

Patient Perspectives of Robotic Interaction in Healthcare:
A Case Analysis of the Kinarm Robot in Brain Function Analysis

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ABSTRACT

The Kinarm assessment, which is the focus of my study, is a robotic standardized assessment tool that measures brain function and memory in elderly patients. The Kinarm assessment remakes bodies in the process of turning bodies into research data. The assessment disassembles bodies in the process of rendering bodily components and functions useless and impossible, and then, reassembles bodies by enabling and constructing new components and different functions. Some elderly patients in my study experienced feelings of fear and discomfort during the assessment. Those who did not, acknowledged the legitimacy of such negative feelings, although they emphasized that they did not experience these feelings themselves. As such, research assistants on the Kinarm assessment project were well trained to perform emotional labour to improve the patients comfort level and overall experience. However, this was not enough. Patients needed to talk about and make sense of their experience in the assessment. Patients appropriated my role as principal investigator/interviewer into primary emotion worker so that they could discuss their feelings and experience in the assessment, thereby, making sense of their bodies, their role, and their feelings in the assessment. The goal of my study is to reveal patients' feelings, beliefs and experiences when technology, specifically the Kinarm robot, is part of their healthcare experience. My findings indicate that elderly patients may experience feelings of fear, discomfort, and nervousness when faced with unfamiliar technologies in a healthcare setting. Patients think differently about their bodies in the Kinarm assessment and their comfort with the robot determines to a large extent how they perform the assessment. I recommend that elderly patients be debriefed following medical procedures that involve technologies that are unfamiliar to them.

TABLE OF CONTENTS

Abstract.....	ii
List of Figures.....	iv
Preface.....	v
CHAPTER 1. Introduction	1
1.1 Robots in Healthcare.....	3
1.2 Evidence-Based Medicine	7
1.3 The Kinarm in Context.....	12
1.4 Research Questions and Findings.....	13
CHAPTER 2. Research Design.....	17
2.1 Field Site and Participants	18
2.2 Data Collection	22
2.3 Data Analysis.....	25
2.4 Limitations	27
CHAPTER 3. Actor-Network Theory in the Kinarm Assessment.....	29
3.1 Patients in the Kinarm Assessment Network.....	32
3.2 Research Assistants in the Actor-Network.....	39
3.3 Kinarm in the Actor-Network.....	42
3.4 Stability and Instability of the Actor-Network in the Kinarm Assessment	43
CHAPTER 4. Remaking the Body with the Kinarm.....	46
4.1 Disassembly/Reassembly	46
4.2 Seeing	53

4.3	Embodying the Kinarm.....	56
CHAPTER 5. Emotional Labour and Emotion Work in the Kinarm Assessment		65
5.1	Emotional Labor and Emotion Work	65
5.2	Emotional Labour of Referring Doctors.....	68
5.3	Emotional Labour of Researchers	69
5.4	Research Assistants	73
5.5	Emotion Work of Patients	77
5.6	Accidental Emotion Work	81
CHAPTER 6. Discussion & Conclusion		87
References		94
Appendices.....		100
	Appendix A: Interview Structure.....	100
	Appendix B: General Research Ethics Board Application	102

LIST OF FIGURES

Figure 1: The Kinarm.....	v
Figure 2: Image on screen of research assistant’s computer. Green rectangle (middle of screen) represents the patient’s body in the chair of the Kinarm. Blue lines represent the arms of the patient (forearm and upper arm). The red dots stand in for the patient’s elbows and wrists/hands. As the patients moves their appendages, the research assistant sees the replicated image on the screen move accordingly. Lights, dots and moving objects also appear on this screen as the patient sees them on their screen.	41

PREFACE



Figure 1: The Kinarm

Suzanne, a research assistant employed by the Center for Neuroscience Studies Kinarm assessment study, met me outside the hospital entrance. This was the first of many encounters I would have with her. We had been emailing back and forth for several weeks and it was nice to finally put a face to her name. She led me down the halls of the hospital to an elevator that we took up several floors to another long hallway. I followed her as she meandered from hall to hall. Finally she opened the door to the Kinarm room. Before my field work began the Kinarm assessment was moved from this large room, with more empty space than machine and a beautiful view, to the small assessment room in the basement of the old hospital with the opaque windows. I did not write the RBANS test (the current standard brain and cognition assessment), as all of the pa-

tients in my study would do when they arrived in the Kinarm room. Instead, I was introduced to the robots. (There are two robots: the exoskeleton, is used mostly for stroke patients and was not observed during my study, and the EP robot, which I observed.) None of the patients would be introduced to the robots as I was. In fact, the Kinarm robot was not pointed out to any patients upon their arrival in the assessment room. Patients were simply directed to the stage of the robot when it was time to get into it. Suzanne showed me both of the robots and explained how they worked. She described in detail how to get into the robot and how the robot would move. This was a luxury allowed me as a researcher, but not allowed the patients in the assessment.

I began with the exoskeleton robot. The chair was wheeled away from the robot and Suzanne gestured for me to sit down. She pointed to the arms of the chair which were higher than most (at about the level of the middle of my biceps) and extended the length of my entire arms. Suzanne adjusted the chair so my body fit into it perfectly, before rolling me into the robot. I will spare the reader the details of the tasks and assessments in the exoskeleton robot since none of the patients in my study were put through the exoskeleton robot and will jump to my experience in the EP robot. After about half an hour of unfinished tasks (unfinished because I was only doing the assessment to see what the tasks were like, and not to provide data), I was released from the constraints of the exoskeleton robot. Suzanne told me to stretch my legs and she offered me a drink of water. I took it. The room was dry, like all hospital rooms where artificial heat was pumped through the ventilation system that functioned as the veins of the hospital buildings. After my brief drink, I was led to the stage of the EP robot. I was not seated at a chair in this robot as all the patients in my study were seated at a desk chair, but rather I was told to find a comfortable standing position because I would be standing for the duration of the assessment. In my experience, the EP robot was raised to a height that allowed me to hold the handles and view the

screen while standing. A black bib that obstructed my vision, making it impossible for me to see anything from my neck down, was fastened with Velcro around my neck. My hands were guided to handles which I help with an intentional connection of my body to this gigantic machine. Suzanne closed off the screen of the robot with two metal shields, leaving a black background behind the screen of the Kinarm that made the lights of the screen visible and my legs (if I could actually have seen them beyond the bib) invisible. I was told to rest my forehead against the forehead pad. I was now in the robot. The assessment could begin. Suzanne gave me instructions before each task which I will reiterate before I describe my experience with each of the 10 tasks. Each of the tasks lasts only a few minutes (1-5).

Task one: Suzanne instructs me to move the red light that represented my hands “quickly and accurately” towards the white lights as they appear on the screen. I asked many questions during the assessment about how it worked and why I was doing what I was doing and what the robot was measuring. I wanted to understand this huge machine that I was confined to. Asking questions, too, was a luxury I was allowed that either patients were not allowed or none of the patients in my study took advantage of. My hands were represented on the screen by small red lights which moved in time and space with my hand. Larger white lights appeared on screen sporadically. I moved the red lights that represented my hand toward the lights in a way that I interpreted as being quick and accurate. The task ended almost as quickly as it had begun and the next one began. I did this same task with my left hand and then my right hand before moving on to task two.

Task two: This task is almost the same, only this time the red light that represents your hands will move in the opposite direction of what you expect, Suzanne explained. Remember to move quickly and accurately, she reminded me. This task was particularly bizarre, for when I

moved my hand forward, the red light moved backwards and when I moved my hand, the red light moved forwards. It was difficult to get used to and especially difficult as my red light approached the white light target. I reasoned that it must be increasingly difficult closer to the target because my brain has an expectation that forward is forward and backward is backward and the closer I get to the target the more determined I become to get to the target as quickly as possible, thus forgetting that the movement of the red light is opposite that of my hand. Again, I performed this task with my right hand and then my left hand before moving onto task three.

Task three: Suzanne called the third task the “mirror match” task. She explained that the robot would move my left hand the first time through the task, and my right hand the second time, and that I should match my right hand and then my left hand with the movement of the robot. In this task, nothing appeared on the screen. The focus, instead, was on feeling, on feeling the robot move my limb and then moving my other limb to the matching position.

Task four: This task was quite similar to the third, only this time I was instructed to move my limb at the same time and speed as the robot moved my other limb into the mirror match position of where the robot left the limb it controlled. This task was the longest by far lasting over 5 minutes between the two sides.

Task five: Task five is described by Suzanne (and the other research assistants, I learned during my field work) as the fun task. In this task, balls fall from the top of the screen and the participant must hit the balls away with the paddles that represent their hands. The balls fall faster and faster until the task ends, seemingly abruptly. This task is interesting because unlike the first four tasks where the participant is able to keep up with the robot and can successfully complete the task, in this task it is not possible to hit away all of the balls. My arms flailed from side to side and top of the screen to bottom as I tried desperately to hit away as many of the balls as I

could. The whole duration of the task I was worrying if I was hitting away enough balls or if I should be performing better on this task based on my age and cognition.

Task six: Task six is very similar to task five except that in task six, shapes fall from the top of the screen instead of balls and the participant is instructed to hit away two specific shapes. Hit away the triangles and rectangles only, Suzanne instructed me. Eight different shapes fell from the top of the screen, but I was only supposed to hit away the triangles and rectangles. Only a few times did I accidentally hit another shape on route to a triangle or rectangle, too determined to reach my prescribed shape to notice the other shapes on the way to it. I am not sure if hitting other shapes not prescribed to me reduced my final score or not, I do not think that it had any effect, but I did not think to ask this or any other questions during the task. I was too determined to hit away all the triangles and rectangles to think about much else.

Task seven: Task seven was timed and, thus, needed to be completed as quickly as possible. This task, Suzanne told me, was similar to connect the dots. Numbers would appear on the screen and I was to connect them in numerical order, 1, 2, 3, 4, etc. There was a trial first that was not scored. The trial only had numbers 1-5. Once the trial was completed and the participant, in this cases me, confirmed understanding, which I did, the real, scored, task began. Numbers 1-25 appeared on the screen. I moved my right hand (this task is done with the dominant hand) through the sequence of numbers 1-25.

Task eight: Task eight was very similar to the previous task. Instead of connecting numbers 1-25, I was told to connect numbers and letters in the order of 1, A, 2, B, 3, C, etc., up to 13. Again, using my dominant hand, I was to complete this task as quickly as possible.

Task nine: Task nine was by far the most difficult. During interviews, many patients in my study explained that this task did not respond well to their movements. I experienced the

same thing. I was frustrated by the delayed response to my actions on screen because the delay resulted in imminent failure. Both hands were required for this task. On screen, the hands appeared to be connected by a bar. On this bar appeared a ball. This task had three phases. In this first phase, the ball could not fall off the bar and the goal was to move the ball into a white target by moving the ball via a balancing act into the target. In the second phase, the ball could not fall off the bar and the goal was to move the ball into a white target by moving the bar and the ball along with it towards the target and then adjusting the balance of the ball on the bar so that the ball met the target. In the third and final sequence the ball could fall off the bar (really, this is all I need to tell the reader, because never in my experience as a participant or an observer did the task go any further than this since the ball did in fact fall off the bar) and the goal was to move the ball into a target by balancing the ball on the bar.

Task ten: Task ten was referred to as the sequence task. In this task, shapes appear on the screen. A certain number of shapes (starting with 3 and increasing by one each time a correct sequence is selected or decreasing by one every time an incorrect sequence is selected) will light up in a sequence. The participant is expected to move their dominant hand, which is represented by a red light on the screen, into each shape in the sequence in the correct order. In my experience, it was rare that anyone made it beyond four shapes in a row. This was the final task in the Kinarm assessment.

Following the completion of the tenth task, I, like all patients before and after me with the exception of those who participated in my study and were led to an interview room instead, was guided back through the hallways and corridors to the hospital exit where I thanked Suzanne (she would thank patients) and we said our goodbyes. This experience would cost patients about three hours of their time, more if they participated in my study as well and went to an interview with

me following the assessment. In exchange for their time, patients were offered a ticket to cover their parking costs or a taxi pass to get home. Patients would receive a call about three months after their first Kinarm assessment asking them to come in and do the assessment a second time. They would be called again a year after the second assessment and asked to return for a third time. I left the hospital, crossed the street, and made my way back to my office to write about what I had experienced.

CHAPTER 1. INTRODUCTION

Although robots and other advanced technologies are increasingly part of the patient healthcare experience, we know only little about how patients experience them and feel about them. This study sought to understand patients' experiences, emotions, and roles when a robot was part of their healthcare.

The Kinarm robot assessment is the object of my research. Kinarm robot is an exoskeleton robot used by neuroscientists at a Canadian university hospital to study brain function and neurological responses in patients with a variety of medical conditions including, but not limited to, Alzheimer's disease, Parkinson's disease, cardiac arrest, and stroke. The objective of my project was to explore the shifting understandings of healthcare and robotic technologies when robots are implemented as part of healthcare. Non-verbal interaction with robots, like that which takes place between patients and the Kinarm robot during the assessment, is the most common contemporary form of human-robot interaction (HRI) (Shaw-Garlock, 2009). Research suggests that these interactions have profound psychological and social effects (see for instance, Turkle, 2011). More research is needed to better understand these effects, both short term and long term. To my knowledge, most of the research on HRI in healthcare does not ask the patients how they feel about their interaction with robot(s) in the context of their care. This is one of the major contributions of my study.

A total of eight elderly patients were involved in my study. Data was collected through ethnographic observations of the Kinarm assessment (which was part of the original Kinarm study) and interviews of patients immediately following the assessment. Participants were referred to the study by a doctor or healthcare provider. My research involved observing

(through ethnography) the participants as they interacted with Kinarm robot throughout the original neuroscience Kinarm study, as well as an interview with participants following the completion of the original study. From this point forward when I write ‘the study’ I am referring to the original neuroscience study. When I write ‘my study’ I am referring to my own research project in which the Kinarm assessment was the object of study.

My study draws on literature in Disability Studies, Science & Technology Studies (STS), and Sociology of Medicine to make sense of patients’ articulations and practices surrounding their robot-mediated care experience. The neuroscience study positioned patients as vulnerable subjects and constructed them as ill by the original study regardless of the state of their health. Patients experienced an array of feelings during the assessment, including frustration at not being able to perform tasks as well as they thought they should be able to, and discomfort with the Kinarm. One of my central findings is that those who were intimidated by the robot tended to seek out ways to assert their control over it, particularly by “cutting the network” (Strathern, 1996). Patients who were more comfortable with the assessment and the robot tended to surrender control to the robot and achieve a higher level of body-machine integration (which is the goal of the assessment) as a means to improve their performance of the tasks than those who were uncomfortable. A second central finding (which was unanticipated) is that in my role as an interviewer, I became (through the patients’ appropriation of me) the primary emotion worker. It was of great value and worth to patients to have someone who understood the Kinarm assessment to talk to following the assessment so that they could make sense of it and share their experience. My study concludes by suggesting that when new and unfamiliar technologies, particularly robotic technologies, are involved in the healthcare experience, of elderly patients who are typically less familiar with technology than younger patients, the need for emotional

labour from healthcare staff increases. It is beneficial to elderly patients to debrief following their technologically-mediated care experience with someone familiar to the situation and the technology.

In this chapter I will first discuss the literature on robots in healthcare, and offer a brief history of the use and development of robots in the healthcare field. I point to the expectations the literature has of robots, discuss the approaches of medical sociologists, and point out some of the areas understudied in medical sociological research on technology in medicine. Second, I introduce the literature on evidence-based medicine, as well as review and articulate critiques from the perspectives of STS and medical sociology. I then explain how the Kinarm can be understood as an example of evidence-based medicine, and pose my research questions. Finally, I review my research findings, and discuss conceptual and practical implications.

1.1 Robots in Healthcare

A technological fix for an aging population?

While some (for example, Shaw-Garlock, 2009) suggest that robotic development has a long history in countries like Japan, a history that is rooted in wind-up tea serving dolls and artificial sexual companions that are traditional in Japanese culture (see Sabanovic, 2014), others (for example, Clark, 1997) uphold that robotic development stems from contemporary progress in technological development. The ELIZA program is often recognized as the first contemporary ‘robot’ (Turkle, 2011), with increasingly interactive robots, such as AIBO, KISMET, PARO and HRP-2, following many years later. According to de Graff, Allouch, and Klamer (2015, p. 1), robots are “hypothesized to [...] decrease the burden of our social and healthcare systems”. In a similar vein, Sabanovic (2010, p. 439) writes, in “future-oriented discussions, social robots often represent ‘technological fixes’—applications of technology meant to solve social problems that

are non-technological in nature—for a variety of pressing issues in contemporary society”.

Robots have been proposed in some cases, and used in others, as solutions for social functions and issues such as caregiving, loneliness, and social exclusion.

Japan proves an excellent example of using robots as a solution for social and healthcare issues. In Japan, robots are celebrated as a solution for the lack of elder care (Sabanovic, 2014). Robots are being used in domestic environments and in nursing homes to look after elderly. With a large aging population, Japan lacks enough person-power to care for the elderly. Elderly are viewed as a burden to society and to their children. Japanese welcome robots to care for their aging relatives, because the use of robots alleviates pressure on them to provide the care required (Shaw-Garlock, 2009). According to Sabanovic (2014), the elderly have been trained to accept care from robots because it allows their children and younger relatives the freedom to pursue their own interests and gives them peace of mind knowing their parents are cared for. Because Japan supports an elderly population about one third the size of the total population, accepts few immigrants into the country, and has low birth rates, there is not enough person power to support the aging population (Sabanovic, 2014). Japan supports a fast-paced lifestyle and a goal-oriented culture. In Japan, the elderly are largely viewed as a burden, their care as a problem. Person-centered elder care is not a priority. However, it is unlikely that the problem of lack of elder care in Japan will be solved with the wide-scale implementation of robots. As the population continues to age robots will continue to be built and recycled to accommodate the needs of the elderly population, but the problem of lack of person power still persists. It is because of this and other similar circumstances (Sabanovic, 2014, p. 360), that the field of robotics has been criticized for proposing “technological fixes” for social problems.

It is quite recently that robots began to be implemented into healthcare. However, the rate of implementation is quite astounding, with computer-assisted surgeries common in hospitals around the world, and robots being used for a variety of tasks and purposes at progressive hospitals. Robots can be used in hospitals as a source of entertainment for children undergoing painful procedures, used for measuring medications, and used as robotic surgeons. Robots can be used in nursing homes as companions for elderly and support for nursing home staff, particularly in countries like Japan, Taiwan, and the United States (see for instance, Chang and Sabanovic, 2014; Jenkins and Draper, 2015; Sabanovic et al., 2013).

While it cannot be assumed or expected that robots and other technologies will solve social problems, they do present the potential to improve healthcare systems. According to Sicotte, Denis, and Lehoux (1998, p. 432), information technology is “aimed at transforming processes that will enhance quality and productivity through the introduction of several mechanisms such as the automation of work processes and other care process innovations aimed at transcending physical and temporal boundaries specific to hospital work”. Policy workers and researchers recognize robots as a possible solution to the lack of healthcare workers, a practice that will enhance productivity and efficiency, and as a financial solution.

Theorizing robots in healthcare

Medical Sociology tends to approach technology in healthcare in one of two ways: either through the lens of social essentialism, that is, the idea that technology is exclusively socially determined or through technological determinism, that is, that technology determines social processes (Timmermans and Berg, 2003). This is problematic because both social essentialism (more often called ‘social determinism’ and thus referred to as such here to fore) and technological

determinism have been highly criticized by sociologists. Social determinism assumes that society is exclusively socially determined, in which case technology has no effect at all on social conditions. If this were true, patients would not have perceptions of robots in healthcare because robots would have no effect. Technological determinism, which assumes that technology determines the social, fails to account for the web of meanings technology has and influences of technologies and other factors on one another 'in practice'. However, studying technology in practice would require an approach which recognizes the mutual shaping of society and technology. Social constructionism recognizes that social processes influence technology and perceptions of technology, and, at the same time, technology influences the social world. In other words, social constructionism attempts to reveal and make sense of the complex web of relations between the social and the technological.

It is of some interest that the vast majority of research on medical technologies in the field of Medical Sociology is not on "technologies", as in machines and computer technologies, but rather on developments in medicine, "technologies" like pharmaceuticals and advanced medical processes like in vitro fertilization. Studies of medical "technologies" tend to be concerned with constructions of the internal human body (see for example, Joyce 2008; Dumit 2003; and Thompson 2005). According to Casper and Morrison (2010, p. 125), "a key shift in medical technology has been the introduction of pills, devices, and other objects, both small and large, which remake bodies, often from the inside out". In other words, these studies look at how the body is altered internally because of and through technology. To my knowledge, little has been done in Medical Sociology on how the body is changed and remade by medical technologies that extend the external body. The focus on revealing the remaking of bodies (such as work on biosubjectivities, Casper and Morrison, 2010, p. 125) has overlooked the need to

understand new technologies (that is, machines and computer technologies) in practice. My study suggests that bodies are not always altered from the inside out, as work on pharmaceuticals suggests, but can also be altered externally through the attachment to medical technologies (i.e., machines and robots).

Surprisingly, there is relatively little overlap between STS and Medical Sociology although each discipline could reap benefits from overlap. STS approaches (including Actor-Network Theory) have proved a good resource for understanding technology in medicine (see for example, Prout, 1996). STS approaches usually attempt to “gauge what technologies do; what caring, curing, or alternatives to these goals they help accomplish” (Timmermans and Berg, 2003, p. 104). Actor-Network Theory (part of STS) is particularly useful to studies in medicine because it acknowledges all factors that contribute to the situation, including persons and things, as well as struggles of power and control. Comparatively, Medical Sociology in its spectrums of social determinism and technological determinism tends to focus on human meaning (Prout, 1996). It is worthwhile to examine and consider the work of Medical Sociology because of its insight. STS, however, tends to take a more holistic approach to the study of technology in healthcare.

1.2 Evidence-Based Medicine

The Kinarm must be understood as existing within the current medical care context which is structured by evidence-based medicine (EBM). Evidence-based medicine (EBM) is a movement in medicine that began in the 1980s but traces back to the 1970s in particular and has roots in medical history as a whole. The term was coined at McMaster University in Hamilton, Ontario, Canada by a group of clinical epidemiologists (Mykhalovskiy and Weir, 2004). Although EBM

is loosely defined, it is generally accepted as being a standardization movement that promotes the use of “best” current evidence in clinical decision making (see for example, Timmermans and Angell, 2001).

The differences between traditional medicine and EBM might seem minute at first glance. In many ways, EBM is not new at all: making decisions based on the best information available is nothing new to medicine. Traditional medicine relied heavily on evidence, but this evidence may have been derived from literature, clinical experience, clinical experimentation, authorities in the medical field, or otherwise. Perhaps the most significant difference between medicine of the past and EBM is the strict reliance on scientific evidence as the *primary* authority in medical decision-making and clinical experience as the least reliable evidence.

What is the ‘best’ evidence?

EBM has been widely criticized by social science literature. It seems to me that the most significant problem to be addressed in EBM is who and what defines and determines what is the ‘best’ evidence. Some (see for example, Fox, 1957, discussed in Timmermans and Angell, 2001) argue that medical knowledge is inherently uncertain and therefore, there is no such thing as “best evidence” in the medical field. Thus, while it is possible to rely on current literature and research as the standard of medical knowledge, this knowledge is never certain. This means that randomized, controlled trials (RCTs) and meta-analyses of RCTs, which EBM acknowledges as the ‘best’ evidence, are never certain, though EBM implies otherwise. Moreover, since medical knowledge is uncertain, it is inherently uncertain whether or when the standard care procedure will be effective for the individual patient. Sacket et al. (1996), who writes from the perspective of social scientists, suggest that EBM should *always* be an integrative approach that combines

best evidence with clinical experience in decision-making. However, EBM's hierarchical structure of 'best' evidence places clinical experience at the lowest point of the hierarchy. Thus, the literature points to tensions between the goals of EBM and the reality of medical practice.

These acts of defining and deciding what is best evidence can be understood as "boundary work". Gieryn (2011, p. 12), who writes on disciplinary boundary work, that is, the ways in which persons within a discipline create and maintain boundaries in order to preserve the authority of the discipline, suggests that there are three interpretive problems that scientists must solve, these are: 1) limits of membership, who and what is included and excluded, 2) judge changing beliefs, and 3) decide what is agreed upon. The difficulty is that none of these problems is easy to solve and there is no unanimity among scientists and physicians. As such, more research is conducted in attempt to absolve the discrepancies within and across disciplines. Through their boundary work, physicians and scientists determine what is 'best' evidence as well as who has the power and authority to create, determine and define what is best. Even more problematic is that the knowledge that is accepted by the scientific and medical community may or may not be the best medicine for all patients. Social scientists point out that what is best for the average may not be best for the individual (see for instance, Mykhalovskiy and Weir, 2004). Thus, boundary work, though effective in establishing the relatively new reform movement EBM, does not always result in the *best* evidence or the *best* treatment.

EBM is controversial among medical researchers. There are several critiques of EBM from the physician perspective. Prasad (2013) cites four main limitations. The first critique is that evidence is limited in its applicability to individual patients (Prasad, 2013, p. 15). Most research concludes with the average effects, but "Is the average effect applicable to your patient? You don't know, you can't know" (Prasad, 2013, p. 15). The average effect is never decisive,

after all, the average suggests that it works for some patients and doesn't for others. The second critique is that there is a "lack of consistent and coherent evidence" (Prasad, 2013, p. 16). Thus, it is difficult for physicians to evaluate what is the best current evidence when studies and results conflict. The third critique is the potential EBM has to "limit creativity and innovation" in healthcare (Prasad, 2013, p. 16). The strict nature of EBM dissuades from changes in medical practice. According to Prasad (2013), new ideas may be stifled before being adequately tested and explored because EBM requires evidence and evidence does not exist for new ideas. The fourth critique of EBM is the lack of time clinicians have (Prasad, 2013, p. 16). As stated previously, EBM makes medicine a career-long learning process where physicians are required to stay up-to-date with current evidence. The problem is that this requires a great deal of time on part of the physicians which is often not available or, in many cases, this time invested in research is unpaid and takes place outside of work hours.

Social scientists touch on many of these same critiques (see for example, Mykhalovskiy and Weir, 2004; Timmermans and Angell, 2001). Another critique of EBM which much of the literature hints at (including Prasad, 2013 (physician); Timmermans and Angell, 2001 (social scientists)), is that EBM promotes the language of risk. Medical diagnoses and treatments are decided upon on the basis of the level of risk assumed according to the literature. In other words, the diagnoses and treatments are not made because of the individual patients, but rather because of the category of risk the literature places them in. Human beings, however, are each unique and the average, or quantified, risk is not always true to the individual.

Theorizing human-robot interaction

Few studies on human-robot interaction (HRI) in a healthcare context have actually asked patients how they feel about their interaction with a robot (for example, Chang and Sabanovic, 2014). Much of the research that has been done on HRI in healthcare has sought to understand the usability and/or integration of robots (see for example, Chang and Sabanovic, 2014; de Graff, Allouch, and Klamer, 2015). The research on HRI in health seems to be primarily concerned with the acceptance of robots (that is, robots being accepted by both clinicians and patients) and seems to overlook how robots affect care from the patient's perspective. Some research on HRI outside of healthcare asks users how they feel about their interaction with a robot, but does so through questionnaires that focus on specific themes and concepts deemed important by the researcher, not the participant/user (see for example, Buchner et al., 2013; Syrdal et al., 2013). This is problematic because questionnaires are limited in what they ask and the responses they allow. For instance, in the case of the former exemplar study (which examined robots in a factory and asked users about their feelings), the survey allowed only positive and negative responses. However, the situation of HRI is much more complex than a simple positive/negative binary can explain.

My work is primarily situated in STS approaches, particularly drawing on ANT. ANT tends to unsettle the binary created "between objective facts rendered by random clinical trials and the unsystematic knowledge of clinical practice" (Mykhalovskiy and Weir, 2004). From an ANT perspective, patients are part of creating the knowledge of clinicians. Patients are integral to clinicians' medical knowledge although EBM suggests that all medical care under all physicians is, or at least can be made, uniform. ANT accounts for the role patients play in knowledge production. EBM assumes that knowledge is always objective, but ANT shows that

knowledge is always constructed in practice. ANT proves an excellent tool for understanding technology use in healthcare because it considers all factors involved in the situation.

I part with ANT in one important respect. ANT is best for understanding technology in practice, but I specifically emphasize the subjective experience of patients. That is, I understand patients as unique individuals who come with a medical history and a life story. My focus on patient perspectives falls under the scope of humanism. In this vein, I privilege humans over machines, while ANT assumes that humans and non-human actions and actors are equal. At the same time, I reject humanism's binary of 'warm care vs. cold technology' and acknowledge non-humans as actors through the application of ANT.

1.3 The Kinarm in Context

The Kinarm exists within the context of evidence-based medicine. The Kinarm robot has been developed with the hope of showing, through extensive clinical trials (thus far the Kinarm assessment has over a decade of clinical), that the Kinarm assessment produces standardized brain function and memory testing. Although, the Kinarm is not yet in widespread use, the intention is that someday soon it will be. At that point in time, the patients who participate will not be referred to the Kinarm by clinicians for the purpose of developing the data pool, but rather patients will be referred to the study to be tested and their results will be utilized in their diagnosis process.

The Kinarm robot assessment is an attempt to standardize the assessment process for brain function and memory tests. In the current neuroscience study, the RBANS test, which is the currently accepted standardized memory test, is performed by patients before they enter the Kinarm assessment so that the results can be compared. At present, because the Kinarm has not

been accepted by scientists or clinicians as the best current memory and brain function assessment, the robotic assessment must be compared to the current standard method to prove that it reproduces the standard. This means that the Kinarm study exists to establish a data bank of best current evidence on assessing brain function and memory in order that physicians might rely on the Kinarm assessment to evaluate the brain function of patients in the future.

We know very little about the true consequences of the use of technology in treatment and diagnosis for patients. In my study, how the patients interact with the technology and, in turn, how the technology interacts with the patients during the assessment is important. ANT makes it possible to understand the network of relations that exist and affect one another throughout the Kinarm assessment. ANT theory is more effective than a deterministic approach (either social or technological) because it recognizes the mutual shaping effect of technology and society. Thus, ANT helps to reveal the role and perspective of the Kinarm robot, the research assistants, and the patients in this study.

1.4 Research Questions and Findings

In order to understand patients' perceptions of robots in healthcare, I analyzed how patients experience interaction with robots in healthcare to inform the following research questions:

- How do patients experience robots in healthcare?
- Are patients resistant to the robot, and if so, how?
- How do patients perceive their relationship with professionals when a robot is included as part of their healthcare experience?

I pay particular attention to embodiment, agency, and affect, all of which provide a framework for understanding the ways in which patients understand and describe their experiences with

robots in healthcare. Paying particular attention to embodiment, agency, and affect is useful to obtain a more nuanced understanding of healthcare robots within larger discussions about technology in healthcare or Medical Sociology that have a tendency to contrast warm healthcare with cold technology (Pols and Moser, 2009).

All patients came to the study with a different back story. Each patient responded to the robot and performed the tasks in a unique and interesting way, though there were some identifiable trends. Each patient's body felt and experienced the robot differently during the assessment. Patients in my study did not want a standardized approach, they wanted a personal approach with somebody talking them through each step, somebody asking them questions about their experience, and someone who listened to their health trials.

Many consequences of EBM revealed themselves in my research on the Kinarm study. It was clear that although the research assistants on the project performed intensive emotional labour (as did the technicians and clinicians who cared for the patients prior to the study and in some cases referred them to the Kinarm study), it was insufficient. Their emotional labour did not allow patients the opportunity to make sense of their own role and responsibility in the study, of their bodies in the robot, or of the Kinarm robot itself. In the context of my study, I became the primary emotion worker, through patients' discussions with me in the interviews they were able to make sense of and come to terms with the assessment. By design, the standardized nature of the Kinarm assessment stripped patients of their individuality. Patients are categorized by ailment in the Kinarm study. Although most patients expressed the need to tell stories about their health and healthcare journey, there was no room to accommodate this in the assessment. The assessment, as a standardized procedure, moves patients through one task to the next with greatest possible efficiency. Patients are never asked about their health, beyond basic questions

like eye care prescription and clinical diagnosis. Some freely offer information about their healthcare experiences (including those that have nothing whatsoever to do with the assessment), which the research assistants acknowledge but tend not to discuss. Only the interviews I conducted allowed patients to explore their role in the Kinarm robot assessment in the context of their health and healthcare journey. This was important to the patients, particularly since most believed that the Kinarm was part of their healthcare. I did not expect the interviews to positively affect the patients in this way. The patients appropriated me to become something different, not a researcher, but a listener, someone with whom to share their stories and experiences both from the Kinarm assessment and their healthcare as a whole.

Patients used different coping mechanisms during the assessment. All patients included in my study acknowledged the legitimacy of feelings of discomfort and fear in the assessment, although many emphasized that they did not feel this way themselves. Patients who experienced feelings of discomfort tended to be most likely to cope with the assessment by disconnecting their bodies from the robot to regain control of it. These patients were more likely to develop performance strategies such as rationalizing that a particular behaviour or pattern that they did had more weight in the scoring than what they could not do. On the other hand, patients who were most comfortable in the robot tended to connect their bodies to the robot with the intention of bettering their score. These patients who were comfortable with the robot tended to intentionally embody the robot. These coping mechanisms may or may not be connected to the age of the patients. More research is necessary to determine whether or not coping mechanisms and feelings of discomfort are correlated to patients' age.

There are some practical conclusions to draw from my study. First, individual stories are lost without direct dialogue with patients that allows them to ask questions and make sense of the

assessment. Second, elderly patients might need more help adjusting to the implementation of new technologies than younger patients who are typically more familiar with technology. Third, it is my recommendation that patients be debriefed about their experience following the Kinarm assessment. Said debrief would improve the quality of care and the overall patient experience. This can be translated to healthcare at large. Patients often undergo procedures that are new to them, even when clinicians perform the procedure often, sometimes even multiple times a day. After the new procedure, patients need the opportunity to make sense of their experience. Most often, it is easiest to discuss the experience with persons who understand it and even who have undergone the same procedure. In many cases, groups have cropped up online, communities have emerged that meet in person, and other resources have been developed and disseminated to help and support those who have specific medical experiences so that they can make sense of the experience and their role in it, for instance groups for chemotherapy patients. However, these groups exist only in some cases and are absent in others. Ultimately, because these groups are independent and usually self-initiated by patients, clinicians cannot assume that such support is available to patients under their care. Thus, support should be provided by medical caregivers first and foremost with external support systems complementing the clinicians' primary efforts. Fourth, standardization black-boxes patients. The Kinarm study shows that standardization is not a means to an end. As medical care becomes increasingly standardized (as is likely under EBM), sense-making and support resources become increasingly important to patients. If medical care is standardized, individualization must be preserved by others means.

CHAPTER 2. RESEARCH DESIGN

To achieve the objective, my study was conducted using two ethnographic methods: interviews and observations. The object of my study is a neurological study using the Kinarm robot that is ongoing at a university hospital. The Kinarm assessment is conducted as part of a study which assesses brain function in patients with a variety of ailments. In the case of this study, patients are categorized as a) cardiac, b) critically ill, c) major surgery, and d) dialysis/renal clinic patients. The principal exoskeleton robot enables and requires the patient to perform a series of tasks during which brain function is recorded and observed. My study was interested in the experiences of patients during the assessment.

To answer the research questions, I conducted a qualitative study, including an observation and interview component, of human interaction with the Kinarm robot in a clinical setting. Observing the participant as they interacted with the robot in real time allowed for the comparison of the patients' articulations of their experience described in the interview with observations made during the lived interaction with the robot. Ethnographic observations are useful because the researcher can see how patients respond and hear what patients say in the situation. In this case, the observations portion allowed me to observe the entire assessment from the point of meeting the patient and bringing them to the Kinarm room, to the end of the assessment when patients were walked back to the entrance of the hospital. I was able to witness each patients' entire Kinarm assessment experience. There were a few key parts of the assessment that were particularly useful to my analysis to observe, including what patients said and how they reacted upon seeing the robot for the first time, the situation when patients were strapped in and set up in the robot, and how patients behaved once the assessment was completed. These points of the assessment yielded particularly rich data.

The interviews allowed me to learn about each patient's experience through their own articulation. In some instances this was particularly helpful, because the patient would explain their reason(s) behind acting a certain way and could connect emotions to actions. However, interviews in themselves are limited because each patient is conscious of self-presentation during the interview. They consciously take measures to present themselves in a particular way through the things they say in the interview. Comparatively, during the assessment responses and behaviours tend to be automatic because of the fast pace of tasks and the context of the assessment. Similarly, observations alone are limited because with only observations I would not be able to learn how patients feel during the assessment or how they articulate their own experience. To combine observations and interviews provides a more holistic understanding of the patient experience during the Kinarm assessment.

In what follows, I will first describe the participants as well as the field site, and then proceed to describe the data gathering and analysis strategies I employed. I conclude this chapter by outlining and discussing problems that occurred during these phases. The ethics board letter of approval is attached in the appendix.

2.1 Field Site and Participants

There are two types of participants included in my study: research assistants and patients. I observed research assistants and recorded ethnographic field notes. I observed patients' interactions with the robot and subsequently interviewed patients. All participants involved were adults (aged 62-85 years).

Field site

The Kinarm study takes place in a small corridor of the hospital blocked by a heavy wooden door. The corridor contains three small rooms. In the first room there is a hospital bed, a filing cabinet, and a chair. To the back left and to the right in the first room there are doors that each lead to another small room. The door at the back left opens to the largest room which contains the Kinarm Exoskeleton robot, as well as a computer for the research assistant, and a chair. The door to the right opens to a room that contains the Kinarm EP robot.

I conducted my study as a graduate student of the university. The institutional involvement of my own study was small, including the university that supported my research as part of my academic degree requirements and the hospital where I conducted my fieldwork. The Kinarm study has a much more dynamic interplay of institutions involved. The Kinarm robot is built by an engineering firm and now sits in a hospital corridor waiting for patients. There are several university professors who are principal investigators of research projects using the Kinarm, some of whom are also medical doctors. These individuals are unseen during the fieldwork, but often refer patients to the study and analyze the data yielded from the study. In both studies there are research assistants who put patients through the robotic assessment. The research assistants are paid employees of the university. There are also patients in both studies who have a variety of ailments who are put through the study.

Research assistants

There were two research assistants included in my study. The research assistants are paid employees of the Kinarm study. The research assistants of the neurological study operate the Kinarm robot, put patients through the Kinarm assessment, and deliver instructions to patients.

Research assistants are participants in the ethnographic research portion of this study because the research assistants are a vital part of the setting and they play an important role in the patient experience. There was usually only one research assistant in the Kinarm room at a time.

However, during the assessments of the first, second and third patients who participated in my study, there were two research assistants involved, because one was being trained by the other to perform the assessments. The research assistants present during the ethnographic research portion of this study were treated as participants (i.e., they received the Letter of Information and had to grant consent to participate in order for observation to take place). I observed the research assistant's interaction with the patient, as well as their interaction with the robot (for example, how the research assistant explains the assessment tasks to the patient). However, I did not interview research assistants, because my study emphasized the experience of patients when robots are part of their healthcare.

Medical care staff

Doctors and other medical staff are not included in my study, though they play an important role in the Kinarm study. Most patients are referred to the Kinarm study by medical care providers. These medical providers include family doctors, cardiologists, surgeons, and various types of technicians. Most clinicians who referred patients to the study are involved in the Kinarm project; i.e., they are researchers as well as clinicians and they use the Kinarm to research patients in their own field, meaning that they work for both the hospital and the university. Some technicians are also doctoral students who work for the project. Other times, persons working on the Kinarm project are given entrance before or during a medical procedure so that they may appeal to patients and request their participation. Medical care providers and neurologists are not

involved in the data collection process in the Kinarm study (this is solely done by research assistants). Neuroscientists analyze the data that is collected by research assistants and draw conclusions from this data according to their study. The neuroscientists conducting the analysis are both university professors and doctoral candidates. The neuroscientists on the project do not treat patients (though there is some grey area with the doctoral students, some perform tests on patients).

Patients

Individuals participating in the ongoing neurological study using Kinarm were referred to the neurological study by doctors and/or medical care providers. The Kinarm study is constantly bringing in participants (that is, the study operates and accepts participants every business day throughout the year). The study has been ongoing since the early 2000s using various participant populations. Participants of the Kinarm study were asked upon agreeing to participate in the neurological study if they would be willing to participate in my research study as well.

Participation in my study was voluntary. All patients asked to participate granted their consent.

The patients in my study are individuals who suffer from disease and/or have undergone a major surgery. All patients that participated in my study were between 62 and 85 years of age. One patient was critically ill. Two patients were cardiac patients having had triple bypass surgery three months before (for both these patients this was their second assessment). Three patients were major surgery patients who had undergone, or were soon to undergo, a major joint replacement surgery. One of these patients was also a dialysis patient. There were two dialysis patients in total. One patient was a healthy control. For three of the eight patients, this was their first time through the Kinarm assessment. The other five patients had been through once before.

Two patients had university degrees. One patient had a college diploma, one had completed grade 13, two had completed grade 12, and two had completed grade 10. All patients were retired and had been for more than five years, with the exception of one who was a farmer. Four of the patients were male and four were female.

2.2 Data Collection

My study involved ethnographic observation (Emerson et. al, 1995) of patients' interaction with the Kinarm robot, followed by an open-ended interview (Denzin and Lincoln, 2000). My project had a participant population of ten: eight patients and two research assistants.

I observed these participants during their interaction with the Kinarm robot (in their assessment) and interviewed them following the completion of their interaction with the robot. Following the ethnographic collection of data (collected through the observation of patient-robot interaction), I guided patients to a private room across the hall from the Kinarm room where I conducted interviews.

The ethnographic portion involved the firsthand observation of the experiences of patients. Their behavior and dialogue provided rich data that could not be obtained through interviews alone. To reiterate, I chose to do ethnographic observations primarily because it allowed me to see how patients responded and what they said during the assessment. Interviews were useful because they give the patients' opportunity to explain why they acted the way they did. Observations allowed me to see how they acted in the first place. Since my goal was to understand patients' experiences with the robotic health assessment, it was necessary to see their experience and not just hear stories about their experience after the fact. To see the assessment from start, when the patients arrive at the hospital and meet the research assistant, to finish, when

the research assistant walks them back to the hospital entrance from whence they came, allowed me to witness what happened in practice. My goal as a social scientist was to understand and make sense of robots in healthcare in practice. In doing so, it was necessary to see the robot in practice, to see the patients in practice, and to see the network that was created by the Kinarm assessment in practice.

I recorded ethnographic field notes by hand during the observation periods. I began recording notes once the patient was in the Kinarm room and not before, although in many cases I was with the research assistant to meet and greet the patient when they arrived at the hospital. My observation was unobtrusive. I was introduced to the patient and then I became part of the backdrop, sitting in the corner of the room behind the patient, out of sight. However, it was clear in some cases that the patients did not forget about my presence. Even when they could not see me, they knew I was there. At times this came out in comments made by patients to no one in particular, comments made using the plural subject. At other times, patients would address me directly. My observation notes included everything I could record by hand about the immediate situation, including words spoken by patients and research assistants, body movements of both participants, actions and reactions. When I could see the screen of the robot and/or the screen of the computer where the research assistant sat, I would record what I saw there. The observation periods, which occurred during the Kinarm assessments, lasted two to three hours (this is the approximate time required to complete all tasks in the assessment). Immediately following the observation period, the interview was conducted with the patient.

I audio-recorded the interviews which took place in a small private room across the hall from the Kinarm room. Interviews lasted 25-50 minutes. Interview questions were open-ended, to guide patients through the interaction. Open interview questions were designed to encourage

participants to describe their experience through stories, metaphors, analogies and processes. The interview was structured in three parts (see *Interview Script* in the Appendix for greater clarification). Interviews were structured around the following themes: agency, embodiment, and affect. The interview was designed to allow patients to talk about what was important to them, what they wanted to tell me. To start, I told patients exactly that, tell me what you want to about the Kinarm. In every case I only posed questions as needed, for instance, if the patient was unsure of where to start talking, or if they became overly sidetracked and were no longer talking about their experience in the Kinarm at all. I did not approach the interviews with a preconceived idea of what I thought patients would talk about; I only had in my head themes that I thought I would find in their discussions.

Patients' stories were vastly different. Patients chose to talk about different things. It was rare that I posed the same question in two interviews because the questions on my interview script were only a guide, I was more concerned about what patients wanted to tell. I did, however, use guiding questions to ensure that patients touched on each of the three themes I was interested in, though in some cases their responses had nothing to do with the themes I attempted to pull out. Most of the patients had no shortage of things they wanted to share with me. One patient seemed to have nothing at all to tell me, in which case I relied heavily on the guiding questions.

Following the interview, I returned with the patient to the Kinarm room where the research assistant was waiting and one or both of us walked the patient back to the hospital entrance. After that point, I would return to the Kinarm room and make additional notes in my notebook about what the patient had said or done on the way out that pertained to my research. After each set of observations and interviews, the data was transcribed and stored securely. Once

all data had been collected for the eight patients included in the sample, I coded the data. I compared the coded interview data to the coded observation data for each patient and then analyzed the data as a whole.

The research assistants were included as participants in the ethnographic portion of this study and were observed as they interacted with patients and the robot. Because patients, and not research assistants, are the focus of this study, research assistants were not interviewed.

2.3 Data Analysis

I cross-examined ethnographic field notes with interview data to compare how interactions with the Kinarm were observed (ethnography) against how participant's describe their interaction (interview) with the Kinarm. All interview and ethnographic data were cross-examined, coded and analyzed. Prior to the data collection phase, a situational map was constructed of the Kinarm project (Clarke, 2005). This allowed for all possible actors, discourses, contexts, and situations at play in the Kinarm assessment to be identified prior to the data collection phase. I drew two more situational maps, one after the data collection was complete and during the data analysis phase. The situational maps were useful for revealing connections between actors and situational factors. They helped to show the situation of the Kinarm assessment in its entirety, including what is and who are unseen in the assessment.

Ethnographic and interview field notes were digitally transcribed immediately following collection of participant data. First I read the transcribed data for themes, called sensitizing concepts in grounded theory. At this point I had three themes that I was looking for in the data: embodiment, agency, and affect. Interestingly, when I began to read the data for themes, because I found other themes that I thought might be more important, I wondered about discarding these

themes altogether. I coded field notes line-by-line using open coding (Emerson et al., 1995; Strauss and Corbin, 1998) after each patient, and before more data was collected. At this point, after coding several participant datum, I noticed that in fact most of the open codes I had used could be categorized under the three themes I had in mind originally and that these were the most salient themes in the data. I continued to look for these themes in the data sets of later patients. After the completion of data collection, all data was coded using focused coding—breaking a code into specific dimensions (Emerson et al., 1995). Focused coding helped me to better understand what was happening and to relate it to the main themes.

I made memos, containing “impressions, thoughts, and directions to oneself” (Strauss and Corbin, 1998, p. 223), throughout the data collection, coding, and data analysis phases. I analyzed field notes and memos thematically and conceptually to build a thematic narrative (Emerson et al., 1995). Again, after analyzing the first few data sets I almost discarded my sensitizing concepts and began anew, but I found in coding that these concepts were in fact salient in the data. This occurred largely because I had entered my field work with a preconceived notion of how these themes would reveal themselves. I had, after all, gone through the assessment myself. I knew my own experience and knew how I would articulate it using the themes of embodiment, agency, and affect. I also know the literature, I am healthy, and I am in my mid-twenties. The experiences of patients—all of whom had never seen a robot, most of whom did not know robots existed outside of the movies, who know little about technology or healthcare beyond personal experience, who were ill, and who were elderly—were not, and could not be, the same as my own. Their articulations of their experiences in the robot *did* reveal the sensitizing concepts, but not at all as I had expected. This is grounded theory. I relied on the data to re-build the theoretical concepts and their meaning according to what I saw in the data.

2.4 Limitations

My study is exploratory in nature. The results are not generalizable. Generalizability was not a goal of my study. The goal of my study was rather to reveal patient perceptions of robots as part of their care. Eight patients' perceptions are shown in my analysis. I should point out that these eight patients were each very different in terms of education, occupation, age and personality. Some patients spoke a great deal in the interview, while others only answered prompt questions with a one- or two-word response and waited for the next question. Some who talked a lot told stories about their experience in the Kinarm, while others spoke more extensively about their health or their life. A larger sample size would have enabled me to explore a broader spectrum of responses and, in turn, would have allowed me to make claims with more certainty about patterns of responses. However, there is a clear limit to the size of a Masters of Arts project. This was a major restriction to my research, though I do not expect that the results would be very different had the sample size been larger, given that the trends in the data were clear and significant. I suspect that a larger sample would simply have resulted in more detail regarding the perceptions of patients. My study does not seek to produce generalizable results, but intends to reveal the perspectives of patients who have experienced a robot being part of their healthcare. These perspectives have been underexplored in sociological literature of medicine and technology. There is a great deal that can be learned from the patient perspective.

It should also be clear that in what follows I present *my* interpretations and perspectives of the data that I actively constructed throughout my fieldwork. I entered into my fieldwork with preconceived theoretical frames that I was looking for in the data. As happens in grounded theory, I nearly threw the theoretical frames away when they did not reveal themselves as I had expected. Thus, although I construct the data in my analysis, it has been constructed according to

the trends in the data, though I began my fieldwork with some expectation of what themes might be present in the assessment. This process is known as abduction in grounded theory, that is, that my observations and themes I was watching for were guided by what I expected based on pre-existing knowledge; still, I was open to new and unexpected themes and trends in the data.

CHAPTER 3. ACTOR-NETWORK THEORY IN THE KINARM ASSESSMENT

The point at which a computing machine becomes a robot is contested by scholars, engineers, scientists and developers (for example, see Cerf, 2013; Shaw-Garlock, 2009; Sabanovic, 2014). At its core, this is an issue of agency. Some, like Cerf (2013), believe that all computing machines perform a function that produces consequential output in response to decoding input. According to this perspective, every machine that digests input, decodes this input and produces output in response is a robot. Thus, all computing machines are (on some level) robots. Others prefer more complex definitions, qualifying robots on grounds of task-orientation, humanoid characteristics, resemblance of the real, interactive computation, artificial intelligence (see Barrat, 2013 for a journalist's synopsis of the robotics industry). Robots are qualified according to these definitions, resulting in systems of categorization that establish a continuum whereby technologies are distinguished as more or less robotic and, thus, more or less agentic (see for instance Okamura et al., 2010, RE: robots in the healthcare industry). Shaw-Garlock (2009) categorizes robots as: 1) utilitarian robots, "domestic or service robots designed to interact with humans for instrumental or functional purposes"; or 2) affective humanoid robots, "designed to interact with humans on an emotional level" (p. 250). A more contemporary categorization of robots is offered by Deniz et al. (2007) (although they write earlier than Shaw-Garlock their categories of robots are more widely accepted contemporarily than are Shaw-Garlock's): 1) "robots as persuasive machines...used to change the behavior, attitudes, or feelings of people"; 2) robots as research tools, "used to test theories of human social development or communication"; and 3) interactive and collaborative robots that fulfill their task-oriented existence by interacting with humans (p. 287). All of these definitions of robots are categorizations of agency where the first category, robots as persuasive machines grants robots

the highest level of agency, while human actors have minimal agency, the second category allows robots minimal agency, while human actors have more agency, and the third category allows robots agency only in relation to humans. Each of these definitions and systems of categorization assumes that robot agency and human agency are in opposition, if the human has agency, the robot cannot, while at the same time, if the robot has agency, the human cannot. Actor-Network Theory (ANT) rejects these systems of spectral and categorical agencies and instead proposes that humans and robots exist together in a network where agencies work to initiate actions and reactions of all human and non-human actors within the network. ANT proves an excellent tool for making sense of robots in healthcare because it allows agencies to be revealed through interaction and does not confine robots to the agentic/nonagentic dichotomies.

ANT understands agency not as a cause which produces effects, but rather as an effect in itself. Thus, humans and nonhumans alike have agency whether as mediators or intermediaries. However, Latour (1992, p. 229) explains that a mediator is a stable entity, a placeholder, while a mediator actively contributes to the chain of action and reaction. A nonhuman can easily behave as an intermediary wherein the nonhuman need not be any particular thing because it acts as any other thing would in the situation. It is difficult to imagine a human actor as an intermediary. In fact, it seems impossible for this to be so since human beings always act. However, according to Sayes (2014, p. 135), ANT abandons all distinction between humans and nonhumans. In relation to humans, nonhumans become mediators, “objects are not means, they are mediators—just as other actors are” (Latour, 1996, p. 240). Thus, humans and nonhumans are agentic actors whose actions are responsible for reactions of other actors in the network. Understanding the Kinarm assessment as an actor-network is useful because it acknowledges all factors involved in the

situation, where other approaches may overlook some important factors that have an effect on the situation.

The Kinarm is a standardized machine created to perform in a particular way every time it is operated. The lights that appear on the screen of the Kinarm are the same size in every test, large enough that most patients, even those with mild visual impairments can see them without seeing aids. Every patient grabs the same handles to maneuver the lights on the screen to perform the tasks according to their instructions which are scripted (and usually read directly off the computer screen by the research assistant or are reproduced verbatim from memory). If the patient lets go of one or both handles during the assessment, the Kinarm stops working. There are a finite number of tasks that the Kinarm can perform. Patients are typically asked to perform 10 tasks which are selected from the roster of tasks according to the patient's condition and the purpose of the assessment results.

Human differences and human error will cause deviations in the assessment from the standard. Individuation is, in itself, agentic. The patients of the Kinarm assessment have agencies, plural. They are significant actors in the network created by the Kinarm assessment. Standardization of human activities does not always work effectively. Hence, the research assistant of the Kinarm assessment is responsible for documenting anomalous behaviour. However, the research assistants also do not behave uniformly across assessments. This is in part because there are several research assistants, but also because the research assistants tend to respond differently to each patient according to his or her needs. The Kinarm robot, despite its manufacture, is not constant either; it is not stable. Machine error disables the Kinarm from performing according to the standard. In other words, the Kinarm robot is a mediator, an unstable entity that participates in the chain of action and reaction. The robot occasionally malfunctions. It

acts and reacts according to the behaviours of both research assistant and patient. It is impossible, then, for each test not to be unique. The actor-networks of each assessment are unique, as are the actions of the actors.

3.1 Patients in the Kinarm Assessment Network

The Kinarm assessment effectively measures how much patients deviate from the average performance of patients of similar age and diagnosis. This is the purpose of the Kinarm assessment: to diagnose deviation from the standard. The average, or standard, performance was determined by averaging the scores of a specific participant population to determine the medium score of each task within this population. Thus, the standard task score is not necessarily the mean (most regularly occurring score) or a score that was even achieved by any individual participant. This is important because according to the logic of standardization, deviation is an act of destabilization. For instance, Jack performed the task where the red balls fall from the top of the screen and he hit the balls away with his paddles (which represent his hands on the screen) in a way that was unique to him:

He starts out slowly, moving the handles towards the top of the screen before returning to their resting position at the bottom of the screen, closest to his body. Progressively he moves the handles faster and faster. There is no longer time to rest between hits. He moves quickly, his body rocking from side to side. His hands are all over the place now, his elbows out wide, taking up space on either side of his body. His forehead is away from the screen now, his back no longer touching the back of the chair. Quicker and quicker. Then suddenly he stops. He brings the handles toward his body in the rest position and looks toward Kelly, the research assistant on this assessment. (Field notes, June 8a, 2016)

I cannot tell how well Jack performed on this assessment. I do not know if he perfectly achieved the standard or if he deviated from it, and if he did, how much and in what way. I cannot ask the research assistants this. It would be a breach of confidentiality, and truly I am not sure they even know what the standard score is or how to compare a patient's score to the standard. This is the

work of the data analysts on the various Kinarm projects. The score on this task could be calculated a number of ways. Perhaps the score is derived from the total number of red balls hit away, or by the percentage of the total balls hit away (I do not know if the same number of balls fall in every trial, though the task is always the same length of time). Alternatively, perhaps balls hit at the side of the screen are of higher value than those in the center of the screen which are easier to hit and the score is derived from the total value of balls hit. The score may even include the calculation of speed. Like me, the patients do not know how the tasks are scored. They are told how to perform the task, but they are not told how to perform *well* on the task. The instructions are clear enough that patients can understand what they are to do, but vague enough that it is up to their interpretation how they achieve the completion. On the same task, Martin performs very differently than Jack:

After explaining the instructions to him, Karen (the research assistant) tells Martin, this is why we lock the wheels on the chair: some people really get going.

“Oh, I don’t get that excited”, Martin responds matter-of-factly.

The task begins. He moves the handles slowly at first, with caution, almost as if to prove that he does not, in fact, get *that* excited. His hands move continuously now, but not quickly.

“And do you know one of these won’t bump another one off, it has to be the paddle”. After a few more movements of the handles he adds, “Da ha!”

Now his hands move faster towards the targets, but still not fast. His body is like stone, unmoving but for his arms which are stiff.

“There’s gotta be a strategy” he says. “I haven’t found it yet!”

Then the task ends. Still he does not move his body. His hands return to the position where they started (Field notes, May 24, 2016).

Once more, I do not know Martin’s score. I cannot compare his score to Jack’s. It is clear, however, that Jack and Martin approached the task very differently. Jack was excited about the

task, moving wildly with elbows side to side in an effort to beat the machine. Martin either was not excited by the task at all or was trying to suppress his excitement to prove that he does not get excited, as he said. Martin's movements were cautious and controlled. It is clear from these two cases that patients do not perform tasks in the same way. The same task will be performed entirely differently by different people. There is no norm. The standard is a calculated artifact, fabricated to create a system of measurement by which patients can be compared.

The physical structure and design of the Kinarm robot allows patients to exercise their agency, specifically, the agency to move the handles of the Kinarm as they feel necessary to complete the tasks. The Kinarm robot is designed to be able to move its own arms. It can also resist movements made by the patient/operator. Most tasks do not involve these features of the Kinarm and instead allow the patient to move the handles, however, their movement is constrained considerably by the structure of the Kinarm. Patients must retain a tight grip of the handles, move the handles within the horizontal plane of motion, and may not move the handles outside of the boundaries of the screen. If these restrictions are not abided by, the Kinarm will immediately stop working. Letting go of the handles and stopping the Kinarm from working is a way of disciplining the machine. Through the handles, patients are able to control their attachment to the Kinarm robot. Their control of their attachment to the machine is limited by the structure of the assessment, which requires that they perform all applicable tasks and do so by holding the handles of the robot, to fail to do so would result in the termination of the assessment. Patients exercised their agency to move and connect to the robot continuously throughout the assessment. Interestingly, the patients who experienced negative feelings during the assessment, such as fear, anxiety and discomfort, tended to most blatantly act in a way that

disciplined the robot. Those who were comfortable with the robot tended to react to the actions of the robot rather than acting in attempt to discipline or control the robot.

Patients often acted in such a way that allowed them to feel as if they were in control of the Kinarm robot. This was especially true of patients who were uncomfortable with the robot and its actions. Wendy had not known that a robot would be part of her assessment. Every assessment begins with pen and paper tasks that are completed at a table with the research assistant. These pen and paper tasks are part of the standardized assessment called the RBANS. Kelly (a research assistant) put Wendy through the RBANS and when it was finished, she told Wendy it was time to get into the robot. Wendy was certain this was the first she had heard of a robot being part of the assessment, and while she was grateful that the Kinarm did not resemble an MRI machine which she is terrified of, she was quite worried that she would not be able to fit in the Kinarm and quite taken aback by the fact that she had to get into a robot. Of course she *did* fit in the robot since the patient is seated in a chair in front of the robot and connected to it from this position. At every opportunity, Wendy let go of the handles. In the middle of the “mirror match” task which involves the robot moving the left handle into a position, the patient then must mirror match the position of the left handle (moved by the Kinarm) with the right handle (moved by them), Wendy let go of a handle:

[Wendy] lets go of the right handle. The robot stops working (as it does) immediately mid-task. Kelly gives her instructions to grab onto the handle so that the Kinarm will work again and so she can complete the task. At this point, the patient’s left arm is at the far left side of the screen where the Kinarm positioned it before she left go of the right handle and instead of mirror matching the position with her right hand, Wendy brings her right hand to touch the left one at the far left side of the screen.

Kelly reminds her, “The robot is moving your left arm”.

“Oh right!” Wendy exclaims before moving her right arm to the far right to mirror match what the robot had done with the left. Then, Wendy continues mirror matching positions with her right hand and saying “okay” after each one until the task is complete (Field notes, June 8b, 2016).

Wendy was uncomfortable with the Kinarm robot and uncomfortable with it moving her arms, particularly in the mirror match task where one arm is moved by the robot and the other is moved by the patient. In the interview, Wendy explained, “you feel like, you know, you’re not gonna control me, I can control you too!” (Field notes, June 8b, 2016). In fact, Wendy did control the robot by letting go of the handles, perhaps more than she could by moving the handles. When Wendy held on to the handles, the *robot* moved her arms and, even when she was the primary force behind the movement of her limbs, she was limited to the horizontal plane of the robotic arms and was lured by the game-like nature of the tasks to follow the lights. When she let go of the handles the robot stopped, giving her time to recompose herself before continuing on with the task/assessment.

Cathy felt similarly about the robot. Like Wendy, Cathy let go of the handles at every opportunity. However, Cathy found it difficult to reconnect with the robot once she had let go. Many times, Kelly (the research assistant) had to guide Cathy back to the handles so she could continue the assessment:

The task is finished. Cathy lets go of the handles... [Kelly explains the next task.] Cathy tries to grab the handles so that she can begin the task, but she cannot find them. She grasps violently with her hands that are hidden from her sight by the shield. She cannot find the handles even with [Kelly]’s directions. Cathy leans to the side to see under the screen so that she can find the handles, but instead she finds that her movement is limited by the bib-like shield that is fastened around her neck by Velcro and her vision is limited by the robot itself. She cannot see her hands. She cannot see the handles. Cathy quickly realizes that her efforts are in vain and she rights herself in the chair. Kelly’s voice is guiding Cathy back to the handles again, a little to the left, more forward... I realize now that Kelly is limited as well, even if she went to the patient’s side, she would not be able to reach the

handles from where they are without moving the patient which would involve getting her out of the robot entirely. Although, I reason in my mind as I watch the scenario unfold, Kelly could open the screen for the patient so she can see her hands and the handles. Perhaps she will if more time passes. Finally, finally Cathy finds the handles (Field notes, June 22, 2016).

Throughout the assessment, Kelly was continually directing Cathy back to the handles which she had let go of at the first opportunity, resulting in similar scenarios. By letting go of the handles, patients, like Cathy and Wendy, act in a way that disciplines the robot; they ‘cut’ the network—one thing stops the flow of something else (Strathern, 1996). They are in control of the movement of the robot. This is especially useful for patients like Wendy and Cathy who are nervous and feel that they have lost control over the situation. They begin to pull control toward themselves by exerting control over the movement of the robot when they feel powerless or out of control, in doing so, they feel like they have regained control over the situation and they feel more at ease. However, in exercising their agency, patients do not truly reposition themselves within the network or gain control of the network. Patients are part of the actor-network of the Kinarm assessment. Each patient’s actions initiate responses from other actors in the network (Kinarm robot, research assistant, etc.), in the same way that the actions of other actors initiate responses in the patient. The Kinarm acts by moving the patient’s body and the uncomfortable patient reacts by letting go of the handles, in turn, the robot acts by disabling movement of its appendages and the research assistant reacts by guiding the patient back to the handles. In this way, control is transferred from one actor to another (in this case the Kinarm, to the patient, back to the Kinarm). The actor-network of the Kinarm is a myriad of actions and reactions performed by actors in the network.

Strategies devised with the intention of out-witting the Kinarm robot were common among patients. Strategies and plans were attempts to beat the machine at its own game before it

could realize it had been outwitted. The difficulty is, however, that the Kinarm tasks are designed to increase in difficulty over time, and, in some cases, to adapt to the user. As such, patients' efforts to beat the machine were often in vain (though some refused to acknowledge the failure of their efforts). Ola explained that the task with the balls falling from the top of the screen was very difficult for her because she could not respond fast enough to hit away all the balls in time. She strategized, reasoning that it might positively affect her score if she were to focus on hitting the balls in the center of the screen and altogether ignore those falling at the side of the screen:

Well, I kind of made up my mind that my score was the best that I can. It was the central part, for instance, with the balls coming towards me with the shapes and I thought that there was no point in worrying about whether I can reach to the sides or not because I'll just miss what's happening in the middle. And I thought maybe it's more significant on the tests to, to deal with that then to try to sort of spread yourself thin over the whole thing and try to hit everything... I strategized (Field notes, May 26, 2016).

Not knowing how her score is calculated, Ola guesses and makes decisions according to her assumptions about the scoring. It is possible that she is correct, maybe the balls in the middle are worth more to the score than the balls at the edges of the screen. It could also be the case that the balls at the sides of the screen are worth more than those in the middle, in which case, Ola would have a very low score. Patients, like Ola, attempted to devise strategies to outwit the robot because these strategies, gave them agency over the robot if the strategy was successful, and if unsuccessful, the strategy at least offered patients the appearance of agency over the robot. That is, Ola's strategy may or may not have positively affected her score. Regardless, her strategy allowed her to manage her feelings by offering a façade of agency. Cutting the network, then, is the only real way to resist the assessment. It seems that patients' becoming competitive in the assessment is exactly the goal of the Kinarm. Patients' strategies to beat the machine proved a similar coping mechanism to letting go of the handles, both were attempts to gain or re-gain

control over the Kinarm. However, neither were successful since the actor-network of the Kinarm is not a spectrum of control, but rather is a network of actors each of whose actions cause reactions in others. In other words, the strategies of patients and attempts at control over the Kinarm robot did not serve to situate the patient in a position of power and control, or subjecthood, over the Kinarm robot, instead, the patients' actions mediated the situation, creating a network of actors and actions.

3.2 Research Assistants in the Actor-Network

The research assistants of the Kinarm project have many agencies in their role, perhaps the most important of which is their role as instructor to the patients. Consider these instructions from Karen:

The first task, Karen explains, is to move the white light into the red lights as they appear on the screen. Move 'quickly and accurately', she instructs (Field notes, May 19, 2016).

These are the instructions Karen gives the patient for the very first task the first time he has ever been in the Kinarm. The instructions are very similar, if not exactly the same as those that Kelly (another research assistant who put patients included in my study through the Kinarm assessment), and presumably every other research assistant on the project, would give their patients. The instructions are vague and leave much room for interpretation. What white light and what red lights? Do a bunch of red lights appear together or do they appear one at a time? If they appear one at a time, how much time will elapse between? The phrase 'quickly and accurately' is key here and is the only explicit instruction the patients are given for this task. Still, what this means is left up to the interpretation of the patient. Here is how this patient performed the task:

He moves his left hand looking down at the screen inside the robot. He is very engaged. Move, move, move...move, move, move, move. "It's like playing Pac Man!" he exclaims as he maneuvers the left handle from position to position to center the white light that represents his hands in the red lights that are the targets for this task. His movements are swift, when reaching for the red light, and patterned, with a pause in between each movement as he waits for the next light to appear. Move, move, move (Field notes, May 19, 2016).

I did not describe his movements as quick and accurate. To me, he moved swiftly and paused before moving again. Although, I should point out here that I cannot see the screen that the patient sees, I can only see his hands moving from place to place and imagine (from my own experience in the Kinarm) what he sees. Perhaps, to him, his movements were quick and accurate. Then again, maybe he forgot this instruction altogether because he was so concentrated on just getting the white light representative of his hand to the red lights (targets).

To a large extent, the research assistants determine how the patients perform the tasks. The research assistant explains the goal of the task and the intended approach to completion. Then, the patient interprets the instructions and performs accordingly. The research assistant watches from their perch at the computer screen which offers them a replication of the screen the patients see (Figure 2.) and can jump in at any moment to offer more instructions or to correct the patient. In the task described above, I did not witness a research assistant correct a patient during the task. This is likely because as long as the patient reaches the white light to the red ones as they appear one at a time, the robot moves them through the task until its end. Other tasks, however, like the task where the shapes fall from the top of the screen and patients must hit them away before they reach the bottom, required regular corrections because without performing the task exactly right, the task could not be completed. For instance, Kelly tells one patient, "vertical rectangle and circle only" (Field notes, May 26, 2016). The patient had been hitting away triangles instead of rectangles. Thus, the research assistants initiate the task and

encourage patients to complete the tasks in a particular way. How the patients interpret the instructions and how they perform the task is up to them. The research assistants, then, establish the actor-network of the Kinarm assessment. They bring the patients into the room, attach the patients to the robot and initiate the commencement of tasks. The research assistants act as stabilizers in the Kinarm assessment network. Other actors can destabilize the network, but the research assistants restore stability by initiating the next task, giving instructions, correcting the patient's actions, or repairing or resetting the robot. The actions of the research assistants cause reactions from patients and robot, thereby creating the actor-network.

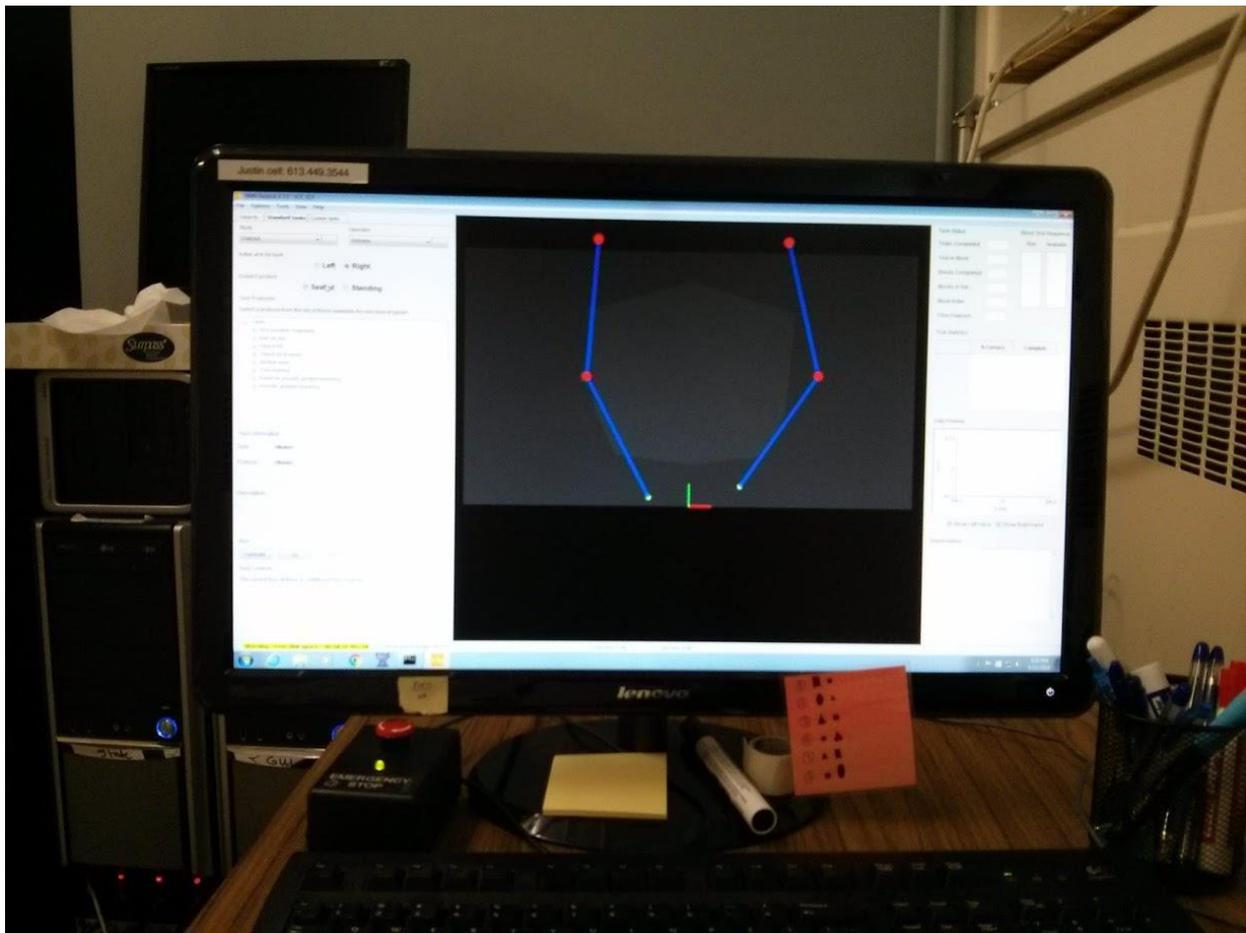


Figure 2: Image on screen of research assistant's computer. Green rectangle (middle of screen) represents the patient's body in the chair of the Kinarm. Blue lines represent the arms of the patient (forearm and upper arm). The red dots stand in for the patient's elbows and wrists/hands. As the patients moves their appendages, the research

assistant sees the replicated image on the screen move accordingly. Lights, dots and moving objects also appear on this screen as the patient sees them on their screen.

3.3 Kinarm in the Actor-Network

Unlike the patient and the research assistant, the Kinarm robot cannot vocalize its agencies. Instead, the Kinarm's agencies are revealed through what the human actors say and do in response to the robot. Glen vividly identified agencies of the Kinarm. In the second task Glen performed, the white light (his hand) moved in the opposite direction of what was expected as he reached toward the red targets that appeared on the screen. This was Glen's experience:

His movement is not fluid and measured like it was during the last task. Instead it is unsteady, constantly shifting. He starts with a big movement and then slowly, slowly and subtly adjusts and readjusts, and then again, another big movement.

The task is still going, it seems long to me...although all of the tasks last only minutes (for each side: left and right).

He tries to draw the handles towards the red targets, but makes constant corrections as he moves in order to account for the white light moving opposite to what is expected.

Karen sits in front of the screen of the computer, her hands in fists, she rests her chin on them. She jots something down, then her eyes return to the screen. Karen has already gotten up from her spot, walked across the room and retrieved a parking pass for Glen to give him at the end of the study to get him out of the parking garage at no cost.

A big movement. Several small corrections. He jerks the handle slightly. His hand has not fallen still since the task began. And suddenly the task is over. Glen lets out a huff of frustration, "He kept trying to run away from me!" He pauses a moment, as if to let it sink in, and then imparts knowledge on us, "If you circle around it lets you in". He says it as if he just shared a well-kept secret with us, with this knowledge, we too can unlock the key to successfully completing this task (Field notes, May 19, 2016).

Glen personifies the Kinarm as ‘he’ who ‘kept trying to run away from me’. By referring to the robot as ‘he’, Glen gives the Kinarm equal agency and equal ability to act as the human patient who is in the machine. The Kinarm is as much an actor as Glen is himself. Additionally, because the Kinarm robot is able to ‘run away’ it has agency to act on its own behalf. Glen’s second remark, ‘If you circle around it lets you in’ indicates that the Kinarm is capable of, and in fact chooses to act by, not letting the patient into the red target. However, Glen suggests that ‘if you circle around’ exactly right, then the Kinarm will grant you access to the target. That is, circling around the target, is the correct way to enter the target, only with this action will the robot allow your white light to enter. This is not a strategy like those described above whereby patients tried to out-smart the machine. In this case, it is the Kinarm that has the agency to determine what actions made by the human patient will be responded to negatively (not letting the white light into the red target) or positively (letting the white light into the red target).

3.4 Stability and Instability of the Actor-Network in the Kinarm Assessment

The Kinarm assessment is an actor-network, with various human and non-human actors composing the network. The three primary, visible actors, in the Kinarm assessment are the Kinarm, the patient, and the research assistant. The Kinarm robot is built to accommodate all patients. There is a chair on the platform of the Kinarm so that patients may sit while they perform the tasks using the handles, but patients also have the option (though they are not informed of this) to stand while performing the tasks. Standing in the Kinarm rather than sitting requires minor adjustments, including raising the height of the screen and the handles. These adjustments are made by the research assistant. There is also the option to be harnessed while standing in the Kinarm with the harness fastened to the frame of the Kinarm that reaches almost

to the ceiling. The process of getting into the robot (which occurs in every assessment) illustrates the network of agencies made possible by the structure of the Kinarm:

Karen [the research assistant] points out that now that the ‘pen and paper tasks’, as she calls them, are completed it is time to get into the robot. “Oh just wait ‘til I get playing with the robot”, [Glen] says. The patient locks the wheels of his wheel chair before rocking back and forth, back and forth, back and forth in order to hoist himself out of his wheelchair. He propels himself forward and is on his feet. He walks slowly, cautiously the few steps to the railing that separates the robot from the rest of the room. Holding the railing with his left hand he shuffles his feet toward the step. Karen warns him that there are two steps to get up to the platform. He takes the first step, pauses, and then the second step, both times stepping with his right leg first. Karen has locked the wheels of the chair that slides into the robot’s structure and is holding the back of the chair so that the patient may easily sit down. He plops himself down on the chair. Karen unlocks the wheels, pushes the chair into place beneath the shelf of the robot and locks the wheels again. Karen fastens the Velcro on the black cover that fits around the patient’s neck like a bib so that he can’t see the handles, his hands or his body beneath it. She closes the black shield that gives the screen a black backdrop so that the lights on the screen are visible and the handles and hands beneath the screen are not. Karen then explains that the white dots that will appear on the screen replace his hands during the Kinarm assessment. Finally, she explains that he must keep his hands at the top of the handles with a firm and complete grip or the robot will stop working, before she walks over to the desk that is next to the robot on the far side of the room. From the computer, Karen can observe the patient’s behavior while in the robot and control the commencement of tasks and restart tasks if necessary (Field notes, May 19, 2016).

The research assistant in this case, Karen, controls the movement within the assessment. She moves the patient through the ‘pen and paper tasks’ at the table, prompts the patient to move into the robotic assessment, helps the patient into the robot, and commences the robotic assessment with the click of a button on her computer screen. Hereby, the research assistant establishes and initiates the actor-network of the Kinarm assessment. The Kinarm controls the movement between tasks. Each task is designed to last a certain amount of time, or require a certain number of actions on behalf of the patient. Once the patient has met the task requirement, the Kinarm

ends the task. Thus, the actions of the Kinarm result in reactions from patients and research assistants. The research assistant explains the instructions to the next task, and then clicks a button on her computer screen. The Kinarm begins the next task, a reaction to the action of the research assistant. During the tasks, the Kinarm progresses in speed and difficulty. Meanwhile, the patient performs the task, moving and being moved by the Kinarm. The patient acts and reacts to the actions of other actors. This is the stable network of the Kinarm assessment: the network working properly without interruption. However, the network becomes unstable when something disrupts it. For instance, when a patient lets go of the handle, the Kinarm immediately stops working, disrupting the network. The research assistant's job in the Kinarm assessment is to minimize the instability of the network. Each actor affects other actors in the network, enabling or disabling actions. The Kinarm assessment is a complex web of actions and reactions, an actor-network.

CHAPTER 4. REMAKING THE BODY WITH THE KINARM

4.1 Disassembly/Reassembly

Ideals of materiality and mortality have been forced into flux by new technologies. It has become difficult to define materiality and mortality in a world where pacemakers and life support keep people alive, prosthetic limbs and joint replacements keep people walking, and pharmaceuticals keep people healthy. Haraway (1991, p. 301) writes, “Any objects or persons can easily be thought of in terms of disassembly and reassembly”. At the most crude level, human bodies are literally disassembled, with human, biological, organic components being surgically removed and replaced by technologies (i.e. knee or hip replacements, pacemakers, heart valve replacements, etc.). At a more abstract, and perhaps more common, level humans are disassembled by technologies that are created to perform the same function better, or a new function that is made necessary for some reason or other (ex. commercialization or health care), and reassembled with the machine as part of their being. Medical Sociology tends to seek to understand how the internal body is reassembled when medical technologies are used (usually inside of the body). For instance, Prout (1996), an ANT theorist and Medical Sociologist, examines how the metered dose inhaler alters and remakes the body from inside out and Oudshoorn (2016) examines how ICD shocks remake the body as vulnerable. Both of these studies look at changes to the internal body, how the body is remade from inside out. Little work has been done in Medical Sociology on the reassembly of the external body. In the Kinarm assessment there is an explicit process of disassembling the material body in order to reassemble the body with the Kinarm attached to it. That is, the Kinarm assessment makes patients feel differently about their bodies because in the assessment, patients bodies move differently, work differently, and behave differently than they do outside of the assessment. I have sought to

understand how the Kinarm robot disassembles the material body—by revealing ways in which the body is inept—and reassembles it by becoming part of the body—the Kinarm extends the external body in such a way that patients feel and think differently about their body.

The beginning phase of the Kinarm assessment reflects the process of bodily disassembly. Participants in the Kinarm assessment are referred to as ‘patients’. Interestingly, they are not really patients in this context. There are no doctors or medical staff directly involved in the Kinarm assessment. The assessment is not used as a diagnostic tool. The assessment does not result in the treatment of patients. In fact, the Kinarm assessment does not directly benefit patients at all. Patients simply volunteer so that their data becomes part of a large database to be used for research regarding the Kinarm assessment. Still, they are called ‘patients’. The term ‘patient’ has severe implications. Discourses create and dichotomize ability vs. disability, healthy vs. ill, normal vs. abnormal. Moser (2000, p. 201) points out that normalization “systematically produce[s] inequality and reproduce[s] exclusions: the main problem is a norm which locates agency, mobility, and a certain subjectivity in a naturalized human body”. To be a patient assumes that one has something wrong with them, they are abnormal because they are ill. The use of the term ‘patient’, then, situates the participants in the Kinarm project as ‘ill’. This is problematic for two reasons. First, some of the patients in the assessment are not ill at all; they are healthy control patients. These participants are still referred to as ‘patients’ and are constructed by the assessment as ill. Second, to position the patients as ill in the assessment is simultaneously to position them as unable, and abnormal. The Kinarm points out where patients have gone wrong, that is, how they have fallen below the standard. Patients are affected psychologically by the realization that they are not as good as they once were since they automatically presume that if they were healthy—had not had a major surgery, had not had heart

failure, etc., or for the healthy patients, had not aged—they would perform well on the assessment. The term ‘well’ here is relative because presumably many of the patients do perform well since the average is the goal, but not understanding that, they want a perfect score in the games of the assessment.

When the patients arrive at the hospital where the Kinarm assessment is done, they are met by a research assistant and guided through the labyrinth of hospital corridors and hallways to the Kinarm room. Patients are usually taken across floors by elevator because it is assumed that this is easier for all patients unanimously. Once in the Kinarm room, the patients are asked a series of basic and superficial questions about their health (such as, their eye care prescription, and their diagnosis), they are, after all, there because of their health in the first place. (Patients are not asked deep or personal questions about their healthcare experiences or how they feel about their bodies or health.) These questions reaffirm the position of the patients as ill. Thereby, patients are disassembled, they are not complete, human beings because of their illness. (It is possible that to allow patients the opportunity to speak about their feelings and their health in detail would simultaneously reduce the disassembly of their body because it would be more difficult to place the patient into pre-determined categories.) Through their illness and the emphasis put on their illness by the Kinarm assessment procedures, the disassembly of patients’ bodies begins. The pen and paper tasks, or RBANS, follows the questions asked by the research assistant. The test consists of a series of delayed and immediate memory and coordination tasks. Most patients do not perform as well as they expect on these tests. As Jack said, the pen and paper tasks taught him that his memory is not as good as it once was, “I’ve always prided myself on my memory. I’ve always been able to remember just about anything but I can see that maybe it’s startin’ to go” (Field notes, June 8a, 2016). This is not a positive take-away from the Kinarm

assessment. Jack *learned* that his memory is not what it once was because the test is framed in a way that shows patients what they got wrong rather than what they got right and the framing of the test causes patients to assume that ‘normal’ is to get everything right. Jack is produced as a flawed, incomplete person by the RBANS. Thus, the body is disassembled through the indication that parts of the body are sub-par or disabled.

Interestingly, even participants who are part of the healthy control group (the fact that there even is a healthy control group speaks to the dichotomization of healthy vs. ill and the normalization of these discourses) are referred to as ‘patients’. They too are shown that they are deserving of the title ‘patient’ when they are asked questions like what prescription their eye wear is, and through the RBANS test which inevitably shows them that they are not as sharp as they once may have been because of age, or at least are not as sharp as others, since presumably the test is created to show what normal is, patients feel that they should be able to do all the tasks perfectly, when in reality many of the tasks were not created to be conquerable. This is how the patient body is disassembled. The first phase of disassembly involves disassembling the patients into data. The research assistants strategically disassemble the patients in the study so that they fit the needs and desires of the study. The Kinarm project is designed to legitimize the Kinarm robot as a standardized assessment tool. The patients, then, are disassembled as objects in the second phase of disassembly as ‘ill’. In the third phase of disassembly, the mind is disassembled through memory tasks that point to what was not remembered rather than what was, then the body is disassembled to fit into the Kinarm and perform the tasks effectively. To do so, the Kinarm must be proven successful at measuring patients of the same objective categories against the standard. Patients who participated in this study, for example, were categorized as major surgery-knee, major surgery-hip, cardiac-triple-bypass, critically ill, healthy control, dialysis-

peritoneal and dialysis-hemodialysis. Patients can be further categorized by the study according to age, gender, and other factors (ex. level of education, economic status, etc.). The categories of illness are particularly important to the issue of the disassembly of the patient's body because there are limited categories of illness in which to put patients.

Regardless of the expansiveness of the categories, no person ever fits them perfectly. Henry fits into three of the categories listed above. He is considered a dialysis patient in the study and further identified as a hemodialysis patient. However, he could also be categorized as a major surgery patient under the hip replacement sub-category because he had a hip replacement three months earlier. Henry might also be categorized as critically ill because he is permanently on dialysis and he has been diagnosed with chronic kidney failure. In the study, though, Henry is only a dialysis patient. The other categories within which he could be placed are entirely ignored. (It would be more difficult to ignore the other possible categories within which Henry could be placed if he were allowed the opportunity to discuss his health in more detail. This is possibly one reason why the assessment is not designed to allow patients to talk in detail about their health.) When Henry arrives in the Kinarm room, Kelly asks him whether he is a hemodialysis or a peritoneal dialysis patient. She asks him about the dialysis clinic he attends bi-weekly. Kelly does not ask about Henry's other health faculties and Henry does not disclose anything more to her. It is not until the interview, when the Kinarm assessment is over, and I ask Henry to talk about his experience in the Kinarm robot, that he tells me about his other health concerns, including a hip replacement surgery that has not healed although the surgery took place months before, that have had him bed-ridden and hospital-bound over the previous months. The Kinarm project disassembles the bodies of patients, like Henry, so that they fit within the closed

categories of the study. The Kinarm project needs patients to be disassembled because without doing so, patients do not fit neatly within the project's categorizations.

Once the body has been disassembled into data and in the practice of fitting the body into the Kinarm robot, it is reassembled with the Kinarm as part of a human-machine hybrid. After the pen and paper tasks are completed, the patients are guided into the robot. The research assistant connects human patient to robot (the leather shield is attached to the neck by Velcro straps) and prompts the patient to initiate their own connection with the machine (grabbing onto the handles and connecting their forehead with the forehead pad).

Now it's time to get into the robot, Kelly tells Henry, the patient. Kelly does not grab Henry's arm to help him up, she simply reminds him that there is a step to get onto the platform of the Kinarm. I am surprised by this. Henry is 85 years old. He has chronic kidney failure and recently had a hip replaced, which due to his age still had not fully healed. But, Kelly is well trained, perhaps she wants to give the patient autonomy and agency, he will ask for help if he needs it. She pulls the chair out from beneath the Kinarm where it has been waiting for Henry. She positions it in the center of the platform and waits for Henry to sit down. Then, Kelly pushes his chair into the Kinarm and locks the wheels around Henry. Kelly closes off the shield under the screen and comments to Henry that it is so that he does not see his hands. She then straps the bib-like black leather thing around his neck and fastens Velcro in place. Kelly passes the handles of the Kinarm to Henry. Put your forehead against here, she says and points to the forehead pad above the screen. Before walking over to her desk, she shows Henry the mirror match task. If the robot moves this hand here, she asks Henry, how would you match it with your other hand? Exactly, she says and walks away (Field notes, June 14, 2016).

Henry's body is reassembled through his physical attachment to the Kinarm. First, he sits in the chair, thereby connecting to it, and is locked in place beneath the Kinarm. Second, Henry's vision is disassembled as the shield and the leather bib close off his vision, making him unable to see as he would were his organic body not connected to and, thus, mediated by the Kinarm. At the same time, his vision is reassembled by the shields which both change his vision and allow

him to see the screen and the lights on the screen of the Kinarm. Third, Henry's body is reassembled when he grabs onto the handles of the Kinarm which extend his body and make it possible for Henry to move the objects on the screen. Finally, Kelly completes the process of physical connection to the Kinarm by showing Henry how to maneuver his new body within the Kinarm structure. The Kinarm becomes part of him through the procedure of getting into the robot.

Vision is disassembled and reassembled by the Kinarm. One of the first questions that the research assistants ask each patient is whether or not they wear glasses or contact lenses. If the patient has been in the assessment before, they are asked if their optical prescription has changed since their last visit. The research assistants are trained to give basic vision tests to patients who do not wear glasses or contact lenses or who are unsure whether or not their prescription has changed. The results are recorded in their file. In this way, the vision of the patient is disassembled. Additionally, the shields (one bib-like and the other that closes off the screen) disassemble vision by removing sensory norms. That is, it is normal (for these patients) to see and feel together. The patients understand the world through their senses. In the Kinarm the patient's senses are managed through disassembly and reassembly. As the patient's vision is closed off by the shields, it is simultaneously directed to the screen and its lights. With forehead to the forehead pad, and body in close to the Kinarm, the patients cannot see much other than the screen. Their vision is reassembled so that the screen is the central focal point.

The human body is disassembled from its organic form and is reassembled with inorganic machinations that perform the same tasks better and make possible the performance of new tasks that are impossible without the attachment. The organic body does not fit within the Kinarm robot. In the Kinarm assessment, the organic body must be disassembled in order for it to 'fit'

into the robot. For instance, organic vision does not allow one to see in the Kinarm robot, and neither does natural movement, which allows joints to move on multiple planes, make it possible for one to perform the Kinarm tasks. The organic body must be a mixture of organic and inorganic parts to fit into the Kinarm and perform the required tasks. The body must be reassembled with bib and shield and hand connected to handle. Without the bib and shield, the patient cannot see within the Kinarm. Without inorganic handle in organic hand extending the reach of the body into the machine, the patient cannot perform the tasks. It is necessary for the organic body to be disassembled only to be reassembled to fit into the Kinarm. The research assistants on the Kinarm project begin the process of bodily disassembly by situating research participants as ‘patients’ who are ill and abnormal even when healthy. In doing so, the patients become exact fits in the study categorizations and the Kinarm robot. Disassembly makes it possible to rebuild the organic body within the Kinarm robot. The body is disassembled only to be reassembled.

4.2 Seeing

Seeing is accomplished beyond vision. Seeing is interactive, it involves recognition, decoding and comprehension. In order to ‘see’, one must recognize the system of signs and decode the signs to produce comprehension. According to Amann and Knorr Cetina (1988, p. 138):

When embedded in talk, ‘seeing’ is interactively accomplished. Thus the process is not just a semiotic process, in the sense of involving a translation into a generalized system of signs. Nor is it mainly a cognitive or interpretive process in the sense of involving individual conceptual decoding. Instead, the process has a speech act and particularly a dialogical or interactive structure.

In the Kinarm, vision is constructed through the process of disassembly and reassembly described above. Every patient views the lights on the Kinarm screen. Seeing, however, comes

about through interactive processes, and thus, seeing is unique to every individual, a subjective process. Every patient ‘sees’ the objects on the Kinarm screen, interprets, and makes sense of these objects differently. The system of signs seen in the Kinarm has different points of recognition for different patients. Patients with experience playing or watching video and computer games commented that the Kinarm’s screen and tasks resemble video and computer games and their consoles, comparing the Kinarm task to Pac Man, Candy Crush and Solitaire, and the Kinarm screen to a computer, Wii or Gameboy. One patient recognized the system of signs as derived from computer games like Super Mario, which she proclaimed during the assessment. However, she informed me in the interview that Super Mario was after her time and that she has no experience with video or computer games and little experience with computers:

I was teasing about Super Mario because I don’t, that would be the generation way below me that had that, right. So I’ve never done anything like that on a computer, so at first it was a bit daunting because I thought, oh what if I can’t do this...(Field notes, June 22, 2016).

The difficulty with the Kinarm, then, is that, while all patients’ vision is reassembled by the Kinarm, some patients do not recognize the system of signs, and thus cannot ‘see’. Others recognize but do not understand the system, their ability to ‘see’ is limited. Still others, both recognize and understand the system of signs. They are fully able to ‘see’. All patients, regardless of what position of recognition and understanding they find themselves in, must actively decode the signs they see. The recognition and understanding of the system of signs is based primarily on past experience with technology.

Previous experience with new technology and electronic gaming was the primary factor contributing to understanding the system of signs of the Kinarm assessment. Age (all patients were elderly) did not prove significant in the data collected as a factor that determined the level of understanding the system of signs, however, patients collectively agreed that age could be a

factor that affects the experience of patients. Susan, a 56 year old, wondered, “if somebody that was 79 [might] find that a bit, I don’t know, scary or intimidating or whatever”. Susan explained that she would think that somebody younger “would think, yeah, let’s do it!” (Field notes, June 9, 2016). The assumption that fear is based on age comes from the fact that older individuals have less experience with digital technology and little or no experience with robots (see Affect section). Comparatively, younger people are assumed to have more experience with technology and experience with electronic gaming which patients felt was important to performance in the Kinarm tasks. During the assessment, Susan yelled out mid hit, “Kids’ll like this” (Field notes, June 9, 2016). Susan assumed that kids would like the task because kids like to play video games and computer games. Jack drew a similar conclusion, the assessment, he felt, “would be a whole lot easier for uh a young person who is used to uh doing a lot of texting or game boying or something along that line than an old guy who never has done any of that stuff” (Field notes, June 8a, 2016). The amount of experience with new technology then is tied to age.

More specifically, previous electronic gaming experience, according to patients, makes it more likely to recognize the system of signs. For instance, Jack recognized the correlation between the system of signs of the Kinarm assessment and that of videogames, “Well, I don’t know much about kids’ electronics, but I did see something they called a Wii one time. I would explain [the Kinarm] as something like that. Or uh, a Gameboy” (Field notes, June 8a, 2016). Here Jack points to ‘kids’ as the primary users of electronics, thereby indicating that adults, especially older adults who did not grow up using electronics are secondary, less familiar, users or do not use them at all. Jack recognized the system of signs based on what it resembled (the system of signs of various videogames including those played on Wii and Gameboy consoles), but he did not understand the system. To mitigate this, Jack attempted to translate his own

experience with technology onto his experience in the Kinarm assessment. Jack applied his own system of signs, “I’m used to operating quite heavy machinery so it’s, it wasn’t, it wasn’t umm, I didn’t find it intimidating or anything” (Field notes, June 8a, 2016). Certainly what Jack saw on the screen of the Kinarm did not resemble heavy machinery, and the system of signs for operating the Kinarm and operating heavy machinery have little if anything in common. However, Jack operates heavy machinery daily in his work as a farmer. He is familiar with the operation and the way that a small action from the control console produces a large reaction in the appendages of the machine. The same is true of the Kinarm robot. Jack brought his past experience, something he knew and understood, to the Kinarm experience, so that, while he could not fully comprehend the system of signs of the screen, he could still perform the tasks based on his pre-existing knowledge of maneuvering machines. This is a process of decoding. Jack decodes the system of signs using his pre-existing knowledge and previous experiences. Previous experience is the primary determinant in recognition and comprehension of the system of signs of the Kinarm assessment.

The body experiences states of instability and flux in the Kinarm assessment. The organic body is strategically disassembled in order to be reassembled as part of the Kinarm itself. In the Kinarm assessment, patients necessarily embody the machine. Embodiment is made necessary by both the tasks the Kinarm assessment requires and the procedure of bodily reassembly. The Kinarm robot transforms the patient into a hybrid of organic and inorganic materials.

4.3 Embodying the Kinarm

As an exoskeleton robot, the Kinarm is designed to mirror skeletal structures of the human body. The Kinarm has arms that extend beneath the screen. The arms are fixed in place by mechanic

shoulders. These arms have elbow joints that make it possible for the arms to flex and extend. The handles are the hands of the robotic arms. Patients hold the handles in their hands, extending their arm from its biological shoulder, through elbow, wrist and hand to handle, elbow, and shoulder of the Kinarm arm. The largest mechanical difference between the biological arm of the patient and the robotic arm of the Kinarm is that the arms of the Kinarm can only move in a horizontal plane, where organic arms can move in multiple planes. The exoskeleton of the Kinarm, then, becomes part of the skeleton of the human patient, a prosthesis of the organic body. Woodward (1999, p. 50) explains:

Over hundreds of thousands of years the body, with the aid of various tools and technologies, has multiplied its strength and increased its capacities to extend itself in space and over time. According to this logic, the process culminates in the very immateriality of the body itself. In this view technology serves fundamentally as a prosthesis of the human body, one that ultimately displaces the material body, transmitting instead its image around the globe and preserving that image over time.

Technology, as a prosthesis, becomes a part of the body, a fusion of human and machine. The human body when connected to technology is less constrained by human limitations.

Conceptions of the body as material and mortal are challenged by the machinations that extend the body. The material body is displaced by technologies as the body is disassembled and reassembled with machine parts. The mortality of the body is altered because the new, technological extensions of the organic body are immortal machinations. Technologies physically extend the body by becoming part of the body and extending its capability. According to Polanyi (1959, p. 63):

an external thing is given meaning by being made to form an extension of ourselves, these beliefs are transposed into more active intentions which draw on our whole person. In this sense I should say that an object is transformed into a

tool by a purposive effort envisaging an operational field in respect of which the object guided by our efforts shall function as an extension of our body.

The Kinarm becomes an extension of the body when it is used in a purposeful and intentional way. Human beings are hybridized with machines that perform specific functions better and faster than the organic human body is capable of doing.

In order for this fusion of human body and machine to occur, the human must first embody the machine. Sobchack (1995) demands that resistance and fear of the body merging with the machine be acknowledged as a valid feeling response. Several patients found the Kinarm robot intimidating at first, but their intimidation wore off as they spent more time in the machine (see section on Affect). Thus, while there may be fear of embodying the machine, technology as a prosthesis is created when this fear dissolves and the machine is accepted as *part* of that body, that is, when the machine is no longer recognized as an entity in itself, but rather is accepted as part of the physical body, a necessary, essential component. Sobchack (1995, p. 211) writes: “the increasing transparency of one’s lived flesh enabled by new technologies as well as the ubiquitous visibility of new technologies leads to euphoria and a sense of the limitless extension of being beyond its materiality and mortality”. Glen felt his body had extended beyond its materiality while in the Kinarm, he was no longer performing the tasks with the handles and arms of the robot; Glen was performing the tasks with his hands:

Yeah, yup, once you get going you think you’re doing it with your hands. Well, ay ye (pause) I didn’t think so much the dots but once I got goin’ at it I thought that I was moving the things with my hands eh...but no I just felt like I was doing it with my hands and not the robot (Field notes, May 19, 2016).

The connection between Glen’s hands and the handles of the Kinarm has reached transparency. Glen is no longer able to differentiate between his organic, human body and the machine. The two entities have become completely one. The materiality of Glen’s human body is changed by

its connection to the machine, making the human body not fully organic. Merleau-Ponty (1962) describes transparency as a product of habit, coming about as a result of comfort and familiarity.

Merleau-Ponty (1962, p. 128) explains this phenomenon:

When I put my hand to my knee, I experience at every stage of the movement the fulfillment of an intention which was not directed at my knee as an idea or even as an object, but as a present and real part of my living body, that is, finally, as a stage in my perpetual movement towards a world. When the typist performs the necessary movements on the typewriter, these movements are governed by an intention, but the intention does not posit the keys as objective locations. It is literally true that the subject who learns to type incorporates the key-board space into his bodily space.

According to this logic, during his first few tasks of the Kinarm Glen is growing in familiarity with the Kinarm robot and his body inside of it. At first, Glen has embodied the robot, but not fully, since full embodiment requires transparency. In time, Glen moves the handles and arms of the Kinarm out of habit. Now he has fully embodied the Kinarm robot. At this point it no longer requires intention to move the robotic arms. Glen has incorporated the Kinarm robot into his bodily space. The Kinarm is part of Glen's lived body and his bodily experience.

The mirror match task is, in essence, a task which tests whether or not the patient has embodied the Kinarm. With nothing to see on the screen, the patient must perform the task by feel, moving their biological arm and the robotic arm in the same way (and in the second mirror match task, at the same time and speed) as the Kinarm's robotic arm moves their organic arm. In this task, the robot moves one of the patient's arms into a position. The patient must mirror match the position with their other arm. Once the patient believes they are in position they say 'yes' or 'okay' to indicate this. Throughout the task, the research assistant watches the computer screen which has a replication of the patient's and the Kinarm's arms and the Kinarm screen. Once the patient indicates they are in position, the research assistant pushes a button to move the

robot on to the next position. In the second mirror match task the robot moves itself from position to position without the interference from the research assistant. This task requires that patients embody the machine. Patients must embody the machine in order to move in unison with and to match the positions of the robot. In the absence of embodiment, this task simply cannot be done, or at least the positions cannot be mirror matched. This task requires the patient to move like the robot and think like the robot to anticipate its next movement. The mirror match tasks encourages patients to become one with the Kinarm in a transparent connection.

Glen embodied the robot. He allowed himself to be connected to the robot, to become one with it so that he could perform the tasks. Glen's hands, around the handles of the robotic arms, moved from light to light, shape to shape, together, as one entity. For Glen, it felt as though his hands were reaching the lights and hitting away shapes, as though the handles and the robotic arms were not there at all. Glen was in the robot. The robot became part of his lived body. Glen was in the screen, hitting shape and light and ball. In the Kinarm, Glen is not fully human. His body is fused with the body of the Kinarm. Human and machine become one. However, it is only through Glen's body that he can experience the Kinarm and the Kinarm assessment. His sensory receptors absorb information and respond accordingly. Glen's body is primary to the experience. The Kinarm robot extends Glen's organic body in space and time, making it possible for Glen to reach into the screen and move the objects inside. Glen's new body extends his materiality. Glen's organic body is fused with the inorganic body of the Kinarm robot making the new body a combination of organic and inorganic materiality. Glen's sense of his own body changes in the Kinarm. Glen knows the limitations of his organic body, but these blur and disappear while he is in the Kinarm. Glen explained that if "you put it in your mind" that you are moving your hands and not the robot, then there are "very few things you miss in

there” (Field notes, May 19, 2016). Glen had to think about his body differently materially in order to perform the Kinarm assessment tasks. Through embodying the Kinarm robot, the materiality of Glen’s body was forced into flux.

Not all patients were as eager and willing as Glen to become one with the machine in a fusion of organic and inorganic bodies. Ola was hesitant with the Kinarm at first. From the start of her assessment until the end, when I lead her across the hall to the interview room, Ola said nothing if not prompted. Even when prompted, her response was brief and to the point. Ola thought deeply about the Kinarm and her feelings during the assessment. She had worried about the Kinarm jerking her limbs around violently, which she would not have liked, she informed me in the interview. She had been in the Kinarm before for an assessment prior to her hip replacement surgery three months earlier. She had also been nervous the first time and found it difficult that she could not see her hands. In the interview, Ola talked and talked. It was as if she had held everything inside for the almost three hours it had taken to get through the assessment. The interview gave her opportunity to share her feelings and make sense of her experience. Ola found that it was difficult to connect to the Kinarm robot because of her reservations. It took her time to come to trust the robot. Ola talked about the shields, one put over her chest like a bib and one that closed under the screen of the Kinarm, put in place so that she could not see her hands:

[T]he first time I wasn’t quite sure why it was being done, whereas after a while the first time I figured out it was so I wouldn’t see my arms moving, so I’d be doing everything by feel rather than also looking down to see which way my arm was going, for instance. Ha, well, [it felt] maybe a little bit strange because normally you can see things unless you are playing a game and you’re blindfolded, but in normal life you’re seeing your, your arms move or whatever and you’re using your sight and your feel to pick up things and move them, so I guess it was, that was a little bit unreal, not, not bad. Once you get used to the fact this is going to be only by touch then you’re fine with it, but at first it’s like woo, you know, there’s something missing. Umm, well you sort of have to trust it, I

guess, I guess that's what I would call it is you develop a trust that it is going to do things, move your arm and so on and that's fine it doesn't matter if you don't see your arm moving...I felt like I was waiting for it to do things with me, with my arm. But I wouldn't say that I felt in control of that...I was sitting there waiting for the next thing it wanted me to do (Field notes, May 26, 2016).

It was difficult for Ola to connect to the robot because it was not 'normal life' without being able to see. Ola's, like all other patients', senses were disassembled when she got into the Kinarm robot. Her senses were then reassembled within the Kinarm. Without being able to see her arms, Ola notices that her vision has been changed. She can still see. She sees the objects on the screen and sees the lights. Ola just sees differently inside the robot than she sees outside of it. Ola has reservations about seeing differently. Her new way of seeing seems uncomfortable and abnormal to her. Still, to some extent Ola embodied the Kinarm in spite of her reservations. Task completion demands some level of embodiment. In time, Ola learned to trust the machine. Her trust for the machine grew throughout the tasks as she realized that the robot would not jerk her limbs around and that she was comfortable and safe in the robot, "I think it was moving at a normal human rate", she said, and later, "Well [I] certainly [felt] physically comfortable, yeah. And I didn't think that anything that the robot did was particularly confusing, like especially when it was moving my arm, I was fine with that" (Field notes, May 26, 2016). The research assistant also helped Ola develop trust in the robot because Ola felt comforted by the human connection, "it was nice to hear a human voice explaining things to me...I liked that this wasn't entirely mechanical" (Field notes, *ibid.*). As her trust increased, she began to embody the machine in a different, more dynamic, way. Once she had learned to trust the machine, she allowed it to move her limbs at its will. However, during the assessment, Ola never fully embodied the machine, her embodiment of the Kinarm was never transparent. Ola provides evidence of the lack of transparency when she says she was waiting for the Kinarm to 'do the

next thing' with her body. She describes herself more as a puppet and the Kinarm the puppeteer, than as an actor who has willfully embodied the machine in order to conquer the assessment. Ola did not feel in control, she felt controlled. Glen, as we have just seen, establishes a successful and transparent embodiment. He shows a desire to embody the machine, a motivation to achieve transparency. He put it into his mind that his body was in the machine. Ola, on the other hand, passively allows the robot to move her, to control her body. She embodies the Kinarm just enough to move the handles and arms when she has to, but she has not will to become part of the machine.

Embodiment, then, also takes will. One has to, at least on some level, want to embody the machine. Ola held the handles with only her fingertips, as if she were afraid that a firm grip around the handles would somehow give the machine permission to manipulate her limbs at its will and strength. She never once let her whole hand wrap around the handles. Glen had a firm grip on the handles. His love for computer games translated into his Kinarm assessment. He fervently hit the balls and shapes away, his body moving as much as his arms and the robotic arms. Glen reached from target to target with veracity. There was power in his movements and excitement in his voice as he proclaimed things like, "I must have been the goal tender for Montreal!" (Field notes, May 19, 2016). It is clear through Glen's reactions to the Kinarm assessment that he found pleasure in embodying the machine. Glen wanted to be one with the machine. He wanted to embody the machine. Glen achieved transparency with the machine because of his willful approach. On the contrary, Ola did not achieve transparency. She only learned to trust the machine and allowed it to move her limbs at its will.

Past experience also plays a role in successful embodiment. Glen is familiar with machines. Glen's quickly learned transparency with the Kinarm may have been because of his

past experience with technology. In other words, the ubiquity of technology in Glen's daily life may have enabled this transparency. Glen is a dedicated computer game player with experience playing games that have similar objectives to the tasks of the Kinarm assessment. Glen repeated throughout the interview, "It was just like being on the computer" (Field notes, May 19, 2016). Glen translated his past experiences, his familiarity onto the Kinarm. The Kinarm assessment was like being on the computer for him because in his mind, this analogy allowed him to make sense of his experience in the Kinarm. Past experience, then, facilitated the development of a transparent embodiment in the Kinarm machine.

Past experience is the most important factor to successful embodiment. Past experience makes it more likely for patients to recognize and understand the visual system of signs of the Kinarm and, thereby, allows patients to make sense of their experience with greater ease. Embodiment is necessary to the Kinarm assessment. Patients must embody the machine in order to perform the tasks effectively.

CHAPTER 5. EMOTIONAL LABOUR AND EMOTION WORK IN THE KINARM ASSESSMENT

5.1 Emotional Labor and Emotion Work

It is often assumed that technology, particularly robotic technologies, remove and suppress human emotions. A major concern about robots in healthcare is the removal of emotions and human connection from care (for instance Turkle, 2011, etc.). With the use of medical technologies, particularly robots, this concern becomes increasingly likely. Care is associated with warmth and human interaction, and contrasted with technology which is cold and inhuman (Pols and Moser, 2009). It is assumed that the implementation of technologies in healthcare comes at a cost that is the warmth of care. It is also true that some (particularly humanists, see Mykhalovskiy and Weir, 2004) understand EBM as a “cold” (Pols and Moser, 2009) form of care. However, in the case of the Kinarm assessment, emotional labour and human connection remain central to providing care to patients. This is true at all levels of the assessment. The doctors, who refer patients to the Kinarm study, provide a high level of care to their patients. The researchers and students involved in the Kinarm project warmly care for their patients. The research assistants who are the front stage (Goffman, 1959; Hochschild, 1979) of the Kinarm assessment engage emotionally and physically with patients. Emotional labour and human connection are clear in the Kinarm assessment. This may be, at least in part, because the Kinarm assessment is still in the research phase and is not yet part of healthcare.

Hochschild (1979, p.7) defines emotional labour as labour that “requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others—in this case, the sense of being cared for in a convivial and safe place. This kind of labor calls for a coordination of mind and feeling, and it sometimes draws on a source of self

that we honor as deep and integral to our individuality”’. Since labour is necessarily a commodity (in a capitalist system), emotional labour is the commoditization of emotion. Hochschild’s (1979) analysis in *The Managed Heart* focuses primarily on the emotional labour performed by flight attendants working for Delta Airline. For these individuals, emotion is commoditized as part of their job. However, Hochschild also makes reference to unpaid and non-commoditized emotion that is performed by individuals, such as a person behaving as though they are sad at a funeral whether or not they are truly sad. Emotion work refers to unpaid emotional labor. Here these terms will be used to differentiate between commoditized emotion (labour) and non-commoditized emotion (work). Emotional labour and emotion work, both, are central to the Kinarm assessment. That is, those involved, both paid and unpaid, ‘induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others’, wherein the proper state of mind is determined by the principal investigators of the project who train the research assistants to appropriately interact with patients. The emotional labour of those employed by the Kinarm assessment maintains the warmth of the care delivered to patients in spite of the presence of and interaction with the Kinarm robot.

Emotion has been commoditized for the doctors, medical care providers, and research assistants; they are paid to show the right kind of emotion; it is part of their job description. The patient, on the other hand, performs emotion according to the feeling rules that they perceive (based on the research assistant’s interaction with them and their pre-existing knowledge and expectations) as acceptable in the Kinarm assessment situation. During my field work, I was fortunate to observe the training process of research assistants. The primary research assistant on the Kinarm project, Karen, was training a summer student who was employed by the project. The summer student, Kelly, shadowed Karen and observed several patients go through the

assessment from start to finish during my first week of field work. We sat together and watched Karen interact with each patient. Karen would point out details and teaching moments to Kelly. Karen instructed Kelly to remind patients of the step when getting into the robot so they would not trip on their way to the platform. She told Kelly to talk the patients through the process of getting into the robot so that they would not feel nervous or intimidated. In one assessment, Karen asked Ola, a patient, if she was comfortable in the Kinarm, because she did not appear to be so. She suggested that a low box put under her feet might make Ola more comfortable (Field notes, May 26, 2016). Ola thanked Karen for being so considerate (Field notes, *ibid.*).

Immediately following this interaction, Karen pointed out her actions to Kelly, “always go above and beyond with the patients”, she said, “you want the patients to feel comfortable” (Field notes, *ibid.*). Perhaps the most important lessons of all were those which were unspoken (or at least unspoken in my presence). Karen always spoke to the patients on their way to the Kinarm room in a way that intentionally built a relationship. When she entered the room, Karen was always speaking jovially to patients. Kelly adopted this same approach to relationship development. She would ask patients where they lived, what hobbies they had, how many children or grandchildren, etc. Karen taught Kelly to show the patients that she cared so that their experience would be most enjoyable. The care work was intentional and part of the professional training for the research assistant position. This is emotional labour.

Emotional labour demands that employees provide high level care, that is, “warm care”, to those with whom they interact. In the case of the Kinarm assessment, emotional labour is part of the job descriptions of those who are occupationally involved in the assessment (doctors, medical staff, researchers, and research assistants). The presence of the Kinarm robot does not dilute the standard of care. In the absence of the Kinarm, the referring doctors provide high level

care to patients, which in turn results in the participation of patients in the Kinarm assessment. Researchers also provide a high standard of care to their patients in the absence of the Kinarm. In the presence of the Kinarm, research assistants provide a high standard of care to patients, treating them both emotionally and physically just as the referring physician has done in his or her role. The standard of care does not change in the presence or absence of the Kinarm robot. All care providers emotionally labour to ensure that patients feel well cared for, comfortable, and unique, this is, after all, their job.

5.2 Emotional Labour of Referring Doctors

Medical doctors, nurses, and other healthcare staff are not involved in the assessment. They are, however, major participants in the Kinarm project as a whole, as either or both researchers and/or referring physicians. Some medical doctors, who are also researchers, use the Kinarm or the Kinarm assessment data as part of their research. These doctors refer their own patients and patients of other doctors, with whom they come into contact, to the study. Some doctors serve only as referees:

I have a wonderful family doc... and we have a really good rapport, you know. And when I say family, I mean everybody from you know, granddaughters and everybody. So she knows the family dynamics and, uh, I think she just thought that I would be someone who would be a good participant. She actually said, I need to find some, umm, what was the term she used? Anyway, it was a positive verb that she used to describe, anyway and she said, I thought about you right away and I thought maybe you might be interested in this. So it was just a conversation. I was in to see her for another issue, because I think, she was just starting to gather patients that might be interested to do this. Although she did say, I was gonna give you a call, but I happened to be in for an appointment, so that's basically how that happened. And she explained what was going to be involved, you know, the two appointments and, I said I would do it (Field notes, June 9, 2016).

This family doctor's good rapport with her patient made it possible for her to recognize an interest on the part of the patient in participating in the Kinarm assessment. Susan agreed to participate because her doctor asked her to and because she was interested. The result may have been different had Susan and her doctor not had such a good relationship. The patients who participated in this study tended to have a good relationship with the doctor that referred them to the study and several had been under the doctor's care long term because of recurring injuries or critical illness. As a whole, patients spoke very highly of the doctors who cared for them.

Doctors play a central role in the Kinarm project. The relationship between doctor and patient is fundamental to the Kinarm assessment. The patient must first trust the doctor in order to accept the referral to the Kinarm assessment. All eight patients that participated in this study spoke extensively about the doctor who cared for them in their most recent healthcare experience. The patients told stories about their doctor(s), reiterated things that the doctor had said to them, and praised the doctor for his/her care. Because many physicians are responsible for referring their patients to the Kinarm assessment, they are the first point of contact of the assessment. The emotional labour of the doctors, then, is extremely important to the Kinarm project because it brings patients into the study.

5.3 Emotional Labour of Researchers

Researchers on the Kinarm project (in some cases) also perform emotional labour. That is, some of the researchers on the Kinarm project are paid employees responsible for treating patient bodies and, at the same time, emotions, just as the doctors on the project do. The emotion work and emotional labour of the researchers has two primary functions: first, it encourages patient participation, and second, it increases the comfort and satisfaction of patients with their care (in

both their medical care and in the Kinarm assessment). The emotional labour and emotion work of researchers maintains the quality of care in the Kinarm assessment.

Matthew is a PhD student who is involved in the Kinarm project. Matthew's emotional labour (for which he is paid and trained) and emotion work (which is both unpaid and not required of him) made patients feel well cared for and encouraged their participation in the assessment. Matthew occasionally puts patients through the Kinarm assessment, though this only takes place when none of the research assistants are available. A critically ill patient had been induced into a coma several months before. Somehow Matthew had become acquainted with the patient's wife and the patient himself, though the patient was not acquainted with Matthew until he came out of the coma. While still in a coma, Matthew had performed a medical procedure on the patient (emotional labour). The relationship between Matthew and the patient and his wife remained strong. Matthew provided comfort to them through their trials. Matthew greeted the patient during his Kinarm assessment and the patient immediately lit up (emotion work). He spoke of Matthew throughout the interview and explained that Matthew had been there while he was very sick and induced into a coma months before (Field notes, May 19, 2016). When the patient had finished the Kinarm assessment, Matthew returned to retrieve the patient and lead him from the Kinarm room to his car (emotion work) (Field notes, May 19, 2016). Upon his return, the patient exclaimed 'Matty!' and they began chatter until Matthew interrupted and asked how much longer the interview would last (Field notes, May 19, 2016). There were two factors to this patient's participation in the Kinarm assessment. First, his wife agreed that he would participate because she was concerned about his brain function and wanted an assessment done on him. Second, the patient and his wife had a good relationship with Matthew and they wanted to support him by participating in the Kinarm assessment with which Matthew is

involved as part of his PhD. In this case, it is clear that the patient chose to participate as a result of the emotional labour that Matthew performed. Matthew provided exceptional physical and emotional care while measuring the oxygen content in the patient's brain, and, in turn, the patient participated in the project. It is also clear that the emotional labour Matthew performed made the patient and his wife feel more comfortable and well cared for than they might have otherwise. Thus, Matthew's emotional labour performed both functions observed: it encouraged patient participation, and it improved comfort.

Justine is another PhD. student. She works with dialysis patients. Justine performs emotional labour. She is paid to treat patients emotionally as well as physically. Henry, a dialysis patient who participated in the Kinarm assessment, spoke several times of Justine and his relationship with her:

[Justine] recorded my brain in the, the, the dialysis and she's trying to relate what goes on in the brain with, with the rest of your, your mental activity as far as I understand. And, uh, she's got to sit down and decode some of it and try and get some relationship from it. I understand there are about 6 people on her list that she's doing.... I can't remember when Justine, first started this. I guess it's been about a year since she started. I know that uh she talked to me when I was uh going to the renal clinic and, uh, that's when I did the first test and she knew that eventually, she knew that my kidney failure was getting worse. And what really happened was that my kidney failure went up to a score of 600 and then it dropped back to 550 again and then it went back up to 600 and that's when I fell and broke my hip and of course that kicked it up to 750 and then to 900 and then they threw me on dialysis and she's been tracking me all the way through that. I'm sure there were some hiccups in here machine when I, I first came on dialysis. Other than that, the hip is improving and it's getting better. Other than that, I'm in good health all the way through this. Except when I was walking to the car and I realized I forgot my wallet, did a quick turn and I fell and broke my hip. That was in February. Other than that, it was somewhere in that period of time that Jessica talked to me and convinced me that this would be a good idea (Field notes, June 14, 2016).

Henry's relationship with Justine gave him reason to participate in the Kinarm assessment. He wanted to support her and her education because Justine had supported him through taking care of him. The Kinarm assessment is framed as part of medical care because the same people (doctors and PhD. students/researchers) who are providing healthcare to the patients are the ones asking them if they will participate. The patients feel that they should participate in the Kinarm assessment to support the individual who has cared for them and their needs. Emotional labour does not necessarily require an equal exchange. Doctors do not necessarily care for patients under the expectation that the patient is now in their debt. In the same way, the PhD. students who provide care to the patients in various contexts do not expect a return for their labour. However, it is more likely that a patient they have cared for and, thus, developed a relationship with, will agree to participate in the Kinarm assessment, than a patient they have never met who they have simply telephoned to ask. In this sense, there is a return for their emotional labour that goes beyond a financial gain. The emotional labour of the doctors and PhD. students/researchers is returned by the patient's participation in the Kinarm assessment which allows the doctor and PhD. student to continue their research. Additionally, in providing medical care to the patient, the PhD. student and the doctor are situated as caregivers. When they ask the patient to participate in the Kinarm assessment, they remain in the position of caregiver, they are not automatically transferred to a position of researcher according to the perspective of the patient. The patient then, perceives the Kinarm assessment as part of their healthcare because the individual who encouraged them to participate has also treated them in the context of healthcare. Patients become objects to be studied and transferred into data. The care work of the researchers, like that of the physicians, has the function of producing participants for the Kinarm study.

5.4 Research Assistants

The research assistants build a safe environment around the Kinarm to ensure patients feel comfortable and well cared for during the assessment. Simple gestures like asking patients if they need a break and offering them food and drink during the assessment make the patients feel comfortable. The research assistants were always pleasant and accommodating with patients, placing the patients at the center of the care they delivered. One patient was completely deaf in his right ear and could not hear the research assistant if she was sitting at the computer desk next to the Kinarm, from where she would usually deliver instructions to patients. The research assistant accommodated the patient by walking over to his left side each time a task finished (Field notes, June 14, 2016). From his left side she provided him with the instructions for the next task. This gesture made the patient feel like the research assistant actually cared about him as a patient and about his experience. This patient said of his experience, “I thought [the instructions] were very good, very accurate. Excellent, yeah. I didn’t, you know, they explained it and what happened was what was explained. It, uh, it all coordinated. They do a good job. Especially talking in my good ear” (Field notes, June 14, 2016). This act is not out of the ordinary, with every patient the research assistants take special care to treat the patient according to their specific needs and individuality. The research assistants were convivial with patients, emphasizing similarities between themselves and the research assistants and relating to patients when possible.

Research assistants manage their own opinions and beliefs, acknowledging and never negating those of patients’ regardless of how offensive and politically incorrect patients may be. Martin was telling a story about what he witnessed at lunch that day (Field notes, May 24, 2016). The patient explained that he was eating lunch in a restaurant and saw a detainee from the nearby

penitentiary with his worker. He described the attire of the ‘punk’: tattoos and baggy clothes. Martin said, “You could just tell he would never reform” (Field notes, May 24, 2016). The way Martin spoke of the detainee was offensive and harsh. As he explained the story, the research assistant sitting across from him at the table where consent forms are signed and the pen and paper tasks of the RBANS are completed nodded along and said the occasional ‘yes’ or ‘mhhh’ as the patient’s story unfolded. The research assistant nodded along because it is her job. With patients, her own opinions and beliefs do not matter. It is her job to suppress her own judgments in order to reinforce positive feelings in the patient. This is what Hochschild (1979, p. 33) calls surface acting, where the research assistant “deceive[s] others about what [she] really feel[s], but [does] not deceive [herself]”. The research assistant put on a face, she performed the positive emotions required of her in this setting so that the patient would continue to feel comfortable and would feel like he could relate to the research assistant. This is expected of the research assistant. Because the Kinarm assessment is situated within the context of healthcare, the patients do not describe the research assistants as such, they refer to them as “the instructor”, “she”, and “the other girl”. They are never called researchers or research assistants. The patients look to the research assistants as though they are technicians or nurses who are putting them through the assessment. As such, there is an expectation of care. The patients expect to be well looked after; they expect to be asked questions about their health; they expect to be given a diagnosis in relation to the assessment.

Research assistants on the Kinarm project are expected to respond to patients in a way that anticipates problems, difficulties and conflicts so as to mitigate these before they occur. This is part of their training for the research assistantship position. In one instance, a research assistant

pushed the patient in a wheel chair from the hospital entrance to the room that holds the Kinarm although the patient had a walker which he usually used to move around:

I hear voices in the hall. One of the voices belongs to Karen, the research assistant on the Kinarm project. Other voices intermingle so I cannot tell how many people are in the hallway. Karen comes around the corner pushing the patient, a heavy set man wearing a blue and white striped dress shirt, his shirt untucked from his wrinkled grey dress pants, in a wheelchair generously provided by the hospital. Beside him is a woman, older but not old, who is carrying a walker that has been compacted so it is easier to carry. The walker belongs to the patient. The patient is disheveled with shirt untucked and pants wrinkled. He is not old either, though the wrinkles etched into the skin around his mouth and the deep pock marks on his cheeks tell a different story: the story of difficult years fighting against sickness and pain.

Karen pulls the chair that is used for the patient's to sit at the small table near the entrance of the room where the consent forms are signed and the pen and paper tasks for the RBANS test administered away from the table and leaves it next to the robot for his wife to sit in while he goes through the assessment. She maneuvers the patient in his wheelchair into the place at the table where the chair was before she sits directly across from the patient (Field notes, May 19, 2016).

If the patient has a walker why is he in a wheelchair? The wheelchair was certainly Karen's suggestion. It allows the patient to move with greater ease and comfort from the hospital entrance to the Kinarm room the floor below, thereby avoiding any potential risks, such as falling, during the travel. Karen makes a point to be the one pushing the patient in his wheel chair through the hospital corridors and to set him at the table in the Kinarm room. It positions her as responsible for his care. Karen also makes the patient feel important, he is, in fact, the most important person in the room, by seating his (healthy) wife off to the side and behind him. Karen seats herself directly across from him and at his level. This is particularly important. The research assistants often take measures to position the patient as the authority or the expert in the situation, undermining their own role in the operation of the Kinarm.

The instructions are a necessary part of the effective execution of the Kinarm assessment. Instructions make it so that every patient is capable of performing the Kinarm tasks regardless of their past experience with technology. Many of the patients praised the research assistants for providing excellent instructions. For instance, one patient explained:

I found she was really good because she'd give you that little piece too to show you exactly too what she meant. I found that her able get through to me because normally I'd think, oh and am I gonna do this right, but she didn't make me feel that way. She was really good (Field notes, June 22, 2016).

Thus, the patients themselves recognize the value of the research assistant. However, in an attempt to make the patients feel important and valuable to the study, the research assistants tend to deflect their own power status and, in turn, raise up the patient to a position of power status that is at least equal, if not greater, than their own. This does not, in fact, change the power dynamic of the assessment. The research assistant remains in a position of importance, however, by seemingly deflecting their own importance, the patients are made to feel valuable. I observed Martin's second time going through the Kinarm assessment. Being of a particular disposition (which he himself described as resulting from having become "jaded" from his time in the world), which Karen seemed to pick up on almost immediately upon introduction, Karen was quick to undermine her own power in the context of the Kinarm assessment in order to give power to the patient (Field notes, May 24, 2016). During Martin's assessment Karen began the instructions with phrases like "as you know..." and "if you remember..." (Field notes, May 24, 2016). These phrases make it seem as though the patient already knows exactly how the assessment and each individual task works. Karen need only remind him. This positions Karen, in Martin's eyes, as an accessory to the assessment more than an essential part of it. The research assistants perform emotional labour that is of great importance to the Kinarm assessment. The emotional labour of the research assistants makes patients feel comfortable, secure and sure of

themselves and their role in the project. Furthermore, the emotional labour of the research assistants has the function of reaffirming patients' decision to participate in the study. Patients go through the Kinarm study 3 times (typically before surgery or an event, 3 months after, and 12 months after that). Through situating the assessment as part of their healthcare, and providing care to patients, research assistants ensure that patients will return to participate in the study again and again until their role as a participant is complete.

5.5 Emotion Work of Patients

The patients, too, must perform emotion work in order to present versions of the self that are culturally and socially acceptable in the situation. The patients entered into the assessment with preconceived ideas of what feelings were and were not acceptable, that is, "feeling is a form of pre-action, a script or a moral stance toward [feeling] is one of culture's most powerful tools for directing action" (Hochschild 1979, p. 56). Hochschild (1979) calls these scripts, which suggest that we should or should not feel a certain way in a certain context, *feeling rules*. Three of the eight patients who participated in this study experienced feelings of intimidation, discomfort or fear when exposed to the Kinarm robot. All eight patients acknowledge that these feelings, intimidation, discomfort and fear of a robot, were legitimate. For example, a patient said that although she was not afraid of the robot, "maybe some people would find that a bit scary, but I didn't find it so. But I could see how somebody would say, oh my gosh, it's moving my arm, but maybe 20 years from now I'll feel that way (laughs) geeze I'll be 92" (Field notes, May 26, 2016).

The word 'robot' itself conjures up intimidating images, but the Kinarm is not like those other robots. This was a popular opinion among patients. For instance, Martin insisted that the

Kinarm was unlike other robots and, thus, others should not be afraid of it. At the same time, Martin suggested that many people would become scared by the title ‘robot’ even though they may not be afraid of the Kinarm robot. Martin explains:

It, it depends on the person obviously but if you have some body and the just the word computer or robot and they seize, they’ll seize. So don’t call it ah, it’s all in the name, don’t call it a robot. I don’t know what to call it, (laughs) but let somebody else figure that out. It’s not a robot. It’s not computerized. It’s not anything. It’s let’s just see if you can line up the little pieces and let it slide by (Field notes, May 24, 2016).

Of course, the Kinarm *is* a robot. It *is* computerized, and it *is* something. This patient has emphasized what the Kinarm is not (to him) in order to juxtapose the unthreatening nature of the Kinarm with the intimidating popular culture images of robots to explain why other patients should not be afraid of the Kinarm, “Oh they’re the same silly people who will, ah, play around on the internet and think for example that these compact fluorescent bulbs emit poisons when in fact they don’t” (Field notes, May 24, 2016). The Internet, then, also teaches the fear of robots. It is possible that Martin uses this strategy of imagining and inventing the feelings others might experience upon hearing the word robot and seeing the Kinarm robot in order to manage his own emotions. At the same time, it is possible that this opinion is more related to Martin’s ‘jaded’ disposition than his emotional negotiation of his feelings during the assessment. Another patient, Susan, explained in response to my question of how she would describe the robot:

I probably wouldn’t refer to [the Kinarm] as a robot. I guess, obviously it has that capability, but uh, I would say, you know, it’s just a square you sit in front of and there’s two handles, it has the ability to move the arms for you but uh, you know, there’s uh, nothing at all intimidating about it, it’s just a, you know, like a, a person that goes in off the street *that doesn’t know anything about it*, just sits down, it just looks like a, when you’re sitting in front of it, like a square that you sit in front of and handles that you move around, so I uh, yeah. So, for me to say for instance, describe to a friend that, you know, that there’s a robot, I’m sure that they would conjure up a picture that is the furthest removed from what it actually

looks like as well, but um, yeah. No, uh, certainly nothing about it is intimidating, for me anyway (Field notes, June 9, 2016, emphasis added).

By emphasizing that “a person who doesn’t know anything about it” would not find it intimidating, this patient is suggesting that it is the preconceived notions of robots that are intimidating, and thus, fear is an acceptable feeling rule. However, the Kinarm, which is *not* a robot in the same way that these conceptions are robots, is less intimidating. Earlier, this same patient explained that her general practitioner had told her “there would be a robo-robo-robot part [to the Kinarm assessment], but you conjure up your own picture in your head of what that’s going to look like, not really knowing until you get in there” and at another point, “I mean I think rationally I knew it wouldn’t be a robot-robot” (Field notes, June 9, 2016). The Kinarm is a robot though. In fact, the Kinarm and robots like the Kinarm are more prominent than the robots shown in movies. Rather than pointing out that the problem might be with the way that popular culture presents robots (as terrifying, villainous, destructive, inhuman machines, like in *The Terminator* and *iRobot*), the patients assume that the Kinarm is not a real robot because it is not like the robots they imagine when they hear the word ‘robot’. Thus, the Kinarm assessment requires patients to negotiate the feelings they experience when they hear the word robot in relation to those when they see and experience the Kinarm robot. This process of emotional negotiation is important to the patient experience.

During the Kinarm assessments the patients actively manage their presentation of self.

According to Goffman (1959, p. 139):

Sometimes the individual will act in a thoroughly calculating manner, expressing himself in a given way solely in order to give the kind of impression to others that is likely to evoke from them a specific response he is concerned to obtain. Sometimes the individual will be calculating in his activity but be relatively unaware that this is the case. Sometimes he will intentionally and consciously

express himself in a particular way, but chiefly because the traditions of his group or social status require this kind of expression...

Impression management is a matter of degree. Patients cannot fully control and calculate the impression they leave on others. Patients enter into the Kinarm assessment with little knowledge and understanding of what is involved in the assessment, the purpose of it, or their role. As such, it is difficult to know what feeling rules apply to the situation. Patients, then, are managing the self that they present during the assessment, while at the same time trying to make sense of the assessment and uncover the feeling rules. Patients are put into a situation where they feel it is necessary to manage their self-presentation. The situation of the Kinarm assessment affects the way patients present and understand themselves and their role in the assessment. Thus, the Kinarm assessment affects the selfhood of patients. One patient made a concerted effort to point out that he was not going to perform well in the assessment before he performed the task; this form of self-expression fits within Goffman's first mode of expression. This patient expressed himself in a way that would produce the kind of response and impressions in others that he desired. During instructions and tasks he would say things like, "I've never been called Mr. Coordination" and "This will be like trying to repeat the story to you. 1, 2, ummm..." (Field notes, May 24, 2016). His discussion of his performance was very negative. Through this negative discussion of his future performance (since he had not yet performed the tasks) this patient is saving face. The research assistant cannot expect him to do well because he has just said he will not, nothing is expected or required of him; yet, if he does perform well the research assistant will be pleasantly surprised. Most patients set themselves apart from others in order to reveal who they truly are, making comments like "I didn't have any problems with it, but I'm sure other people would experience a whole, you know, the unknown, not knowing what's, but I was fine with it" (Field notes, June 9, 2016). This was a common theme in the interviews,

patients would explain, ‘I can understand why someone might feel this way, but not me, I didn’t feel that way’. This reflects Goffman’s second mode of expression. The patients who made comments such as these were calculated in their remarks. They felt it was necessary to point out that while it may be possible to be uncomfortable and intimidated by the Kinarm robot, they were neither intimidated nor uncomfortable. These patients may have been largely unaware of their position, but still calculated in their decision to emphasize that they were not afraid, thereby saving face. Many patients acknowledged and emphasized the legitimacy of feelings of discomfort and fear when faced with the robot. This is a cultural or ‘traditional’ mode of expression. The patients acknowledged the possibility of negative feelings in regards to the robot because culturally and socially these feelings are acceptable, though not necessary. Thus, patients acknowledged these feelings though they may not have felt this way themselves. The management of self-expression is calculated and tailored such that patients only present the self that they want to be revealed to the researchers and research assistants involved in the study.

5.6 Accidental Emotion Work

Doctors that provide medical care to the physical body, also provide care to the mind and soul of the patient. Doctors perform emotional labour, treating patients with kindness, respect and care. While doctors treat the body, they also answer questions about medical procedures, address concerns, comfort patients and their families, express empathy, and more. Doctors care for body and mind, treating both physical and emotional wellbeing. In the Kinarm assessment doctors are not present. Their role in the Kinarm assessment stops at the referral to the project. Research assistants treat patients and perform emotional labour, but their primary goal is to make patients comfortable while going *through* the assessment. They ask the patients very few questions about

their health, all of which are non-invasive and superficial, such as, “has your prescription for your glasses changed since your last visit?” (Field notes, June 9, 2016). The research assistants’ emotional labour starts and stops with the assessment. The Kinarm assessment does not provide patients with the opportunity to discuss their experience, or make sense of it. Since the Kinarm assessment is a materialization of EBM this scenario may be reflective of the current healthcare system. The research assistants on the project are the only point of contact for the patients who participate in the assessment. These research assistants do not perform the emotional labour that treats the mind and emotions of patients. That is not part of the Kinarm assessment. Patients talk to family members and friends after they have been assessed. Henry admitted that he spoke to his family, but it was difficult to describe his experience to them:

Well, I described it to, uh, to my family to a certain extent, but uh, it’s very difficult to describe, but that you have two controls, and sometimes one moves one with you and the other one you have to follow. The lights are all good. Umm, I don’t know how I’d best describe it to someone, but that it’s really testing your coordination and your brain control (Field notes, June 14, 2016).

The Kinarm is difficult to describe because, as several patients pointed out in this study, the word ‘robot’ provokes images of man-like machines from popular culture representations. It is difficult to describe the Kinarm robot which looks nothing like a man or any robot the patients have seen before. As Glen said, “Well it sort of baffled me at first when I first saw it. I’ve never seen one before eh” (Field notes, May 19, 2016). If it is difficult to explain the Kinarm itself to others who have not seen the robot, how much more difficult it is to explain the experience to someone who has never experienced it themselves.

In the context of this research study involving the Kinarm assessment, where patients were interviewed after their assessment and observed during it, *I became* the primary emotion worker, treating the emotions of the patients as they attempted to make sense of their experience.

My emotion work was entirely unintentional. The patients' appropriated my role as researcher to that of emotion worker; I became someone with whom they could share their experience and their feelings. After the assessment was completed, I took the patients across the hall to a small room in the hospital where I conducted the interviews. During the interviews patients would admit to me how they felt during the assessment, they would ask questions about their role, about the Kinarm, and about the study, and patients would tell me about their health and all that they had dealt with in sickness and health (some over many years, others only recently). I was asked several times if I had been through the Kinarm assessment, "Did you have to do it? Did you go through the machine and try it?" asked Glen (Field notes, May 19, 2016), and when I was not asked, I admitted to patients that I had been through it and told them of my own struggles to perform tasks and how I felt about it, I told one patient who complained about the length of the assessment, "Yeah, it's long. It's certainly not short. When I did it they said, oh it will take you about two hours to go through, mind you I had to do every single task between the two robots...[because] I had to understand what patients go through [in every possible task]" (Field notes, June 22, 2016). The patients seemed to be comforted knowing that I shared in their experience. After they learned that I had done it as well, the patients would often provide me with stories about their experience that were more detailed than those they told before that point.

Susan explained:

Umm, well of course everyone wants to do well on them, so as I said the last one was, not difficult, and not disappointing, but more curiosity about what's going on in, you know, in my head in terms of when, I'd tend to, you know when the sequence would come on, I'd plant the first 3 in, I don't, I look at it and it's there so I know that I'm not going to have any problems with that, so trying to keep the other coordinated, you know, to go from the left or right or whatever, and I'd think I'd have it and then the minute that I'd start to move, the first three would be fine and I'd get the fourth, but then for some reason, it jumbled a bit after that. I just, I'm saying to myself what's, what's going on, why can't you do this, but uh,

it's still fun for me. I don't think there's any right or wrong here, it's just to uh get the results right, so yeah (Field notes, June 9, 2016).

Since I have gone through the assessment as well, it is safe for Susan to articulate that everyone wants to perform well during the tasks because, presumably, I too wanted to do well when I did the tasks. Susan managed her own negative emotions by rationalizing that these emotions were experienced by every person who went through the assessment. By confiding in me, Susan is reaffirming her attempt at emotion-management. Susan's description of her rising frustration with the sequence task is also exposable because, no doubt, having experienced it, I understand what it is like to struggle with the tasks and not perform as well as I expected. Because we shared the experience of the Kinarm it became easier for patients to share their feelings with me about their experience.

Patients left the Kinarm assessment with many questions. Some left in anticipation, wondering how they did and hoped they would soon see results, others left wondering what they had just spent the last two hours of their life doing. Overall, the patients were unsure about their role and reason for being in the Kinarm assessment. I sat down to interview Wendy. As soon as I had finished explaining that I was interested in learning about her experience with the Kinarm and how she felt about it, she asked me, "What I thought about it, well, it made you think for sure, but ah I'd like to know what it's doing, like is it helping you tell me that my right hand isn't as good as my left, or, what does it do, like what's it telling you?" (Field notes, June 8b, 2016). I explained the Kinarm and its various research projects in as much detail as I could. Wendy nodded along. Later in the interview she asked, "How long has it been in use?" (Field notes, June 8b, 2016). I explained that I did not know the exact date of when it started being used in that hospital, though I knew it was over a decade ago. (I have since learned it was in the early 2000s.) The rest of the interview was more of her asking me questions and me answering than the other

way around. Wendy had been uneasy about the robot and uncomfortable during the assessment. She needed her questions answered in order to feel more comfortable with her experience. When Wendy no longer had any questions about the Kinarm, I asked her how she came to be in the study. She described the story of her health up to that point:

It started out many, many years ago. This hip right here (points to hip). And oh the pain was unreal. So anyway when anything happens on this side obviously you baby this side (points to healthy hip), or you push on this side (points to healthy hip) and baby that side (points to painful hip). Well, then this one got worse and worse (points to healthy hip) and it overpowered this one, so now I have to have both done. But I said, do one and I have to see about saying yes to the second one. But I also have two bulged disks in my back so my L1 in lumbar is, oh it starts with a 'c', I forget. And I refused that surgery. I said to my husband last night, I hope I made the right decision with the right [hip] being first. That's basically what what it was. I can't walk stairs hardly or long walks, I can't do long walks. I go to a store and I, say I go to Costco, I can't do the whole store while I'm there, I can only do part of it and then come back in another few days and do the other part because I just can't do that. (P-Yeah). I won't use a wheel chair because that's for old ladies. (laughs) And uh, the doctor gave me a cane because it takes the pressure off it, well that worked for a couple days and then I said, I don't want to do this, everybody's lookin' at me. So I just didn't want to do it. So anyways, well, we'll see what happens after it's all over. I, I'm scared. Because there's so many things that could go wrong with it. But it'll be fine ((Field notes, June 8b, 2016).

Wendy admitted her fear of having her hip replacement surgery which was scheduled to take place one week later. This was outside my scope of training. I am not a doctor, trained to respond with answers that acknowledge the patient's fear while at the same time promoting the surgery as the right choice. I was only able to respond as a human being, a person in conversation, with empathy and acknowledgement. I shared a story with the patient about my own mother who has had both of her knees replaced. I told of my mother's surgery and her quick recovery. I told of my mother's ability to run now (though only short distances), when before her surgery she could hardly walk. I tried to provide Wendy with reassurance by sharing my own experience, just as I

had done with the patients when we spoke about the Kinarm assessment. In the position of interviewer, I became the primary emotion worker. Patients admitted their fears, asked questions, looked for answers, and talked about their experience in a way that allowed them to make sense of the Kinarm assessment and their feelings during it.

It is commonly assumed that healthcare which is necessarily warm and requires emotional involvement and technology which is cold and unfeeling are incompatible, based on the preliminary assumption that the presence of technology reduces the requirement of human labour. However, warm care and cold technology are falsely contrasted. The presence of technology does not automatically eliminate emotional labour and emotion work which are the primary components of care. Good healthcare necessarily involves physical bodily treatment and emotional treatment simultaneously. In the Kinarm assessment, the staff and researchers involved *did* manage to perform emotional labour in combination with the robotic assessment, although at times patients could have benefited from more emotional labour. *Healthcare* does not become devoid of emotional care in the presence of technology. Care and emotion, as evidenced in the Kinarm assessment, are fundamental to the treatment of the body. The body and mind must be effectively treated simultaneously to achieve the highest level of care. Healthcare is always an emotional labour. There is a lingering fear among social scientists and the general public, however, that healthcare will involve less warm *care*, and thus become colder, over time this may be so, but is not necessarily true in all situations.

CHAPTER 6. DISCUSSION & CONCLUSION

Robots are becoming increasingly familiar sights in healthcare facilities around the globe.

Hospitals and nursing homes have welcomed robots as solutions to social issues. For instance, robots are perceived as a solution to the lack of person-power to care for the elderly and the ill.

Robots are presumed to increase productivity and efficiency, while at the same time decreasing costs. Companion robots are posed as a solution to the problem of loneliness for patients in long-term care facilities. The realities of the productive and beneficial uses of robots are yet to be determined since the implementation of robots to solve social problems is still in its early stages. Social studies of robots in user-contexts are also in their early stages with very few long term studies and few decisive results. Research indicates that human-robot relationships are possible (see for example, de Graff, Allouch, and Klamer, 2015), however, the extent to which these relationships can develop is still in question. At the same time, research confirms that human users (including clinicians, employees, and patients) question the usefulness and practicality of robots in medical care contexts (for example, Chang and Sabanovic, 2014). Social science research overlooks the ways in which robots in healthcare implicate the healthcare experience for patients, something that can only be understood through asking patients directly how the use of robots in healthcare changes their experience. In this sense, my approach to studying the Kinarm assessment is a useful and complementary contribution to existing research on robotics in healthcare because I combined ethnographic observations of the assessment with patient interviews focused on how patients feel about their experience, thus obtaining richer data about patients' perspectives.

Most important to patients was the emotional labour of human actors within the network of the Kinarm assessment. Patients emphasized the plausibility of feelings of discomfort and fear

while engaging with a robot such as the Kinarm. While several patients emphasized that they did not experience these feelings themselves, they vocalized their concern for other patients who might. Patients offered several suggestions to alleviate feelings of discomfort and fear in others, including not referring to the Kinarm as a 'robot' since the word 'robot' comes with certain negative (i.e. fear) connotations. Some patients in my study did experience feelings of discomfort and fear during the Kinarm assessment. For these patients, the research assistants played a vital role. Patients who felt uncomfortable and fearful during the assessment emphasized the importance of the clear instructions delivered by the research assistants and the accessibility of the research assistants (for example, asking questions or clarification). Clear instructions and clarification made patients feel like they could perform the assessment tasks in spite of their fear (and often perceived lack of technological capability). All patients regardless of emotional response to the robot felt well cared for by the research assistants. Patients drew my attention to actions of the research assistant(s) during their assessment, including speaking in the 'good ear' of a patient who was deaf in one ear, asking repeatedly if a patient needed her glasses to see the screen, concern for comfort of the patient exhibited by offering a box to go under a patient's feet when she was stretching to reach the floor, and providing food and drink for patients as they had need. The patients sincerely appreciated the efforts of the research assistants, however small or large, because it made them feel like the research assistants cared about them and cared about how they were feeling.

Emotional labour makes a significant difference for patients. Patients want to feel well cared for. For patients, quality healthcare hinges on the emotional labour of clinicians, the treatment of body and mind. One patient in this study drew my attention to an experience he had in the same university hospital where he waited what felt to him like ages for a phlebotomist to take his

blood. He had already undergone another medical assessment and needed blood work done before he could be moved to the next medical procedure. He explained that the nurse has forgotten about him (or at least he assumed she had because no one had come to check in on him or offer him a reference of time). Finally, he left the room he was in and approached the first hospital employee he could find to inquire about the whereabouts of the phlebotomist. This staff person apologized and explained to him that she knew how to perform the procedure but she could not because of unionization and he would have to wait for the phlebotomist however long they might take. The patient was upset at the time and his upset lingered months later when he reiterated this story to me. He had not felt well cared for because no staff member took the time to perform emotional labour while he waited for the treatment of his body. Even once the phlebotomist finally arrived, she quickly took his blood and left him to wait for the next procedure. Emotional labour is clearly important to patients, but it may or may not be important to policy makers, clinicians, and others who determine care standards. Emotional labour makes healthcare less efficient and less financially productive. My research clearly shows that emotional labour is important to patients, but it is up to policy makers to determine whether or not emotional labour is important to the quality of healthcare.

Studies on technology in Medical Sociology theorize how technology (usually pharmaceuticals) alters the body from the inside out. Conversely, I looked at how medical technologies change the body by extending the body in space and time. Patients' bodies were disassembled in the Kinarm assessment through various processes. For instance, patients' vision was disassembled in the assessment first, when research assistants asked if their eye care prescription had changed (oftentimes patients were unsure and were subsequently put through an eye examination to test their vision) and second, when patients were put into the robot. Patients'

bodies were reassembled by the Kinarm robot. With forehead touching the forehead pad of the machine, the shield and bib attachment obscuring their vision so that they could not see their appendages and could only see the lights and shapes on the electronic screen (until they dismantled their body from the machine, most often by simply moving their forehead away), patients' sight was reassembled. Seeing in the Kinarm is different than seeing outside of the Kinarm. Patients acknowledged that the Kinarm changed their body. Some patients felt awkward or disconnected from reality and their lived body in the Kinarm because of the way the Kinarm remade their body. Others felt that their new body (both organic and machine) could better accomplish the tasks and produce a better score. The Kinarm assessment disassembles the body by rendering natural behaviours and organic components incongruous and reassembles the body by extending the external material body with the Kinarm robot, thereby making new behaviours possible and (sometimes) necessary. Thus, while some technologies have been shown to alter the internal body, it is made evident by the Kinarm assessment that technology can also extend the body. It is clear in my findings that this assessment changes the way that patients feel about themselves, but does this have lasting effect? Furthermore, if external medical technologies have a significant effect on how patients feel about themselves, what does this mean in regards to the production of vulnerability?

My findings revealed that patients felt differently about themselves and their bodies during the assessment. The structure of the assessment, where a perfect score is impossible, often made patients feel inadequate and 'stupid'. While patients who were most comfortable in the robot intentionally connected their body to the machine, moving and being moved by the machine in a seamless connection of organic and inorganic, patients who were least comfortable intentionally disconnected their body from machine effectively cutting the network. Each of these methods

proved to be coping strategies for patients while in the robot. The former coping strategy made patients feel like their body was extended by the machine and like they were physically in the screen, hitting away or moving towards objects. The latter coping strategy tended to occur because patients were nervous in their own body in the machine. That is, patients felt that their physical restrictions (for example, poor memory, slow movement, old age, lack of familiarity with video games, etc.) were exacerbated by the machine so that they felt that no matter what, they were not going to perform as well on the tasks as others who did not have these restrictions might. In many ways, my role as interviewer, which patients appropriated as primary emotion worker, made a space where patients could explain their feelings about their body.

Patients knew that they were part of a research study, though most, if not all, thought that somehow this research was part of their healthcare and would, thus, benefit them (and their health) which it does not directly do (and likely, considering the age of the patients will not indirectly do either). The patients agreed to participate likely in part because of their expectation of personal benefit. None overtly admitted to this, though many asked me at the end of the interview when they or their doctor would receive the results of the assessment. A few patients pointed out that they had agreed to participate in the study to support a physician, technician, or PhD. student that they were fond of. (Thus, the emotional labour of the physician, technician, or student established a relationship with the patient resulting in their support of the project as participants.) A few patients said that they were excited to participate to help other patients in the future who might benefit from the Kinarm assessment. (Patients who said this assumed that the Kinarm robot would be best suited as a rehabilitation tool, and was not as suitable for patients with their same condition, in these cases, cardiac patients.) Overall, patients were happy to participate. It is possible that they would have been less excited about participating, or may not

have participated at all, had they known that the assessment was not part of their healthcare, and, in fact, the results would never be delivered to them or their treating physician.

It seems to me that clinicians resist standardization by performing emotional labour, which under EBM is increasingly emotion work (unpaid and unrequired). Clinicians treat patients emotionally and physically (as in the days of traditional medicine, see Hochschild 1979). However, as the healthcare system changes evermore under EBM the opportunity and resources for emotional labour/emotion work from physicians may decrease. In my study, research assistants performed considerable emotional labour in the Kinarm assessment. The goal of their labours tended to be to make patients more comfortable in the assessment and to reinforce continued participation. Their emotional labour begins and ends with the assessment and is very overtly framed around the assessment. The emotional labour of clinicians visible in my study revealed that clinicians perform emotional labour framed by the medical care they provide to patients, but that they perform emotion work outside of and above the clinical framework (for example, coming to say 'hello' to patients during the Kinarm assessment and walking them to their car afterwards). (However, there were no examples of physicians performing emotional labour/emotion work outside of their medical care.) My study suggests that elderly patients might need more and a different kind of care than was provided in the Kinarm setting: care that includes learning about patients and their stories. This is problematic because clinicians' time is restricted (Prasad, 2013). EBM is often linked with approaches that emphasize efficiency, and efficiency means that clinicians have restrictions placed on their time in particular. Within the Kinarm assessment, even a small effort, like asking patients about their past health, would have made these elderly patients feel better cared for and more like an individual.

My study also raises the question of how best to integrate elderly patients into an increasingly technologically-mediated healthcare experience. It was extremely important to the elder patients that they have an outlet to make sense of their experience in the assessment. As the interviewer, I had a very important role in patients' experience. The interview allowed the patients to talk through their experience and make sense of it. It is likely that this is also true in other instances where technologies are used as part of the care elder patients receive. If patients could speak about the assessment after the fact it would make their experience much more positive. My results suggest that it may be best to debrief with patients after a procedure that is technologically mediated. It is possible that support groups may be sufficient for patients to make sense of their technologically mediated healthcare experience. Perhaps even, over time when the elder population is composed of persons who are more familiar with digital technology the usage of technology to diagnose, assess and treat patients will be increasingly less problematic and more of an expectation among patients. Certainly more research is required to better understand the changing landscape of healthcare and the effects of increasingly technologically-mediated healthcare on patients and clinicians.

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APPENDICES

Appendix A: Interview Structure

ENTRY

Meeting and informing the patient about interview process and patient rights; handing out researcher and GREB contact information if patient has questions or concerns after the interview; signing of consent form.

PART 1

Explain project and lead into question:

“I am interested in robots in healthcare. You may be aware that robots are being used in healthcare more and more often in many ways, for example, the Kinarm. The doctors here use the Kinarm to understand brain function in patients. I am interested in how patients experience interacting with robots. Now, I would like to learn about how you personally feel about working with the Kinarm. Perhaps, you can start by telling me about how you experienced working with the Kinarm over the last two hours and what this felt like. I will not interrupt you. You can tell me anything that comes to mind. Later, I will come back to some of the things you have said and ask you about these things.”

[Focus patient on Kinarm routine if they do not know where to start:]

- “Maybe you can start by telling me about how you felt when you saw the robot”
- “Can you tell me about how it felt to get into the robot?”
- “Can you tell me how it felt as you went through the tasks?”

[The goal of this part of the interview is to get the participant to talk about their own experiences within the Kinarm study. This portion of the interview will involve open, unstructured questions, in order to access tacit notions of experience, embodiment, and affect through eliciting narratives, metaphors, examples, and anecdotes. The primary themes that will inform the interviews are affect, embodiment, and subject/object.]

PART 2

Robot-patient-interaction

Questions picking up on clues immanent to the patient’s narrative according to analytical themes of the study:

- 1) Distribution of agency between patient and machine
 - Can you describe the process of getting set up inside of the robot?
 - How would you describe the way in which the robot responded to your movement?
 - Can you describe the process of performing the tasks?
- 2) Embodiment & sense-making
 - Can you describe how you perceived the instructions for performing the tasks?
 - Can you describe the tasks that you felt were really difficult?

- Can you describe how you dealt with these difficult tasks?
- Can you describe how you figured out how to perform the tasks?

3) Affective dimensions

- How would you describe the Kinarm robot to someone who has never seen it?
- How did it feel to be attached to the machine?
- How did you feel when you were inside of the robot?
- What did it feel like to be inside of the robot?
- How did you feel when you were performing the tasks?

PART 3

The patient as subject of healthcare and object of medical knowledge

“Can you tell me about your healthcare journey/trajectory with this condition and how you came to be involved in the Kinarm study?”

- How would you describe your role while working with the robot?
- How do you understand yourself/your role while you are in the robot?
- How would you describe your interaction with the doctors while working with the Kinarm?

EXIT:

“Thank you very much! You have answered all of my questions. Is there anything else that you would like me to know that we haven’t talked about yet? No? Do you have any questions for me before you go?”

[Record patient’s age, gender, occupation, and condition]

Appendix B: General Research Ethics Board Application

1.0 APPLICANT

Paige McGillivray, Master's Student, Sociology, Queen's University

2.0 PROJECT TITLE

Patient Perceptions of Robotic Interaction in Healthcare: A Case Study of Kinarm in Brain

Function Analysis

3.0 PROJECT DETAILS

3.1 Abstract:

This research project seeks to contribute an understanding of human interaction with non-communicative robots in a healthcare setting to the existing body of sociological research on human-robot interaction. This project is exploratory and will provide a basis for my Ph.D. research in the future. The objective of this project is to explore if and how the implementation of robots into the healthcare system is indicative of shifting understandings of healthcare. I will investigate how patients experience interaction with robots in healthcare to inform the following research questions: How do patients experience robots in healthcare? Are patients resistant to the robot? How do patients perceive their relationship with professionals when a robot is included as part of their healthcare experience? In order to answer these questions I will conduct a qualitative study, including an ethnographic and interview component, of social interaction with an exoskeleton robot in a clinical setting.

3.2 Method:

In order to answer these questions I will conduct a qualitative study, including an ethnographic and interview component, of human interaction with an exoskeleton robot in a clinical setting. Field access to this research has been secured. The principal exoskeleton robot is currently being used by neurologists at Kingston General Hospital to study sensory, motor, and cognitive function of various participant populations including Alzheimer's and stroke patients, among others. Said robot enables and requires the patient to perform a series of tasks during which neurologists' record, observe, and study brain function. My research project will involve ethnographic observation (Atkinson et. al, 2001) of participant's interaction with the robot, followed by an open-ended interview (Denzin and Lincoln, 2000). This project will involve 8-10 participants. Observing the participant interact with the robot in real-time will allow me to compare the patient experience articulated in the interview with my own observations made during the lived interaction with the robot. Ethnographic field notes will be recorded during observation. Interviews will be audio-recorded and transcribed. Field research will take place in the spring and summer of 2016. Following the completion of the interviews, data will be cross-examined, coded and analyzed. (See appendix A for interview script.)

3.3 Location of the research:

My research will take place at Kingston General Hospital and will be complementary to an ongoing study conducted by of the Center for Neuroscience Studies. Access has been granted for this research study.

4.0 RECRUITMENT OF PARTICIPANTS

4.1 Type of Participants:

There will be two types of participants involved in this study, the patients working with the exoskeleton robot, and the research assistants facilitating the patient-robot-interaction.

The main informants of this study are the patients. They have previously agreed to participate in the original Kinarm study and have also agreed to participate in this study. These participants are the primary focus of this study and will participate in an interview following the ethnographic observation of their interaction with the Kinarm. The lay participants in this study will be individuals who suffer from minor ailments that do not affect their cognition, as well as individuals who make up the control group of the original study, that is, healthy individuals with no known health conditions. All participants involved will be adults (aged 18+).

The research assistants who are employed by the original Kinarm study will be participants in the ethnographic research portion. There is always one research assistant who is charged with operating the Kinarm and delivering instructions to the Kinarm study participant. There is usually only one research assistant in the room; however, there are several research assistants working on the Kinarm project, and so the research assistant that is operating the Kinarm may not be the same over the whole study. The research assistants present during the ethnographic research portion of this study will be treated as participants (i.e. they will receive the Letter of Information and must grant consent to participate in order for observation to take place). I will observe the research assistant's interaction with lay participants as well as their interaction with the robot. The research assistants will not be involved in interviews.

4.2 Are they participating as expert informants? Are these individuals vulnerable for any reason?

The lay participants involved in this study will not be of a particular group. They will be a cross-section of participants from the existing neurological Kinarm study. These participants are not expert informants.

The research assistants of the original study are, to some extent, expert informants since they have put many participants through the original study in the past and have extensive experience using and managing the Kinarm robot. The research assistants, however, will not be interviewed for the current study. The research assistants will only participate in this study through their interaction with participants and the Kinarm during the original study.

Vulnerable patients who are not able to give informed consent due to their condition (ex. Alzheimer's and stroke patients) will be excluded from the participant pool, and will neither be observed nor interviewed.

4.3 Describe your method/steps/procedures that you will use to obtain your participants.

Individuals participating in the ongoing neurological study using Kinarm (through the Center for Neuroscience Studies) are referred to the study by physicians and medical care providers. These participants will be asked upon agreeing to participate in the neurological study if they would like to participate in my research study as well. The letter of information for my study will be delivered at the same time as that of the neurological study. Participation is voluntary.

Recruiting participants through the neurological study has the advantage that I will limit the storage of patients' personally identifiable information to the consent forms which will be destroyed after the 30 day drop-out period. This means that I will not have to store, code, or anonymize personal data (i.e. recruitment letters, emails, spreadsheets, field notes, interview recording).

4.4 Number of participants anticipated:

8-10 lay participants will be sought for this study. That is, 8-10 participants will be observed ethnographically and interviewed. I am not seeking a specific number of research assistants to participate; rather, research assistants will be asked to be participants as they perform their duties of employment for the neurological study. One research assistant is in the room with the participant and Kinarm at a time. The number of research assistants may be as few as one and as many as 8-10 (according to the number of lay participants) depending on the work schedule of the research assistants. The research assistants will not be interviewed.

4.5 Source of participants:

Participants will be individuals with various medical conditions that have previously agreed to participate in the original Kinarm study conducted at Kingston General Hospital through the Center for Neuroscience Studies at Queen's University.

4.6 Copy of recruitment method:

N/A

4.7 Remuneration / Compensation:

No compensation will be provided to participants of the study.

4.8 What procedures will be followed for people who wish to withdraw at any point during the study?

Should a participant desire to withdraw from the study at any point, data collection will stop immediately and all data collected on the individual (field notes, interview recording, consent form) will be destroyed immediately following their decision to exit the study. The participant will be thanked for their participation up to that point, and debriefed on the data collected about their person and the process for destroying their data.

4.9 Follow-up procedures:

There are no follow-up procedures as part of this study. Once the interview portion has been completed, the patients' participation is over.

5.0 ASSESSMENT OF RISKS

The only anticipated risk of this study is that lay participants may find themselves feeling tired by the time that they are involved in the interview component. In order to mitigate this risk, participants will be offered a short break following their interaction with the Kinarm robot and will be made aware that they can take a break at any time throughout the interview if need be.

The only perceivable risk that may be encountered by the research assistants who participate in my study is that they cannot be properly anonymized. The Kinarm robot is used in a limited number of hospitals in Canada. Even when the name of the university and the hospital are anonymized it there are few possibilities. The research assistants will also be anonymized; however, it may be easy to decipher which of the few university hospitals in Canada use the Kinarm, and so, research assistants may be recognized by persons who know their job title and role.

6.0 BENEFITS

Student researcher: increase understanding of individual experiences of robots in healthcare; increase understanding of human-machine interaction in a healthcare setting.

Participants: no direct benefit is anticipated for participants; however, it may be beneficial for them to discuss their experiences with the Kinarm robot in order to make sense of their experiences. Indirect benefits might include changes in the Kinarm routine should it become apparent that patients experience problems which escaped the attention of the scientists conducting the neurological study.

Scientific community: the study will contribute to understandings of human-machine interaction; this study seeks to contribute to a better understanding of whether or not, and if so, how, robots are an expression of shifting notions of healthcare.

7.0 PRIVACY:

7.0 Confidentiality and Anonymity:

No personally identifiable data about patients will be stored or recorded. All data about participants will be anonymized; all data will be kept confidential.

7.1 - 7.8 What steps will be undertaken to respect a person's privacy?

I will not be involved in the recruitment of participants, but rather, will be informed by the research assistants of the neurological Kinarm study when an individual has volunteered to participate in my study as well. Thus, I will not have access to personal information of patients. During the ethnography portion of this study, data will be recorded under a numerical code for the participants (eg. Participant 1), which has no link to the personal information of the participant. Names of participants will not be recorded. The interview portion of the study will be audio recorded. Participants will be instructed to avoid saying their name throughout the interview so that their name is not recorded. Consent forms will be held separately from all data collected and will be in no way correlated or traceable to the data collected. Consent forms will not be coded to link participants' names to data. Participants are informed in both the letter of information and the consent form that they have a 24 hour period after the completion of the interview to withdraw from the study. After which time participant data will no longer be

identifiable as theirs and thus cannot be destroyed. Consent letters will be destroyed after 30 days.

Research assistants involved in the original Kinarm study will also grant consent in order for ethnographic observation to take place in their presence. Research assistants will be anonymized in data collected. All data collected will be confidential. Consent letters will be destroyed after 30 days.

Along with the consent form, a cue card will be given to participants (both lay and research assistants) with the contact information for the Queen's University Ethics Review Board, as well as the contact information for Paige McGillivray (principal investigator). Participants are to keep this card so that, should they have any questions about their rights as a research participant or about the study, their questions may be answered.

7.8 Provide specific details about the security procedures for the data.

Only Paige McGillivray (primary researcher) will have access to the data. All data will be stored on a personal USB stick. Data will not be connected with participants' personal information in any way.

8.0 INFORMED CONSENT

See appendix ii for letter of informed consent.

APPENDIX

Appendix i: INTERVIEW STRUCTURE

ENTRY

Meeting and informing the patient about interview process and patient rights; handing out researcher and GREB contact information if patient has questions or concerns after the interview; signing of consent form.

PART 1

Explain project and lead into question:

“I am interested in robots in healthcare. You may be aware that robots are being used in healthcare more and more often in many ways, for example, the Kinarm. The doctors here use the Kinarm to understand brain function in patients. I am interested in how patients experience interacting with robots. Now, I would like to learn about how you personally feel about working with the Kinarm. Perhaps, you can start by telling me about how you experienced working with the Kinarm over the last two hours and what this felt like. I will not interrupt you. You can tell me anything that comes to mind. Later, I will come back to some of the things you have said and ask you about these things.”

[Focus patient on Kinarm routine if they do not know where to start:]

- “Maybe you can start by telling me about how you felt when you saw the robot”
- “Can you tell me about how it felt to get into the robot?”
- “Can you tell me how it felt as you went through the tasks?”

[The goal of this part of the interview is to get the participant to talk about their own experiences within the Kinarm study. This portion of the interview will involve open, unstructured questions, in order to access tacit notions of experience, embodiment, and affect through eliciting narratives, metaphors, examples, and anecdotes.]

PART 2

Robot-patient-interaction

Questions picking up on clues immanent to the patient’s narrative according to analytical themes of the study:

- 4) Distribution of agency between patient and machine
 - Can you describe the process of getting set up inside of the robot?
 - How would you describe the way in which the robot responded to your movement?
 - Can you describe the process of performing the tasks?

- 5) Embodiment & sense-making
 - Can you describe how you perceived the instructions for performing the tasks?
 - Can you describe the tasks that you felt were really difficult?

- Can you describe how you dealt with these difficult tasks?
- Can you describe how you figured out how to perform the tasks?

6) Affective dimensions

- How would you describe the Kinarm robot to someone who has never seen it?
- How did it feel to be attached to the machine?
- How did you feel when you were inside of the robot?
- What did it feel like to be inside of the robot?
- How did you feel when you were performing the tasks?

PART 3

The patient as subject of healthcare and object of medical knowledge

“Can you tell me about your healthcare journey/trajectory with this condition and how you came to be involved in the Kinarm study?”

- How would you describe your role while working with the robot?
- How do you understand yourself/your role while you are in the robot?
- How would you describe your interaction with the doctors while working with the Kinarm?

EXIT:

“Thank you very much! You have answered all of my questions. Is there anything else that you would like me to know that we haven’t talked about yet? No? Do you have any questions for me before you go?”

[Record patient’s age, gender, occupation, condition, and type of healthcare coverage]

Appendix ii: CONSENT FORM (DOCTORS)

Date: February 1, 2016

Project Title: Patient Perceptions of Robotic Interaction in Healthcare: A Case Study of Kinarm in Brain Function Analysis

Principal Investigator (PI): Paige McGillivray

Department of Sociology

Email: 15pmm@queensu.ca

Faculty Supervisor: Norma Mollers

Department of Sociology

INVITATION

You have been invited to participate in a research study. The purpose of this study is to explore the shifting understandings of healthcare as a result of the implementation of robots into the healthcare system. Your participation is helpful because this study seeks to understand human-robot interaction in a healthcare setting and, as a research assistant in the neurological Kinarm study, you are involved in this interaction.

Please initial on the line beside each heading to indicate that you understand and agree to the terms.

WHAT'S INVOLVED _____

You will be observed during your interaction with the participant. Ethnographic field notes will be recorded by Paige McGillivray (principal investigator) during this observation. You must be AT LEAST 18 years of age to participate in this research.

POTENTIAL BENEFITS AND RISKS _____

Possible benefits of participation include a greater understanding and awareness of the experience of robots in a healthcare setting.

All data will be anonymized and will be kept confidential. The only perceivable risk to you as a participant in this study is that there are so few studies using the Kinarm robot in Canada that it may be easy for individuals who know your role and job title to identify you through the results of this study. This is a minimal risk.

CONFIDENTIALITY _____

All information you provide will be stored securely by Paige McGillivray. This information is confidential and will not be connected to your personal information or your name in any way. Observation data will be held on a disc drive that only Paige McGillivray (principal investigator) has access to. This consent form, which contains your personal information, will be kept separate from the data collected through observation. There will be no way to connect consent forms to observation. After 30 days consent forms will be destroyed.

VOLUNTARY PARTICIPATION _____

Participation in this study is voluntary. You may decide to withdraw from this study at any time and may do so without any penalty. Please note that because the data collected will not be connected with personal information you have up to 24 hours after the observation period to withdraw from the study. After this time it will be impossible to identify data with a participant.

SHARING OF RESEARCH RESULTS _____

Results of this research will be shared with other researchers and may be published in professional journals after the study is completed. If you wish to receive a copy of the research findings please contact Paige McGillivray using the contact information provided and this will be made available to you.

CONTACT INFORMATION AND ETHICS CLEARANCE _____

If you have any questions about this study or require further information, please contact Paige McGillivray using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Queen's University. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at 613-533-6081, or chair.GREB@queensu.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT

I agree to participate in the study described above. I have made this decision based on the information I have read in the Letter of Invitation and this Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time, up to 24 hours after my participation.

Name: _____

Signature: _____ Date: _____

Appendix iii: CONSENT FORM (PATIENTS)

Date: February 1, 2016

Project Title: Patient Perceptions of Robotic Interaction in Healthcare: A Case Study of Kinarm in Brain Function Analysis

Principal Investigator (PI): Paige McGillivray

Department of Sociology

Email: 15pmm@queensu.ca

Faculty Supervisor: Norma Mollers

Department of Sociology

INVITATION

You have been invited to participate in a research study. The purpose of this study is to explore how understandings of healthcare change when robots are involved in the healthcare system.

Your participation is helpful because this study seeks to gain an understanding of your experience with the Kinarm robot.

Please initial on the line beside each heading to indicate that you understand and agree to the terms.

WHAT'S INVOLVED _____

As a participant, you will be observed during your interaction with the Kinarm robot. Following your interaction with Kinarm you will be asked to describe your experience through a series of interview questions. Participation will take approximately 45-50 minutes of your time. You must be AT LEAST 18 years of age to participate in this research.

POTENTIAL BENEFITS AND RISKS _____

Possible benefits of participation include a greater understanding and awareness of the experience of robots in a healthcare setting. You may find participation in this study to be tiresome since the interview follows the completion of your participation in the Kinarm study. Please inform me (Paige McGillivray, principal investigator) if you begin to feel tired and would like to take a break at any time during the study.

CONFIDENTIALITY _____

All information you provide will be stored securely by Paige McGillivray. This information is confidential and will not be connected to your personal information or your name in any way. Observation and interview data will be held on a disc drive that only Paige McGillivray (principal investigator) has access to. This consent form, which contains your personal information, will be kept separate from the data collected through observation and the interview. There will be no way to connect consent forms to interview data. After 30 days consent forms will be destroyed.

VOLUNTARY PARTICIPATION _____

Participation in this study is voluntary. If you wish, you may decline to answer any questions or deny your participation in any component of the study. Further, you may decide to withdraw

from this study at any time and may do so without any penalty. Please note that because the data collected will not be connected with personal information you have up to 24 hours after the interview to withdraw from the study. After this time it will be impossible to identify data with a participant.

SHARING OF RESEARCH RESULTS _____

Results of this research will be shared with other researchers and may be published in professional journals after the study is completed. If you wish to receive a copy of the research findings please contact Paige McGillivray using the contact information provided to you and this will be made available to you.

CONTACT INFORMATION AND ETHICS CLEARANCE _____

If you have any questions about this study or require further information, please contact Paige McGillivray using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Queen's University. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at 613-533-6081, or chair.GREB@queensu.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT

I agree to participate in the study described above. I have made this decision based on the information I have read in the Letter of Invitation and this Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time, up to 30 days after my participation.

Name: _____

Signature: _____ Date: _____

Appendix iv: Letter of Information

February 2016

Student Principal Investigator:
Paige McGillivray, Sociology, Queen's University

Faculty Supervisor:
Norma Mollers, Assistant Professor, Sociology, Queen's University

**Patient Perceptions of Robotic Interaction in Healthcare:
A Case Study of Kinarm in Brain Function Analysis**

Dear participant,

This is a letter of invitation to participate in a research study about the use of robots in healthcare. This study is being conducted at Kingston General Hospital, through Queen's University. This study has been granted approval by Queen's University ethics board in compliance with the Canadian ethics guidelines.

The purpose of this research is to explore the shifting understandings of healthcare as a result of the implementation of robots into the healthcare system. This study involves an interaction portion and an interview portion. Should you choose to participate in this study, you will be observed during your interaction with Kinarm. A one-on-one interview will immediately follow the observation period. You will be asked questions about your experience during your interaction with Kinarm robot. All information disclosed will be confidential.

The expected duration of the interview is 45-50 minutes. Because of the length of time it takes to complete the tasks with the Kinarm robot, you may be quite tired by the time the interview begins. If this is the case you may ask the researcher for a break before the interview begins. You are not required to answer any of the interview questions and may simply inform the researcher that you choose not to answer at any time. Please know that you may withdraw from this study at any point. Should you choose to withdraw, all data collected up to the point of your withdrawal will be destroyed. You may withdraw from the study up to 24 hours after the study is complete.

After the 24 hour time period is complete your research will be included in the study. Your name will not be connected to the information about your experience. The data will be held on a disc drive that only Paige McGillivray (principal investigator) has access to. The only personal information that will be collected is in the consent form. This form will be destroyed after 30 days. As stated previously, the consent forms will not be connected with data. Your anonymity will be protected throughout the research process. No personal information will be made public.

This research seeks to contribute to the larger body of Sociological research on human-machine and human-robot interaction in healthcare.

Should you have any additional questions about this study, please do not hesitate to contact me. If you have any questions about your rights as a research participant, please contact the Research ethics board at Queen's University (613-533-6081, or chair.GREB@queensu.ca).

Thank you,

Paige McGillivray
Graduate Student
Sociology
Queen's University
15pmm@queensu.ca

Appendix C: Ethics A



May 16, 2016

Miss Paige McGillivray
 Master's Student
 Department of Sociology
 Queen's University
 Kingston, ON, K7L 3N6

GREB Ref #: GSOC-131-16; Romeo # 6018266

Title: "GSOC-131-16 Patient Perceptions of Robotic Interaction in Healthcare: A Case Study of Kinarm in Brain Function Analysis"

Dear Miss McGillivray:

The General Research Ethics Board (GREB), by means of a delegated board review, has cleared your proposal entitled "**GSOC-131-16 Patient Perceptions of Robotic Interaction in Healthcare: A Case Study of Kinarm in Brain Function Analysis**" for ethical compliance with the Tri-Council Guidelines (TCPS 2 (2014)) and Queen's ethics policies. In accordance with the Tri-Council Guidelines (Article 6.14) and Standard Operating Procedures (405.001), your project has been cleared for one year. You are reminded of your obligation to submit an annual renewal form prior to the annual renewal due date (access this form at <http://www.queensu.ca/traq/signon.html>; click on "Events"; under "Create New Event" click on "General Research Ethics Board Annual Renewal Form for Approved Studies"). Please note that when your research project is completed, you need to submit an Annual Renewal Form in Romeo/traq indicating that the project is 'completed' so that the file can be closed. This should be submitted at the time of completion; there is no need to wait until the annual renewal due date.

You are reminded of your obligation to advise the GREB of any adverse event(s) that occur during this one year period (access this form at <http://www.queensu.ca/traq/signon.html>; click on "Events"; under "Create New Event" click on "General Research Ethics Board Adverse Event Form"). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example, you must report changes to the level of risk, applicant characteristics, and implementation of new procedures. To submit an amendment form, access the application by at <http://www.queensu.ca/traq/signon.html>; click on "Events"; under "Create New Event" click on "General Research Ethics Board Request for Amendment of Approved Studies". Once submitted, these changes will automatically be sent to the Ethics Coordinator, Ms. Gail Irving, at the Office of Research Services for further review and clearance by the GREB or GREB Chair.

On behalf of the General Research Ethics Board, I wish you continued success in your research.

Sincerely,

A handwritten signature in cursive script that reads "John B. Freeman".

John Freeman, Ph.D.
 Chair
 General Research Ethics Board

c: Dr. Norma Mollers, Faculty Supervisor
 Dr. David Murakami Wood, Chair, Unit REB
 Ms. Michelle Underhill, Dept. Admin.