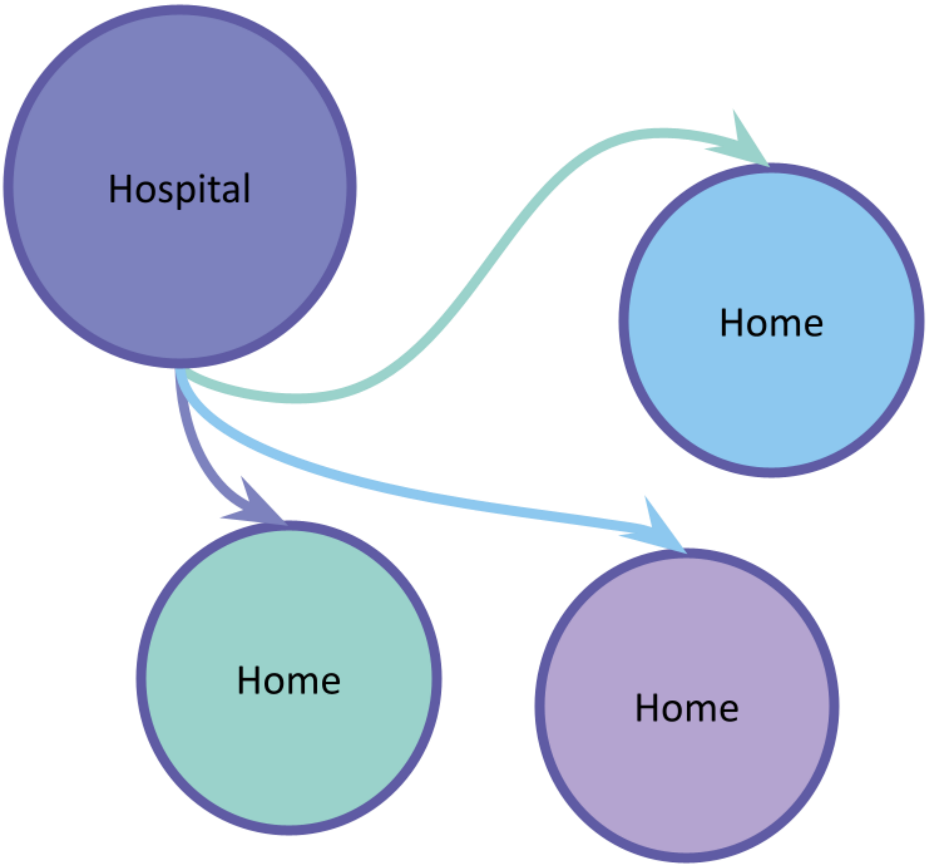
Task-shifting in Home Health Care

Multiple case study of health care tasks shifted to patients.



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Abstract

Introduction: This thesis addresses the phenomenon of task-shifting from health care professionals to patients when treatment tasks are performed in patient homes. 3 cases were selected to represent different layers of shifted tasks.

Methods and theoretical framework: The project followed a multiple case-based approach. Semi-structured interviews we conducted with health care professionals and patients in the 3 cases. The analytical framework was composed of conceptions of treatment responsibility and quality with the task-shifting phenomenon as an overarching theme. Theoretical input on homes by Winther (2006), Heidegger (1951) and Douglas (1991) were used. Care theories proposed by Mol (2008,2010) and Pols (2010,2012) concerning active, tinkering patients and the notion of care teams were applied and conceptions on scaffolding by Botin (2020) & Botin et al. (2015,2016) were utilised to conclude the insights gained.

Conclusions: The 3 cases revealed both differences and similarities in regards to treatment quality and treatment responsibility. Regardless of the types of tasks shifted, instruction played a large role in patient understandings of quality assurance processes. Patients take calculated risks as part of their daily life and health care professionals balance risks of adverse health care events with the incentives for sending patients home. A key incentive is QoL as measured or felt by healthcare professionals and patients, respectively, and a key measure assuring the quality of home health treatment is the reporting of adverse health care events. QoL is increased because of the mobility achieved by sending patients home with portable technologies.

The weight of responsibility is especially heavy when communicating with health care professionals who do not understand or attempt to comprehend the extent of a patients' specialised treatment and needs. Patients were seen to take on the role-responsibility needed to responsibly handle their home treatment, however, in situations where the responsibility is refused or deemed irresponsibly placed, the primary care sector can be engaged. Some patients expressed a sense of moral responsibility to ensure the quality of their medicine and to not waste the resources given to them.

Homes can be rebuilt to fit treatment-related items and adaptive aids, as there is some importance to the home not resembling a hospital. Rebuilding requires planning for the collective good with co-dwellers. Health care professionals, family and devices contribute in different ways as important members of the care team, and networks can be consulted to strengthen the assembly of the team.

Contents

Introduction

This thesis addresses the phenomenon of task-shifting in home health care from a techno-anthropological perspective. Within the phenomenon there are concepts describing notions of quality and responsibility, there are diseases, treatments, patients, health care professionals and much more. The thesis starts off with a walk through the problem field from where a dive into three specific home health care cases is made. It continues with a field walk among the places and spaces presented by case informants and ends in a panorama where the problem field and the field walk are intertwined.

Incentives to moving care

The boundaries between home and hospital are continuously pushed towards homecare, for which the incentives are numerous and varied. The 2021 financial agreement between The Danish Government and The Danish Regions presents a financial incentive provided that The Danish Regions meet four criteria for reducing hospital admissions and increasing the number of virtual hospital treatments (Regeringen & Danske Regioner 2020:9). This is converted into social incentives through the implemented *“Safe, Near and Easy”* strategy with the vision to improve general health in the population while also improving the feeling of comfort and trust in the quality, as well as the coherence, of treatment of Danish citizens. Moving treatment processes closer to the patient is argued to *“make life easier”* for citizens as they engage either virtually from their homes or physically at the nearest treatment centre (Danske Regioner 2018:7). Treatment coherence should prevent individual citizens from feeling like a messenger when they, as a patient, have more points of contact in the health care system. Coherence is defined as “*(...) close and binding professional-operational collaboration between the hospital, the general practitioners and the municipal primary sector”* (Danske Regioner 2018:8). Bridge-building efforts should be made among health care professionals to ensure coherence in treatment, and technological measures like apps and videoconferencing should improve availability and access for patients (Danske Regioner 2018:8f).

The quality of treatment should be consistent no matter where it is performed, and this goal is to be reached by focusing on developing the competencies of health care professionals in handling emerging technology and in shifting tasks (Danske Regioner 2018:10).

Quality of Life and treatment

Moving care from hospitals to homes has been shown to increase Quality of Life (QoL) for many patients, who, as a consequence, have the chance to regain their roles as citizens. The

World Health Organisation (WHO) defines QoL as *“individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”* (WHO 2012:11), which relates to the fact that life quality is dependent on many aspects besides health. The concept of health-related quality of life (HRQoL) emerged as a term describing the impact of disease and treatment on daily life which can be measured using a number of internationally recognised tools developed across the world (Haraldstad et al. 2019, 2646ff). The sensitivity of these tools is difficult to define as with many qualitative methods. They do, however, provide important insights into the consequences of disease and treatment and can provide a base for medical decision-making (Haraldstad et al. 2019:2642).

Adverse health care events

A tool for continuous measurement of quality in the Danish health care system is the reporting of adverse health care events, which are events that result in harm or the risk of harm to patients. The reports are used in statistics or to handle single events for the purpose of preventing repeated occurrences (Styrelsen for Patientsikkerhed n.d.; DPSD 2021). According to law, health care professionals who become or are made aware of such an event are required to report it (Sundhedsloven 2019, 61).

Nosocomial infections

An incentive that affects both QoL and regional economics is reducing the number of nosocomial infections. They are defined as an infection occurring in a patient in a hospital, or other health care facility, in whom the infection was not present or incubating at the time of admission. Studies show that many of these are preventable if hygiene recommendations are followed by both patients and health care professionals (Gubbels 2016:21f). Another preventative measure is for patients to have distance to the hospital during treatment and for patients to be in their homes in known microbial environments.

Technology in home health care

Home health care procedures are in many instances facilitated by technology. Expanding the use of telemedicine technologies allows patients to have consultations with, and be monitored by, health care professionals while remaining at home. In some instances, the monitoring is done by individual patients and the information is forwarded to the relevant health care professionals. In Denmark, telemedicine and telehealth are used as synonyms and cover both care and treatment *“(..) carried out using information and communication technologies by which the patient and the providing healthcare professional are made independent of physical* *meetings"* (Sundhedsdatastyrelsen 2015:7f). Initiatives within telemedicine include many areas such as pulmonary diseases, psychiatry, diabetes, heart disease to name a few (Telemedicinsk Videncenter 2020). The Epital Care Model and the Constant-Care concept are presented as examples hereof in the following section.

Epital Care Model

The Epital Care Model is an example of a telemedicine approach designed for patients with varying degrees of chronic obstructive pulmonary disease (COPD). The scope is to provide an all-in-one solution with round-the-clock monitoring, care and coaching tools to ease all the aspects of the chronic disease such as self-monitoring and delivery of medicine from the pharmacy. The ultimate goal is patient empowerment and to let *"(...) patients be citizens again"* by allowing them a life with as much freedom and independence as possible (Phanareth et al. 2017; Epital Health 2021).

Constant-Care in IBD

Another example is the use of the eHealth Constant-Care concept for patients with inflammatory bowel diseases (IBD). Both data on QoL and disease activity are gathered and reported by the patient, the latter requiring regular testing for inflammation markers in faeces. The data is evaluated by health care professionals, but studies show that patients could take on this task themselves and adjust their own treatment according to the data. Not only did self-monitoring and self-adjusting result in improved reported QoL, but they also reduced the number of disease relapses and, as a consequence, the number of acute and routine visits to the hospital (Hansen et al. 2020:1766f; Pedersen 2015:2,14).

The cases studied

A recurrent incentive and consequence of telemedicine and home health care approaches, in general, is the well-being of the patient measured in empowerment and autonomy. The patient becomes a member of the care team as they are increasingly involved in handling their treatment.

The cases analysed in this thesis, as presented below, move along the borders of telemedicine but have not been defined as such. The emphasis is on the technology that facilitates patients returning to their homes by simply bringing along said technology. However, no monitoring is performed or reported using telemedicine tools while patients are at home. Consultations in the analysed cases are performed while patients are physically present at the hospital and contact from home is limited to phone calls, which specifically serve to resolve doubts and questions as well as technical problems with the portable technology. I argue that there is proximity to telemedicine approaches in these cases as the processes for moving treatment and the shifted tasks resemble the examples above. The analysed cases, therefore, have the potential to be expanded with tools that fall within the definition of telemedicine.

Task-shifting in health care

When care and treatment are moved from the hospital to the homes of patients, there is not only a shift in location but a shift in tasks. Said tasks are commonly shifted to health care professionals in the primary care sector, but emerging technologies allow some tasks to be shifted to patients as well.

In an opinion published in 2019, the European Commission (EC) expanded on the simplicity of WHOs task-shifting definition as *“the rational redistribution of tasks among health workforce teams”*. An argument is that the distribution of tasks should indeed be rational and follow the competencies of the health care professionals instead of only shifting tasks downward in the hierarchy to save resources (de Maeseneer et al. 2019:14). Patient care can be enhanced if a health system places tasks in the most appropriate hands and the EC acknowledges that these hands may belong to patients or their families. The concept of the “expert patient” attests to the fact that patients develop specialised skills in handling their long-term conditions, as is often the case for patients with chronic diseases (de Maeseneer et al. 2019:4,26). Furthermore, the expert patient may contribute beyond their own care by extending their knowledge and skills in self-management to others. This could be both patients with similar conditions as well as health care professionals who develop care processes for the specific condition (Cordier 2014:854). This challenges traditional hierarchies and professional norms, where the patient-health care professional relationship is unequal. The vertical hierarchy exists among health care professional groups as well, by which, for instance, nurses traditionally answer to physicians (de Maeseneer et al. 2019:15,18). The EC encourages erosion of these hierarchies arguing that:

> *“European health systems must embrace flexibility in professional roles, including task shifting if they are to respond to changing circumstances and maximise health gains”* (de Maeseneer et al. 2019:9)

Flexibility is needed in a fast-changing world in which health care innovation is continuously reshaping care processes. Here, task-shifting can serve to strengthen “*(...) health system resilience, efficacy and effectiveness as well as patient experience and autonomy”*, by contributing to sustaining financial and social resources within the system (de Maeseneer et al. 2019:7f).

Task-shifting to patients and their families is recommended though caution is advised to balance opportunities with risks. Continuous patient involvement is key to ensure empowerment and a common understanding of goals and expectations for the care and treatment patients receive and take active part in (de Maeseneer et al. 2019:28,65).

The responsibility aspect

As the incentives for task-shifting are laid out above I argue that there are unanswered questions on the topic of responsibility. These concern the placement of responsibility for treatment and the responsibility for preserving the quality of the treatment as the treatment is moved from the hospital to patient homes.

The *“Safe, Near and Easy”* strategy addresses responsibility in the goals for increasing treatment coherence. Management systems in hospitals should assume responsibility for creating coherence through close cooperation between departments and sectors that may be part of the individual patient's treatment course. Furthermore, every patient should be allocated a physician responsible for the patient’s course of treatment when it is performed across different departments in the hospital (Danske Regioner 2018:8,11). An implemented measure in the hospitals is the “Patient-responsible physician” concept which places the overall treatment responsibility on one specialist physician, who must communicate across the departments involved in a patient’s treatment. Individual responsibility for decisions made by all physicians involved is legally binding, however, coherence and success of the treatment must be ensured by the patient-responsible physician (Danske Regioner et al. 2015:5; Danske Regioner 2017:4). The responsibility covers the transition between hospital and the primary sector as well, and pilot projects showed sufficient coordination with the general practitioner, who assumes the treatment responsibility after the patient is discharged (Danske Regioner 2017:15).

The felt responsibility

The cases studied in this thesis reveal a gap in the conceptions of responsibility. The patients perform treatment tasks in their homes as outpatients, without supervision. The treatment responsibility is placed at their respective hospital departments, but the responsibility for performing the treatment tasks correctly has shifted to the patients. I argue that there is a felt responsibility in these cases, worthy of further study.

People leave the hospital to continue treatment at home but they do not leave their roles as patients. This role requires assuming responsibility for treatment tasks that you, as a patient, was instructed in at the hospital and may be called “role responsibility” (Vincent 2011:17). Furthermore, patients may feel obligated to perform these treatment tasks correctly to ensure their quality. There is a sense of ‘moral responsibility’ to being a patient that can handle their treatment tasks with care and without wasting resources (van den Hoven et al. 2015:134).

A study of outpatient management of acute leukaemia patients revealed how patients and their families felt the shifted responsibility when transitioning from inpatient to outpatient. It was described as a struggle throughout the treatment even though the responsibility felt lighter in periods in which patients were feeling well. Assuming responsibility was a premise for having treatment at home, which weighed heavier than the felt responsibility for treatment tasks (Østergaard Jepsen et al. 2016:71f; Fridthjof 2019:41). Having patients at home proved important for the families as well, who did not question or refuse treatment tasks even when these seemed overwhelming and stressful (Østergaard Jepsen et al. 2016:72). The responsibility felt by family members surprised many despite having been informed and prepared by the health care professionals. They describe being in a state of constant hyper-awareness, which continued even if the family member and patient were apart (Jepsen et al. 2019:8)

The thesis origin story

The seed of the idea behind this thesis was planted while adding finishing touches to a precursory project as part of my Techno-Anthropological master's course work. During the project work, I dove into the lived world of people who receive treatment with temperature-sensitive biopharmaceuticals in their own home administered by themselves. The purpose seemed straightforward: to discover what complications might interfere with patients' compliance with the set transport and storage requirements of the volatile medicine and shed light on existing and potential ways to support compliant practices. However, as is often the case when collecting qualitative data, the issues and insights that come to light reveal a plethora of potential directions in which to steer the research. Some of these served to soften the cold concepts of 'transport' and 'storage' by adding personal thoughts and individual considerations. It became obvious that the informants all had become actively engaged in adopting their treatment to their particular situations, which required deliberate and, at times, subconscious tinkering. Other directions remained unexplored and turned into seeds of ideas yet to take a final form. Among these was the notion of responsibility, which became a recurrent seed, initialised by pondering organisational responsibility for treatment and, furthermore, the quality of said treatment. However, determining which profession and which governmental branch have and take responsibility for home health care practices gives little more than an organisational overview. It does not address how the weight of responsibility might be felt by those who are on the receiving end of home health care or how they interpret quality assurance, which is a natural part of health care in a hospital setting.

Purpose

My research for this thesis was inspired by a single process which I have now defined as the phenomenon of task-shifting. More specifically task-shifting from health care professionals, who traditionally handle treatment and care tasks, to patients, who are briefly trained to handle said tasks in their own homes. These task-shifting processes are made possible because of medicinal technologies which, in the 3 cases studied, are in the form of biopharmaceuticals, chemotherapy, and nutritional fluids, respectively. The first is held in simplistic syringes and pens and the last two of these are combined with more complicated infusion-pump technologies. However, both the syringe/pen and the pump are devices allowing the medicinal treatment to enter your body and home. I aim to view the socio-technical system, comprised of devices, patients and health care professionals in task-shifting processes, through a techno-anthropological lens. This means studying the potential of these processes to be robust, professional and socially responsible solutions to the societal challenges, which incentivise moving treatment from hospitals to homes (Aalborg Universitet 2020).

The purpose of studying multiple cases is not chiefly to make grounds for comparison, it is rather to gather potent insights and pool them together for a substantial understanding of the topic at hand occurring in the space between hospital and home.

Research strategy

As put forth in the section above, initial hypotheses on the subject of task-shifting originated in the analysis of previously collected qualitative data (Spradley 1979:219) and can be summed as follows:

- Task-shifting from health care professionals in the hospital to patients in their homes leaves an undefined space between the two places.

- In home health care the responsibility for individual treatment and quality-assurance measures that follow are, to an extent, shifted onto patients.

These hypotheses were derived inductively and served as the basis for a continuous shaping of the research questions in this thesis, which were further cultured as data gathered in the course of working on the thesis (Yin 2018:147).

Problem formulation

Based on the problem field portrayed in the presented phenomenon, concepts and hypotheses, the problem formulation is constructed as the following question:

How are the quality of treatment and the treatment responsibility perceived by patients and health care professionals in home health care, in cases where care and treatment tasks are shifted from health care professionals to patients?

The cases

This section serves to give a brief description of the three cases in the multiple case study. The cases which form the empirical basis for this thesis belong to the greater world of health care. This is a world which is continuously expanding its borders to include the walls of places that patients understand as home - a place where they are not necessarily patients. The topic explored is not a specific disease and the specifics of the treatment of this disease, but instead a phenomenon that allows parts of health care practices to shift place and space.

Case 1 - Biological medicine

The patients and their hospital connection

Case 1 involves many different patients who are affected by many different autoimmune diseases, such as; arthritis, psoriasis, asthma, and inflammatory bowel diseases (Marstrand Reersted 2018; Saber et al. 2009:66). What these patient groups have in common is the severity of their symptoms caused by chronic disease. The prescription of these biopharmaceuticals is not done lightly but requires a vetting process where patients, who are not deemed adequately treated, may be offered the treatment. This carefully regulated approach is the result of the high cost of the biological medicines, which are only accessible from certain hospital departments required to follow guidelines from the Danish Medicines Council (Danish Medicines Council n.d.; Sundhedsstyrelsen 2021:3). Within the rheumatological treatment field, the majority of patients are examined and treated by specialised doctors in the primary sector. However, those who are eligible for treatment with biological medicine must also pass through a rheumatological hospital department, though most often as an outpatient. Only in a worst-case scenario, such as a severe infection, would admission to a rheumatological ward be relevant (Sundhedsstyrelsen 2021:1f). In the current setup, this limits the patient-hospital interaction to consultations, check-ups and medicine collection as opposed to admission for treatment and monitoring, which was the case when biopharmaceuticals first emerged.

Since then, biological medicine has moved from drip stands by the patient beds to syringes in the hands of nurses and, ultimately, into the hands and homes of the patients themselves (Hagerup 2009; Bittner et al. 2018:436). As an outpatient, you collect the costly and volatile medicine at the hospital and transport it to your home for storage and self-injection according to the given instructions. These are provided by caring professionals, who teach patients how to handle the pen or syringe and, sometimes, nudge them to overcome the hurdle of self-administering for the first time. Having to master this task takes up much headspace for patients, who are living the reality of erratic bodies affected by irregular and perhaps worsening symptoms and side effects. The consequence is seen in how little energy is left to focus on all the other information given during this teaching session, which might be no more than 45 minutes. Because there is a lot to learn when treatment tasks are shifted and a problem is then, for the health care professionals, to emphasize how important correct transport and storage is for the quality of treatment and, ultimately, the biological function of the medicine inside patient bodies (Jacobsen 2020).

The technology and the shifted processes

The technology in this case is contained in pens and syringes that patients collect at the hospital and bring into their homes (figure 1). However, due to the volatility of the products transported, supporting solutions are needed to enable the patient to safely transport and store biopharmaceuticals at home. Supporting solutions, however, differ depending on the hospital department which prescribes the medicine. A cooling bag with cooling elements is always recommended but some patients are required to bring one, with little or no specification to the requirements which the cooling bag should meet. Other patients are handed a suitable cooling bag, chosen by the hospital, as a step in collecting the medicine (Jacobsen 2020).

Figure 1: Pen (above) and syringe (below) with biosimilar medicine (Medicin.dk, 2021)

Storage, on the other hand, does not differ significantly, as patients choose the one place which keeps the temperature at a constant cold level. However, domestic refrigerators often have poor airflow and, therefore, are not fit for temperature-sensitive biopharmaceuticals. Studies using temperature data loggers have shown that 50-83% of patients participating in the studies have stored their biological medicine at temperatures not compliant with the recommended temperature range (Vlieland et al. 2016:707; Santin et al. 2020:3).

The process that has shifted is, in this case, solely the self-administering of a biopharmaceutical contained in either a syringe or a pen. Previously, patients were required to be present at their associated hospital department just to receive a quick injection every 1-2 weeks. However, in implementing the shift, new considerations emerged concerning methods to store medicine according to the guidelines recommended by the pharmaceutical company producing the medicine (AbbVie 2020; Danish Medicines Agency 2020). Here, the most addressed issue is temperature, though mechanical mishandling, like violent shaking of the injection device, could result in similar problems, such as the denaturation of the proteins that make the biological medicine fulfil its purpose in the body. Denaturation refers to an irreversible misshaping of proteins, causing them to lose their intended function (Santin et al. 2020:2; Sridhar et al. 2018:740; Vlieland et al. 2016:705).

In summary, case 1 is a case of medicine changing hands, comparable to picking up a standard prescription at the pharmacy. No project has preceded the procedure, as was the criteria for case 2, and no prolonged hospital stay is considered necessary to learn how the processes around the tasks function.

Case 2 - Chemo To Go

This case has its origins in a project entered in an innovation competition arranged by the hospital Rigshospitalet which now houses the implemented procedure proposed in this competition in 2013. Winning the competition meant financial backing for the project, which was implemented throughout 2015-16, at all 6 departments treating leukaemia patients in Denmark (Appendix B3:30; Fridthjof 2019:6). The incentive to cut the amount of time that patients with leukaemia spend hospitalised is not new. According to Katrine, the project nurse who initiated the home chemotherapy initiative, ideas on how and when to send patients home during long periods of chemotherapy treatment have been pondered for the last 10-15 years (Appendix B3:31). At the same time as the initiative was being implemented, the design of the solution was improved through a codesign project named Chemo To Go, Please! The aim was to encase the portable treatment unit in a fashion that made it as safe, subtle and comfortable as possible, unlike the prototypes that resembled clumsy medical equipment in comparison (Justice 2016; Chemo To Go, Please! 2016).

Figure 2: The Chemo To Go, Please! design (Rigshospitalet,

The patients and their hospital connection

The chemo bag or backpack, as developed in this project, is for patients with acute myeloid leukaemia (AML). The main treatment is typically intensive chemotherapy given in 3-4 cycles within 4-6 months where one cycle lasts 5-8 days. This is followed by a period where the patient is sensitive to infection due to the immunosuppressive nature of the treatment (Fridthjof 2019:8f,28). Patients, who are deemed eligible for home treatment, spend 2-3 days admitted at the hospital ward during which a central venous catheter (CVC) as depicted in figure 4 is inserted into the body and attached to the portable, programmable infusion pump (PPP). The days admitted also serve as an instructional phase, in which information is given about the treatment, side effects, the automatic function of the pump and possible errors and the handling of these. The patient is hereafter recategorised from an inpatient to an outpatient. Previously, patients could go home between doses but had to return to the hospital for each dose. The use of PPP technology has changed this and decreased the frequency of hospital checkups from once a day to once every 3rd day, depending on the individual treatment profile (Fridthjof et al. 2018:1f,4; Appendix B3:32).

The technology and the shifted processes

The chemo-bag enables patients to continue treatment at home because of the PPP technology. The pump is pre-programmed to start and stop at specific times and to function at specific speeds according to the individual protocol established by health care professionals. Furthermore, any adverse tampering is prevented by an access code, which assures that patients are not able to change settings (Fridthjof et al. 2018:2). The task shifted to patients is, therefore, to observe and to react if they discover a discrepancy between their instructions and how the pump functions. Any critical error is announced by the pump with an unstoppable alarm thereby coercing the patient attached to react and contact the hospital (Appendix B3:37).

Figure 3: The chemo bag with the pump inside (Medicinsk Tidsskrift 2015)

Similar to the medicines in case 1, there is much to be said about chemotherapy as a biotechnology, which is beyond the scope of this thesis. Patients are, however, never required to interact with the fluids, as in case 1 and 3. They may choose to take on the task of disconnecting themselves from the pump when the treatment cycle is finished or have a family member trained to do so. This requires an understanding of hygienic handling of the CVC, which includes flushing to prevent CVC related infections. Through an initial study, it was found that 74% of AML patients managed to handle the task and successfully disconnect from the pump (Fridthjof et al. 2018:1,4).

Case 2 patients are offered the chance to shift from inpatient to outpatient care by agreeing to shift tasks onto themselves and possibly family members. Their responsibility essentially means correctly handling the bag as a complete item.

Case 3 - Home parenteral nutrition

Sending patients home with parenteral nutrition is a long-established approach with its origin in 1970. In comparison to cases 1 and 2, case 3, and the task-shifting in it, therefore, serves as the most established in terms of seniority. It is, however, a relatively rare condition with around 500 affected patients in Denmark (Moltsen 2020).

The patients and their hospital connection

Patients in need of parenteral nutrition are affected by various underlying conditions resulting in intestinal failure. The common denominator is that they are not able to absorb nutrients through their intestines and must, therefore, receive fluids with soluble nutrients intravenously (Bielawska et al. 2017:1f). The treatment can be temporary but also lifelong and is offered as home treatment by only 5 highly specialised hospital departments in Denmark (Sundhedsstyrelsen 2017:6). At Rigshospitalet, the speciality is part of the Department of Intestinal Failure and Liver Diseases and consists of a HomeCare outpatient clinic responsible for approximately 240 patients and an inpatient ward. When patients are first treated and their nutritional program established, they are admitted to the ward for an average period of 21 days. During this time, a CVC is inserted, their program is fine-tuned, and they go through a strict and individual training process with the purpose of shifting all parenteral nutrition tasks safely onto them. The key resource is a document called the ‘Drip book’, which the patients are asked to consult or refer to if needed (Rigshospitalet 2021; Appendix B5:62). The hospital cooperates with the primary care sector for patients who require assistance to do the home parenteral nutrition (HPN) treatment and a pharmacy combined with a delivery service provided by a specialised external company. This company provides the patients with their needed fluids and utensils and ensures that quality is preserved through transport and delivery (Rigshospitalet 2021:2; Buur & Søgaard n.d.). When it is time for patients to return home, they are accompanied by a nurse who assists in organising the practicalities around the HPN treatment. The patient and the nurse select a suitable space for the many treatment items and plans a qualified setup to prevent adverse health care events such as mixups of utensils or hygiene issues (Appendix B5:63).

Figure 4: Functioning CVC (Rigshospitalet 2021)

The technology and the shifted processes

The technology in the case of HPN is a synergy of nutritional fluids and the pump used to put them in the body. Figure 5 depicts the pump attached to the fluids and figure 6 shows a backpack designed specifically for the purpose of containing the nutritional fluids and the pump. For the technology to be applied, the patient must have a CVC inserted, similarly to patients in case 2. However, more tasks have shifted for the patients in case 3, who manage the entire treatment process on a daily basis. Preparation of the nutritional fluids is a detailed process that requires a systematic and sterile approach (Rigshospitalet n.d.). Connecting and disconnecting is also done by the patient and, in comparison with case 2, there is a degree of flexibility as patients choose the speed at which fluids are infused. This is necessary since a treatment program might consist of different types of fluids (Appendix B5:67).

Figure 6: Micrel pump (Micrel n.d.)

Figure 5: Backback designed for the Micrel pump and fluids (Micrel n.d.)

Comparative case summary

The table below provides an overview of the cases and allows a comparison of selected characteristics.

	Case 1 **Biological medicine**	**Case 2** **Chemo-to-go**	**Case 3** **Parenteral Nutrition**
Established	2009	2016	1970
Technology	Syringe or pen containing biological medicine	Bag with pump and chemotherapy	Nutritional fluids, pump and utensils
Instruction	45 mins Outpatient	2-3 days Inpatient	Average of 21 days Inpatient
Treatment frequency	1 injection every 1-2 weeks	Up to 48 hours at the time for 5-8 days	Daily up to 12 hours (most common)
Shifted tasks	- Transport - Storage - Self-injection	- Monitoring the pump function - Possibility of disconnecting - Following instructions	- Medicine preparation - Connecting and disconnecting - Receiving and organising deliveries

Table 1: Cases and descriptions

Theory

To address the issue of task-shifting in the selected home health care cases I will, in this section, present ways to think about the places the tasks shift between. Task-shifting in itself implies that the people that tasks shift to must be engaged and active in a different way. Therefore, I approach the shifted care practices by using care-related concepts proposed by Annemarie Mol (2008,2010) and Jeanette Pols (2010,2012). Ultimately, the notion of scaffolding in health care (Botin 2020; Botin et al. 2015,2016) will be presented to tie the ends between the devices, patients and health care professionals present in the shift.

The meaning of home

A definition of the home and the hospital is required to illuminate the practices existing in the space between the two places. This section is based on an exploration to answer questions about what ‘homebuilding’ and being in the ‘home’ means to a person. The insights of this exploration then serve to set ‘home’ in juxtaposition to the meaning of the places you stay outside your home.

The home

The home you build and modify for yourself serves as a reflection of the person building and modifying. It can reveal a ‘life narrative’ about its inhabitants before they themselves have the chance to tell it. It is a space located in a specific though not necessarily fixed place that you can routinely leave and return to while you live your life. It is a space you have brought under control, for it to be called home in the first place (Winther 2006:27; Douglas 1991:289). According to Heidegger (1951), there is an existential connection between being in the world and the wish for dwelling. To be in the world is to dwell, and we ‘are’ when we dwell. Dwelling is how we, as humans, are on the earth and building also implies preserving and nurturing. But to attain a space to dwell, it must first be built. In this understanding *“Dwelling and building are related as end and means”*, however, the act of building can in itself be dwelling if we are indeed capable of dwelling when we build (Heidegger 1951:348ff, 363; Winther 2006:134).

In her work ‘Hjemlighed’ Ida Wentzel Winther proposes four categories to illuminate the conception of ‘home’. They derive partly from a social analytics perspective and partly from a culture phenomenological field study. The categories are depicted in figure 7.

Category	**Home (as idea)**	**The home**	**To feel at home**	**To home**
Definition	Idea, Conception & turning point	Shelter, House, Residence	A vibe	Tactics
Description		Private, Intimate Tactile Everyday practices	Included Feeling of family	
Location		Locally & spacially rooted	Mobile vibe	Mobile
Type of territory	A-territory	Re-territory	De-territory	More-territorialisation

Figure 7: Winther's categories of home (Winther 2006:168f,177)

Home (as idea) does not apply to a specific home but covers a normative perception of what a home is thought to be. It is an a-territory where historical and cultural ideas codefine the abstract ideological construction of the home. Though difficult to distinguish from *Home (as idea)* the next category; ***The home*** is where these abstract perceptions become concrete and everyday routines and practices are performed. *The home* is not a closed space unaffected by its surroundings, but it is a re-territory where influences from the outside world are adapted and individualised by those who inhabit the home. ***To feel at home*** is a vibe that reflects a certain mood. It cannot be situated but can occur in a certain room or with certain people or items, which is what makes it a de-territory. This implies that the feeling can travel if the people and items travel with you. What seems important is a hint of recognisability or repeatability, both of which can spark the sensation of feeling at home. ***To home*** is understood as a tactic that can be employed in different locations. If you master this tactic, you can *"(...) act as if you are at home, do as you would at home, behave homely"* (Winther 2006:171) in spaces that are not in your actual home. A 'more-territorialisation' happens when tactics help you to willfully establish a temporary home, that feels homely, where the unknown and unhomely is reshaped into something well-known and familiar. The tactics vary according to the individual, and they can either establish the mood of feeling at home in a space or create coherence in what seems incoherent (Winther 2006:167-172)**.**

Planning and sharing the space

The home is also where you stock the things you need to not only live but also to survive. The refrigerator accommodates your hunger as long as you remember to fill it up with the food you like to eat. As Douglas (1991) puts it:

> *"Storage implies a capacity to plan, to allocate materials between now and the future, to anticipate needs. A stocking up anticipates a running-down of supplies, which implies continual reallocation, repair, renewal, in short an intelligent plan. For the sake of the plan, space is differentiated, parceled out, allotted to different intentions."* (Douglas 1991:295)

For some people, stocks of prescription medicine and supporting medical utensils are also vital to keep your body functioning. Unlike the contents of a refrigerator, these do not necessarily have a natural location in a home but must be allocated one. Some can be put in a medicine cabinet or next to your cereal for the sake of remembering to take them at the right moment, with the right food. And some are too big to fit these natural keeping places. Space must be assigned that fits the intention of storing and using these items according to instructions given by the prescribing health care professionals. If you share your home, there must be a common understanding about the spaces allocated to medicinal items, so that they remain untouched, sterile and safe to use when the time is right. Here, it is a matter of sharing resources, though not of the consumable kind as exemplified by Douglas (1991:295f). The resources shared are the spatial ones, when a shared refrigerator must have room for temperature-sensitive biopharmaceuticals or when the guest room is doubling as a medicine cabinet (Appendix B1, B4). This too comes with a needed consensus on financial resources, because while the costs for medicinal items might be covered by the hospital, remodelling your home to house them or buying appliances that ease your symptoms or side effects, are not and can be costly. Budgets serve to structure the collective effort, and plans that serve the individual, such as the aides mentioned above, must be evaluated alongside the need to pay the bills or save for the future. Therefore, the amount of commitment to achieving a collective good for the home is pivotal for inhabitants living in it (Douglas 1991:297, 299).

The room

A home can contain many rooms in which different rules apply depending on the time of day and the people who enter. The kitchen can serve as a place to prepare food, but it can also be where you go to prepare your pills or syringes for the day. It might also serve as a place where you have a coffee while doing an online interview with a researcher asking about your treatment. Rooms can be multifunctional in this way. They can serve one purpose, such as containing a comfortable bed to sleep in, while also being a place for treatment as the pump you are connected to can be on your nightstand while you rest (Winther 2006:29,46). Each room has a function, which reflects the rules and values imposed by the inhabitants of the home. According to Winther (2006):

> *"Rules are normative – they do not tell how people always act (routines), neither how you should act (law); but they tell how you should act if you want to take part and be a part of certain contexts" (Winther 2006:28)*

These rules can exert structure, but they can also be characterised by the tyranny they impose. Mary Douglas (1991) mentions the 'friendly uniformity' that can dictate the menu in the home, according to one inhabitant's medical needs (Douglas 1991:303). In the same manner, rooms might be closed off at certain times because an inhabitant needs a calm environment to arrange the medicinal fluids for the night. The user of a room leaves traces of the use. The space of each room and what they contain can be explored by *"(...) looking at who is allowed to be where, with whom and how? And who can do what, with whom, when and where?"* (Winther 2006:28)

The temporary home

Mary Douglas adds the notion of the 'nonhome' as a serviceable place, where happiness is possible. It might contain domestic things but what lacks is the familiar arrangement that allows for *"(…) the regular cycles of home life"* to happen (Douglas 1991:289). A few of these are suggested in the following.

Hospital

The hospital consists of many 'unhomely' items. The bed you borrow is meant to accommodate many patients, some with other needs than yours and some with exactly the same. In either situation, it is only for as short a time as possible. There might be comfortable sofas, coffee machines and televisions showing news channels, but these materialities are put in place to serve all that find themselves admitted to the hospital department, or perhaps those visiting such a person. These are things you might find in a home, though they are not 'homely'. Then there are the items that do not frequent the 'home as an idea'. Syringes, medicinal fluids hung on drip stands and sterile plastic utensils seem normal and in place at the hospital, but in some cases, these must follow you home. The question is then how to incorporate these anomalous materials in your home so that the 'unhomely can start to belong and become homely. Here, tactics are needed to mediate the process of shifting hospital items to items in your home and ultimately make them seem domesticated (Winther 2006:86).

Travel

When travelling it is the norm to bring essential things with you that cannot be picked up in the nearest supermarket. You might also pack the toothbrush you prefer and that brand of sunscreen you trust in case these special items are not available at your destination. For some people, vital medicines are on the top of this list of essentials. A hotel room or your summerhouse can feel like home if tactics are used to do so. For them to make these spaces into a more-territory, they must use tactics that make the storage of the medicine or the way you can arrange and order them in a foreign cupboard feel controlled (Winther 2006:170ff; Douglas 1991:289).

For the modern human, smaller travels happen every day. It is the flow of life to move between many different arenas where work, homelife and the practices in between happen. There is tension separating the repetitive and stagnant everyday life from the nomadic need for constant change and the demand to learn new things. Winther visualises the tension as two poles pulling in each direction:

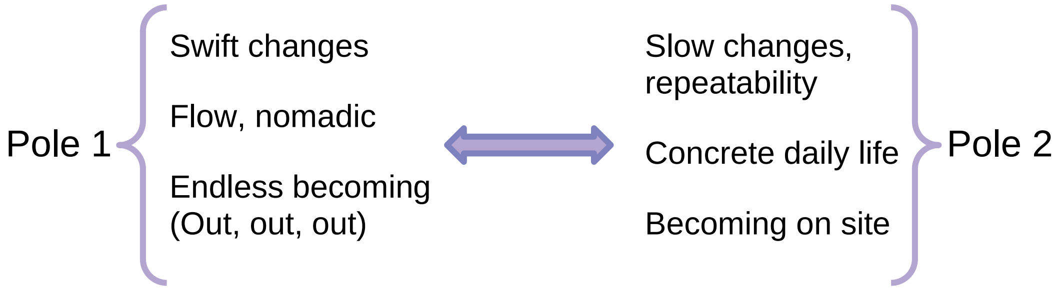

Figure 8: The tension of being in modern society (Winther 2006:10)

Between the arenas, which exist across the spectrum of the two poles, we carry ‘nomadic objects’ in the shape of mobile devices with the possibility to connect globally. These objects enable us to live a somewhat nomadic life and nomadism becomes a way of being in the world (Winther 2006:7,147). In the same manner, having a pump or a cooling bag with biopharmaceuticals become ways of being a patient in the world because these technologies free you from the hospital bed.

Concepts in Care-shifting

Shifted care tasks come with an expectation of completion. It is now up to the patient to either perform the tasks or establish timely contact with those who can assist if any circumstances should prevent the shift from being successful. Either way, the patients are required to *do* something.

The active and tinkering patients

'Good care' is described by Annemarie Mol as the moral processes of improving the lives of the people cared for, though whether an improvement has improved something can only be determined by the individual (Mol 2008:75). Bringing treatment into the homes of patients requires a great deal of individualised considerations, which justifies an inquiry into individual experiences. In the chosen cases the patients all *do* a lot, though in very different ways. They are active in their treatment which is not solely done *to* them but also *by* them, however tedious and demanding they might be (Mol 2008:7). Mol adds to this:

> *"Care is not attractive (...) you have to engage actively in care, painfully, enduringly, and as a prominent member of the care team. That is demanding. And yet you may take these demands on board, because suffering from complications is likely to be a lot nastier."* (Mol 2008:25)

Being inactive means dealing with other, less attractive situations. Because without treatment there is either no life or life with progressing chronisities. However, by caring, the patient *"strives after as much health as her disease allows"* (Mol 2008:28,78). In the cases of home health care, striving and caring means tinkering to make the treatment and the shifted tasks fit your life and home. You can tinker *"(...) with bodies, technologies and knowledge – and with people, too"* (Mol 2008:12). Technologies must be adapted to the person while the person adapts to the technology (Mol et al. 2010:14f).

Care as a shared effort - the trinity of patients, professionals, and devices

As mentioned above the patient is a prominent member of the care team. They tinker, but this is also done by the health care professionals, before and during treatment. When relying on technologies that have to follow the patients to their homes these tinkerings become a team task. Jeanette Pols points to the shared aim of care and care devices to *"improve daily life with disease"* and continues:

"If a device is to be helpful, patients, nurses and devices have to establish fits between them, shaping problems as well as good care." (Pols 2012:136f)

Here, the importance of a shared approach to problem-solving is put as a focus for ensuring good care practices, when the care team is located in both hospital and homes. By looking at different cases of telehealth, Pols shed light on the fact that *"(...) the possible role of the professional and the type of responsibility taken by the patient"* were highly set-up dependent (Pols 2012:17). Thus, accentuating the manifold varieties of care that come into existence when more components have to be assembled to fit the shared goal of good care.

Mol and Pols share the same goal in their research, which is to create an adequate language to talk about previously unspoken things in care practices and within these the technological innovations that allow care to travel (Mol et al. 2010:10f; Pols 2012:15). A suggestion for discussing travelling care mediated by technology is to view the domestication of devices with a material-semiotic lens, which can illuminate how people and objects shape each other in home health care. This approach allows analysis of how technologies are unleashed and tamed through daily use, which then enables the confidence in people and patients to tinker with the technologies to *"(...) invent new applications"*. Ultimately, an analysis of the ways the technology dictated or enabled processes should complete the picture of mutual human-technological relations in home health care (Pols 2012:17ff).

The all-embracing structures

Inspired by Martin Heidegger's concept of 'Gestell' meaning the way humans are 'enframed' by technology, the notion of 'scaffolding' emerges. By slightly nudging the interpretation of 'enframing' in a less dystopian direction Lars Botin (2020) argues that *"Scaffold, as concept and term, better describes the ambiguity and ambivalence of modern technology (...)"* (Botin 2020:44). Technology can invoke ambivalence as people must relate to it in a different way, which happens as your home turns into a small-scale pharmacy, or your bed becomes a place where you are connected to a pump. Therefore, ambiguity follows these technologies as the individual decides on how or whether to domesticate them. The purpose of scaffolding is to *"(...) build scaffolds in order to construct structures that protect, support, maintain and renew fragile and vulnerable bodies and identities of humans"* (Botin et al. 2016:189). In the three cases studied in this thesis, this applies to the care practices that patients experience and in some situations are actively taking part in. Their identities might be fragile and vulnerable as they react to the condition of their erratic bodies, which is why scaffolds have the potential to bring relief. In a well-assembled scaffold, the segments fit like the pieces of a puzzle, though they can be assembled in a multitude of ways (Botin et al. 2016:189; Botin 2020:46). This is essential when scrutinising the best-assembled scaffold since the patients taking over shifted care practices are a varied group of individuals with different challenges, needs and wishes, each with their idea of home.

The shared scaffold

Scaffolds should be built to scaffold patients as well as the health care professionals and family members who engage in the shifted care practices (Botin et al. 2015:10). In addition to this scaffolding should be viewed as a team effort to *"(...) construct the scaffold together for a specific purpose"* (Botin 2020:46f). Whether it is medicine in a cooling bag, or a device connected to a patient that leaves the hospital to be transported home, it is ultimately a joint process. It requires the involvement of health care professionals, patients and at times family members who all contribute to a specific purpose. The ultimate goal is to build a scaffold that can ensure good quality treatment, despite the fact that some treatment tasks have changed hands and place.

Analytical framework

The theories presented above inspired the construction of an analytical framework as visualised in figure 9. The conceptions for home and homebuilding by Heidegger (1951) and Winther (2006) are applied and distinguished from the conception of nonhomes proposed by Douglas (1991). The nonhomes are enriched by Winthers' (2006) concepts of nomadism and the notions of planning and sharing suggested by Douglas (1991) in turn serve as a social view of homebuilding with co-dwellers.

Task-shifting is viewed as the umbrella phenomenon of interest, which sparks questions about the concepts of responsibility and quality in task-shifting processes as presented in the introductory section of this thesis.

The care concepts applied are the conceptions of active and tinkering patients and their part in the care team (Mol 2008,2010) as well as the trinity of devices, health care professionals and patients (Pols 2012).

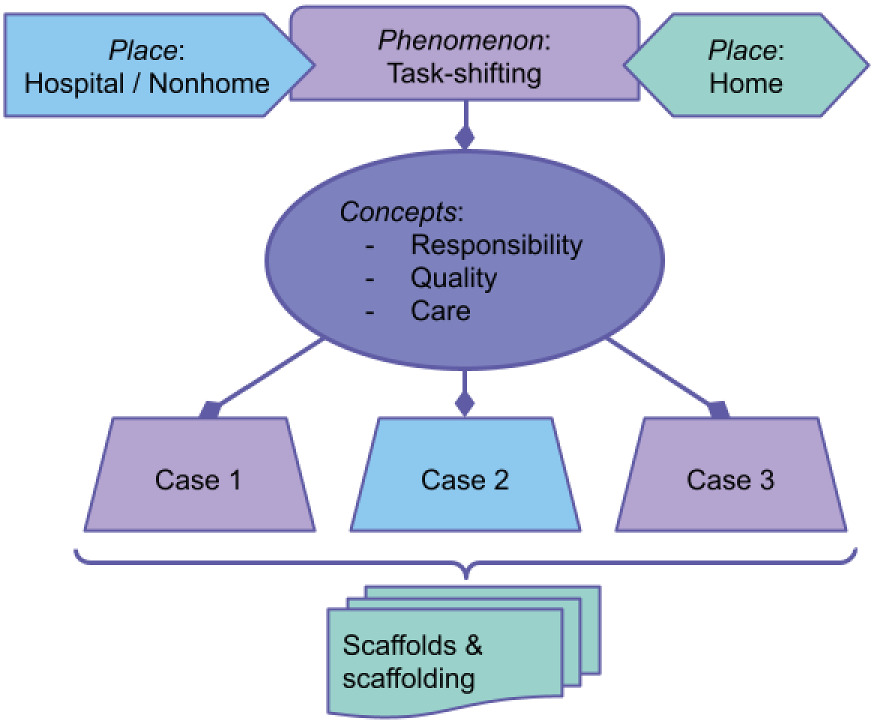

Figure 9: Visualisation of the analytical framework

The places, phenomenon and concepts will be applied to all three cases throughout the analysis. To conclude the analysis the conception of scaffold building (Botin 2020; Botin et al. 2015,2016) as supporting structures for the trinity in health care task-shifting processes is brought into play.

Research methods

In this section, the research methods chosen for the multiple case study and their use in data collection and processing are presented. This is followed by a brief reflection on the theoretical and experienced shortcomings of the methodology.

Initial overview

The initial methodological step taken was creating an overview of potential cases and informants, who could shed light on the task-shifting to be researched. Inspired by the concept of stakeholder mapping (Stickdorn et al. 2011:143), I created a map of the people and organisations of interest and their connection to home health care cases.
By using the map I began to make inquiries, which in some cases resulted in further additions to the map, which is visualised in figure 10:

*Figure 10: Map of potential organisations, cases and informants of interest and relationships between them. Those represented in the thesis as the 3 cases are marked in **bold**.*

The final list of informants is a product of availability combined with a consideration of the level of task-shifting involved in the case. The list is displayed in table 2.

Source	**Case and perspective**	**Method & length**
Doctor Hanne Lindegaard & Nurse Marlene Lynggaard Rheumatological department C, Odense Universitetshospital	Case 1 Health care professional view	Google Meets 34 minutes
Lone Rheumatological patient self-administering biological medicine	Case 1 Patient view	Messenger 1 hour 20 minutes
Katrine Seier Fridthjof Project nurse establishing the Chemo To Go method at Rigshospitalet	Case 2 Health care professional view	Microsoft Teams 1 hour
Thesis by Katrine Seier Fridthjof on patient experiences	Case 2 Patient view	-
Louise Bangsgaard Nurse specialist in parenteral nutrition at Rigshospitalet	Case 3 Health care professional view	Microsoft Teams 53 minutes
Marianne Patient receiving parenteral nutrition and member of the HPN patient association	Case 3 Patient view	Microsoft Teams 1 hour

Table 2: Overview of informants divided into cases

Case-based approach

This thesis aims to understand task-shifting as a complex socio-technical phenomenon in home health care. The word in itself implies that the phenomenon involves many groups and by addressing both the group which tasks were shifted from and the ones the tasks were shifted to I aimed to *"retain a holistic and real-world perspective"* of each case (Yin 2018:31). The 3 cases have been chosen to explore different views on task-shifting by approaching them through a multiple case study of a contemporary and context-dependent phenomenon, where many variables of interest can emerge from the data (Yin 2018:38f; Flyvbjerg 2006:222). The variables are limited by the organisations and persons included in the case and defining these and their geographical location serves to bound the cases as suggested by Yin (2018). As evident in table 2, the informants who contribute the majority of the gathered data represent 3 different task-shifting situations. They can, however, only convey their experiences with their own homes and connected hospital departments, though the treatment might be offered at many hospitals and in many homes across the country. Here, it is up to the researcher to make analytic generalisations aided by hypothesis and theoretical input, where the case study can *“shed empirical light”* on the theoretical concepts previously presented (Yin 2018:43,51,56). Pols’ argument that an ethnographic study *“(...) does not need large quantities of patients but may learn from small, pioneering practices”* aligns well with the applied methods in this thesis, where few informants are engaged in each case (Pols 2012:15).

Multiple and multi-sited case study design

The rationale behind choosing multiple cases was not to make a comparison of literal replications, but rather to study how the task-shifting phenomenon presented itself in each case as theoretical replications. The cases are chosen as maximum variation cases to ensure representation of different degrees of established-ness and seniority. They are not approached holistically but with the purpose to illuminate the effects of the phenomenon embedded in each case (Yin 2018:69,72; Flyvbjerg 2006:230).

The design can be argued to be multi-sited where people and their medical technology are followed from the hospital to their homes and on to other places of activity that this mobility allows (Marcus 1995:96). I have been guided through these sites by patients and health care professionals and subsequently put the sights in a larger perspective, thereby doing what Winther (2006) calls a “field walk” (Winther 2006:12f).

Literature search

The source of my knowledge originated in working with the case of biological medicine. From there I wanted to develop the work on that case in a direction that made it useful as part of a multiple case study. For that, and to find ways of viewing and analysing the cases, I sought to find literature in the following areas:

Field	**Output**
Medical literature (PubMed)	- Understanding the treatment - Understanding the diseases
Problem specific literature (PubMed, Scopus, general internet search)	- Understanding home health care - Understanding task-shifting
Literature on concepts - Responsibility and quality (general internet search)	- Defining the concepts - Building a solid analytical framework
Theoretical literature (Authors and concepts search)	- Building a solid analytical framework - Understanding the meaning of 'home', care practices and scaffolds as supporting structures in health care.

Table 3: Overview of literature search

Searches were initiated strategically using the 5w's method (Zins 2000:1237), followed by a citation chaining technique (Siu 2021). Browsing through search engines like Pubmed and Scopus assisted by general internet searches ultimately provided a useful corpus of literature. Some documents were recommended by informants and served to give case-specific insights. Documentation, archival records, interviews, direct observations, participant-observation and physical artefacts are six sources of evidence proposed by Yin (2018) in case studies (Yin 2018:109f). In this thesis, the interview data provides the most substantial part of case evidence, which is supported by the suggested documentation and physical artefacts as described in the following section.

Interviews and physical artefacts

As a consequence of adapting to governmental guidelines, all interviews were conducted online using various media (Danish Health Authority 2021). The interviews followed a semi-structured approach where interview guides developed for either health care professionals (Appendix A2) or patients (Appendix A1) were utilised as supporting tools. The 5 interviews were planned to represent both the view of the health care professionals and the patients in each case. This illuminated the differences in the lived world of and language used by the informants (Kvale et al. 2016:49f; Spradley 1979:71f). The semi-structured method was followed to endorse leaving the track if the informant wanted to steer in additional directions relating to the suggested themes. As quoted in Kvale, 2007; Spradley (1979) advocates making the informant your teacher, allowing the researcher to perceive their lived world from their point of view (Kvale 2007:2). I aimed to create rapport with the informants so that the lived world of both sides could be illuminated (Spradley 1979:78ff). With this approach, I gained knowledge on the logistics of shifting tasks along with how these shifts were received and perceived. The questions in the interview guides were divided into topics according to the analytical framework, to assist the ensuing coding work.

The interviews were conducted during the first months of 2021 (Appendix B1, B3-5), except for one which was conducted as part of the project work in the fall of 2020 (Appendix B2). However, since this thesis is greatly inspired by the preceding project, it was of great use to revisit the transcription with a new set of concepts contained in the coding framework proposed in table 4 below.

The physical artefacts found their way into the data as a direct result of the patient interviews. Both patients agreed to share pictures of how their treatment had been incorporated into their homes and these are included in the results section. These pictures serve as representations of the artefacts in their home and their partaking in this thesis is, therefore, as virtual artefacts.

Data processing

This section describes how the interviews were transformed to analysable data points.

Transcription

Interviews and following transcriptions were all performed by the author of this thesis, which eliminates any discrepancies between understandings gained during interviews and the subsequent analysis of the transcribed data. Excess words, exclamations and sounds made while pausing have been left out in the transcription process while taking great care not to compromise the intended meaning. This was done on the assessment that the conversational aspects of the interview would not be relevant for the subsequent analysis (Kvale et al. 2016:239f). The interviews were all conducted in the native language of the informants, and all included quotes in the thesis have therefore been translated by the author. These translations have been done with great care to portray the intended meaning as closely as possible (Spradley 1979:20f).

Developing coding nodes

The process of determining the nodes for coding of the semi-structured interview transcripts followed both a concept- and data-driven approach (Kvale et al. 2016:263). Firstly, theoretical and thematic inputs were chosen according to the initial hypotheses. These inputs shaped the structure of the interview guides and subsequently served as the main theoretical and thematic nodes in the coding framework. Secondly, a read-through of all the interview transcripts was done to gain an overview of the qualitative data. This rendered an expanded collection of thematic nodes, to which subnodes were added during the coding process by condensing the meaning of what was said and transcribed (Kvale et al. 2016:267).

Coding

The interview transcripts were analysed using the NVivo software (QSR International 2020; Woods et al. 2016:600; Yin 2018:144). This eased the coding process, as it is possible to keep an overview of the predetermined nodes as well as adding subnodes while coding progresses. The framework can be seen in table 4:

Theme	Theory
Incentives	Care - Active and tinkering patients - At the hospital - Domestication & mutual relations
Logistics - Patient - Resources	Feeling of comfort - Health care professionals
Patient unions	Home - Planning - Space - Tactics
Quality assurance - Adverse health care events - Contact - Measurement - Quality of life	Lived World - Anecdotes
Responsibility - Felt - Shifted - Taking known risks	
Shifted tasks	
The technology	

Table 4: Nodes of the coding framework

The framework above was inserted in the NVivo 12 software and the coded data was subsequently analysed and refined by adding subnodes to nodes where the references were numerous. Ultimately the references were divided as listed in Appendix C, in which a brief explanation of the origin of each node is also included (Kvale et al. 2016:262). The extent of each node and subnode is visualised in figure 11:

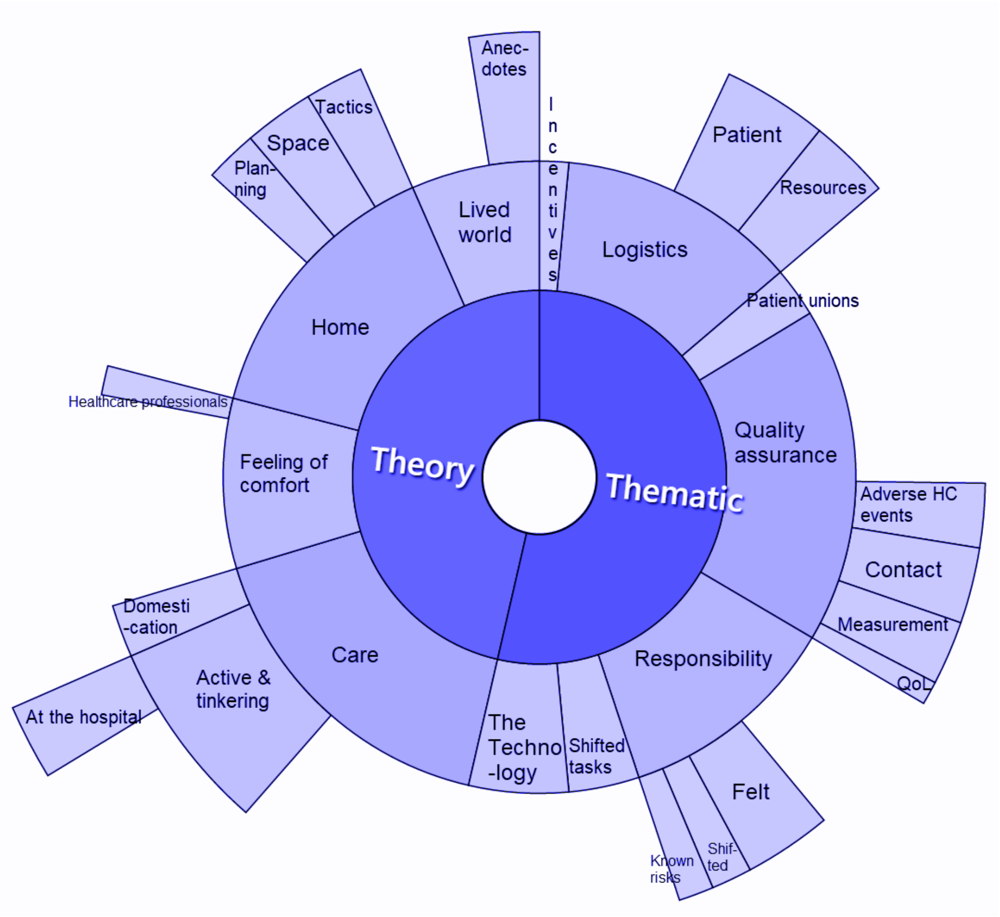

Figure 11: Nodes and subnodes sized according to their number of coded references.

Methodological reflections

Proximity to the field

An initial concern was to apply ethnographic methods in a field that has been guarded tightly by COVID-19 restrictions. The phenomenon of interest exists in a field where people are especially vulnerable to infection while dealing with disease and treatment which limited my access to homes and hospital departments. The data has been gathered through interviews where observations were confined to virtually entering homes and offices through a screen while physically being in my own home. A relevant critique is whether the lack of in-person observation has obscured the proximity to reality, which is a strength in case studies (Flyvbjerg 2006:236). However, according to Yin (2018) *"(...) case study research is a form of inquiry that does not depend solely on ethnographic or participant-observer data"*, which gives rise to the argument that the chosen methods have prevailed sufficient access to the studied phenomenon (Yin 2018:44).

An additional reflection on proximity is the choice to include case 1 in the research since the topic of biological medicine had been the focus of previous project work during the fall of 2020.

The concern was whether the known case could subconsciously assume a larger part of the thesis than the other chosen cases. This concern was negated by the realisation that diving into cases 2 and 3 created the same motivation for research.

This provokes a final reflection concerning the research depth of each chosen case. While focusing on one phenomenon, a conscious decision to leave out many essential facts about the cases has been made. The specificities about the diseases, side effects and how the technology works on and in the body has not been elaborated, though it could have further enriched the analysis. Accepting this risk of overlooking interesting aspects is a matter of choosing the scope for the thesis and a dilemma for every researcher with a deadline.

Generalising from case studies

Case studies are subjected to a discussion of their value in forming generalisations and their validity compared to theoretical knowledge. Becoming an expert in a certain field requires both theoretical and context-dependent knowledge unless a scholar wishes to end up stranded as a novice in a pile of books (Flyvbjerg 2006:221f). Flyvbjerg (2006) argues that case studies not only provide a nuanced view of reality but also contributes to the development of skilled, intuitive researchers:

> *“Like other good craftspeople, all that researchers can do is use their experience and intuition to assess whether they believe a given case is interesting in a paradigmatic context and whether they can provide collectively acceptable reasons for the choice of case.”* (Flyvbjerg 2006:233)

The choice of cases in this thesis follows the maximum variation principle and the cases have indeed been selected intuitively based on the reasons previously listed. The purpose of this thesis is not to propose generalisations but to enlighten the insights gained which may happen to contain cross-case generalisations. As argued by Pols (2012) regarding the study of innovative health care practices resembling case studies: *“Research that fits is caring research; it can be used to improve the practices it studies”* (Pols 2012:151). Generalisations or not, the analytical insights presented in this thesis are meant to leave space for improving task-shifting processes.

Results

This section provides a summary of the insights gained from the 5 semi-structured interviews conducted. A summary of the themes derived from the first transcription readthrough can be explored in appendix D.

Patients

In meeting Marianne and Lone their descriptions along with the pictures and videos they subsequently provided gave me a tour of the spaces, which were related to their treatment. Even though I did not physically enter their homes to see those spaces, the data serves as a social articulation, which came to be as a result of my inquiries (Winther 2006:21).

Both informants provided additional perspectives that originally fell outside the scope of this thesis. Some of these were assessed to add value and were included in the analysis, such as Lone's use of adaptive aids and both informants' emphasis on the worth of patient unions and networks (Appendix B1,B4,D).

The patient perspective in case 2 derives from qualitative data on AML patient experiences with transportable digital infusion chemotherapy gathered by Katrine during her thesis work.

Case 3 - Marianne

The following pictures (1-6) show how Marianne has rebuilt and taken her guest room under control to fit her treatment-related items.

(1) **(2)**

Picture 1 & 2: Marianne's guest room after a delivery from the pharmacy.


(3)


(4)

Picture 3: The extra cupboard purchased for the purpose of containing parenteral nutrition fluids at ambient temperatures. Picture 4: The guest room wardrobe containing medical utensils.


(5)


(6)

Picture 5: The guest room when all is unpacked and stored. Picture 6: The wine fridge purchased to contain parenteral nutrition fluids at controlled temperatures.

Case 1 - Lone

The following pictures (7-15) show the spaces that Lone has taken under control to fit her treatment-related items, as well as a selection of the adaptive aids she has incorporated in her home. The pictures were accompanied by explanatory videos, in which Lone elaborated the use of the different items and spaces.

Picture 7: The biological medicine filling up the top shelf of her refrigerator door.

Picture 8: A shelf in a kitchen cupboard containing Methotrexate syringes, supplements and Lone's portable toilet bag.

Picture 9: The cooling bag and cooling elements used to transport the biological medicine.

Picture 10 & 11: Drawers filled with adaptive aids and arthritis-related training equipment.

Picture 12: Lone's cutlery drawer with space allocated to adaptive aids.

Picture 13: The dosette boxes used by Lone to facilitate daily medicine consumption.

Picture 14 & 15: Adaptive aids for reading and writing, respectively.

Health care professionals

The interviews with the health care professionals associated with the cases gave a brief look into the organisational structures and incentives involved in task-shifting processes as well as the limits of allocated resources. The views on responsibility in treatment became evident in each case along with the different methods for approaching home health care and instructions prior to task-shifting. Quality and quality assurance were present in each case as both measurements of life quality and adverse health care events as well as shifted hygiene procedures (Appendix B2,B3,B5;D)

Analysis

This section serves as a field walk through the data, where we move from homes and rooms to nonhomes and hospitals. Above the field hovers the notions of quality and responsibility in treatment. To conclude the field walk the insights are condensed and subsequently viewed through a scaffolding lense. Many variables emerged from the data and a careful selection of them are presented here. Not all are, however, directly related to the phenomenon of task-shifting.

To be home

Throughout the 3 cases, there was a consensus that being at home was a good thing as opposed to being at the hospital. For the patients, it means being more loosely tied to the hospital, though in very different ways. Lone expresses relief in not having to travel to the rheumatological department more often than she already has to and for her, it was never considered a possibility to choose to go there for a treatment she could do in her own kitchen (Appendix B1:3). What would be an inconvenience for Lone would be greatly restricting for Marianne, who would be bound to a hospital bed every night, or worse, was it not for the pump and her ‘home pharmacy’. She elaborates by saying;

> *“So it is crucial that it can happen at home. Before you had this home treatment, you would leave patients like us to die. Because there was nothing, it was unthinkable that you could have all that treatment at home”* (Appendix B4:56).

The carefully individualised parenteral nutrition program not only assures that Marianne can live but also allows her to, somewhat, live as she pleases. Having the treatment as an essential component in her home enables her to combine working life with life as a patient, constituting her lived world as a combination of the two (Appendix B4:47). Her being in the world means having built a home that allows her sufficiently nourished body to dwell and to move from her dwelling when she needs to.

The bag she meticulously packs with nutritional fluids connected to a pump lets her have treatment at home because she has become competent in performing all steps herself. At the same time, the assembled items contained in the bag becomes, as a whole, a nomadic object in the sense that it lets her travel between work and home. In this interpretation, I allow a slight twist of the concept used by Winther (2006). Because the pump does not connect the wearer globally and allow being in more spaces at the same time, but it does allow the wearer, through its portability, to connect with the world outside and travel between places.

Here, there is a similarity to the patients in case 2. The difference is the starting point of travel because a patient receiving chemotherapy does not connect herself to the pump-medicine unit contained in the backpack like the patients in case 3. This is done by health care professionals at the hospital with the purpose of letting you travel to your home, wearing the nomadic object. For these patients, the continuation of homely tasks and events is an incentive to carry around the pump. Katrine explains that some patients:

> *"(...) actually feel they can have a life alongside* [the treatment] *because it is not about logistics back and forth from the hospital. But one can, for example, invite your band home in the living room and play or have visitors"* (Appendix B3:36).

This exemplifies how you can both receive chemotherapy and 'home' at the same time. The tactics employed depend on what feels like home to you, whether it is going for walks or cooking with your spouse or just exploiting the sheer freedom of doing these things exactly when you want to (Fridthjof 2019:23). This freedom can apply to less simpler comforts as well, considering the patients' changing feeling of well-being. Katrine describes how most patients *"(...) go home and stay with their family on the sofa or they just want to sleep in their own bed and throw up in their own toilet"* (Appendix B3:41). Being in the home you know with the things and people you choose to place in it can make patients feel at home even when they do not feel well. Patients report feeling *"brought out of the disease"* which also creates a sense of comfort for family members, who might find it difficult to visit at the hospital (Fridthjof 2019:24f).

A viral incentive

A recurring subject is the momentum created by the COVID-19 pandemic which has served as an incentive to shift tasks. For the patients frequenting the rheumatological department at OUH, this means saving time on finding good parking because they now collect their biological medicine using a drive-through solution set in place by the hospital pharmacy (Appendix B2:19). Lone has experienced how filling out the obligatory questionnaire before each check-up has been moved online and, therefore, into her home. For her, there is comfort in answering questions about her personal physical and mental well-being in a place where she can feel at home and not *"(...) stand there facing the entire waiting room"* while also feeling the stress of being called into the doctor's office at any moment without having time to finish up the questionnaire (Appendix B1:14). Drawing on her former role as a project nurse who experienced the benefits of sending patients home first-hand, Katrine cherishes any opportunity to reallocate resources and competencies to patients and home care nurses in the primary sector. Her current position allows her to see the bigger picture and move around the hospital bureaucracy in a different way. Her role-responsibility has changed from setting sail on a local project to coordinating home health care at a regional level. *"There is a lot of potential"* she adds while explaining how the pump technology could benefit other patient groups such as those receiving long-term antibiotic treatment (Appendix B3:30,33).

Conclusion: Receiving treatment at home is the preferred solution for patients, who may shed their patient identity. It is facilitated by nomadic objects which make home treatment synonymous with having treatment wherever you want. Including the home in treatment and care allows patients to go to work and 'to home'. COVID-19 has saved time that can be spent at home instead and has the potential to push for more patients to be able 'to home' or feel at home while receiving treatment.

To send home

For a patient, who has to accept their role as a patient, being able to go home might be a welcome approach to treatment. Referring to the chemotherapy pump, Katrine explains that:

> *"Now it is such a standardised solution that there are also many patients who do not ask a lot of questions about it. And that is, so to speak, nice - but sometimes it is also a bit dangerous"* (Appendix B3:40)

The danger is assuming that you can 'home' as you always do just because the treatment is portable. Katrine elaborates how important it is for the health care professionals to catch on if a patient seems dazzled by the freedom as she tells anecdotes of patients going to the pub or enjoying the nice weather with the chemo-backpack fully exposed in the sun (Appendix B3:40,42). Ultimately, you are still a patient receiving chemotherapy, which is essentially a process of slowly absorbing cytostatics into your body to kill rapidly dividing cells. Therefore, being at home requires a sense of role-responsibility, as you must be the patient the health care professionals deemed fit for home treatment.

There is a balance between freedom and consequences which falls on the instructional skills of the health care professionals and the patient's approach to health literacy about their disease and treatment. This balance is felt by nurses as the fine line between knowing your patient and trusting them. For prescribers of biological medicine, trust is key when the expensive medicine is handed to the patient because after that point it becomes a 'black box' as to how it is handled (Appendix B2:19f). However, Marlene adds that they can tinker with the amount of medicine which patients can collect each time if the health care professionals get the feeling that a patient is not able to handle the biopharmaceutical according to guidelines. Another checkpoint is what could be called the ‘no bag, no medicine’ policy, which only allows patients to collect their biological medicine if they remember to bring a cooling bag (Appendix B2:23f). Patients in case 1 must show a sense of moral responsibility to receive their biological medicine, which was a point Lone emphasised as well: *“One certainly has to take care to store it* [the medicine] *correctly because it is very expensive to have to discard it”* (Appendix B1:18). Lone feels the moral responsibility not to waste resources even if they do not come from her own pocket.

At the HPN department, nurses have to be very experienced to be allowed to train patients in handling individual treatment tasks. As Louise puts it:

> *“If you find it hard to discharge the patient, then we usually also say; ‘maybe you should wait a bit with training patients’ because it is simply part of this task to trust that they become better when they come home”* (Appendix B5:69)

Louise uses the metaphor of driving a car, by which the training nurse gives the patient a driver’s licence without this immediately making the patient an expert. They might know all the rules, but they still have to learn how to drive habitually and how the patient chooses to drive from then on is for them to decide. As Louise puts it: *“(...) eventually you find a way to follow the flow when we are on the highway driving 120 km/h”* (Appendix B5:65f). In the terms of care concepts, the HPN patients tinker until they reach a point where their lifelong treatment tasks become domesticated. They become the most active members of their care teams as they tame the technology which has been unleashed in their homes, and patients may even confidently apply the technology differently than they were originally taught. Marianne explains how she has adapted her nutrition to her morning routine by having the pump next to her at breakfast and might even hang it outside the shower cabin, well aware that showering while connected to the pump poses a minimal risk of infection (Appendix B4:48).

Lone has experienced a similar process of domesticating her biological medicine where at first she found a suitable space for it in her refrigerator and then she tinkered with the way she injected it. With the pen it could feel like a bee sting, so she actively requested the syringe so she was able to control the speed. Taming the technology, however, took *“(...) a good while before I just thought ‘out of the box and done’ and that was that”* because she had to gain the courage to inject herself in the beginning. Now it has become a tacit action from taking the syringe out of the box in the refrigerator to the moment when the liquid is in her thigh (Appendix B1:3f).

Resources and individualised care

The time set aside to gain an understanding of the patient's resources is limited to outpatient consultations for case 1. Furthermore, the expectation is for the patient to acquire a cooling bag and to have a domestic fridge at home, which are, arguably, two fairly ordinary items that both may already be in a private home. For case 2, the treatment is predetermined and starts shortly after the patient is admitted to the hospital ward. Thereafter, the evaluation of the right amount of time for the patient to spend at home begins. Receiving chemotherapy through the pump is standard but the hospitalisation time must be subjected to tinkering to coordinate both resources that await you at home and how you are affected by the treatment. As Katrine points out:

"(...) they cannot come home from day one because we need some days in which we get to know them [the patients] *and find out which resources do they have, and who is around them, and where do they live and in what?"* (Appendix B3:39).

Similarly, the patients in case 3 must be evaluated and emphasis put on returning to their lived world as it was before their bodies succumbed to intestinal failure. Rebuilding begins by accurately fitting the parenteral nutrition to each patient, and the initial hospitalisation time is, therefore, a prolonged process. However, the department, in which Louise works as a clinical nursing specialist, specialises in sending people home with a 'driver's license' in personalised parenteral nutrition and has strict instructional care practices in place to do so. The last of these is following the patient home, to support them in finding the right space to store their medicine and utensils and ensuring they have qualified room to meticulously and hygienically prepare the nutrition (Appendix B5:63,66). These are considerations that have been discussed with the patient during the inpatient weeks, so the nurse can get an idea of the physical framework of the home. It is also a way to encourage a patient to imagine possible paths to incorporate their new vital essentials in their home, which might in turn change how they view home (as idea). The ultimate goal is to help patients return to the lived world, which they, when asked, express a longing for, *"[s]o their parenteral nutrition becomes integrated into their lives and not the other way around"* (Appendix B5:66). In other words, domesticating the treatment is encouraged for each individual patient, in each their individual way because when they step out of the hospital, handling the treatment becomes a lifelong premise for being in the world (Appendix B4:56,B5:65).

Conclusion: You are responsible for being the patient that you implied you were, meaning that trust is placed on those who show that they can take care of their own treatment process. If health care professionals are proven wrong in the assumption that trust could be placed in the patient, responsibility for acting on this observation solely belongs to those who have responsibility for the treatment. Rules for home treatment are set in place to assure that correct procedures are followed, which ultimately benefits the collective good of the care team. Long-term home treatment processes are eventually domesticated in different ways by using individual tactics.

The family resource

Next of kin are mentioned in all 3 cases as a valuable resource. They can be an extra set of ears when a substantial amount of information needs to be processed in very little time (Appendix B2:25,B3:36), and they can be a supportive set of hands that dial the number to the hospital helpline (Appendix B5:70). They can be active in the treatment tasks too, agreeing to have these shifted to them instead of the patient. In case 2, the treatment happens during a set period of time and shifted tasks, ending with each cycle of chemotherapy. For the patient, it may seem natural to disconnect from the pump, when it has fulfilled its purpose, and a family member can assist with that (Appendix B3:36). In case 3, there is a reluctance in having a family member accept such a shift. Because the treatment is lifelong, so is the responsibility, which is an issue the HPN department discusses thoroughly with the family member, who wishes to take on that burden (Appendix B5:62). Louise points out that in cases where patients are not up for the shifted tasks, the first option should be to involve the primary care sector: *"So preferably we want family members to remain family members in their original role and not have them assume all of the care entirely"* (Appendix B5:61). This role means being a supporting pillar in or near the patient's home, throughout the either delineated or lifelong treatment program (Appendix B5:70). However, it should be thoroughly reflected upon before family members add treatment responsibilities to their role-responsibility. Family pillars are advantageous but not having them does not exclude a patient from being treated in their own home. The presupposition is that every patient can come home and having fewer resources is not seen as a reason for the patient to *"(...) necessarily be deprived of the opportunity to come home"* (Appendix B3:36). As a perspective on quality assurance measures, Louise emphasises that *"[w]e do not deprive the patient of their autonomy"*. She illustrates how strict instructions in sterile procedures that the patients are given do not always correlate with the cleanliness of their homes (Appendix B5:65). Here, it becomes a matter of explaining the rules for best practice, while still allowing the patients to interpret these individually. If having your dog occasionally sleep in the bed next to you makes you feel at home, then only you can ultimately take responsibility for that infection risk (ibid). Tinkering with instructions might be a tactic to make the hybrid state you are in when connected to your pump feel homely.

The network resource

Amid care evaluations by hospital staff and considerations about what resources await you at home, we find people like Marianne. Her anamnesis and driven work in the HPN patient union make her an experienced advocate of task-shifting in case 3. Marianne is considered an expert patient who both masters her own treatment and extends this mastery to others by giving talks for both health care professionals and patients (Appendix B4:57). For patients, who have undergone life-altering surgery, it can be a hard transition to life dependent on frequent and regular treatment. Therefore, having someone, in whom the patient can mirror themselves, is a valuable resource for both health care professionals and the patients. Marianne's experiences and stories can bridge the gap between hospital and home, which can seem impossible to overcome. She stresses the importance of listening and being able to:

> *"(...) place yourself where they are. That you don't start with 'you can just travel to the USA' and all kinds of things if everything comes down to 'can I get down the stairs and do the shopping"* (Appendix B4:57)

Marianne represents one who has gone through all the stages and found a way to pass through them. She advocates meeting and understanding patients in their current capacity but also wishes for them to be challenged in ways that inspire ambitions and goals (Appendix B4:54). Some of these ambitions revolve around domesticating the items and tasks that are suddenly a necessity to have in your home. Here, reflecting your situation in someone, who already successfully absorbed the foreign medical items and invasive care tasks into their home and their lived world, can spark the confidence to start this process yourself. Even though the HPN patient union is young with just 5 years running, it is a resource to a small but very specialised group, who might not find a home in other patient unions. Marianne affirms this point by stating; *"Here we are all normal"* (Appendix B4:58f).

The opportunity for reflection, offered by the HPN patient union, is something that Lone has been missing, not only for herself but for the other person in her home. She suggests how an event hosted by The Danish Rheumatism Association could strengthen how her spouse perceives and understands her lived world. Such an event would be a space for family members to mirror their experiences as co-dwellers with a person with chronic disease and discover how *"all that, which is cumbersome in everyday life* [with chronic disease] - *it is very common"* (Appendix B1:12). For Lone, it is not handling her injections that bother her because these have become habitual. It is the realisation that she gradually has to ask for more and more help, as her body slowly succumbs to chronicity (Appendix B1:16).

Conclusion: You have to know each patient and outline their resources to paint a bigger picture of what and whom they are going home to and in which mental state they are able to leave the hospital. Alongside this care practice, health care professionals must make sure that the medicinal treatment plan is constructed to be the best fit for each individual patient. Case 1 reflects care that is divided into care for the body done at the hospital and care that helps the body function in the home. It is completely up to the patient to find networks and methods to tinker with the latter. Case 3 is an example in which there is a smoother transition between these two care practices because of the collaboration between the HPN department and the HPN patient union. Having the support of someone who has been through the process of domesticating a changed life world can help you rebuild your home in a way that once again reflects your image, which now includes hints of patient life.

Planning, sharing and aiding

The gradual need for more or different adaptive aids means that Lone has to be creative. There are items available that are designed to make everyday life tasks easier for arthritic bodies, such as special cutlery and devices to help button a shirt (Appendix B1:9f). And then there are the carefully chosen consumer objects because not all shampoo bottles or door handles are easy to open (Appendix B1:16f). Both of the above require planning when shopping for the household, and when tinkering with the interior structures of the shared home to fit your needs. Trivial tasks, like pulling out a shirt from a stack of clothes or reaching for the kitchen faucet, suddenly appear to be insurmountable. It also requires budgetary planning which involves all who live in the home. *"We just cannot afford it all",* Lone concludes when talking about all the ways she and her spouse could rebuild their home to make it more accessible to her (Appendix B1:10). Here there are situations where solutions are chosen out of 'friendly uniformity' because in a shared home it is not only Lone who has to come to terms with needing adaptive aids. A recent instalment is an extra seat for the toilet which facilitates better hygiene but was *"(...) a huge thing to overcome for both me and my husband"* because it looks like a disabled toilet (Appendix B1:9). The same process of coming to terms with their shared lived world was when they acquired a new car with automatic gears. Again there was the sense of having a type of aid that was not previously needed combined with a feeling of something lost because *"(...) you feel more like you are driving a car when you can change gears"* (Appendix B1:11). However, concessions can be made to serve the collective good of those living in the home.

Another commitment to the collective good is rooted in the allocation of space. Not only for the medicines and items belonging to treatment but also for the misplaced vacuum cleaner which can pose a threat to entering your closet. For Lone, it is important to trust that her temperature-sensitive biological medicine is not moved around in the refrigerator, where wrong placement can mean that it is subjected to frost. But it is also beneficial that those you share your home with can put themselves in your shoes which, at times, means strategically putting your actual shoes in places where your spouse will not have to move them (Appendix B1:10). These considerations can be the care efforts that determine whether Lone follows through on an action or not. She mentions a rather simple example of preferably not stacking things in the refrigerator and elaborates;

> *"I go and open the refrigerator and then I say 'oh I actually won't bother, I am a bit busy right now' and then I close it again. If I see that I have to lift this and that to reach it"* (Appendix B1:10f)

These misplacements do not necessarily deny Lone feeling at home but small considerations from her co-dweller make it easier for her to dwell in their home as well. In other words, she benefits from having her spouse use tactics that allow her 'to home' in the sense that her home becomes more accessible.

Conclusion: Where patients in case 3 are sent to gradually regain their territory in and around their home by rebuilding it to fit their abruptly emerged needs, those who experience gradual deterioration must continuously re-territorialise to fit their changing needs. For them, dwelling is a continuous process of adapting your home as your physical capabilities fail to keep up with the home you have already built because stocking up for what cannot be anticipated is not possible. Modifications can also mean that you have to come to terms with adaptive aids with which you did not previously identify. Care is a shared effort, especially when you share a home with someone who needs you on their care team.

The room for treatment

The items needed for the shifted tasks take up a differing amount of space. For patients in case 2, the technology and the bag that encases it do not leave the persons' side. It has to be placed in all the rooms you place yourself in. At the most, you have a kit of utensils to assist disconnecting from the pump which must find a temporary space in your home. The relatively short treatment period does not allow a lot of space for domesticating the pump, nor for it becoming habitual. The patients describe both consciously and subconsciously keeping an eye on the function of the pump for the duration of the treatment (Fridthjof 2019:28).

The chronicity of case 1 and 3 means taking or rebuilding larger chunks of home to make space for medicine and treatment utensils. For Lone, this means altering small parts of many rooms because she needs a whole shelf in her utility room for the cooling bag, space in the freezer for the cooling elements, space in the refrigerator for the temperature-sensitive biological medicine and space in a kitchen cupboard for the ambient temperature medicine and supplements. For both Lone and Marianne the most critical point in time is just after medicine collection or delivery respectively as seen in pictures 1, 2 & 7 (Appendix B1:6,B4:48). Six syringes in a fridge door means less room for milk cartons, because the medicine is to be kept in its boxes (Appendix B1:5ff). Besides the medicine, Lone has to make room for many adaptive aids which are present throughout her home. She has acquired many smaller kitchen machines, with easy-to-use buttons and angles she can hold onto without pain, but contemplates investing in one that can do it all to save space (Appendix B1:16). Not everything which aids her movement with arthritic joints has been produced for that purpose but many items are carefully picked to do so, to help her 'to home', to facilitate dwelling.

Marianne has taken control of the guest room and made it multifunctional by rebuilding part of it. Taking over the guest room wardrobe was insufficient, so putting in a wine-fridge and an extra kitchen cupboard to make space for all the different utensils and fluids was necessary, as shown in pictures 3-6 (Appendix B4:48). This controlled space is chaotic when she receives a delivery, which she depicted in pictures 1 & 2, so she prioritises putting everything in place. A specialised transport company has the key to her home and the driver places the boxes in the right room for Marianne to handle:

> *"And then when I come home, I empty boxes and everything and throw the cardboard in the dumpster. I try to get everything done as fast as possible because otherwise you just have a lot of boxes"* (Appendix B4:48)

She points to the importance of swiftly incorporating the unfamiliar and unhomely into the controlled space because she needs the room to be less like a hospital and more like her guest room (ibid).

Things must be moved to make space for the necessities that treatment items have become, which means that you have to make space or cram in these then homeless things elsewhere. Lone has to rearrange the contents in her refrigerator because the biological medicine has been allocated a fixed place in the door. *"It is a bit of a hassle"* she says and repeats this when describing how she has to remember to put the cooling elements in the freezer in time for medicine collection (Appendix B1:6). Even if there is enough space to let the freezer be the only storing place, it complicates other tasks if she has to move them around to access the edible contents in the freezer, with her arthritic hands in pain because of the cold (Appendix B1:5).

The rules to be broken

When Marianne closes the door to the guest room it becomes her space, and a closed door signifies this rule. For her, there is a ritual to preparing her daily nutrition, which she has done every day for so long that it has become tacit knowledge. The ritual includes watching something she likes on the television, which is her tactic to defer the ritual from being only treatment to also being a way 'to home'. *"It has become my space"* she says though it turns out her space can be imposed upon, and the rules broken. The trespassers are her kids who realised that their mom was in a fixed place for long enough for them to sit on the bed and discuss *"(...) the state of the world"*. Thus, the ritual changed to sometimes incorporate this interaction, which they continued doing over the phone after moving away from home. *"(...) then they say, 'can you call when you prepare your nutrition?'. Then I have them in my ears while I am making it",* Marianne elaborates (Appendix B4:49). The guest room has become multifunctional not only constituted by the items in it but also by the people who are invited or invite themselves in.

Conclusion: A home can be built by picking items that facilitate the way you move in the home. Patients can choose to take control of a space, whether it is a drawer or a room, to rebuild this space to fit their medical needs.

The nonhomes

The gathered qualitative data gave a glimpse of which care practices and issues were present when the home was left behind.

The domestic trips

The regular cycles of home life can be disrupted because of an adventurous need for travel. For Lone, this could be a trip to their summerhouse, where she can feel at home because of the recognisability and repeatability it represents when she and her spouse go there together. She does, however, need to apply tactics to more-territorialise the summerhouse and these are to bring certain items with her. The kitchen utensils she needs to help with the cooking and the pills carefully sorted in dosette boxes for each day are already packed in a portable plastic box and toilet bag, respectively. As Lone explains, *"I have to make it easy. I don't want anything inconvenient when I have to pack for the summerhouse and get out the door"* (Appendix B1:8f). These items help Lone carry on as she would at home, because at home she has already arranged things to be more accessible and strategically practical. Because the biological treatment is biweekly, a shorter trip does not have to include the medicine and the hassle of keeping it at a set temperature range. The hassle is bringing kitchen utensils instead of tactically buying duplicates to leave at the summerhouse. The operative word here is 'buy' because *"(...) it would have been smart to have had all of it up there but I cannot afford it"* she says (Appendix B1:9,3).

The treatment scheme that case 1 patients follow does not serve as a deterrent for them to travel if they feel up to it. What they must consider is how to plan so they may safely bring the necessary stock of biological medicine with them without compromising their moral responsibility of keeping it safe. That part is characterised by individuality and is, therefore, not part of the instructions given by the health care professionals in the first place. The approach is, however, that anything is possible because *"[w]e have young people who go travelling, backpacking, who try to bring it in portable refrigerators",* Hanne explains (Appendix B2:19). Here, the rheumatological department recommends the patients to contact them so that suitable advice can be given on which tactics to apply in individual situations (Appendix B2:27). With a background in nursing, Lone has an inquisitive attitude to her disease and treatment. However, she has acknowledged that some information should simply be acquired when needed. She explains:

> *"(...) before I wanted to know a lot, now I don't think it matters - if I am going travelling and I can't find information to read about it, then I have to contact them* [the department]. *That is how I feel now because it is unimportant to know something I will only need in a year or more"* (Appendix B1:4)

Lone is active in seeking information through networks, such as Facebook or The Danish Rheumatism Association, and she also took the incentive to consult an ergotherapist (Appendix B1:10,13ff). She aims to get her questions answered as they arise because her needs are constantly shifting. Getting answers supports Lone in tinkering with the way she injects her medicine, the food she eats with her nutritional supplements and how to secure the quality of her biological medicine during travel (Appendix B1:4f).

Mobility across borders

Marianne has ventured beyond the borders of Denmark on numerous occasions and had her fair share of strenuous experiences along the way. One of these was arriving in the south of France to find her pump broken during the flight. To facilitate getting her infusions of carefully packed and imported nutritional fluids, she bought a nail to hang the fluid bags on. She explains her interim solution by adding: *"Well then I had to let it drip in via gravity and I hate that. Because then I am suddenly tied to a hook"* (Appendix B4:49f). Eventually, Marianne's mobility setback was solved because of her ingenuity in calling the company producing the pumps and that company's express delivery to a little village in the French Alps. Even though travel is cherished by Marianne, she admits to breathing a sigh of relief the moment she steps back on Danish soil because of her awareness that she is *"on my own",* as she puts it (Appendix B4:49f). As long as she is in Denmark, even if it is away from home, she knows that getting in contact with a secure lifeline, the HPN department at Rigshospitalet, is just a phone call away. In contrast, she feels that there is *"(...) just an extra layer of responsibility, on me that is when I am travelling"*. Here she refers to the role-responsibility of a travelling HPN patient, packing everything she needs and getting it transported safely (Appendix B4:44,46,49). She also alludes to the responsibility of finding a rapid way home if she needs to return, as was the case when her catheter ruptured during a trip to England (Appendix B4:50).

Though she has gone through different ordeals when travelling, Marianne still actively advocates giving yourself the freedom to do so. The HPN patient union offers group travel in a safe manner where a specialised nurse is always one of the company of travellers. This approach offers a sense of comfort because patients travel with people with similar medical needs and the casual presence of a health care professional. As Marianne points out; *"(...) for several people it has been an eye-opener because 'oh wow, you can do that'. And many have had the courage to travel on their own afterwards"* (Appendix B4:59).

The travel perspective in case 2 is somewhat incomparable to case 1 and 3 because the patients are considered inpatients throughout the chemotherapy treatment. The chemo bag has, however, induced mobility in their lives. For those still physically present at the hospital ward, it has eased even something as trivial as bathroom visits and created opportunities for the patient to go for a walk in the park. When you leave the hospital, it is with your treatment in your backpack along with a treatment plan of scheduled checkups and a date where the pump should be disconnected to finalise this round of treatment (Appendix B3:32f). Therefore, case 2 does not present the same issues regarding travel abroad. There is, however, a point to be made about the mobility you gain when you hybridise with a pump instead of a drip stand. Patients can feel distancing from the role as a patient in a positive way, making them confident in resuming daily tasks in their lived world along with allowing flexibility to join social events. Having the bag with you means you do not have to miss your daughter's birthday, and you can go visit your workplace or participate in a planned seminar (Fridthjof 2019:24f; Appendix B4:47). Disease makes bodies erratic and so too does chemo-treatment, which means that any freedom of mobility is conditioned by your well-being at any given time. AML patients must, as both patients and part of the care team, be mindful of their moral responsibility to care for themselves during treatment. This is where the comfort of the physical home becomes a safe retreat because you can make the rules on who to invite in and decide a timeframe as well (Fridthjof 2019:27).

Conclusion: Having specialised medical needs does not hinder acting on adventurous notions. It does, however, take a sense of confidence to trust that any emerging challenges can be addressed, even when you have assumed the responsibility of being far from your domestic lifeline. Travelling with people who reflect your own situation is a way to induce confidence to more-territorialise hotel rooms abroad. Mobility is key because it awards freedom to join in the local and international activities you want to if your body allows it.

Hospitalised

A disruption can also be abrupt and unplanned because your erratic body needs hospitalised care. For patients in cases 2 and 3, there is a special connection to their hospital ward that starts when they are admitted and connected to their respective pumps. Part of this connection is the care given at a distance by the health care professionals, as exemplified by the Chemo To Go project, where resources were initially being reserved for the unknown potential challenges:

"For the first 2 years, the patients were still admitted so they had an empty bed (...) even though they were at home. In this way, we would get a picture of how many call in and what are they calling for? And how many resources should we use for this? And then it was actually a comfort for the patients to know that if they became ill then their bed was there" (Appendix B3:37).

Patients were given a home away from home in case they needed it until it was established that the majority were doing practically, physically and mentally better at home. However, having a hospital bed with your name on it is not equal to that space being a de-territorium where you feel at home. Ultimately, the Chemo To Go project resulted in a de-hospitalisation that induced "de-patientalisation", in the sense that patients feel less like patients at home. In their home, patients can regain control by being in a space that they control and they may remain active instead of passively receiving treatment in a hospital bed (Fridthjof 2019:35).

Being your own expert

The careful and strict process of learning how to do your own parenteral nutrition program establishes the connection between the HPN department at Rigshospitalet and its patients. If admission to the ward becomes necessary, it is a place where patients actually relax in the sense that they get to take a break from the role-responsibility that is preparing their own nutrition. Louise refers to patients expressing how it feels like having an eternal infant *“(...) that you cannot hand over to the grandparents. That you are just responsible for all hours of the day, all day. That is every day, all week, all year”* (Appendix B5:68). Therefore, the HPN department is the only place where patients can fully put their trust in the health care professionals because they do things precisely by the book. The “drip book” that is, which is the source that patients are advised to refer to if they find themselves in the care of other hospital wards. The HPN department not only equips its patients for a lived world on their own, it also equips them with the confidence to stand up for their treatment, which at times means facing down a person in a white coat (Appendix B5:68f). The HPN department strives to send their patients off to become expert patients who can erode traditional health care hierarchies. Through her work in the HPN patient union, Marianne has heard multiple stories where this was the case, which correlates with her own experiences with having to act as *“(...) my own doctor and nurse, and that is very tough”* (Appendix B4:44). The difficulty is the negotiation with the nurse or doctor, where the goal is to have them trust your competencies and literacy in your own disease and nutrition while engaging in cooperation. However, patient inclusion is not always a matter of course, which is why patients are led to apply tactics and attempt tinkering. Marianne recalls how she has resorted to little white lies to, in one instance, get a sterile infusion line that had not been dragged across the floor. *“If you have tried having sepsis just once, then you fight tooth and nail for it* [your CVC] *the next time”,* she elaborates (Appendix B4:52). In other situations, Marianne has needed to be active in encouraging care activities such as laboratory tests, which a doctor ordered on her suggestion, in one case, while also confessing to not being able to interpret test results. Here, applying a tactic to get things done ended in Marianne tinkering with how to read the results, because she knew she could always call the HPN department for guidance. This lifeline did, however, not stop her from feeling *“(...) very alone regarding the treatment and the handling of the sterile* [processes]*, and making sure that I got the fluids that I needed”* (Appendix B4:45).

Marianne has managed to navigate her way out of these situations but not without losing all confidence in the care provided at other hospital wards that do not seem to understand the specialised needs of HPN patients.

Losing control

The concern about who will care for you is put into a future perspective by both Marianne and Lone, who have both had experiences with not being heard. The moments Marianne feels the most uncomfortable is when she is admitted to other hospital wards because she has to be attentive in ways that she does not when at home or even travelling. She addresses the scenario of becoming *“(...) so ill that I cannot prepare my own parenteral nutrition”* by pointing to the fact that other hospital wards most probably would not be able to handle the task (Appendix B4:45). Lone expresses concern that she would not be able to articulate her needs if she happens to become a resident at a nursing home in the future. She fears that the staff would not be aware of how different the days with chronic arthritis can be, or how much the biological treatment can hurt if injected too fast. Her fear originated in her experience being schooled at such a nursing home as a nurse *"(...) and I know how much myself and my colleague knew about it* [arthritis]*"* she notes about her previous lack of knowledge (Appendix B1:12).

Conclusion: Making selected items portable allows accessibility to travel whether it be taking a bus to your home or an aeroplane to the south of France. The responsibility you feel for your own treatment is heavier when you are outside the familiar frames of your home where routines govern the treatment process. Admittance to a different hospital ward can add to this burden, if correct treatment depends on whether you establish your role as expert patient and challenge hierarchies. You may need to negotiate and make your voice heard as well as your competencies respected. When respect is given, task-shifting happens and patients regain some control, though the controlled space is incomparable to the one in their home.

Quality perceptions

The notion of QoL emerged throughout the interviews though in different ways. Both Katrine and Louise had done studies of this using standardised tools to conduct them, thereby establishing QoL as a definitive incentive for home health care with shifted tasks (Appendix B3:39,B5:66). Mentions of 'life quality' were frequent in the interview with Marianne, especially when referring to HPN patients in general, and in the conclusions in Katrine's qualitative studies as well (Appendix B3,B4; Fridthjof 2019:35,43).

A way to measure quality is for both health care professionals and patients to report adverse health care events, though it is a system most used by the former. For the HPN department, the relatively low amount of adverse event reports is a testament to the success of the task-shifting as well as a defence against those who try to change it. Louise explains how they at times argue: *"(...) if you say it is so unsafe, then I would expect getting more adverse health care event reports, which we do not"* (Appendix B4:67). The long-established HPN care regimen has left the health care professionals confident in the task-shifting process from hospital to home, and this confidence is channelled to the HPN patients. This means that they are trusted to act when something is or seems wrong, which was the case when Marianne received a delivery of wrong fluids or when she received a box of fluids with dirt on it (Appendix B4:51). The quality assurance taught to patients is principally centred around sterile procedures, which is why, for patients like Marianne, it has become habitual to be attentive. *“So everything that touches the floor I won’t use when I am unpacking”,* she explains (Appendix B4:50). In case 1, the shifted quality measures involve sterile procedures, but more emphasis is put on the condition of the biological medicine. Before self-administering, patients are instructed to examine the liquid which should appear clear. A cloudy liquid could indicate a denaturation of the proteins and could be caused by wrong storage and transport, which is why these logistics are a big part of quality assurance for medicine sensitive to temperature and mechanics (Appendix B2:23).

Patients in case 2 are not required to take on actual treatment tasks, but they are expected to act if something is or seems wrong during the treatment. To facilitate this responsibility, Katrine describes how, when starting the Chemo To Go project, her department carefully systematised every bit of information that the patient would need about treatment using the chemotherapy pump. Here, the information is both technical in understanding the pump and the medicine pumped through it and also physical because there are many things to be informed about when cytostatics are pumped into your body. A system was needed because health care professionals could no longer just pop into the room and provide details as they became relevant. *“We were used to a smooth transition”,* Katrine explains and gives an example of the kind of situation that helped them tinker to ultimately ensure the quality of treatment: *“We experienced that the patients came back and said ‘Oh, it is now that I am losing my hair - I did not realise that’”*. (Appendix B3:37).

Besides the difficulty with timely information, there was also a question regarding too much care. As a quality measure, and to ease the mind of health care professionals at the start of the project, patients would be called to check-in. However, the patients saw this as a nuisance so *“(...) we listened - we have included the patients a lot in this”* (ibid). Ultimately, a system was developed which clarified the tasks and responsibilities of the treatment team, in which the patients were important and active team players (ibid).

The calculated risks

Calculating risks in relation to shifted tasks in home health care is carried out in two arenas. The first of these concerns health care professionals, who are ultimately accountable for the treatment, and must adjust their care to whether tasks are shifted to the patient or the primary care sector.

Katrine sees great potential in shifting tasks from the hospital to the primary sector, however, an effort is required to shift the competencies as well (Appendix B3:33). Otherwise, moving the treatment responsibility will pose a risk to the comfort of the patients and the quality of the

treatment if primary care nurses are not able to answer patient questions and find proper solutions to technical problems. In case 3, this responsibility has shifted for a number of patients who found themselves incapable of handling their own nutrition. However, similar to when their patients get admitted to other hospital wards, the HPN department must be diplomatic and negotiate with the individual home care nurses, to make sure that both the nurse and the patient feel comfortable in the arrangement (Appendix B5:63,68). In comparison, there are different risks involved when shifting tasks to people without a health care background. By stating: *“The absolute biggest barrier in this has been the health care professionals",* Katrine points to the ambiguity felt by health care professionals when sending patients home (Appendix B3:39). For this reason, the care team discussed *“(...) to what extent did we notice something before, that we do not think the patient would have noticed?”* (ibid). This type of discussion encapsulates the dubious nature of task-shifting because it requires a give-and-take negotiation of control between those involved even if the shared goal is patient autonomy. Patients might only have the set of guidelines given to them by the hospital department, but how they apply them is up to the individual, which leaves room for tinkering.
The other arena is run by the individual patient who knowingly goes against guidelines to fit their treatment into their lived world. Marianne takes risks when she feels it is safe to do so. When she goes out to dinner, for instance, and has to connect to her pump, she might do it in the non-sterile restaurant wardrobe. Calculating risks still takes planning, which Marianne describes in this situation:

> *“Well, if I am out and I disconnect, then I just bring a 10 mL saline flush in my bag, and I do not start putting on gloves and all sorts of things. I just disinfect and inject with my hands, which I, if I assess them to be clean or not, just go wash them”* (Appendix B4:48).

Assessments are made and the best-fit solutions applied, whether it be for an evening out or a holiday abroad, as previously described.

Conclusion: Whether QoL is used as the official concept or casually, it is a recurrent notion with both health care professionals and patients, to whom it is a central incentive for home treatment. There is comfort in strict guidelines given by the hospital providing treatment because, when no shortcut or tinkering is allowed, you trust that the guidelines are there for a reason. It also gives patients confidence to convey such guidelines to a third party. Health care professionals can struggle when tasks are shifted because they not only have to trust that instructions are followed but also that subtle signs of side effects are noticed by the patient. Allowing risks is, however, a necessary compromise to having patients experience the comfort of their home and the recognisability of doing daily tasks or the freedom of participating in social events.

Analysis results

Theoretic or thematic phrase	Insight condensed	Cases represented
Bringing space under control	The space needed to be brought under control depends on how voluminous the treatment items are. There is importance in bringing the allocated space under control swiftly to minimise the hospital feeling. The rules posed for a controlled space can be broken and rituals changed.	1 & 3
The home as a reflection	Reflecting in others can help a patient rebuild their home to reflect them. There is courage to be gained by travelling abroad with others in whom you can reflect your own situation.	1 & 3
Building and dwelling	Rebuilding a home for medical needs to allow dwelling with a body affected by chronic disease. Adaptation of the home is a continuous process for patients with advancing chronicities.	1 & 3
Winther's (2006) four notions of home and territories	The home (as idea) can change because it has to be envisioned with treatment items in it. Covid-19 has shifted tasks such as drive-in collection of medicine and filling in questionnaires. Patients can feel at home while doing certain shifted tasks. Being home means freedom to use tactics 'to home', but there is a danger to this freedom that is negotiated with trust in and knowledge of the patient.	1 & 2 & 3

	Accessibility facilitates patients' ability 'to home' and it depends on the people and the adaptive aids in your home. More-territorialisation of nonhomes can be achieved by the accessibility of portable aids and treatment items.	
Planning and sharing	Rebuilding requires budgets that allow it and a consensus that it benefits the collective good of the home. Budgets concern both finances and space allocation. Rules are the groundwork for responsibly sending patients home and the rules benefit the collective good of the care team.	1
Nomadic objects	A pump allows mobility to travel from the hospital and enables travel from home to work, seminars or social events.	2 & 3
Active and tinkering patients and professionals	Tinkering is done by professionals who get to know a patients' body, person and resources. Patients must actively find and join networks and within them, there can be an inspiration on how to tinker. Patients can be active and tinkering when at the hospital, especially if the ward does not fully comprehend your treatment scheme. Being an active patient can mean being observant and reactive to potential issues.	1 & 2 & 3
Domestication	Tinkering is a big part of domesticating long-term and lifelong treatment. Temporary treatment cycles do not leave room for domesticating a technology	1 & 3

Responsibility	Role-responsibility is assumed by following instructions and using the resources you have as a patient at home. Moral responsibility occurs as patients' efforts to not waste resources. Health care professionals can struggle with patients leave their ward where they can follow them closely. Responsibility of treatment should only fall on family members where it is temporary or if they fully understand the consequences. The felt responsibility weighs heavier when travelling, especially where a lifeline is further away There can be discrepancies between felt and taken responsibility for treatment when patients are admitted to other wards. Concern is voiced about having others do your treatment and care if they are not specifically trained to do so. The negotiation between the hospital and the primary care sector or the patient is crucial to ensure good individual care.	1 & 2 & 3
Quality	Quality measures are challenged by the autonomy given to patients when they leave the hospital. Quality can be both improved and measured by both qualifying and quantifying when tasks are subjected to errors (adverse health care effects), caused by patients, professionals, or devices. QoL is both an incentive and a tool to measure the effects of home health care.	1 & 2 & 3

Table 5: Analysis results

Scaffolding the trinity

This section provides an additional perspective on the insights presented in the analysis and the results listed in table 5. To do so, the terms of scaffolds and scaffolding (Botin 2015,2016,2020) and the trinity that constitutes the care team (Pols 2012, Mol 2008) are applied.

The three cases present three perspectives on what constitutes a care team. Technology is present in all three of them but how the health care professionals and family members engage differs. Differences attest to the many ways a scaffold can be constructed to fit a case or an individual. In case 2, the development of the home health care solution was done by asking *“what can happen?”* (Appendix B3:37), because it seemed crucial to be prepared for every potential flaw when the department started sending patients home. This approach, combined with trusting the patients and listening to their feedback, has left a symbiotic trinity in which patients, their devices and health care professionals are all cared for. They are pieces of a well-assembled scaffold within which problems, as well as good care, are shaped. The same can be argued for case 3, though the goal, in this case, is to let the patients loose in a much more autonomous manner. There is also an extra player on the care team in the role of a supplier of utensils and nutritional fluids (Appendix B5:60). This extra link means that patients must be able to react if errors should occur in regard to delivery. The key word in case 3 is confidence because it is essential to the way patients perceive the parenteral treatment as part of their life world and how you understand and are able to defend the treatment process when needed. *“So I think the approach is very dependent on your outlook on life and worldview”,* Marianne concludes after sharing a story of a patient who opted out of the pump solution and, furthermore, named her drip stand after a teacher she hated (Appendix B4:55). Not all patients choose to become experts and scaffolds must then be assembled accordingly for individual patients who refuse the offer to shift tasks. The HPN department offers confidence and autonomy to those who choose to take it, and those who do not are offered the same treatment with fewer tasks shifted to them. Either way, scaffolding happens because fits between devices, professionals, family members and patients are established based on the individualised needs and resources of the patients.

The actively strengthened scaffolds

"(...) to have parenteral nutrition, in itself, is not worse than having a leg or arm prosthesis. It is a nuisance and you wish that you did not have it, but it is a premise for living life" (Appendix B4:54).

Marianne does not view her nutrition as medical treatment limiting her but instead as an opportunity for living (Appendix B4:48,54f). Lone shares a similar view in the sense that preparing a syringe is no different for her than opening a pill bottle with vitamins which improves her life. *"I do not feel it is something I have taken over from someone",* she explains when asked how she views the treatment task that is self-injection (Appendix B1:3). They both actively take part in their treatment and they both actively seek knowledge and support in networks outside the hospital as well. These networks are not part of the trinity that constitute the built scaffolds, mentioned in the section above, but they tend to strengthen them. Facebook networks and services offered by patient unions provide knowledge and support through reflection in others with similar experiences. They also enable people to acquire knowledge when they need it and when the scope of the inquiry falls outside the care of the health care professionals (Appendix B1:13,15,B4:47,53).

Conclusion: A well-assembled scaffold must leave room for patients to tinker and fit devices and treatment into their lived world and their home. This implies that health care professionals should be able to trust them to do so. Such trust can be obtained through preliminary care and training during which patients' resources are revealed. On the other hand, patients should trust that their problems can be solved, and questions answered despite this care being provided at a distance. The trinity that constitutes the core elements of scaffolding can be strengthened by networks actively engaged by the patient.

Discussion

In this section, a selection of discussion points is presented. Firstly, the issue of terminology for the cases where tasks are shifted to patients in their homes is addressed. Secondly, the analytical insights are positioned in comparison with the *“Safe, Near and Easy”* strategy (Danske Regioner 2018) and lastly, a discussion of case selection will finalise the section.

Who does home health care?

Through researching cases and literature and in the interviews with health care professionals an imbalance was discovered regarding terminology. It seemed that despite rigorous searching and inquiring a suitable name did not exist for home health care that involves patients assuming treatment tasks. In the literature, home health care popularly represents care performed in patient homes by health care professionals belonging to the primary care sector (Di Mascolo et al. 2017; Jones et al. 2019).

Both Marianne and Lone describe how their treatment is just something that they do. They do no longer see it as treatment but increasingly as a premise for living their best life possible. The question remains on whether a new term or terminology is needed that covers home health care in cases where patients perform the tasks included in their care. Finding new ways to conceptualise health care in these cases may contribute to the empowerment of the patients involved (Østergaard Jepsen et al. 2016:24,73).

Fitting the strategy

The *“Safe, Near and Easy”* strategy can be subjected to interpretation by analysing the title alone. The Danish word translated as ‘safe’ in this thesis is better translated as the trust citizens have in the quality of the health care system which makes them feel comfortable in using its services. As a patient whose life depends on highly specialised daily treatment, Marianne has little trust in hospital departments other than the HPN to correctly handle her parenteral nutrition. She is not alone in this mistrust, which she elaborates with an anecdote about a fellow patient, who experienced devastating malnutrition due to a lack of knowledge and responsiveness from health care professionals while admitted at a non-HPN department. Their refusal to follow this patient's appeal for them to contact the HPN-department led him to subsequently tell his wife to dump him at the square of a city further away if he ever became this ill again. This way he was certain that the ambulance would not transport him to the hospital where the adverse health care event happened (Appendix B4:46). Lone has experienced mistrust as well when meeting health care professionals she did not feel comfortable with. In line with the concept of the patient-responsible physician, she wishes that her regular consultations at the hospital would not be with different physicians, nurses and pharmacists every time. Lone is aware that resources do not permit having *"(...) the same nurse, they* [the department] *cannot handle that. But if it was just 2-3 you see* [in consultations]*"* (Appendix B1:7).

The word 'near' first of all describes the goal of moving treatment and care nearer patient homes. Secondly, it contains a sensory interpretation as well, referring to the feeling of being near the ones providing your treatment in terms of easy access and contact. Patients in all three cases experienced ease in contacting the department responsible for their treatment, though the severity of the treatment, understood as the consequences of postponing it, was a key factor in regard to response time. Lone often had to wait for the phone to ring, even though she was given an official consultation timeframe. For her, this was a nuisance but not alarming, as her treatment with biological medicine can be postponed for a day or two without noticeable consequence (Appendix B1:5; Hansen et al. 2020).

The last word in the title requires less interpretation, as it simply refers to the goal to have patients navigate the health care system easily, across departments and sections. This has proven difficult for patients in case 3, who often experience a lack of understanding from health care professionals at other hospital departments. The argument that the HPN department loses its 'jurisdiction' in terms of treatment responsibility (Appendix B4:45) is in contrast with the ambition to assign patient-responsible physicians to patients crossing departments. In this case, there seems to be an inconvenient gap for patients receiving specialised treatment to fall through, as HPN patients are seen as outpatients belonging to the HPN outpatient clinic and not as inpatients with ties to the HPN ward (Appendix B5:60).

Some aspects of the *"Safe, Near and Easy"* strategy are recognisable in the cases, especially when it concerns the vicinity of care to patient homes. Others illuminate gaps where certain groups of patients may fall through because their specialised treatments do not match generalised approaches to creating coherence across departments. Despite the intention, the strategy, as a whole, has yet to prove its worth as a robust, professional, and responsible solution.

Case selection in hindsight

The cases have been chosen partly by the availability of informants as previously described. The choices have left a layer of patient involvement unexplored, which concerns the self-monitoring aspect. The shifted tasks follow different levels of involvement though none of them can be considered within the realm of telemedicine. The Constant-Care for IBD case could have enriched the analysis and the insights gained from the analysis process, as IBD patients in that case both perform a point-of-care analysis, which normally belongs in biochemical laboratories and subsequently act on the results. Those two processes happen without the interference from health care professionals, which leaves an interesting discussion of trust-based care that has eroded traditional patient-health care professional hierarchies.

Chosen case representatives

Patients like Lone do not reflect all patients receiving biological medicine and neither does her home. Not only does she have to make space for the foreign objects in her fridge and cupboard, but she must also continuously adjust her home to her body’s changing needs. This means arranging things in ways that make them accessible for arthritic hands or buying products that make everyday tasks like cooking, cleaning, grabbing clothes from your closet and opening your shampoo bottle easier. At times these products make tasks surmountable that otherwise were not (Appendix B1:10f). Some of these are designed to be aides for people affected by arthritis and some are just deliberate choices made in the aisle for cleaning supplies in the supermarket. What is evident is how these aides and carefully chosen items slowly fill up a house (pictures 7-15). In comparison, other people receiving biological medicine might do so because of severe asthma or psoriasis for instance (Jacobsen 2020). These patients must consider both the transport to and storage of biopharmaceuticals in their home, but they do not need to consider aids and well thought out shampoo purchases on the same scale.

A patient like Marianne represents an expert patient who is confident and empowered in ways that many HPN patients may not be. Her lived world includes a perception of responsibility that reflects her confidence, which is the case for her ways to tinker with quality assurance as well. Marianne represents many HPN patients through her role in the HPN patient union and brought several anecdotes to the table for that reason. However, neither Lone nor Marianne can fairly be attributed the burden of representing all patients within their respective cases and generalisations must, as a consequence thereof, be made with caution.

Conclusions

In this concluding section, the insights gained through analysing and discussing the data and literature is condensed to answer the question posed in the problem formulation:

How are the quality of treatment and the treatment responsibility perceived by patients and health care professionals in home health care, in cases where care and treatment tasks are shifted from health care professionals to patients?

As expected, the three cases revealed both differences and similarities in regard to treatment quality and treatment responsibility.

Regardless of the types of tasks shifted, instruction played a large role in patient understandings of quality assurance processes. Domestication of these processes, especially when care is long-term or life-long, often lead patients to tinker for the purpose of merging treatment with their lived worlds. Both health care professionals and patients calculate risks. Patients take calculated risks as part of their daily life and health care professionals balance risks of adverse health care events with the incentives for sending patients home. A key incentive is QoL or 'life quality' as measured or felt by health care professionals and patients, respectively, and a key measure assuring the quality of home health treatment is the reporting of adverse health care events. QoL is increased because of the mobility achieved by sending patients home with portable technologies. The mobility covers local movements in patients' homes or to supermarkets, birthday parties or to their jobs, as well as international travels.

Instructions and a sense of being near the instructing hospital department inspired confidence to, for some, assume daily life and for others to assume the responsibility of 'being on your own' in another country. The weight of responsibility is especially heavy when communicating with health care professionals who do not understand or attempt to comprehend the extent of a patients' specialised treatment and needs.
Patients were seen to take on the role-responsibility needed to responsibly handle their home treatment, however, in situations where the responsibility is refused or deemed irresponsibly placed, the primary care sector can be engaged. Such engagement requires negotiation between the treating hospital department and home care nurses, to ensure tasks are performed in a way that the department deems correct and responsible. Some patients expressed a sense of moral responsibility to ensure the quality of their medicine and to not waste the resources given to them.

A criteria for sending patients home with treatment is for health care professionals to know them, their needs and their physical, mental and social resources, though all patients are expected to return home with the right structures and support systems in place.

The home is where empowerment and autonomy are powerful allies that help patients combine their lived worlds as patients and dwellers. Homes can be rebuilt to fit, and sometimes hide, treatment-related items and adaptive aids, as there is some importance to the home not resembling a hospital. Rebuilding requires planning for the collective good with co-dwellers, as not all remodelling fits within the shared budget.

Health care professionals, family and devices contribute in different ways as important members of the care team, and networks can be consulted to strengthen the assembly of the team.

A potential in patient unions

It was originally beyond the scope of this thesis to investigate the topic of patient unions. The data, however, revealed their significant role for both patients and health care professionals. It also illuminated the gaps between hospital departments and the patient unions and struggles to close those gaps. I argue that further study of this gap could benefit both patients and health care professionals. Patient unions hold the potential to be the piece of scaffolding that could support and, thereby, ease the shift between home and hospital. Patient unions also play a role in patient empowerment which is crucial in sending patients home with continued treatment (Wilson 2013). The empowerment aspect is twofold where confident treatment handling is one side and the other concerns confidence to resume life in your lived world, whether this includes travelling or acquiring perfectly fitting adaptive aids.

For the HPN patient union, there is an issue with reaching the relevant patients. From the three cases, this union already has an exceptionally engaged relationship with the HPN department at Rigshospitalet, however, HPN patients are distributed across the country. People like Marianne are passionate expert patients, who work to encourage empowerment and autonomy by showing the path to an independent and confident lived world. These intentions are inhibited, however, by regulations on data and patient security, which do not allow health care professionals to pass information about a patient without their consent (Appendix B4:55,58). This means that the HPN patient union must rely on the HPN department to inform patients about the union's existence or trust that patients find out on their own.
This leaves an exploration to be conducted on how information about relevant initiatives could reach the patients, who would benefit from them and when to approach patients who must be in a mindset to receive them. Such exploration could involve information and network technologies, thereby yielding great potential as a future techno-anthropological project.

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List of appendices

Appendix A: Interview Guides

- A1: Interview Guide, Patient view
- A2: Interview Guide, Health care professionals

Appendix B: Transcripts

- B1: Interview with Patient receiving biological medicine, Lone
- B2: Interview med Overlæge og Sygeplejerske fra Reumatologisk afdeling C, OUH.
- B3: Interview with Chemo-To-Go Project Manager, Katrine Seier Fridthjof
- B4: Interview with Patient receiving parenteral nutrition and HPN board member, Marianne
- B5: Interview with Nurse specialist in parenteral nutrition, Louise Bangsgaard

Appendix C: Coding framework

Appendix D: Thematic summary of interview transcripts