their care, similar to a personal care assistant (PCA), through a consumer-directed option. Often this is in unusual cases in which a Home Care Agency is not available near-by. This option is funded through Medicaid and the rules vary by state. Some allow the payment to be directly to spouses and parents, while other states give the payment as a stipend to hire another member of the family (or any PCA) who is not legally responsible to the care recipient<sup>70</sup>.

<sup>f</sup> Families with low incomes may also receive the Supplemental Security Income (SSI) for those over 65, up to nearly \$700 per month for an individual. This, as well as spend-down rules and other Medicaid benefits, can help substantially in care for older persons<sup>71</sup>. However, the costs of complex care are substantial and can diminish the help of supplemental incomes quickly. Further, the qualifications for Medicaid and the SSI can miss large proportions of society who are not poor enough to qualify for assistance but do not have enough income for private care services to be sustainable.

losses, both to the individual and to the economy, are substantial<sup>8</sup>. This may especially be the case since women generally outlive their husbands, in which cases family caregiving for an older mother is then done by working adult children<sup>18</sup>. The loss of work adds to an even larger factor caregivers consistently admonish: isolation<sup>21,43,52</sup>. The regimens, tasks, and equipment needs of the patient and the patient's inability to leave the home isolates caregivers into the confines of their home. Caregivers must plan work, events, and activities around the needs of the care receivers<sup>48,55</sup>. Caregivers also often take on new tasks and fill multiple family roles which, in many cases, means the caregiver must leave aside their own social functions<sup>24,58,72</sup>. Nor can caregivers make many future plans because the needs of the care receiver's illness may change abruptly at any time<sup>14</sup>.

Many of these issues stem from the medical system's underpinning values. The focus of our medical system is on highly technical, skill-specific and intensive, and, unfortunately, often impersonal curing<sup>47,73</sup>. The needs of an aging society that is reliant on long-term "mundane tasks" which require nearly continuous care<sup>27</sup> challenges this focus by creating a need for both long-term physical and psychological care. Chronic conditions do not fit neatly into the established culture of standard medicine<sup>18</sup>. Many chronic conditions have no known, or at least singular, underlying cause, have no cure, are not acute and short-term, and often are the beginnings of a person's decline to death. In many ways, chronic care has become synonymous with home care. It is a direct challenge to the standard medical model as home care is not necessarily, or even predominantly, acutely medical in nature<sup>17</sup>.

The situation can leave patients in a sort of medical Limbo. Patients, though ill, are not able to accept their illness but rather are expected to assume their previous role as a participant in the family and the community<sup>19,26,52</sup>. This can put undue pressure on them leading to patients feeling as though they are a burden on their families caring for them<sup>14,49</sup> and decreasing their perceived quality-of-life<sup>16,74</sup>. The aspiration of being at home may further be lost as the home is medicalized in order to support its new function to act more as a clinic or mini-ICU, with its many availabilities, than as a home<sup>17,19,26,69,75</sup>.

Home caregiving for ventilator or nutrition dependent patients can be the most complex and taxing services delivered in the home<sup>15,30</sup> with care for LVAD patients also quite similar<sup>74</sup>. In the elderly, the complexity may be exacerbated due to the increased frailty in the condition of many of these patients which has encumbered their mobility<sup>15,76</sup>. These patients, due to illness and overall weakness, are unable to leave their homes. They and their caregivers are homebound<sup>43,48</sup>. Due to their weaknesses, these patients also have a difficult time mutually contributing to their home care<sup>54,66,76</sup>. Further, many of these patients will have varying amounts of dementia and other comorbidities<sup>25,53,55,74</sup> which may require the even more support devices and treatments<sup>15</sup>. This places great demands on their family caregivers in order to stay home.

### *Gender and Care Work*

The unbalanced allocation of the care work has been submerged under the prominence of medicine's technological capability to move patients home with increasingly fragile, though stable, conditions. Home is not only a place of security,

privacy, and familiarity but has also been established culturally as the place of women's work<sup>18,47,77</sup>. Female family caregivers are constantly found to make up the majority of caregivers, ranging from 66%<sup>12</sup> to over 80%<sup>27,36</sup> of caregivers. Most living-in-home female caregivers are spouses<sup>8,12</sup>, though adult daughters also often participate<sup>12</sup> such as in the case of caring for an older woman. Due to this differentiation in care work, the physiological, social, and financial burdens of caregiving are inequitably carried on the shoulders of women<sup>18,47</sup>. This may be expected since wives generally outlive their husbands. Countering that fact, however, is the overwhelming majority of formal care workers who are women and provide care services as nurses or, more often, as nurse aides through home healthcare services<sup>18</sup>.

Gendering of care work continues<sup>47</sup> and is established as feminine, even when males are the ones performing it. Increasingly, men are taking roles as caregivers<sup>12</sup>; however, their experience is still different. Men report spending fewer hours in care work, spend less time on activities such as bathing, toileting, and dressing but more time with aspects of care such as finances, and feel less burdened than women<sup>12</sup>. Women are supposed to be caring and nurturing in order to maintain the home. Women internalize and express socially ascribed female gender traits which align to the task of caregiving in such a way that their role in care work is unquestioned<sup>47</sup>. They fit an expected role in taking care of tasks which are supposed to be within the private sphere of the home<sup>18,56</sup>. The needs of the greater health system, the public sphere, are supported by home care and caregiving tasks. This greater interaction of public and private spheres, though, is treated as though they are completely separate from each other<sup>21,28</sup>.

## *Shifting Cultures*

Technologies have contributed in great measure to the ability to move patients from hospital to home<sup>19</sup>. Patients and their family contribute to this change in place since elderly patients, and their caregivers want to go home if at all possible<sup>22</sup>. Such a desire is predicated on the many ideas the term *home* evokes. Home may mean independence<sup>21,28,54</sup>, privacy<sup>19,21,26</sup>, affection<sup>19</sup>, freedom<sup>19</sup>, familiarity<sup>22,26,54</sup>, aging-in-place<sup>36</sup>, and intimacy<sup>26,54</sup>. Though the ability to care for patients at home via the miniaturization of many mechanical devices has many benefits it also has, as has been presented, many drawbacks. Home technological devices are a part of the overall context of the standard biomedical model which represents the U.S. medical system and ethic<sup>47,73</sup>. This model has not changed even though the place has. Decreasing the average length-of-stay (ALOS) has become a measure of good healthcare<sup>16</sup> and has been continuously decreasing over the past decade<sup>5</sup>. Decreasing the ALOS by sending patients home is desired not only as a means to cut costs<sup>16</sup> but also as a way to support patients' quality of life<sup>78</sup> and their autonomy<sup>17</sup>. It is behind this aura of autonomy in which life-sustaining technology may do more harm than good in the home environment. Autonomy decontextualizes the patient. They become any patient who rationally wants to go home and will use the technology to get there. They become separate from their home and the greater connection one has to home above it being a house. The caregiver too becomes another element of the background which autonomy removes from the patient's home

context. Rather, the patient's autonomy, and the technology making that autonomy available, takes precedence.

In this first part, I have summarized what is known regarding home caregiving. In outlining these issues, I have presented that a new contributor to this form of care is the increasing technologic abilities within medicine which has decreased ALOS and made more acute and complex conditions "stable" enough for home care. The dominant ethical theme supporting this continuous development is patient autonomy. People are supposed to be more autonomous in their home. Patient autonomy, however, provides a limited contextual view into the technology based home caregiving situation. The position of the person cared for at home becomes ambiguous. They are not in a completely medical situation requiring institutional care, as they are home, but they are not in a non-medical situation either, they are in a medicalized home. They are in a medically and mechanically supported, but very socially contextualized, situation that has no true fix or cure. The needs of the patient beyond the autonomous body-machine are forgotten. Even more importantly, the caregiver is also forgotten. He or she is left in a vulnerable situation in which they lose their autonomy as well and become a subject of technological isolation.

## **Part 2: Autonomy in Home Care—Feminist Bioethics and Relational Autonomy**

### *Autonomy in Home Care?*

Patients' dignity, privacy, and individuality, it is argued, are maintained, by moving their care to their home<sup>19</sup>. In the home setting their personal autonomy will be infringed upon far less since they are no longer under the powers of the medical institution. Patient autonomy is a crux of modern medicine and established through bioethics as a way to allocate power away from physicians and place more power within the individual. It is an idea in which patient self-governance is meant to balance out the paternalistic practices of medicine in which physicians carried all the power, practitioner autonomy, regarding medical decisions<sup>79,80</sup>. Autonomy, furthermore, is an established abstract idea which describes patients' self-determination through personal rights, individual choice, and independent decisions<sup>80</sup>. It also assumes the patient is an individual making rational, individualistic choices about his or her life in the context of moral philosophy and full knowledge<sup>79</sup>. As a result, autonomy has been heavily used to support the movement of health care into patients' homes.

Upholding patient autonomy becomes difficult due to the nature of home care practices. Supporting patient autonomy becomes especially challenging because too many "autonomies" are present at once to support. The family wants to support the autonomy of the person they remember, capable and more or less self-sufficient. The person could have a completely different version of their autonomy, of who they are and the life they want to lead. A physician, however, may want to uphold the autonomy of the

patient, but assume (perhaps wrongly) that the patient is an informed, rational, decision maker examining his or her independent choices. This patient may not be the same ideal person the family has in their mind nor that the patient has in his or her own mind. As a result of these conflicting views of the patient's autonomy, to view home care through the lens of patient autonomy is not only flawed but misleading and counter-productive. Home care is inherently not an autonomous situation but rather an arrangement which is dependent on a patient's relationship to someone else, his or her family caregiver, and their social situation as this arrangement is placed back in the community<sup>26</sup>. Returning to the home may actually interfere with the notion of improving patient autonomy<sup>18,19</sup>.

Additionally, some expectations of the medical institution may not translate to the home, either. In the hospital, an elder sick person can be just that, sick<sup>19,72</sup>. Alarms going off from devices and not being around family as often due to illness effects are part of being hospitalized with an illness. At home, the patient can be expected, and expects of themselves, to be engaged and involved in life, retaking family roles such as husband and father, even though they may be unable due to effects of their illness<sup>19,52</sup>. In other words, the person does not have the autonomy to be who they are because they are expected to or had hoped to fit the role of someone they were. Thus, in such a situation, autonomy is compromised as the dichotomy of self before and after illness confuses the appropriate role and actions for the patient. Therefore, autonomy, even diminished autonomy<sup>80</sup>, is far too simplistic in its view to account for the diversity of "autonomies" it is trying to represent. Nor can it, being patient centered, account for the changing demands on the family caregiver.

Autonomy acts as a reducing agent, able to reduce out the context in which the individual person is placed<sup>79</sup> and avoids incorporating the intricacies of caring family relationships<sup>24</sup>. Autonomy is a poor ideal to uphold in home care. It makes generally false assumptions. It presumes the patient is an ideally situated, healthy, able, independent, and knowledgeable patient. Home care patients are in non-ideal situations, are progressively and chronically ill, disabled to some degree, by definition are dependent, and are often uninformed. The standardizing structure inherent to autonomy creates many issues such as caregiver's work burden and isolation. Without accounting for the broader aspects within home care, home care can have quite the opposite effect of upholding a patient's sovereignty.

### *Technology Changes the Home*

Those requiring home technologies, as well as bodily care requirements, usually require facilities with higher-levels of care than are generally available, making it, ironically, difficult to go anywhere but the home<sup>81</sup>. Thus, technology is added to the already complicated home care environment. The home and private life, and the individualism attached to both, are changed in many unanticipated ways. The machine becomes a part of who the patient is, creating a new norm and relationship for the family's life at home<sup>28</sup>. Changes made to medicalize the home make it at once both a place of safety and of vulnerability<sup>21</sup>. It is a place of familiarity and privacy but also now a place of strangeness and medical and technological intrusion. Things that were enjoyable before, such as going out together, being with friends, eating together, and sex

become hardships and battles<sup>69</sup>. Caregivers and patients may not comprehend that in order to gain life at home they abandon the life, the selves, they knew<sup>29</sup>.

Because of these hardships, home health devices can have an especially poignant effect on crippling patient autonomy. Technology does not erase the disease, but rather, brings attention to itself and its necessity and actually reinforces the disease's presence<sup>82</sup>. Mechanical ventilators, both invasive and noninvasive, distort the patient's image of his or herself<sup>28</sup>. A tracheostomy is a constant reminder of reliance the patient has on something beyond themselves. Masks for noninvasive ventilators leave patients feeling estranged in their home environment having their face and expression constantly covered and words distorted<sup>29</sup>. Patients using home ventilators, dialyzers, and enteral tube feeding are unable to act as the autonomous person they want to be as the tubes get in the way of activities, require adherences beyond their control, and the machine keeps control of their daily routine and activities<sup>83</sup>. Home enteral or parental tube feeding devices are perhaps the most harmful to a patient's self-image. These devices completely alter the home's cultural environment in a specific manner. The cultural attachment given to family meals is destroyed as the person is unable to fully participate in this familial gathering and eating is reduced to simply basic nourishment<sup>48</sup>. The patient at home using home total parental nutrition (TPN) or a home enteral nutrition (HEN) device loses an important interaction of their daily life. They lose the cultural comfort and intimacy of sharing the meal and sharing this time with their family<sup>48</sup>. Another aspect of their life becomes completely medical and technological.

Though the person is alive and in the privacy of their home, essentially autonomous by many definitions, they have lost part of what makes them that person; the complete opposite of the intent of going home. They lose their ability to have a social and active life<sup>50</sup>. For many, the loss of control of their life is the most emotionally damaging aspect of home care<sup>16</sup>. With hopes of privacy, choice, and individuality, home is tied to a patient's sense of autonomy and is conceived as congruent with patient autonomy. Life-sustaining technologies change and medicalize the home, changing what the home used to be. Going home means dependency on technology and, via that technological home, the autonomy of the patient and that of the caregiver are dependent on the technology that makes "home" possible. What it means to be home and what it means to be autonomous completely changes. The devices are, as one patient stated, "keeping me alive, but I'm not living"<sup>82</sup>. Their autonomy is lost.

### *Technologic Isolation*

With the inclusion of medical devices, caregiver autonomy is also impacted as they are given advanced technical roles. They must expand their knowledge to include the proper functioning of devices, how to use them properly, how to clean and sterilize them well, and how to avoid errors which set off alarms. In some cases they must make the patient, their family member, uncomfortable in order to properly use the equipment<sup>82</sup>. These devices require monitoring and adjustment such that they produce the best outcome for the patient, tasks which have usually been the responsibility of nurses and physicians<sup>29,81</sup>. By making these devices amenable to use in the home, costs are cut by

removing the human capital needed to monitor the equipment since the caregivers are allocated these tasks instead. Home care devices, however, were designed after their institutional counterparts<sup>29</sup>. They were not originally designed for home use, which has led to operating issues that create more burdens for caregivers. The demands of these are high and technological isolation of caregivers leaves them with burdens to bear financially, temporally, socially, and personally.

Caregivers are further obstructed from usual interactions with the loss of their social sphere<sup>82</sup>. They are unable to go out often, other than to get supplies or go to the grocery store, because the needs of their technologically supported care receivers are high and constant<sup>52,72</sup>. They must plan for regimens of oxygen, dialysis, and tube feeding, on top of a common issue of incontinence<sup>48,69,83</sup>. Caregivers must make care plans around social events or skip the events completely<sup>48,75</sup>. In some cases, the needs of the care receiver and the regimen required with the technology are so demanding that caregivers are not able to leave the home even for a short amount of time<sup>50,52</sup>. Even when caregivers in these situations would have guests, they must again plan activities around treatment regimens, and, especially in the case of those on enteral feeding, plan in such a fashion as not to upset their care receiver. Often, they find it easier to just not have people come into their medicalized home anymore<sup>48,52</sup>. In a certain fashion, the home becomes its own institution isolating the patient and caregiver away from the world outside their home.

Isolation is one of the greatest burdens caregivers confront. The shift home of near professional, technical, and complex caregiving work becomes not only technologic overload but also leads to “technologic isolation”<sup>22</sup>. The reliance on complex medicine

regimens and technologies, along with patients only stable enough to stay in the home, ties the caregiver to their home<sup>48,75</sup>. These family responsibilities are removed from medicine's view. They are isolated in their homes away from medicine, especially powerful actors in medicine such as physicians<sup>20</sup>. Instead, because they no longer can be rescued by medicine, the patient and the caregiver are removed from the system to which they have become an anomaly; left with only the bare essentials to sustain them at home.

Further, these families' isolation from society in general hides the full extent of these responsibilities from a greater cultural conversation regarding medical care and reform<sup>84</sup>. Family caregivers provide physical labor needed to support care recipients. They also provide direct medical care and emotional support to their care receivers<sup>30</sup>. They provide the care needed to maintain patients' lives as it is something they feel they should do and that medicine has delegated they should do. Caring is an ethical responsibility involving value judgments to promote persons' well-being<sup>85</sup>. The home devices transfer the emotional work and the ethical responsibility of patient care to family members. Families gain feelings of satisfaction in taking these responsibilities but may not be prepared for the overwhelming nature of the patients constant and complex needs<sup>48</sup>. As stated by one husband<sup>52</sup>, for example, "I promised to look after her [marriage vows] and I can't, that's breaking my heart." Without anyone to help them in this new unfamiliar situation, caregivers feel isolated and invisible at home adding to a feeling of vulnerability<sup>21</sup>.

Support for patient autonomy has promoted the use of devices such that the person's body remains functional. In the current medical environment in which medical

staff is expected to do more things in less time, devices are means by which responsibilities can be transitioned from physician to the machine supporting the body and, by extension, to the caregiver supporting that machine. The relationship to the physician or nurse is able to be severed with the care for the patient left to the capabilities of the device and the hands of patient's family<sup>81</sup>. The position of the person cared for at home becomes ambiguous. They are not in a completely medical situation requiring institutional care but they are not in a non-medical situation either<sup>17,81</sup>. They are in a medically and mechanically supported situation that has no true fix or cure. By moving their care to the home, their needs are hidden from public and political view. This extends the problem of isolation as care work staff become the families main and only social contact<sup>21</sup>. With them leaving the picture, families feel as though they have no one to talk to<sup>52</sup>. This isolation does not support the patient's individuality either as part of who they are is being among others<sup>29</sup>. In the process, the needs of the patient both medically and beyond pure medicine are forgotten and the patient's caregiver is left to handle a nearly unstable medical and social environment.

### *Quality of Life and Autonomy*

Despite the limited resources available to caregivers, studies which show improvements for patients' living situations encourage family caregiving to continue. Caregiving has been supported by numerous studies showing improved patient quality of life. But whose quality of life and what quality is being assumed? For example, physicians generally judge their patient's quality of life differently than their patients

judge their own quality of life<sup>86</sup>. Quality of life is a subjective experience. However, this measurement is used as though it is a common standard that describes a general experience defining what quality is to anyone<sup>83</sup>. One of the main ways it has been measured over time has been through the indicators of deficiencies in activities-of-daily living (ADLs), such as eating, bathing, and toileting, and instrumental activities-of-daily living (IADLs) such as financial management, laundry, and service phone calls. The IADLs are supposed to take caregiving work into account, by estimating what simpler tasks a person would be unable to do his or herself. These assessments, however, miss many of the nuances of a complex home care environment.

Much of the literature in aging and caregiving has focused on the care receiver<sup>32</sup> and ways to improve their outcomes at home. Home medical technologies are a normal way to meet and support patient's ADL needs and improve their consequent QOL outcomes. As ADLs were constructed to measure a patient's more physiologic needs, technologic support of that physiology will improve their ADL scores. However, the technologies also create numerous new tasks. Measured improvements in patient ADL/IADLs may be falsely associated with improvement in home care as these measures have not been modified to account for how much the home care environment, and the care required to maintain that environment, has dramatically changed.

An update in how these parameters are measured, which would also include many other matters such as traversing the confusing medical system, has not been adopted. It is especially needed in IADL measurements where caregiving activities are generally captured<sup>87</sup>. The technologies used in the home have made situations more stressful and

complex. Extra care, supplies, and coordination demands are created through the use of home medical technologies. The new tasks required to care for IADLs have not been incorporated in a substantive way to account for the work, competencies, and skills caregivers must learn and attain to continually fulfill body and technical demands<sup>69</sup>. They may need to do gastronomy, ventilator, or catheter care, titrate medications, dose many medications at regular and proper intervals, and continuously monitor the patient's health. Though they are used as measures of care needs, ADL/IADLs were not meant to measure caregiver demands, needs, and requirements<sup>51</sup>. The optimism surrounding the technologies' capabilities forgets that a caregiver is there to use and maintain the technology that keeps the patient home.

### *The Forgotten Caregiver*

The ADL/IADL measurements have completely and systematically disregarded the caregiver. Though the physical aspects of the patient's care may be the focus of medicine and can be met by a machine supporting the patient's lungs, kidneys, or digestion, a family member is expected to take care of many other aspects of patient care which are not necessarily or completely illness related, including social needs of the patient, especially in the case of complex elderly patients<sup>22,24,41,54,88,89</sup>. They must also take care of the patient's device maintenance, emotional state, home finances, grocery shopping, movements, and laundry. The extent of abilities and needs of *the patient* are measured using ADLs/IADLs with less regard to the person who takes care of the ADL/IADL deficiencies. These measures are extremely limited and flawed<sup>51,87</sup>.

Additionally, by focusing solely on the patient's quality of life, they further support an individualistic standard and gendered perception of patient autonomy.

The caregiver's life is governed by the needs of the patient<sup>48</sup>. The individuality of the caregiver is stripped away at the behest of the needs of the care receiver and the demands of the technology keeping him or her alive and at home<sup>55</sup>. The caregiver sacrifices his or her autonomy at the expense of the autonomy of the care recipient, a result of the limiting focus on patient autonomy. Caregivers are unable to self-govern their own lives and become so focused on the needs of the care receiver that they do not have the chance to take care of themselves and consider their own needs<sup>26</sup>. As stated in one example, "I have no time to think about myself,"<sup>43</sup> the needs of a patient at home are so high. These care needs do not end at night, which, as shown by Exley and Allen<sup>26</sup>, is especially harmful to caregivers:

"I said 'you can't [stay at home] because I can't cope with this if we're having no sleep,' I was kipping in the day and having no sleep at night because she was in pain because the pain seemed to come at night."<sup>26</sup>

Caregivers sacrifice their time and assimilate to the routines of their care recipients, in a sense, becoming confined by their caregiving role<sup>51</sup>.

The emotional work involved in caring for a loved one at home, as important, demanding, and time consuming as it is, is left out of the measurements concerned with patient deficiencies<sup>51</sup>. This area of care unique to family caregiving, due to the

relationship involved, is overlooked in place of the tangible and specific physical work tasks. Policies are usually based on ADL/IADL insufficiencies. Tasks for ADLs generally require more physical work whereas IADLs rely more on organizational and management work. In policies, ADLs are given more weight than IADLs although, due to the time and emotional demands, they have both been found to be significantly equal to constraining caregivers<sup>87</sup>. Further, the two areas are significantly correlated to each other due to the unaccounted for nuances underlying the care of requirements for persons with ADL and IADL needs<sup>51</sup>.

While caregivers gain experience and knowledge in the medical care of their care recipient, they are often viewed as a material resource of task management for formal care services<sup>21</sup>. Caregivers perceive having little power in comparison to health professionals, and will try to hide their knowledge if they feel it would upset a nurse or physician, even though they are the ones in the most contact with the patient, the most experienced in caring for the patient, and often the most knowledgeable in caring for the patient<sup>14,82</sup>. Here again, the self-determination of the caregiver is undercut by a gendered power structure and a focus on the autonomy of the patient. In order to care for the patient's autonomy the healthcare system may act in a dismissive fashion to the knowledge and abilities of the caregiver presuming professional knowledge is better for the interests of the patient<sup>75</sup>.

Caregivers, however, have unique knowledge such as an individual person's normalcies<sup>90</sup>, small physiologic changes between visits<sup>42</sup>, continuity of care<sup>42</sup>, and care management of both the patient and the team<sup>51</sup> all of which can be, and often are,

clinically relevant to the medical care of the patient<sup>42</sup>. To acknowledge this means recognizing the importance the caregiver-recipient relationship provides beyond the focus on patient-autonomy which automatically defers to medical knowledge. Service provisions based on measurements of care recipient inabilities and deficiencies assume a standard type of care need and thus a standard caregiver<sup>51</sup>. Through identifying the needs of the autonomous patient, the caregiver and their knowledge of the care recipient's needs are reduced out of the picture to a standardized constant. Caregivers lose their own individual personality.

The needs of a care recipient alone are based on limits in ADLs and IADLs. Not included in this is an assessment of the possible limitations of and need for support for the caregiver<sup>87</sup>. Even IADLs, which are supposed to account for caregiving, are focused on limitations of the individual patient which caregivers, it is assumed, will take over. Nor do these measure account for how illnesses change these needs: grocery shopping becomes supplies shopping, driving becomes appointment keeping, laundry becomes sanitation, and telephone calls become a series of time consuming hoops to clear device needs<sup>69</sup>. Overall, the requirements of the family in caring for the patient are often not included in the process of making a care plan<sup>25,74</sup>.

There isn't an informed consent process for family care givers<sup>91</sup>. Families are not necessarily well prepared, either materially or dynamically, to take on the full scope of caregiving. Few families have the requisite two people recommended for home caregiving requirements. This is especially problematic, if not outright dangerous, for moving and lifting care-recipients<sup>69,90</sup>. The infrastructure, a stable home, a willing family

member, and an amenable schedule, for the care of the complex patient is assumed. Little attention or assessment is given to the well-being and the situation of family caregivers. It is this reality—one in which the caregivers are forgotten, minimalized, and brushed aside—that results from the gendered nature of care giving and the blind focus on patient autonomy.

### *Autonomy Overlooks Gendered Care Work*

Women are expected to be keepers of the home and be home bound. It is not an unnatural idea for medicine to accept, or overlook, this aspect of the role of caregiving since it is congruent with the acculturated idea of a woman's place. The idea is so entrenched that the systematic discounting of this work goes unnoticed even as more men become involved in the work<sup>47</sup>. The home, as the socialized place of women, is placed in the context of the private sphere rather than the public sphere. As such, the work of caregiving these women and an increasing number of men do, and the caregivers themselves, is made economically, politically, and socially invisible by its absence in any cost analysis<sup>18</sup>. Caregivers provide a huge subsidy to the state. Their services as informal caregivers are not paid; however, the value of their service, the cost it would otherwise take to care for people, is taken into account in making decisions regarding medical allocations of funds<sup>18,47</sup>. As such, the value of their work is in its devaluation<sup>18,21,41</sup>.

The ADL/IADL measurements also continue to promote gendered ideas and arrangements and do not capture the full extent of care required for complex patients<sup>69</sup>. Their simplicity and quantification make caregiving appear as any other housework

chore, presenting this care as a traditional form of women's work<sup>69</sup>. Though men are more involved in caregiving in part due to sheer numbers, as noted earlier, their experience as caregivers is different from those of women. If a second person is available, women are generally more likely to handle caring for ADL deficiencies whereas men are more likely to take on IADL areas of work<sup>69</sup>. That is, women are still expected to nurture the body and men are still expected to manage a house. This is an effect of assumed and acculturated divisions of labor mirrored by autonomy as a concept based on the premise of not just any individual person but presupposes an individual person with a masculine character. The discretion given to patient autonomy and the use of technology does not account for the encroachment on the individuality of caregivers who are still overwhelmingly female and identify with culturally identified feminine traits<sup>92</sup>. The feminine characteristics of love, familial obligation, and nurturing are subliminally exploited in order to support the current status of caregiving as beneficial to the patient's autonomy yet detrimental to the patient and caregiver as a whole<sup>18,22</sup>. The relationship is further strained by its isolation to the home.

Following from the acute care ideas of doing and using technology, caregivers can receive reimbursement for medical equipment and for some skilled work from assistive caregiver services<sup>33</sup>. Medicare is set up to provide reimbursement for care up to sixty days after an acute event and hospitalization, after which point any further care must be paid for directly by the family<sup>24</sup>. If one does not have an acute event but still requires a great amount of care, one does not qualify for services<sup>18</sup>. Medicare does not reimburse for 24-hour care and overnight care is much more expensive to provide<sup>33</sup>.

These qualifications are still based in an acute-care model of medicine in which illness is short and fixable. Neither of these is true in chronic home care. Like many entrenched structures, the principle of autonomy hides the creation of privilege and oppression<sup>79</sup>. The work of caregiving, and the person doing it, is marginalized, as “women’s work” has been, so that it is inexpensive, expected, and unseen.

### *Relationships and Relational Autonomy*

Despite the challenges, families have accepted these incredible levels of responsibility. But how extensive are these responsibilities? Here, the family relationship is critical. Families provide caregiving at home despite the burdens it creates because they feel their relationship to the care receiver fosters needed stimulation and interaction that the recipient would not otherwise receive anywhere else<sup>69</sup>. Caregivers should not have to abandon themselves so extensively that their needs are only seen after they have reached a breaking point. Without focusing on the relationship, the idea of autonomy assumes a depersonalized relationship like that of patient-physician relationship. Family caregivers do not have the luxury of such distance in the relationship. Exactly this lack of distance enables family to continue in their work despite many of the issues they face. They want to create a life that is as good and as close to normal as possible for their family member since this makes them feel accomplished in putting forth their best efforts<sup>48</sup>. Their efforts are driven by trying their best to maintain the person as a person, as the person to whom they are related, not just as an element of their job. Caregivers

take the caring role not just because the person has certain deficits requiring care but because it helps maintain the overall integrity of the person.

To focus so much on patient autonomy and how home health care can support it overlooks the fact that a person using home healthcare does not have autonomy in the individual, rational sense<sup>8</sup>. The person is, by definition, dependent. They are dependent on medications, on a machine, and, most importantly, on family for caregiving. Those ill enough to require complex treatments and medical devices are generally not well enough to handle them alone<sup>87</sup>. They are reliant on various networks and relationships for care. Caregiving is a direct result of a person's dependency, their inability to govern themselves, or a loss of autonomy<sup>93</sup>. The home care arrangement is, also by definition, not based on an individual and an individual's choice but on a relationship and choices within that relationship. Without incorporating the inherent relational aspect of caregiving, the focus on the patient's autonomy has completely discounted the autonomy of the caregiver.

Because of this, the relational underpinning of caregiving is extremely strained in the home care setting. In the hospital, a professional relationship between patient and provider is established. Certain norms of body function and privacy invasion are accepted as part of being a sick individual. At home, such freedom in these boundaries is not as established and may damage the relationship in which certain familiar boundaries are required to be crossed<sup>19,69</sup>. Caring for an individual at home requires taking on certain

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<sup>8</sup> This could be argued for many areas of healthcare in general, as many feminist ethicists have done<sup>18,47,79</sup>.

aspects of the “body work” or the “dirty work” of caring for a leaky body, elements of care that are generally not seen or discussed<sup>21,26</sup>. Administration of medications, especially IV medications which may cause pain, also requires caregivers to surpass an unfamiliar threshold for which they are not prepared<sup>51,82</sup>. The intimacy of the relationship on which caregiving is reliant is lost as certain boundaries are broken in the name of a patient’s care requirements<sup>16,48</sup>.

The importance of relationships cannot be overlooked. Without a proper caring relationship, medical technology can endanger one’s sense of autonomy<sup>83</sup>. The person’s sense of self, their very being, becomes a product of a device. However, we define ourselves through others and through communities. Autonomy does not necessarily mean being individual and self-enclosed but includes being reliant on and related to other people who help define oneself in the world. Proper support, through dependence, helps uphold one’s independence<sup>54</sup>. Relying too optimistically on the capabilities of life-sustaining technologies leaves the patient and the caregiver feeling vulnerable, objectified, and dehumanized. Being seen by nurses and physicians is an important part for patients and caregivers in maintaining their autonomy as it makes them feel important and acknowledged as persons<sup>83</sup>.

Without this support, the relationship is strained to a degree that contempt between the caregiver and receiver can exist<sup>64</sup> and destroy the loving relationship on which the obligation of care work has been based<sup>26</sup>. The lack of support caregivers have when placed back in the community leaves them unable to focus on tending to the individual person. The duties of the caregiver move beyond the relational boundary into

areas that are part of a professional caregiver understanding. The relationship changes from wife-husband or daughter-parent to caregiver-client<sup>17,69,91</sup>. Only after the needs of the care receiver become so high that the caregiver begins to see the care receiver bodily and mechanically, rather than personally, do they, often with some strain and guilt, relinquish their caring role<sup>66</sup> as seen by Levine and Hart<sup>69</sup>:

“After twenty-two years of marriage, the marriage as I had known it ceased to exist. We became parent and child...After four years of coping alone I placed my husband in a facility where he has been since...This is a devastating experience.”<sup>69</sup>

The caregiving duties, the lack of support, and a reliance on technology strained and changed the relationship which allowed the system to use the family for caregiving. The dimensions of caregiving became so overwhelming, in this case, that the system ultimately lost the resource on which it relied. The system is so focused on the autonomy of the patient it has forgotten that this *public* system itself is reliant on a *private* and intimate social relationship. A relationship which is required to incorporate increasingly technical, complex, and overwhelming tasks<sup>72</sup>.

Autonomy does not support caregiving. The patient’s individuality is reliant on outside social inputs from others such as physicians and especially family, as Hilde Lindemann<sup>94</sup> describes. The patient’s individuality is contingent on an expression of values that are influenced by an established relationship with another person. A more useful concept, which has guided this entire analysis, is what has been described by feminist bioethicists as “relational autonomy”<sup>79,95</sup>. Neither the caregiver or care receiver

has autonomy in the moral, masculine, individualistic, or philosophical Kantian sense. Defining a patient's autonomy becomes so problematic since a person's states are constantly shifting as technology's impact on a person's identity constantly shifts and the future continually remains uncertain.

The caregiver and care receiver have a shared autonomy due to their relationship. It is reliant on the history and experiences which make up that relationship between the care receiver and the caregiver. Such a concept relies not on notions of principles that apply to any standardized individual but rather on the lived experience of the persons involved in a caring relationship in the situation of concern. In the concept of relational autonomy, medical decisions are not made just by an isolated individual but between persons involved in relationships who have been ingrained with certain personal values as well as the influence of societal expectations<sup>47,79</sup>.

### *Summary*

Without focusing on the relationship in the middle of the entire caregiving enterprise, many artifacts of the situation are left out. Caregiving cannot simply be broken down into a cost-effective analysis of the system's monetary savings since caregiving activities are actually not accounted for in these analyses by being externalized from the system. The inclusion of such relationships, though, is even more important since the health and well-being of the care receiver is directly correlated to the health and well-being of the caregiver and the family<sup>89</sup>. Nor can a straight cost-benefit analysis be used on the caregivers.

Measurements of ADLs and IADLs are limited in that they are singular in scope but actually represent a multidimensional phenomenon. While it may appear promising that caregivers take on the responsibilities willingly and may gain certain benefits from doing the work, a focus on caregivers gaining a net utility through their work is far too narrow<sup>96</sup>. It allows things to remain unchanged and for caregivers to be left in unstable home care environments. It focuses on one person, alone, without realizing the measured benefit to a caregiver is a result of a relationship and, more importantly, the continuation of that relationship; a relationship that needs, but has little, outside support.

It is the independence of the shared relationship that needs to be supported and assisted. As dependencies change, those in a caring relationship intrinsically trade support between each other and their own individualities as the social situations change. For caregivers of technologically—reliant and medically complex patients, however, the support in the relationship becomes one-sided and falls completely on the caregiver<sup>27</sup>, as seen in Bjuresäter<sup>48</sup>.

“It was me who had to keep track of most of the practical things, it became too much for him [the patient] it was the feeding formula and medicine and so much... I accepted it, because I know him so well and I know that he would not have pulled it off”<sup>48</sup>

Patient autonomy assumes there is not an overwhelming cultural pressure for a caregiver to choose otherwise, that is, to not provide care. The caregiver’s autonomy in the relationship has become irrelevant to the capacities of the technology.

The goal of medicine is, and has been, to fix and to cure<sup>47</sup>. This has been based in a model of medicine, the acute-care model, which focuses on fixing faulty parts quickly and efficiently in order to bring a patient back to health. Patients requiring home caregiving, however, will not be cured and generally will decline in health over time<sup>41</sup>. This does not fit in either the practiced or economic model of medicine in the U.S. in which reimbursements are based on skilled actions and technologies which bring about quick resolutions. This in turn results in long-term home care being extremely expensive when it is viewed within the usual scheme of acute medicine. Home medical devices have become the medical institution's escape from the time, cost, and the underpinning relationship of formally caring for those with long-term needs.

These very technologies meant to give patients more control threatens their individuality and ends up turning against their needs of more personal care. An overly optimistic reliance on the efficiencies of home care technologies to replace professional help, especially when everything says that help is needed, is damaging<sup>76</sup>. Technologies that are meant to generate greater autonomy also constrain it through behavior and action definition<sup>82</sup>. Defining what behaviors are allowed, what aspects of personality and what decisions are acceptable allows the human-technology interfaces to transform identities and disrupt what it means to be human, to be a person, in a harmful way<sup>97</sup>. What it means to be living is redefined as the machine becomes both a part of the body yet still a separate entity reminding one of dependence<sup>28,88</sup>. One cannot be autonomous without being dependent on technology.

Autonomy is built on the conceptions of rationality, reasoning, individuality, and control. Similarly, medical technology is founded on values of rationality, reasoning, individual performance, and body control. These values are infused into the technology through a social process within what is referred to in Social and Technology Studies as a sociotechnical system. This is a cultural system in which society and technology build each other through values which determine what technologies to create and how to use them.

Technologies are created through judgments by scientists and engineers who also carry and transmit, through the technologies, social values. Little consideration was given during design to how importation of medical devices into the home would affect the meaning of the social environment<sup>26</sup>. Abstraction through patient autonomy has left out other members of the healthcare process. The main focus on ethical decision-making has been narrowly placed on the physician-patient relationship and the conflict between paternalism and patient-autonomy alone. While patient autonomy can be an important factor in determining a patient's needs, it is a socially situated and defined aspect of a patient<sup>79</sup>. It is defined by technology that keeps the person alive allowing the individual, the family, and the physician to have a choice to, respectively, practice, maintain, and support the patient's autonomy. The system supports autonomous choice because technology has made that choice available. Autonomy, as I will show in the next section, is an artifact of this larger sociotechnical system.

With the deference given to personal autonomy, though, medicine acts as though it has little power<sup>98</sup>. While autonomy is meant to help balance against the paternalism of

physicians, the physicians still have the power to define what that autonomy is<sup>99</sup>. As the patient declines at home and more attention is focused to the disease and failing organs and less on the individual's life story, any autonomy they had is progressively eroded away. We have become so focused on upholding this abstract idea that every other element of concern, including the patient, has been abstracted away to the point that the patient is no longer being treated but, rather, their autonomy is. Autonomy becomes the person's estranged body that is disconnected from their self and lived context<sup>100</sup>. Thus, in order to support autonomy, the person must be rescued technologically, lest their autonomy die with them. This is part of what leads to the overwhelming power of the technological imperative.

### **Part 3: Technology in Caregiving and the Sociotechnical System**

#### *The Place of Medicine and Medical Knowledge*

In this section, I will be describing home caregiving as part of a sociotechnical system. Such a system connects technologies with the social values which created and promoted them such as hierarchies, gendered roles, and, where I will start, geography. The need to provide informal caregiving follows from the change in the place of sickness and the movement of the ill person<sup>69,77,101</sup>. Although the place of care has changed, many of the values around illness and care have not. This is not the first time the place of medical care has changed. Place is an important factor of consideration in the medical care of patients. Historically, patient care was primarily done in a person's home<sup>77,102</sup>. It is only within the past century, however, that the hospital and medicine, as we think of it, gained the cultural and authoritative standing as the place and the way to overcome illness via powerful medicines and devices<sup>47,102</sup>. The hospital soon became established as the scientific nerve center of the medical world<sup>102</sup>. Medicine was no longer to be an array of diverse trades and practices but a profession with authority led by knowledge of the natural sciences in its practice and development. Medicine was to move forward by competent individuals well versed in biology, chemistry, and physics as well as physiology, pathophysiology, and pharmaceuticals. Knowledge of these subjects would lead to not only medical physicians but medical scientists and physician-scientists<sup>103</sup>. Development of laboratories, as was dictated by the Flexner Report<sup>104</sup>, occurred in concert with this as research and technology became domains of medicine.

Place is an important aspect of developing knowledge. Scientific knowledge is created in isolated, ordered, and controlled spaces that are deemed legitimate locales of knowledge creation<sup>105</sup>. These areas of knowledge development represent places of rational thought separated from the social context in which it is embedded and which are supposedly impartial to the specific particularities of location<sup>102</sup>. Thus knowledge, and the artifacts it produces, becomes detached from the context in which they will be used as though the distinctiveness of location and person will have no impact on what is supposed to be universal knowledge and fact. Holding up this premise is the exclusiveness of places in which medical knowledge is created. These are not just any places; rather, they are legitimate places.

These locations, hospitals and laboratories, are places of knowledge production, clustered together to assemble authoritative persons such that scientific action is continuously segregated from socialization and rendered publicly invisible<sup>105</sup>. These places also legitimate the knowledge they produce because of the ability to control the variability in their specific spaces<sup>47,102,105</sup>. This knowledge is not only legitimated but is also rendered a standard that is considered universal. Rational thought, however, is always situated and affected by the place in which it is created. This contests the notion that science and its artifacts, such as medical devices, can be considered universal<sup>102</sup>. How such devices act in one location may be quite different in another environment; however, they are rendered as being the same, universal, in all places and contexts.

Thus, even when medical devices are used outside of a legitimate place—such as in home care—the perception of the device remains that of a standard piece of

equipment. Precisely because it is not a controlled context, the home has been rendered an illegitimate place of producing knowledge. Additionally, although family caregivers must gain a great amount of expertise about disease processes and technologies used for care, this is discounted knowledge<sup>23,27,44</sup>. This knowledge is deemed unworthy because standardization of medical science through the idea of universalization allows it to dominate the home.

Place is also important in shaping identities and fostering the sense of self-agency<sup>106,h</sup>. As stated in the previous section, home—as a concept—and autonomy are intimately linked. Institutions function by homogenizing people whereas individual agency is associated with homes, hence the desire of those with chronic illnesses to remain home. Complex technological medicine is able to shift home because of its perceived universality, which is gained due to the authoritative power it has because it was created in a legitimate place, making it theoretically mobile and universal. In other words, medical science and knowledge is treated as universal regardless of place<sup>105</sup>; that is, institutional practices and technologies are assumed to operate the same in all places.

Ignoring the specifics of place overlooks the immense power technical knowledge has over changing and controlling society<sup>102</sup>. The interests of particular actors, the patient and the caregiver are, however, specific to their place, namely the idea of home<sup>105</sup>. This creates a conflict between the goals of living in a home, and what that is thought to mean,

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<sup>h</sup>This concept has made it difficult to discuss separately autonomy and technological systems, which are associated with specific places. While I have separated autonomy and home technological systems into different sections, I do not see them as mutually exclusive.

and the goals of medicine. While the place in which one receives healthcare is significant, place is often ignored in health services provisions<sup>81</sup>. *Home* care, in the sense of allocation of resources, may only signify a change in place of care rather than a conceptual shift in services provided<sup>17,26</sup>. It assumes that what is manageable and, more or less, straightforward in one place of care is easily translated to a new place of care and assumes that “place” is the only changing variable. The re-domestication of medical care challenges straight-forward distinctions in medical and non-medical as numerous social aspects typically invisible in healthcare facilities are now rendered visible in the home<sup>107</sup>.

*Medicine and the Body—Biomechanization, Routinization, and Normalization*

The body has been conceptualized in the bioscientific scheme through breakdown, reduction, and separation of physical parts<sup>108</sup>. Reflecting the specialization across medicine, the body is broken down into specified, and essentially mechanical, parts<sup>109</sup>. It is described through data, providing means of standardization and control over the body<sup>110</sup>. Through the process of biomechanization medicine has been given scientific, technologic, and cultural authority over the body<sup>73,102,108</sup>. The abilities of laboratory medicine allow the body to be objectified through data and lose the sick person behind the data<sup>101</sup>.

In this model, the focus of practice has shifted to making physicians a mechanic or technician concentrated on fixing or replacing the broken part(s) without dealing with the person in a larger social context. This has implications concerning the process of dying and the proper provisions of care<sup>97</sup>. Care becomes aligned with, and reimbursable

through, technologic devices which support aspects of the body rather than care being a greater construct which recognizes more intangible personal needs. Bodily fragmentation challenges the integrity of the body both physically and psychologically. The body becomes understood as malleable and fixable machine, abstracted away from the lived context, from the person who lives in the body<sup>108</sup>. This has become part of a standard, medical routine.

Medicine is able to manage patients and caregivers, an entire section of society, by disciplining individual bodies<sup>102,111</sup> through medical technologies that dictate specific parameters requiring bodies to stay within certain generalized standards<sup>82,112</sup>. The process of keeping the body within certain parameters through treatment is the process of routinization of a treatment<sup>113</sup>. Through routinization, a standard notion of control over the body is accepted and allows complex devices to continue to be naturally accepted<sup>82</sup>. Such natural acceptance lends weight to the argument of technologic determinism, in which, technology essentially decides its own use acting as a nearly autonomous thing. Patients, and families, place hope and trust in the abilities of these technologies to extend their lives and to make their lives better<sup>110</sup>. Indeed, they have been conditioned by society to do so<sup>88</sup>. They hope the devices will make life easier and make the person as they were, “normal.”

For medicine to create a normal body the body is first viewed as not normal, incapable, or simply disabled<sup>114</sup>. The aging body is subject to a disablement process<sup>115</sup> in which interventions are used to improve the task and performance capability of a body in order to avoid the actual disability<sup>76</sup>. Organs and metabolic functions are tied to vast

arrays of numbers and images, a technologic surplus of data, which define truths of the body and bodily norms<sup>20,116</sup>. This data allows the body to be defined by risks. Even away from the institution these risks define normalized boundaries which requires constant institutional ties<sup>110</sup> and surveillance<sup>101</sup> to avoid surpassing.

Life-sustaining technologic devices are designed in legitimizing spaces according to such data sets and risk factors. This results in exclusionary social and political practices that do not consider the lived experience and the imperfect functionality of technologies<sup>82</sup>, such as the fact that tubes will become kinked and tangled when a person rolls in their sleep. The growing amount of data which is used to define a normal body shifts the responsibility of keeping the body normalized from the healthcare institution to the patient or, more correctly, the caregiver<sup>20,110</sup>. It becomes the caregiver's responsibility to keep the patient's body normal because medicine can.

### *From Technological Optimism to the Technological Imperative*

The culture of our medical system privileges life-extending technologies through a societal culture which attaches considerable value to the amount of life perceived to be remaining. Routinization allows the transition home of this medical culture. The medical institution's optimism in, and ability to, technologically support the body via complex devices and medication regimens are transitioned out of the acute-care environment and into the home<sup>81,82</sup>. This follows the goal to cure, whether possible or not, that drives many of the decisions made in medicine<sup>98</sup>. Yet, aging is not a curable condition<sup>18,89</sup>. However, medicine has come to identify the use of technology with human flourishing<sup>73</sup>. The

imperative to use technology has created the ability to sustain greater complexity of illness states in older individuals for longer lengths of time. This practice has become so unquestioned it has reached the point of being routine treatment<sup>15,84,113</sup>.

Families are expected, under immense pressures, to make difficult decisions regarding medical care of the care recipient and bear the responsibility for those decisions<sup>51</sup>. The patient's autonomy dictates making his or her own future through a supposed choice among various treatments which are supposed to improve and extend their life<sup>110</sup>. Though the use of life-sustaining technologies is presented as a choice, a choice does not really exist. The technological imperative implores patients and caregivers to choose technology over other possibilities. This imperative is set-up by other influences before the individual even is presented with a choice. Evidence-based medicine creates data and statistical proof of a device's ability. Medicare, using this evidence, expands what devices qualify for coverage. In turn, Medicare's policy influences private insurance coverage as well, leading to the newly covered device becoming a standard of care. Physicians then, through established routine, follow this standard of care. Forces beyond individual patients have made the decision<sup>106</sup>. These forces are so powerful and create such an underpinning ethical imperative<sup>20</sup> that to do otherwise becomes an incompetent choice.

Patients, or caregivers, are supposed to make competent choices in their medical care. Due to the technological imperative, the choice leans one way as the acceptance of the use of technologies is often associated with the user's competence<sup>39</sup>. Treatment becomes a given which masks the normalizing power of medicine<sup>79</sup>. Medically complex

older patients require complex, high-tech medical home care support systems in order to stay alive<sup>82</sup>. To suggest alternatives to these tools of life sustainment, especially against the patient's own expectations to have them<sup>89,110</sup>, would seem incompatible with the technological imperative's impact on modern medical practice and societal expectations regarding life sustainment<sup>106</sup>. The combination of medical, political, and societal expectations strengthens the technological imperative to the point of giving it moral significance<sup>20,113</sup>. In this way, regardless of benefit, the technical necessity becomes an ethical necessity. The abilities of technologies take away the notion of a choice of a specific treatment. Rather the underlying imperative drives the decision. The ethical responsibility and imperative to care for aging patients and extend their lives is offloaded onto family caregivers<sup>20</sup>. Society and medicine expects this of them.

This is a choice that is taken away from individuals and families by much larger cultural forces. The aging body is not able to fit to cultural norms of independence, virility, and invincibility<sup>111</sup>. It is subject to stigmatization of incapability. It is defined as ill and becomes subject to medical control<sup>47</sup>. It has become unacceptable to allow the body to age without device intervention to keep it "normal" and living<sup>89,110</sup>. The use of these technologies is driven by a desire for power and control over nature and the body<sup>73,108,117</sup>. This quest for power extends to the desire to control, or even prevent, aging—and by extension, dying<sup>73</sup>—by nearly any means necessary until no further technologies are available<sup>106</sup>. The use of technology dominates because it is usually much easier to identify what can be done over what perhaps should be done<sup>118</sup>. What *can* be done takes precedence over what *should* be done; this is the technological imperative<sup>119</sup>.

Medicine, and healthcare more generally, has become dominated by and extraordinarily reliant on science and technology<sup>73,118</sup>. Powerful motivations exist to promote the use of medical technologies. Through decisions to reimburse specific life-extending technologies, Medicare policies provide legitimization to such medical technologies. The legitimization by Medicare goes even further as its decisions influences private insurers to offer similar services, legitimizing it further. It then becomes a legitimate standard of practice. This reflects values and priorities in medicine regarding the structure of healthcare delivery which is underpinned by an ethos of optimism<sup>10,20</sup>. Through this technological optimism, all problems become manageable through technological expansion and use<sup>118</sup>. Such a mode of medicine is highly supported and, essentially, encouraged by Medicare. It supports mechanization of the body, promotes the routinization of the technologies' use, and, thus, supports the technological imperative.

Knowledge development and technological innovation have become the defining measure of medical progress<sup>47</sup>, helping underpin the technological imperative in medicine<sup>113</sup>. From this culture of ever greater scientific and technologic inquiry, medicine has surpassed much of its powerlessness over life. In establishing a “medico-technical power”<sup>98</sup> medical science has redefined many meanings around life and the end of life<sup>73</sup> with consequences that threaten the goals of home care<sup>i</sup>. Despite this potential threat, the technological imperative determines that technologies are the efficient, cost-effective

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<sup>i</sup> Which begs the question: what are the goals of home care? The answer to this has been, briefly, to support patient autonomy and quality of life. There are issues regarding this and their relation to the goals of home care. However, as I intend to focus mainly on aspects of medical devices of home care in this section, I will save that discussion for the concluding section.

answer. Though issues exist with technologic home care, the technologies were developed in legitimate places producing legitimate knowledge. This legitimate knowledge becomes legitimate medical knowledge making the medical practices legitimate. Further, the technological imperative provides this knowledge a power and momentum which is hard, if not impossible, to question.

Thus far, I have explained the significance of place in science and medicine. Place signifies not only a location but a practice of knowledge development, legitimization, and authority. Due to the lack of variability, the knowledge and technology developed from these places is assumed to be universal regardless of the social variances of a place, such as the home environment. The acceptance of this knowledge and the technologies it produces is reinforced through the technological imperative granting these technologies a great amount of deference in their development and use. But the devices themselves have many of their own issues as well, especially in the home. This has great implications for the design and the use of the home devices developed from this knowledge, as I shall now explore.

### *Design Issues in Home Medical Devices*

A significant issue among home medical devices is their user friendliness, or, by their very design, the lack of it. It was found that ICU physicians, in a test setting, faced large ease-of-use barriers in using mechanical ventilators designed for home use including evaluating settings and turning off alarms<sup>120</sup>. Alarms have been identified as one of the top medical technology hazards. Maladjustment of or desensitization to alarms,

due to numerous false alarms, are large problems in home device use. At home, these issues are enhanced especially due to extraneous household noises or caregivers diminished ability to hear<sup>121,122</sup>. The ICU physicians also inadvertently made changes to the preset settings when trying to evaluate the ventilator's current settings and parameters of the machine<sup>120</sup>. Though similar studies have not been done on other home devices, the complexity of other technology based caregiving scenarios likely may face similar user problems.

This has large implications on the expectations of family caregivers as they have little training, varying levels of technical comfort and skill, and varying levels of physical limitations, such as dexterity or ability to read a small screen; yet, they are increasingly becoming the most active users of these health technologies<sup>82</sup>. Despite serious ease of use concerns, home care devices, such as infusion therapies, dialysis, and ventilation, however, are advertised in such a way as to align with upholding patient autonomy<sup>72</sup> as expressed in the previous chapter. They are supposed to allow a person to return to “normalcy” and their home. Advertisement brochures for these same devices show pictures with clean, happy and smiling, and not ill looking persons<sup>82</sup>. They are meant to evoke ideas of ease and comfort for the patient, alone<sup>j</sup>. These devices are not well designed with a caregiving relationship in mind.

Designs focused on individual patients overlook the issue of time. Time is a major issue for caregivers. The medical institution and the domestic household run on different temporal rhythms. Devices are designed to easily be supported in a clinical time environment but become intrusive to support domestically<sup>37</sup>. Live-in caregivers, usually

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<sup>j</sup> An image search on Google will prove this point.

spouses or adult children, take on the greatest amount of care work, providing about forty hours of care work per week, if not more<sup>8,59</sup>. The burdens of this can be immense and caregiver fatigue is common<sup>23,57</sup>. This can contribute to caregivers being unable, despite their efforts, to provide adequate home care. Sleeping to recover, however, is another problem.

Most home device technologies are equipped with a multitude of alarm systems in order to make sure power is not too low, tubes are not tangled, and dosages are correct. Tubes have tendency to tangle or kink during the night as the person, naturally, rolls around. This sets off alarms which the caregiver then must lose sleep over in order to fix the issue<sup>37</sup>. Caregivers also lose sleep just due to the need to monitor patients through the night<sup>39,43</sup>. Part of this is to do their care at home as best they can. But part of this is, again, an issue of design. These medical technologies run on their own time, “technological time”<sup>37</sup> which assumes around-the-clock monitoring similar to that of an institutional setting. They are not designed to accommodate a six hour sleep cycle. The shift of complex technologies to the home shifts the time and activity organization of the family to match a clinical type routine<sup>75</sup>. Without further support, the design of the technologies restricts the caregiver’s movements in time and space, a multidimensional restriction by design.

A further stressor from these devices is that they can, and do, fail. This is not unique to medical devices, though the level of acceptance among medical devices seems strange. Among those on home ventilation, it was found that every device failed at least once<sup>123</sup>. Every single one—would you buy a car if I told you it was guaranteed to break

down, unexpectedly, within a year even if you care for it meticulously? Among those on continuous ventilation, 74% were found to have an episode of ventilator failure<sup>123</sup>. This is strange since although failure is incorporated, in any field, into the economics of designs, generally the failure rates are fractions of a percent i.e. 1 per 10,000, if not even stricter.

Unfortunately, the human body is an extremely harsh environment to expose devices to, internally or through external fluid contact. Natural immune responses, bacterial invasion, and highly repetitive use all contribute to wear, degradation, and bio-noncompatibility. For instance, mechanical overload and pathological deterioration leads to LVAD failures as well as, due to clotting complications, the increased incidence of neurologic complication<sup>74</sup>. In 2012, the FDA MAUDE database showed over 500 reports of adverse events for home mechanical ventilators, home dialysis, LVADs, and over 200 reports for home nutrition devices<sup>124</sup>. While these device failures may be moderately infrequent, and vary in severity, they are essentially guaranteed and are frightening events for caregivers<sup>74</sup>.

In fact, caregivers' anxiety is often related to the thought that the patient may suffer from a sudden acute event for which the caregiver is unprepared<sup>14</sup>. Devices present another means by which an acute event can occur through the unexpected failure of the home device. Such events can be expected to increase with the increase in home care acuity and the increased use of complex home medical equipment<sup>11</sup>. Adding to this are issues in quality control in which the settings of a device do not necessarily reflect the output of the device<sup>125</sup>. That is, the pressure or dosage settings on a device may not reflect the actual pressure or dosages delivered to the patient. Such discrepancies could

lead to decreased quality in care despite caregivers' efforts. Also these discrepancies also can cause acute events which look like an acute disease progression or complete device failure, but are rather an inherent malfunction. While such issues may be caught by nurses or physicians in round-the-clock care, these are issues caregivers may not be able to catch, or even have the knowledge to notice, as they are not as experienced in medical care.

### *Caregiving and the Sociotechnical System*

The continuation of progress regardless of the potential consequences is a creation of the technological imperative<sup>20,126</sup>. It gives technology a mandate and momentum within healthcare which is difficult to impede or stop<sup>116</sup>. Routinization creates treatment rituals which are so habituated into the medical practice that “technological consequences,” such as the need to care for a complex patient for greater lengths of time, are seen as separate from that ritual<sup>113</sup>. Rather, cultural influences on technologies are viewed separately from their initial design, creation, and use. Values such as curative rescue, rather than long term care, define device needs and designs. Biomedical science is assumed to be a disembodied field that is able to transcend disorderly societal complications<sup>102</sup>. However, science is not above culture but rather is a part of culture. The separation of these domains continues through political and economic drivers which overwhelm social, humanistic, and ethical consideration and separates those who could make more humanistic considerations regarding devices, such as engineers, away from these consequences<sup>127</sup>.

Decisions regarding device design and use are made far earlier in the medical stream, well before an autonomous individual patient or a consulting practitioner. It can be difficult to imagine an environment when these devices did not exist. Somebody had to design a ventilator to be small, quiet, portable, and yet still able to provide the proper oxygen saturation to a person at home. Somebody had to design a flexible, sterile material to be used for an ostomy for home enteral nutrition or dialysis. However, when these materials, components, and devices were and are researched, designed, and even evaluated, they are separated from their place in the social domain<sup>126</sup>. They are treated as pertaining to any (an average) patient in any (an average) environment completely out of environmental, financial, and disease context<sup>82</sup>. Designs are created on behalf of users in controlled hypothetical scenarios which cannot hope to completely represent the true home care situation<sup>72,82</sup>. They are not designed with regard to place and the greater scheme of the social dynamic.

These devices are designed from a larger social structure assuming a large family obligation. There has long been the idea that families have an obligation to care for their family members who are sick or disabled<sup>14,21,24,56,75</sup>. This in itself does not seem morally unsound. But to extend this obligation of families to take on the medical care of family members as they decline and become ever more medically complex is more troublesome. The extension of the familial obligation is created. It is made by decisions which create that patient and the possibility of the situation<sup>128-130</sup>. Without the technological ability, a choice is not available to either the patient or the caregiver. A choice is engineered from an ability through technology to allow such a decision. However, the choice is already

decided by previous forces, and the rational, autonomous patient will “choose” accordingly. The obligation to care is created as the caregiver does not have the autonomy to choose otherwise. The technological imperative becomes a moral imperative to for the caregiver to provide care.

The moral imperative is a result of the science and engineering that produced the device. Science and engineering are social practices. They are grounded in historical and geographical settings<sup>102</sup> that are tightly intertwined with social, economic, and technical aspects of the world, creating “sociotechnical systems”<sup>131</sup>. Thus, engineers and researchers are moral actors within medicine who make moral decisions that determine what type of medicine will or will not be practiced<sup>112,131</sup>. Technologic advances create certain social practices with certain expectations. Designers define the actors with these expectations. Home care devices are expected to be used at home, to be monitored constantly, and for the patient to be cared for daily. They presume a family caregiver will acquiesce to those expectations. Caregivers are defined through values regarding the use of a device in a way which assumes and predetermines their role as the users<sup>132</sup>. Users, the caregivers, are an inherent part of the device’s design.

Usually, technologies and ethical analysis of their uses are viewed from within the situation they are in rather the situation they came from. This creates a separation from the devices and their creators. Biomedical engineers and biomedical scientists should not be separated from the realities and consequences of their artifacts, since they are intimately connected<sup>127,131</sup>. The social is embedded in the technical<sup>126</sup>. Bioethics, for example, is in many ways a social reaction to and an extension of the biomedical

sciences<sup>131</sup>. It should be recognized that the decisions made by researchers and engineers build the sociotechnical systems which intertwine technologies with social practices, arrangements, and relationships<sup>97,131</sup>. The stresses caregivers face are in part due to life-extending home technologies<sup>22</sup>. Life-extending technologies allow for a person to choose to remain at home. As such, the technology creates choices which even allow for consideration of what a person would choose to do. But because the person has a choice, we need to support of their autonomy in making that choice. Autonomy becomes a moral artifact of science and engineering as choices becomes ethical choices: to treat, to live, to live in what way, or to provide care. Further, these devices biomedical engineers create make and remake “the body” in medicine: kidneys become dialysis, hearts become LVADs and pacemakers, lungs become ventilators, and guts become infusion devices. The body, through ways to mechanize and maintain it, is itself a moral artifact of choices from science and engineering<sup>129</sup>.

These far reaching effects of the upstream decisions regarding home medical device are not only pragmatic, systematic, or economic decisions. By their very nature, these decisions scientists and engineers make are inherently ethical decisions<sup>127,131</sup>. Because of the possibilities and consequences of their work, the public expects those trained in this field to be introduced to bioethics<sup>133</sup>. These aspects were incorporated into the Biomedical Engineering Society Code of Ethics for Biomedical Engineering in 2004<sup>134</sup>:

...

Biomedical Engineering Health Care Obligations

Biomedical engineers involved in health care activities shall:

1. Regard responsibility toward and rights of patients, including those of confidentiality and privacy, as their primary concern.
  2. Consider the *larger consequences* of their work in regard to cost, availability, and delivery of health care. (emphasis added)
- ...

The powerful consequences the biomedical sciences can have have been recognized throughout the construction of the distinct profession of biomedical engineering. In the development of the profession, it was seen as a need to understand and anticipate *potential* consequences of technologies<sup>127,135</sup>. Included in the recommendations of this development, such as through the Accreditation Board of Engineering and Technology, was a need to educate biomedical engineers with community concerns through a properly established education in bioethics<sup>127</sup> in order to incorporate ethical, legal, justice, and social concerns into the profession<sup>135</sup>. This was recognized as an appropriate as well as needed part of the growth of the profession since a code of ethics would follow from the Institute of Electrical and Electronics Engineers (IEEE) Code of Ethics as well as the incorporation of ideas from the Hippocratic Oath to recognize the biomedical engineer as a large part of new medical practices and thus include the biomedical engineer's responsibility to the public's health<sup>127</sup>. The benefits which initially support a device's implementation are often transformed into harms in their practical application through unconsidered and unintended consequences<sup>136</sup>. This is due to medicine being more than a technical system. Without accounting for this, biomedical engineers can be left unaware of the potential affects their knowledge may have on the health of human lives<sup>127</sup>. These limited views are taught early.

A reductionist approach is taught to student engineers, allowing one to essentially “unsee” information which is thought irrelevant, and reduce out much of the social information which is truly vital to the design and implementation of new technologies<sup>128</sup>. These factors, however, are not scientific, measurable, or material and are cast aside in considerations. This has large effects, especially for biomedical engineering and the biomedical sciences, since directly or indirectly the “material” of concern is not inert but living<sup>127</sup>. With the reductionist scheme of the biosciences focused intently on replacing worn out parts of the body, the full extent of family responsibilities in technology based caregiving is removed not only from the isolated problem statement, but the entire health care delivery system<sup>84,97</sup>. The elderly are not a highly represented group among engineers and the issues they face are not represented well. The decisions from scientists and engineers regarding the care of the elderly, however, can have significant impacts in limiting the choices available to caregivers and have the effect of making them an oppressed population<sup>79</sup>.

### *Caregivers: The User*

Life-sustaining home devices may seem to present a means by which to improve a patient’s life and well-being. However, whether or not the patient’s life is longer and improved depends greatly on the caregiver who takes on the technologic care. The ethical responsibility of continuing to use technology and care for the person requiring it is transferred out of the medical institution and into the hands of the patient and caregiver. The caregiver must provide device maintenance and input for the well-being of the

patient, even if he or she questions if it is doing any good. As these ethical decisions become removed from health care professionals, they also become removed from their responsibilities as moral agents within the caregiving relationship<sup>118</sup>. The technology, instead, becomes the means of professional care for the patient while the caregiver uses the technology to maintain the patient.

Is the home device user supposed to be a nurse, the patient, or the caregiver? The advertising for home medical devices is directed at nurses and patients while generally ignoring the role of the home caregiver<sup>82</sup>, calling into question who is supposed to be the “user”<sup>137</sup> of the home device. The advertisements do not picture family caretakers, do not picture full home environments, and do not discuss how easy or complicated they are to use. The method of achieving the goals in caring for a patient, and the goals themselves, can be very different between the family caregiver and a home care nurse<sup>66</sup>.

Caregivers are the actual end-users of this technology<sup>137</sup>. They find many complications with these devices precisely because these devices were not initially designed for caregivers in the home<sup>138</sup>. These devices add another level of complexity to home care as they were originally designed for a certain place, a hospital, with constant institutional oversight and not to be simply transferred to another place, the home, with partial uninformed observation<sup>72,139</sup>. These devices were originally designed for professional, well-trained users<sup>139</sup>. Family caregivers have to cope with not only the technology specifically but also the social implications and limitations of the technology due to this design assumption. Caregivers are not a team of nurses or physicians, are not

well trained, are not paid, and *are* on call 24/7. These are requirements the caregivers must cover due to the original place for which the device was designed.

### *The Sociotechnical System of Medicine and Gender*

. One of the values transmitted and perpetuated throughout the design process, as part of the sociotechnical system, is gendered roles<sup>k</sup>. Technologic artifacts, and the technical studies which produce them, are highly gendered<sup>130</sup>. Scientific and engineering spaces, such as laboratories and hospitals, have been consistently masculine in character<sup>102</sup>. They are linked to symbolic characteristics of masculinity giving them the status of power, control, and domination<sup>47,128</sup>. They reflect the historical gendered divisions of labor. Extending from this, technology and technical competence are also tied to the idea of masculinity<sup>129</sup>. Such ideas are inculcated into the socialization of science and engineering very early in the process through reductionism.

A double standard is created in which female caregiver's knowledge in using technical devices is not given recognition as technical competence even though men's design and use of technical devices is automatically attached to technical competence<sup>140</sup>. Women are the main users of home medical equipment both as caregivers and as care recipients. Handling complex medical devices and patients at home forces caregivers to

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<sup>k</sup> While what is written to this point, and what will immediately follow, has been supported heavily by literature, I will anecdotally acknowledge that in reading these materials I was overwhelmed with how well and accurately they described my experience in biomedical engineering education and working at 3M Corporation.

learn many new facts, techniques, and means of management of patients. They must become technically competent, at least, in order to provide care. While this knowledge is unique and likely useful in the design and improvement of home care devices, such user knowledge is not given much value or is shunned as illegitimate knowledge<sup>138</sup>. Yet, these devices, designed from an overwhelmingly male dominated field, despite the issues they create, are not seen as an issue. The device gains legitimacy through the assumed competence of engineering while the caregiver's issues are assumed to be part of their incompetence in home care.

Engineering, both in education and in the workplace, is not only overwhelmingly represented by men<sup>1</sup> but also by masculine traits<sup>128</sup>. This domain is highly privileged due to expertise of a specific knowledge base which brings with it a high degree of power and authority over both technology and who or what that technology effects<sup>131</sup>. An especially powerful driver is control over nature<sup>130</sup>. A certain pleasure is garnered from discovering and mastering parts of the natural world<sup>128,130</sup>. Let's face it, scientific medical research is really cool. Learning how these things of the body work is intensely satisfying. But, within the biomedical sciences, the desire to have control over and to master the body has no end in sight and no goal, beyond economic, to necessarily go with it. The goal becomes to create progress based on the idea of some inherent value for need of that

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<sup>1</sup> For example, the University of Minnesota's College of Science and Engineering 2012 incoming freshman class was made up of just over 28% females<sup>141</sup>. Though values for Biomedical Engineers were unavailable, in 2012 in the U.S. work force, 17.7% of Chemical Engineers and 4.5% of Mechanical Engineers were female<sup>142</sup> (the two most similar to Biomedical Engineering).

progress<sup>126</sup>. What exactly is meant by progress beyond the idea of an ability to fix anything is often my question.

Women who do enter these fields often are required to give up aspects of their feminine identity<sup>130</sup> as both men and women are pressured to “do masculinity”<sup>143</sup>. Thus the overall dominant culture of the field does not change. The technical culture of “power over” instead of “power with”<sup>143</sup> continues to instill into technology the ideas of domination and paternalism. Characteristics which may be valuable and essential to technical work in the cultures of science and engineering, such as collaboration, social interaction, and emotional recognition, are viewed as part of femininity which has been attached to powerlessness<sup>128</sup>.

Engineering, however, is defined by power, control, and mastery—not necessarily for bad reasons either. Engineers, with their knowledge and training, should have control and mastery of their study. Responsibility, though, should also be part of that power. Often those most vulnerable to healthcare technologies are those who are most powerless in its use<sup>29</sup>. The interpretive flexibility given to creators of innovations may reinforce the privilege of certain authorities, such as technological medicine, over the accounted needs of others such as family caregivers<sup>82</sup>.

Design criteria should change to go beyond the mechanical and aesthetic needs of a home medical device, but also the social needs of those who use the device including professional needs, respite care needs, and temporal needs of the household. Those who could inform these goals, caregivers, are unable to make significant contributions to the design or study of home medical devices. Their interests in a domestic environment are

far different from the interests of a designer in a laboratory or test-setting<sup>105</sup>. I do not mean scientists and engineers can or should predict the future. However, the questions I believe they should ask have not even been raised. They should have more forethought, such as possible ethical and social consequences, in order to challenge how the solution to a problem is approached. To do this may require introducing new people with different experiences to the process.

Generally those who are most affected by technologies are under-represented upstream at the design phase and over-represented downstream at implementation<sup>128,129</sup>. The impact of this is enhanced due to the sexual division of labor which has historically excluded women<sup>129,130</sup> as well as characteristics typically associated as feminine out of the realms of science and engineering<sup>143</sup>. The exclusion of women from these areas excludes them from making a significant contribution at the research and design phase of a technology<sup>130</sup>. It continues to visually support that technology and its creation is a masculine domain only requiring such input. Women's inputs are usually found further "downstream" in the process<sup>129</sup>. Women's role as caregivers, or the feminine association of caregiver such as the stay-at-home nurturer, can be reinforced from caregiver's use of home devices which are embedded with gendered values<sup>112</sup>. The separation of the public (corporate) and private (home) spheres is challenged due to this.

The engineers assume an existing support-system and infrastructure for home care devices. No dissenting voice is available to question whether it matters that what they create and design will affect a person on the other end of the line; the caregiver. It is assumed that a caregiver, a nurturer, is available, especially since caregivers generally are

not asked if they are willing to take on a caregiving role which now includes complex, technological care. This assumption greatly undervalues the technical work caregivers must perform<sup>129</sup>. Already stated, caregivers provide politically and economically invisible labor. More importantly, they are also an invisible design requirement of home medical devices that allows the devices to function. Caregivers do not only provide the medical system a labor force such that patients can be placed in homes rather than institutions. They provide the designer the needed inputs of device support, maintenance, configuration, and the feedback required without which these devices would not work. This configuration of the user has the odd effect of excluding the user<sup>137</sup>. Caregivers are so innately part of the device's requirements, their own needs are forgotten.

### *Cultural Shifts via the Sociotechnical System*

The concepts of routinization and normalization, elements which reinforce the technological imperative, have transitioned home. The idea, and the hope, that the patient body may be conditioned to normalcy via medical devices has not changed but rather has extended to new locations. The effects brought by expanding the capability of medicine to extend human life allows medicine to extend authority into new areas of life, control the body, and transform the place of illness, in this case, the home. The mechanization of the body into separate fixable entities is another aspect that also follows technological devices home. It is built into Medicare reimbursements which cover durable medical equipment, skilled nursing, and physical therapy but does not cover overnight care, other daily care needs, or caregiver's loss of work. Patients are viewed as purely a body of

fixable parts subject to medical tasks. The disease is separated from the body, and the person, and the daily work to care for the patient is omitted.

Caregivers are expected to care for that body and its medical needs, which, once the patient and the medical device have merged into one entity, includes the daily care of the device<sup>49,69</sup>. Visible work for the body, which is usually technical and traceable is given far greater privilege over not only the other task-oriented work informal caregivers must do in order to support the patient, but also the invisible work they perform, and the time they take to do it, to make theirs and others tasks easier<sup>23,42</sup>. Furthermore, family caregivers see the entire person, their integrated and lived body<sup>108</sup>, instead of seeing the patient and device as a single unit. They take on not only specific tasks but the “emotional caregiving” that comes with the relational nature of their work<sup>54</sup>. Schumacher identified this integration of knowledge regarding the person’s illness as well as aspects of the person’s identity as one of caregivers’ unique skills<sup>44</sup>. This skill and these aspects of chronic care are excluded as the technologic acute care paradigm remains focused on the skilled, body needs of the patient-device.

Reimbursements for home care perpetuate the acute model of care by favoring substitutes for acute and institutional care rather than those peculiarities which are distinct to the home<sup>17</sup>. Discharge planning is also stuck in an acute process by focusing on what can be done for a few weeks rather than for far longer periods<sup>18</sup>. The aging body is marginalized and defined through risks such that it must be intercepted by devices in the hopes of restoring some ideal, which in turn marginalizes the person further<sup>101,114</sup>. The cultural ethos of medicine that marginalizes the aging person by trying to prevent

ageing is moving into the home without a clear goal to what it is, or is not, trying to do there.

These devices were designed with the assumed user being a medically trained individual such as a nurse or physician. The need to explain the proper use, monitoring, and handling of these devices, the need to perform technical care<sup>37</sup>, in a simple manner was not assumed by designers as the user in mind was conceptualized in the medical paradigm as a person who already had this knowledge<sup>136</sup>. The movement of devices home changed these needs, even though home care became an option in part because of these very intensive devices<sup>29,72</sup>. The design regarding home medical devices did not change drastically in this shift.

Though practical and aesthetic design needs such as being smaller and maybe quieter are often met, overall it wasn't the device's design that had to change. Elements of acute medical culture came with them. Acceptance of these devices' failures parallels acute medicine in which using a treatment with the knowledge of its likely failure is considered better than doing nothing at all<sup>136</sup>. When these devices do fail, oftentimes the fault is placed not in the lack of needed oversight and support in complex home care by trained specialists such as registered nurses or physicians<sup>125</sup> but rather in improper care, improper use, damage, or tampering caused by the caregiver<sup>123</sup>. The enormous amounts of work, physically and emotionally, is not considered as part of the bioscientific basis, the legitimate knowledge, which determines the design or use of these devices<sup>84,91</sup>. The parameters evaluated in designing these devices are limited to those which have a quantitative biomedical character which can be translated to efficiency and efficacy<sup>136</sup>.

Thus, the devices and their underlying philosophies didn't have to change. The home had to change, the routine of daily life had to change, the family dynamic had to change, the social dynamic had to change, and the patient themselves even had to change.

The original movement of medicine from a person's home to the hospital was the movement of the person to a new institution. The culture of the home, what made home a home, did not come with it. Rather, the hospital is anything but a home-like environment. Presented in this section is why the movement back to the home is such a different kind of change. It represents an economic, political, and cultural shift, in not only the physical geography but the moral geography<sup>77</sup>.

Unlike the home-to-hospital shift, the present movement from hospital back to the home is not the movement of the body alone but the medical culture through the devices which have been attached to the body<sup>29,81,82</sup>. It is the change in family caregiving from a social system to a sociotechnical system. This includes, as has been presented, the mechanization and normalization of the body via routinization of devices supported by the technological imperative. The movement has come about relatively quietly due to the habituation of the continual use of technology within medicine<sup>113</sup>. The transfer of complex technology to the home via medicalization has allowed the culture of medicine to slowly diffuse into the domestic environment<sup>16</sup>. However, home medical technologies are not placed in the societal and relational contexts of aging or of home care. The result being that as the social system shifts to more of a sociotechnical system, the powers behind the technology have only considered the technical needs.

Engineers have designed devices to help this transition; however, a usual reductionist approach to the problem has left the patient and their caregivers in a flawed and marginal situation. Technologies incorporate medical values<sup>136</sup> such as normalization, control, and gendered roles. They also carry ethical values as they are intrinsically designed and evaluated through ethical values<sup>112</sup>. These devices are supposed to, are designed with the intention to, support patient autonomy and give people greater quality and control of life. Home medical devices have been designed, however, in conjunction with the previously explored limitations of patient-autonomy and have not been designed with a valued approach to family caregivers. The reliance on and the optimism in the abilities of the technology to replace other social supports for home caregivers has left caregivers in an isolated and marginalized home situation which is not healthy for them or the patient.

By insisting that bioethics travel upstream well beyond the physician-patient relationship, I acknowledge the vast door I am opening. Others in the stream—such as marketers, businessmen, politicians, etc—also have ethical responsibilities<sup>84</sup> as they too are, explicitly or implicitly, involved in major medical decisions around medical technologies and policy. This does not, however, exempt scientist and engineers from a responsibility that is broad in scope and should be accounted for in designs<sup>131</sup>. Biomedical scientists and engineers are shaped by and are shaping the sociotechnical system. The physician-patient relationship exists within this system in which decisions have been made far earlier in the process by a confluence of forces. This recognition gives scientists and engineers certain responsibilities beyond what is currently thought,

especially as the designers of the artifacts of the sociotechnical system<sup>131</sup>. I believe this is a door worth kicking open and exploring further, as encouraged by authors such as Susan Sherwin<sup>79</sup> as well as many Social Technology Studies (STS) authors. But, for the sake of focusing this document, and based on my own experience, I concentrated on the implications to scientists and engineers while indirectly acknowledging they are affected by other actors. Bioethics should pursue these areas, since bioethics is a product of this medical sociotechnical system.

## **Conclusions**

In the efforts of medicine to constantly and consistently extend life, prominent ethical issues related to the end of life and what should, or should not, be done technologically often arise. An existential crisis arises as meaning around human life is put into question. Often left behind, as Virginia Warren<sup>144</sup> identified, are housekeeping issues. The term perhaps fits better in regard to caregiving than many other medical ethics concerns. The very issues concerned with caregiving are in keeping together a house. The goal of home care comes into question. With inadequate time given to patient and family education, move to early discharge, and a lack of support services, what goal is it which is trying to be achieved? Is the goal of home care to extend one's life in the home or make their care better in the home? Somehow, these became distinct options.

In hopes to make home care better, home medical devices have become the new hope for quality. Considering long-term care services and policy concerning long term medical care are at best incoherent, medical devices have become the fall back on which to place hopes in quality and care. Technology will not necessarily make home care better, just at home. Mechanization of home systems does not necessarily make things better nor decrease the amount of work needed<sup>145</sup>. Adding life-sustaining devices to the home care repertoire, in fact, increases demands on family caregivers. This follows an overall trend toward fewer health professionals and more family care. Yet, the decades of research seem to show, this is exactly the opposite of what is needed. Without a proper support system, the optimism behind these technologies overlooks the "housekeeping issues" which creates more problems than it solves. This overwhelming evidence of

caregivers' needs has changed little in the approach within our evidence-based medical system.

Human aging and finitude are viewed as a problem for which there are many ways to respond<sup>97</sup> such as funding greater care resources. Yet the medical response has been to stop both. Through mechanical means, people become means rather ends, a means to unknown ends, as technology allows for a “perpetual becoming”<sup>101</sup>. A person's future, a drawing down of intensification, or an acceptance of finitude, all constantly shift as patients become a means by which to change their own future. This has come on policy promoting the ethics of life sustainment. These technologic means become routinized such that they become something to do and part of a ritual more than something that makes a difference. They are part of a routine and culture of doing. Policy trends have created a nexus of social expectations and obligations, beyond default technological means, for which our modern society is not prepared<sup>26</sup>. The devices' effectiveness outweighs their costs, both monetary and socially, and the ethical responsibilities that families take on remain invisible<sup>20,84</sup>. Rather, the focus of fixing and curing abandons those who are neither fixable nor curable and those who care for them. They do not fit within the incoherent system and are abandoned to their home in the hopes technology will figure it out.

Home care has become the cost-effective model to treat and maintain those with chronic conditions because it relies on cutting expenses by cutting care. Costs are limited by limiting care through who, what, and when<sup>18</sup>. In order to reduce costs, reliance on nursing homes, and reliance on government programs, more is expected of family

members, including covering the costs and management of complex care. Yet, most every study documenting the work family caregivers must do concludes that informal caregivers would be overtly better off and relieved by the inclusion of more professional, quality care especially from nurses and physicians. Technology has remained the cost-effective answer.

While medical technology has gotten better at extending the edges of life, it has not removed the needs for care and the burdens for such at those edges. Home medical devices have become medicine's escape from the time, cost, and the underpinning relationship of formally caring for those with long-term needs. Long-term care for chronic diseases does not fit into the current medical mold. The disease is not going to be fixed and, in essentially all cases, is the beginning of a slow decline toward death. Patients and family face a tension between technology that extends life and an imperative which promotes its use versus wanting to age and die without intervention<sup>84</sup>. Home was, in the past, the most common place for dying and death. Patients want to go home to be among people and away from high-tech medicine, to age at home, and die at home. Despite this, even as more Medicare patients have been found to die at home with hospice services, the number of ICU visits in the last month of life and the number of late transitions within three days of death all increased since 2000<sup>146</sup>. Home has started to become a place of isolation and mechanization of the body, cessation of aging, and avoidance of, an ironically inappropriate place for, death. These ideals have all transitioned to the home without consideration of the consequences of this shift of care and burden onto family members. Many factors have contributed to this movement and

adoption of this near standard-of-care. However, this does not mean it is not a mode of care full of ethical flaws.

Emphasis still remains on what care family caregivers can provide, rather than how can services support the care of both the patient and the caregiver. The ideology of medicine focuses on changing bodies that are dysfunctional rather than changing the structures of support or correcting a lack of them<sup>11</sup>. Through this, caregivers become another cog in the system. Study conclusions describe ways in which to assimilate them to the demands they are placed in: How can we train them to perform in their duties better? While better family training and information is needed, without a support system, it may prove fruitless. Further, this blames the caregiver. It blames them for not being knowledgeable, for not being prepared, for not having time, for not having the finances, and for not having an objective approach to their situation. The further extension of the acute care model compels us to “cure” the caregiver via training and education exercises without supporting them in their “treatment.” Rather, what is truly required is an introspective assessment of the situation that is our own creation; an assessment of what technologies we keep using and giving moral weight and support unquestionably despite the issues that result.

Caregiving is work. If medicine is going to rely on caregiving, the model around it has to change otherwise it will overburden a freely offered system to the point of not having it. High-tech home care cannot be used to substitute for ‘high touch’ care<sup>22</sup>. A means through which the issue of long-term care may be better framed is to remove it from the disease oriented medical system and rather frame it as a public health issue.

Caregiving is broad, long term, affects a large portion of the public, and, as has been documented, affects caregivers' health<sup>147</sup>. Public health measures could promote and advocate for caregivers by viewing them as a whole group rather than just a few, disparately affected individuals. This measure would also highlight the need to promote preventative health measures, such as primary preventative care and screenings, for the stressful, complex, and multifaceted environment of caregiving, especially technology based care<sup>147</sup>. Caregivers do not necessarily know how to handle this life-long situation and can lose themselves doing it. In these new locations of medicine, both patient and caregiver need to be seen as patients with different and unique needs<sup>54</sup>. In this view, medicine could and should reintroduce the idea of the house call in order to provide quality home care and avoid readmissions which are costly both to the system and to patients<sup>148</sup>. Along with Patient-Centered Medical Homes (PCMH), which promote the use of a chronic care model, though they have their own issues<sup>149</sup>, introducing house calls as a main attribute of home medical care would be greatly beneficial to the care of both patients and caregivers.

Technology presents, however, an easy out to a difficult problem—which could be a complete thesis in itself—that of the limited long-term care workforce. Many obstacles are in place which systematically limit the expansion of a high quality, long term care workforce such as limited career opportunities, lower prestige, and lower wages<sup>150</sup>. Unfortunately, this leads to inverse relationship in need. As one ages and starts to experience more chronic conditions, the patient is left with the lowest paid, trained, and least consistent workers while others are attracted away to other areas of the

healthcare system. This issue will only become worse as the number of geriatricians, and especially geriatric psychologists, per capita continues to decrease<sup>151</sup>. While the Patient Protection and Affordable Care Act (ACA) has many provisions which could help in expanding and legitimizing this area of work, this too faces many obstacles such as limited funding, current lack of preparation to meet goals, and a lack of systematic change to recognize time over procedure<sup>152</sup>. This stems from a greater issue of having no coherent policy for long term care. Despite the need to view it as a distinct sector within the healthcare system<sup>150</sup>, it is being translated as though it were simply another extension of the acute care system. Through this, the false congruity of high-tech and high-care is shifting into home care.

Home care presents a struggle between heroic and humanistic medicine<sup>89</sup>—apparently they cannot coexist. Patients are placed home in ever more volatile but “stable” states. Physicians should still be involved to ensure the care and health of these patients, especially since the health of the caregiver directly influences the quality of care to the care recipient. However, the system has made little incentive to remain involved. Just about every study concerning family caregiving, whether discussing burdens or gains of caregiving, reaches the same conclusion: families need more professional support—especially registered nurses and physicians—in their caregiving. Despite promoting an evidence-based health system, this evidence seems to have been ignored. It is of note that the overwhelming majority of studies concerning long-term care which produce this evidence which promotes the need for more hands on, humanistic practices are published in the nursing literature not the medical literature. Rather than make structural changes

and investments which might promote more professional training and support, technology has been the heroic go-to, safety net, standard of care instead. The technological imperative has moved home.

Currently, the technological imperative allows for technology to dominate society as the impetus to use the technology is extremely strong. Its use is habituated before it is even realized an issue may exist. In this way, the practice aligns very well with Technological Determinism. Few things stand in the way. Science and engineering are separated from society and construct a specific viewpoint which greatly affects that society. This limited scope does not account for the many political, behavioral, cultural, and social realities that affect interactions among patients, families, and their environment.

In order to move on the spectrum from technological determinism toward a greater and more balanced degree of social determinism, referred to as a social construction of technology (SCOT)<sup>97</sup>, social values within technology should be recognized. Technology is studied and designed through certain social values, created based on certain social assumptions, such as gender roles, and is used within a social network. Designers are one “node” of many in the sociotechnical system<sup>131</sup>. Building on this idea is to develop a technology-in-practice framework in order to incorporate a more sociologic view<sup>2</sup>. This attempts to move away from technological determinism for a more socially balanced approach to the use of technologies. A way to achieve this would be to gain the input from users, particularly lay users, and incorporate their knowledge into the design and evaluation process<sup>112</sup>. It is at that stage, before the technology becomes part of

a routine, that the most flexibility in changing a technologies end result may be found<sup>106</sup>. In this way, the culture should change to include a greater degree of responsibility, an Ethics of Responsibility, on the part of biomedical science and engineering.

Unfortunately, although it is science, even field science is not given as much credibility due to the place in which it is performed<sup>105,153</sup>. Science has become the domain of medicine. But it is nurses, again, who are in the field the most—at least right now—and do most of the study in this area. This experiential science and learning, however, is critical to the goals of improving home care and gaining user input. Patients' reflections on how they see their body and their life can add to how to best treat them in their home, especially with life-sustaining technology. Family caregivers, as a way to recognize their contributions to the system and their care knowledge, should be tapped as teachers to designers and other health professionals<sup>24</sup>. Further, it ought to be the responsibility of engineers to seek out the people and the environments in which home care devices will be used in order to gain a greater practical knowledge<sup>107</sup> of a chronic care living situation. They should spend time with those currently in a technologically complex caregiving environment to experience how devices not only help but may impede the lives of both the patient and the caregiver. This knowledge would be greatly beneficial in performing more practical and situated trial runs of these technologies. Engineers can use this knowledge and collaborate with caregivers to bridge professional and cultural boundaries in order to support a practice of technology which will better account for the place and context of home care devices.

As the pace of transferring medical technology increases, the need to refine these technologies so they do not feel intrusive is of great importance. Since they have been designed out of context, these technologies increase awareness of the incompatibility of technical, social, and natural time frames. These technologies need to be pleasing and functional in design to make them less intrusive on the person and the home life. Design criteria needs to expand, needs to be “un-black-boxed”<sup>82</sup>, beyond the reductionist approach which signifies engineering and is characterized by narrow views of complicated system. The view should be expanded to include the social impact of these technical artifacts which is actually vital to the design and implementation of these devices.

This requires a cultural shift within science and engineering itself including assumptions regarding gender. While drawing more women into these areas of research and design is not a complete fix in itself, it still may have a significant effect on the values and expectations carried in technologic artifacts<sup>130</sup>. This shift is also needed in order to recognize the great responsibility within medicine the biomedical sciences have to the world they construct which a foundation in one of its creations, bioethics, especially beyond principle ethics, could help achieve. Social factors of technology should be a major focus as well. Too great a focus on using technology over other options can impair the very capacity to be aware of an ethical dimension in that use<sup>118</sup>.

Home, as design input, needs to change from a location to a context. Home is not about a building; it’s about people. Patients want to be home because they are surrounded by family, friends, community, and familiarity—not just because it is a house. The

technologies which medicalize and deconstruct what home was, and what being home meant, destroy the very goal of going home at all. Home medical care is not just concerned with caring for the patient, taking care of the medical and technical needs, but caring about them as a person in a new stage of being which generally requires a humanistic aspect to their care.

Technology does not replace people nor does it replace care. It can enhance care if, in a currently feminized way, we nurture our technologies. The value of technology must include more than mortality outcomes and bioethics cannot just follow medicine in this way<sup>73</sup>. Bioethics needs to challenge medicine in the initial use of technologies rather than just analyze how they are used after the fact. Biomedical scientists may be useful in bridging this gap. What biomedical science can give to ethics, in terms of medical and primary design context, bioethics may return in representing the needed nonmedical contexts in which people live their lives. I am not one to argue we should not use technology to improve healthcare, especially at home. In fact, despite the criticisms, I believe technology should be used in the home. But should is far different from can. Currently, we can use life-sustaining technologies at home. However, this ‘can’ requires that we take a deeper look at what society then should do with such abilities. Without changes within the healthcare system, and greater structural changes around it, especially concerning home care and caregiving, perhaps these technologies should not be going home yet.

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