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A Sociomaterial Analysis of Team-based Care for Patients with Advanced Heart Failure

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Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy

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A SOCIOMATERIAL ANALYSIS OF TEAM-BASED CARE FOR PATIENTS WITH ADVANCED HEART FAILURE
(Thesis format: Integrated Article)

by

Allan McDougall

Graduate Program in Health & Rehabilitation Sciences

A thesis submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy

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Abstract

This dissertation explores team-based care for patients with advanced heart failure (HF), especially care practices associated with integrating palliative care. Its three integrated articles explore advanced HF care as a team-based health care phenomena, focusing on both objects and people as integral for team activity. The dissertation utilizes the theoretical framework of sociomaterialism to explore the overarching research question: how do materials mediate and influence the integration of palliative and cardiac care for patients with HF? Study data take the form of 15 team sampling units (TSU), each of which consists of a patient interview and an interview with at least one caregiver and one health professional identified by that patient as members of their care team. Data were analyzed through the lens of actor-network theory (ANT).

The first study delves into the sociomaterial underpinnings of HF self-care, focusing on patients and caregivers involved with fluid management in their domestic lives. The study highlights the material effects of fluid and its management for patients and caregivers, as well as the way these material effects build into wider network effects. The manuscript discusses how ANT can enrich recent calls in the HF self-care literature for increased attention to ‘context’ in HF self-care.

The second study explores how our understanding of health care teamwork shifts when materials, like fluid, are described as actors on the HF team. The paper describes the agency of fluid, a heretofore taken-for-granted material in descriptions of team-based HF care. Fluid is a matter of concern at the centre of interprofessional collaboration between cardiologists and nephrologists. The study advances one of the core theoretical insights of my dissertation,—collaborative entanglement—an innovative construct for understanding and reconceptualizing phenomena that researchers and policymakers frequently label ‘interprofessional collaborative tensions’.

The third study directly engages the ideas and values of palliative care integration for HF. The paper argues that while sociological explanations are crucial to policy programming around palliative care (PC) integration, they are insufficient for fully appreciating the challenges faced by HF care teams who are actively trying to integrate PC. The paper attempts to answer the question: why does palliative care integration fail even when human roles are clear, local culture is supportive, and team knowledge is accurate? ANT is invoked to re-frame the discussion about ‘under-utilization’ of PC services for patients with HF.

Each of these three analytic projects contributes to a growing interest in sociomaterialism amongst medical education researchers in Europe and North America. In the final chapter, key ideas from the overarching analysis are explored alongside methodological reflections. While the focus of this study is fluid, hopefully these results and insights can inspire further innovative sociomaterial inquiry in medical education. Keywords: Sociomaterialism, actor-network theory, health care teams, palliative care, heart failure, qualitative research
Co-Authorship Statement

I completed the following work under the supervision of Dr. Lorelei Lingard. My supervisory committee members, Dr. Anne Kinsella and Dr. Mark Goldszmidt, also provided extensive written and verbal feedback on every aspect of this work. Each will be listed as co-authors on forthcoming publications from this dissertation.

Several colleagues from the “Palliative Care on the Heart Failure Care Team” research group, will also be co-authors on publications resulting from this dissertation.
Acknowledgements

This dissertation required the generosity, love and insight of my wife, Jessica. Along this journey, we’ve been engaged, married, and have had two children. Thank you for your patience and support.

To my sons, William and Walker. There are no words to describe how grateful I am to have you join your mother and I in this life. Today, William, you helped me shovel the driveway for the first time—until we had to go inside because you were too wet from eating snow. Today, Walker, you smiled your first big grin at me for the very first time—right after I asked you to please stop crying. Each day brings another milestone to celebrate, and another story to share. Compared to you both, this dissertation is an insignificant part of my life’s work—although when you’re older we can discuss how you each helped me finish it in your own way. Thank you for inspiring me every day.

I’m very blessed to have an incredible family. To my grandma, Stella, you’re the character I aspire to be. To my parents, Sam & Debbie, thank you for believing in me. To my in-laws, John & Helen, thank you for adopting me. To Caitlyn, thank you for always checking in; and to Bryan, thank you for always making me laugh.

I also thank my supervisor, Lorelei, for giving me a chance. You are my role model.

I’m honoured to have been a part of the the Schulich School of Medicine & Dentistry Centre for Education Research & Innovation for 5 amazing years. Sayra, thank you for always listening. Mark, thank you for showing me what it means to be a medical educator. Holly, thank you for the medical education research acronyms cheat sheet. Elaine, thank you for teaching me everything I know about research ethics. Valerie & Josh, for allowing dozens of opportunities to learn about palliative care. Stella & Meredith, for supportive advice and reassurance. Saad for new insights, Tavis for validation, Kori for making me feel needed, and Lisa for mentoring when you didn’t mean to. Several Schulich faculty provided thoughtful insight and friendship over the years. Thank you to Wael, Chris, andLaura, leaders in the field and exceptional people I’m grateful to have known. I sincerely miss you all and look forward to whatever the future may hold.

Thank you to the research participants who graciously offered their time for this work. I entered your homes, I met your loved ones, I listened to your stories, and in some cases I read your obituaries. This work would not be possible without you.

I would like to acknowledge the “Palliative Care on the Heart Failure Care Team” research group, a team of health researchers and health care providers in Ontario, Nova Scotia and British Columbia. Their expertise and insights have played a supportive role advancing the progress of this work.

Finally, special thanks to Tom Barber for years of great advice—not the least of which was suggesting that I move to Ontario.

“I THANK all who have loved me in their hearts,
With thanks and love from mine. Deep thanks to all
Who paused a little near the prison-wall
To hear my music in its louder parts
—Elizabeth Barrett Browning,
Dedication

To my Grandfather,
William A. Glen VIII,
For always believing
in the value of education.

... We miss you.

Where is Antioch, brother?
“Ten miles on and on;
Ere you reach the city's gates
Sunlight will be gone.

“Ten miles of dust and a hot sun
To lash your head and back.
The man who comes from Antioch
Has found a better track.”

I wandered down the road
Fearful of earth and sky;
It seemed as if the lagging fields
Would never pass me by.

And then I asked a maid;
“How far is Antioch, lass?”
She said, Nine miles of clear, blue sky,
And nine of waving grass;

“Nine miles to walk with wind
Blown hither from the sea;
Nine miles to watch the red-plumed birds
Flame in the dark-plumed tree.”

Oh, then the fields went by
With swift and lovely feet;
And I was soon in Antioch
And laughing down a street.

—Wilson MacDonald
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<td>ANT</td>
<td>Actor-network theory</td>
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<tr>
<td>CGT</td>
<td>Constructivist grounded theory</td>
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<td>HF</td>
<td>Heart failure; Congestive heart failure</td>
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<td>HPE</td>
<td>Health professional education</td>
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<tr>
<td>ICDs</td>
<td>Implantable cardioverter defibrillators</td>
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<tr>
<td>ICMDs</td>
<td>Implantable cardiovascular medical devices</td>
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<tr>
<td>LVADs</td>
<td>Left-ventricular assistive devices</td>
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<td>NYHA</td>
<td>New York Heart Association</td>
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<tr>
<td>PC</td>
<td>Palliative care</td>
</tr>
<tr>
<td>PD</td>
<td>Peritoneal dialysis</td>
</tr>
<tr>
<td>PRT</td>
<td>Personal rapid transit</td>
</tr>
<tr>
<td>STS</td>
<td>Science, technology &amp; society</td>
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<tr>
<td>SSK</td>
<td>Sociology of scientific knowledge</td>
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<tr>
<td>TSU</td>
<td>Team sampling unit</td>
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Introduction

“We look for medicine to be an orderly field of knowledge and procedure. But it is not. It is an imperfect science, an enterprise of constantly changing knowledge, uncertain information, fallible individuals, and at the same time lives on the line. There is science in what we do, yes, but also habit, intuition, and sometimes plain old guessing. The gap between what we know and what we aim for persists. And this gap complicates everything we do.”

Atul Gawande, Complications: A Surgeon’s Notes on an Imperfect Science, 2002

1.1 Background

The doctoral project presented here takes place in the context of a research program investigating the recent call to integrate palliative care (PC) for patients with heart failure (HF). The broader research program explores how interdisciplinary HF care teams—made up of patients, family members, and health care providers who are distributed across departments, institutions and regions—currently perceive this integration. This broader research program pays particular attention to the communication and coordination practices of teams caring for patients with heart failure.

---

1 A note on abbreviation: heart failure, also called congestive heart failure, will be referred to as HF throughout this dissertation. Palliative care, on the other hand, is a more nuanced term. Unlike HF, a disease, palliative care connotes a medical specialty, a health care practice and, in some cases, a physical space. Therefore, the abbreviation PC will be used as a typographic convention to increase readability in several areas where the term frequently occurs in quick succession.
advanced HF\textsuperscript{2}. As the primary research coordinator for this project, for over 20 months, I participated as the methods were refined in pilot work (Lingard, McDougall, Schulz, et al., 2013) and data were collected from two of five sites. My unique analytical contribution to this research program has been to explore the role of materials in the integration of palliative care by advanced HF care teams. Specifically, my primary research question asks: how do materials mediate and influence the integration of palliative and cardiac care for patients with advanced HF?

1.1.1 Heart Failure and Palliative Care

In Canada, HF rates are epidemic, with deaths from advanced HF set to rise with an aging population (Ross, Arnold, Liu, et al., 2006). Studies have found that deceased HF patients often wish to die sooner, and their family members believe their dying loved ones are offered invasive life-prolonging therapies instead of access to palliative care options (McCarthy, Hall, Ley, et al., 1997; Lynn, Teno, Phillips, et al., 1997; Heyland, Groll, Rocker, et al., 2005). Care for these patients often remains focused on acute interventions, with rates of associated hospitalizations, procedures and intensive care admissions rising until the end of life (Hupcey, Penrod, Fogg, et al., 2009; Hupcey, Penrod, and Fenstermacher, 2009). While patients who receive in-home palliative care are more likely to die at home, consistent with expressed wishes of most patients (Linkewich, Setliff, Poling, et al., 1999), the majority of HF patients die in hospital (Kaul, McAlister, Ezekowitz, et al., 2010). Palliative care integration has been positively associated with family satisfaction (Gries, Curtis, Wall, et al., 2008), patient satisfaction (Gade, Venohr, Conner, et al., 2008), and decreased health care expenses (Unroe, 2011).

\textsuperscript{2}The distinction between mild, moderate and advanced HF is debated both in the literature and amongst the many HF health care professionals I met with over the past four years. While the study’s sampling rationale will be expanded below in section 3.1.2, I wish simply to mention at this early juncture that the study’s goal was to recruit patients with HF who would likely be requiring palliative care services in the near future. We used the term ‘advanced HF’ to describe this group.
1.1.2 Why does palliative care for HF matter?

Health policy organizations have argued that while a strategy should exist to manage the palliative care needs of hundreds of thousands of Canadians who will die from advanced HF during the next decade, few will have their palliative care needs met in a timely fashion, resulting in decreased patient quality of life, added distress for the family and substantial costs for the health care system (Health Information, 2010; Howlett, 2011; Carstairs, 2010). Within the last decade the American Heart Association (Hunt, Abraham, Chin, et al., 2005), American College of Cardiology (Hunt, Abraham, Chin, et al., 2005), the National Heart Foundation of Australia (Krum, Jelinek, Stewart, et al., 2011), the Cardiac Society of Australia and New Zealand (Krum, Jelinek, Stewart, et al., 2011), the European Society of Cardiology (Jaarsma, Beattie, Ryder, et al., 2009a) and the Canadian Cardiovascular Society (McKelvie, Moe, Cheung, et al., 2011) have generated official statements and guidelines for the integration of palliative care for patients with HF.

Supported by recent research focusing on palliative care integration for patients with HF, the recommendations advise more multidisciplinary collaboration (Kini and Kirkpatrick, 2013), earlier communication about palliative care with patients and caregivers (Bekelman, Hooker, Nowels, et al., 2014), earlier integration of palliative care alongside active therapies (Dionne-Odom, Kono, Frost, et al., 2014; Allen, Stevenson, Grady, et al., 2012), more research into predictive models for prognosis (Gadoud, Jenkins, and Hogg, 2013), and more palliative care education for health professionals involved in caring for patients with HF (Green, Gardiner, Gott, et al., 2011). The domains of both research and practice have been increasingly active: federal palliative care funding in both the U.S. and U.K. has increased tenfold since 1997, correlating with three times as many palliative care scientific publications (NIH, 2013). Despite these efforts, there remains limited utilization of palliative care services by patients with HF (Green, Quill, Amir, et al., 2014; Lemond and Allen, 2011).

A noteworthy imbalance in palliative care access for patients with HF exists when compared
to patients with cancer (Adler, Goldfinger, Kalman, et al., 2009). The majority of patients with HF die in hospital compared with cancer patients (Kaul, McAlister, Ezekowitz, et al., 2010), who often receive in-home palliative care and are more likely to die at home consistent with their expressed wishes (Tolle, Rosenfeld, Tilden, et al., 1999). Despite its reputation, cancer does not necessarily mean a poorer prognosis compared to HF (Askoxylakis, Thieke, Pleger, et al., 2010), which can be as ‘malignant’ as many common types of cancer (Heyland, Groll, Rocker, et al., 2005; Hupcey, Penrod, Fogg, et al., 2009; Hupcey, Penrod, and Fenstermacher, 2009; Stewart, Ekman, Ekman, et al., 2010).

Hospice care statistics further illustrate the gap in palliative care access for patients with HF. The percentage of patients with HF who enroll with palliative care has been estimated as low as 10% (NHPCO, 2012). In the U.S., a study of hospice service usage observed an increase in HF patient enrollment during the last 6 months of life-increasing from 19% in 2000 to 38% in 2007. However, one third of those patients received palliative care during the final week of their lives or less, compared to 55% of patients with cancer enrolling in hospice and only 15% of those patients being admitted during the final week of their lives (Miesfeldt, Murray, Lucas, et al., 2012). While progress is slowly being made, gaps in access and care persist.

1.1.3 Proposed solutions to the palliative care gap in HF

To date, many discussions around how to improve the integration of palliative care services for patients with HF have been sociological in their orientation, emphasizing the social characteristics of integration such as culture, stigma, and gaps in knowledge. Some argue that palliative care integration is challenged by ‘culture clashes’ between cardiologists and palliative care providers (Gott, Frey, Robinson, et al., 2013; Gott, Gardiner, Ryan, et al., 2013), where the former group are interventionists focusing on ‘rescue therapy’ (O’Leary, Murphy, O’Loughlin, et al., 2009; O’Leary, 2009) and the latter group are the ‘Grim Reaper Service’ (Kavalieratos, Mitchell, Carey, et al., 2014).

Others argue that there is a stigma attached to palliative care that originates in a lack of
understanding by cardiologists over what palliative care means and how patients might interpret a palliative care referral (Fitzsimons, Mullan, Wilson, et al., 2007; Fitzsimons and Strachan, 2011). There is also an overall lack of understanding of what services palliative care can offer HF patients, and how those services will contribute to current cardiovascular best practices (Chattoo and Atkin, 2009). Finally, research has suggested that confusion over role transitions between cardiologists and palliative care providers is part of the problem (Green, Gardiner, Gott, et al., 2011).

One of the most popular advocated solutions for improving HF patients’ end-of-life experiences is improved communication among health professionals, patients and families, and health services (Ratcliffe, 2007; Ryder, Beattie, O’Hanlon, et al., 2011; Murray and Boyd, 2011; Howlett, 2011; Lewis, 2011). Interestingly, though, the goal of improved palliative care communication and coordination is complicated by a dominant culture of technological intervention in cardiac care. Technologies, drugs and rehabilitation programs allow patients to live longer than ever before, despite research findings that these material elements of HF can create additional symptom burden and existential anxiety for patients nearing the end of life (Tan, Chinnappa, Tan, et al., 2011; Kamphuis, Verhoeven, Leeuw, et al., 2004).

Some have termed these interventions ‘ironic technologies’ (Kaufman, 2010b; Kaufman, 2010a) and this interventionist approach a ‘therapeutic imperative’ (O’Leary, 2009). Bioethicists in particular have focused on implantable cardiovascular medical devices (ICMDs)—surgically implanted devices that deliver an electric jolt to the hearts of patients who may face sudden cardiac death—as technologies that reinforce death-denying social assumptions and cause increased suffering (Kaufman, 2010b). Some research for example claims that patients and physicians often do not discuss how ICMDs can create painful end-of-life scenarios for patients (Padeletti, Boncinelli, Brachman, et al., 2010) and morally complicated situations for family members and health care providers (Sherazi, Daubert, Block, et al., 2008).
1.1.4 A fundamentally team-based issue

Research advocating team-based solutions for the growing population of patients with advanced HF undergirds the calls for more effective palliative care for patients with HF (Soubhi, Colet, Gilbert, et al., 2009; Fortin, Bravo, Hudon, et al., 2005; Howlett, Fortin, Heckman, et al., 2010). In my field of health professional education (HPE), research on teams has offered several new theoretical frameworks for viewing health care teamwork, including collective competence (Hodges and Lingard, 2012), distributed teamwork (Lingard, McDougall, Levstik, et al., 2012; Lingard, McDougall, Levstik, et al., 2014), and complex adaptive systems (Ladonna, Bates, Tait, et al., 2015; Strachan, Kaasalainen, Horton, et al., 2014; Currie, Strachan, Spaling, et al., 2014).

Sociomaterialism, or sociomateriality, is also a theoretical framework gaining attention in HPE (Fenwick and Edwards, 2010a; MacLeod, Kits, Whelan, et al., 2015). This approach considers how materials influence human activity. When applied to studying team-based care for patients with complex chronic conditions, sociomaterialism regards health care teams as being composed by both humans and nonhumans (Bleakley, 2012; Fenwick and Edwards, 2010a). Sociomateriality is the primary theoretical framework for my research. While I take the stance that complex patient care is fundamentally a team-based issue, I also believe it invites a revised understanding of what we mean when we say ‘team-based care’. As a sociomaterialist, I have organized my study from the standpoint that a health care team is more than just a group of people collaborating to achieve shared goals.

The sociomaterialist approach of actor-network theory (ANT) is of primary importance to my work. ANT is known for a particularly radical account of what types of phenomena social research are worthy of focusing. While ANT is similar to other social theories in its focus on interpreting and understanding social phenomena like health care practice, it proposes complete symmetry between nonhumans and humans. Unlike other sociomaterialist approaches, ANT compels researchers not only to blend materials into social descriptions but to balance attention given to humans with attention given to nonhumans (Fenwick and Edwards, 2010b).
ANT has been used in studies exploring a range of health care-related topics, including health care infrastructure and information technology (Cresswell, Worth, and Sheikh, 2010; Greenhalgh and Stones, 2010; Ackerman, Tebb, Stein, et al., 2012), clinical care for patients with atherosclerosis (Mol, 2002b) and palliative care practice in intensive care (Hadders, 2009). Little research has yet used ANT as a framework for analyzing HF patient care. While Mol (2010) and Law (2007) takes issue with ‘using’ or ‘applying’ ANT as a theoretical framework, education scholars have taken a pragmatic stance on working with ANT (Fenwick, 2003; Fenwick and Edwards, 2010a; Fenwick, 2010; Fenwick, 2014a). One way to imagine how ANT can be operationalised in research follows the title of the opening chapter of a recent monograph on ANT in education: “a way to intervene, not a theory of what to think” (Fenwick and Edwards, 2010, p. 1). From this pragmatist ANT stance, the purpose of a social theory should be to guide how one chooses to “intervene” instead of just to analyze. Fenwick and Edwards (2010b) provide a heuristic of exploratory questions and a vocabulary of key terms to operationalise ANT. Chapter 2 expands on ANT and includes descriptions of its key terms, epistemological orientation and ontological propositions.

1.1.5 What makes exploring the integration of PC in team-based HF care timely and important for Health Professional Education (HPE)?

Attempts to change team-based practices are ultimately educational phenomena. They require coordinated efforts across multiple disciplines and often institutional and geographical boundaries. How, why, and whether to ‘intervene’ in team practice are central questions for health professional educators, researchers and policymakers. While, like all doctoral studies, the selected focus of this work developed adventitiously, the integration of palliative care in team-based HF care offers a unique and particular challenge to the future of health care. It is an area where policy and practice will require revision, and is therefore an opportune area for my HPE research.

Importantly, the context of my work has primarily taken place in the context of medical education. This dissertation features a predilection toward medicine and physicians. This is in
no way the voluntary occlusion of nurses, occupational therapists, and other health professionals. Rather, my academic and professional appointments were all within the Schulich School of Medicine and Dentistry. Many of my collaborators and colleagues were physicians and this has influenced my work. Therefore, the focus of this work is primarily grounded in medical education, even while I refer to the field of HPE throughout this dissertation.

1.2 Research statement

The objective of my sociomaterialist research project is to explore the function and influence of materials on the integration of palliative care on HF care teams, made up of patients, caregivers and health professionals. At its outset, my research project focused on technological devices such as ICMDs, due to the perceived important physiological impact they have on patients and their prevalence as technologies of cardiac care for patients with advanced HF. However, in performing ANT the researcher must attune to other phenomena, also known as ‘matters of concern’, that may emerge as exerting significant influence, positive or negative, on the context of study. As I proceeded, I attended to a broader array of ‘materials’ than these overt technologies, and became particularly interested in nonhuman phenomena that applied pervasively across teams rather than as powerful agents on only a few. The focus of my research gravitated toward interstitial fluid, a point upon which I will elaborate throughout the next seven chapters. Overall, the aims of my study were: 1) to describe how patients and HF team members perceived and experienced material phenomena in HF care; and 2) to trace the influences of these perceptions and experiences of materials on the integration of palliative and HF care.

1.3 Chapter overview

The chapters that follow this first introductory chapter attempt to deeply explore the integration of palliative care in team-based HF care from a sociomaterialist standpoint. Chapter 2 provides an in-depth exploration of ANT as the methodology informing this work. Although the broader
study in which this research takes place used constructivist grounded theory (CGT), my study applied ANT to the study data in which I was most intimately involved. This chapter primarily is a foray into the foundational ideas of ANT.

Chapter 3 outlines in detail my research process. It provides a detailed background on the overall research program in which my study sits. This section then focuses on the design of my specific project, including my approach to reflexivity, data analysis, and writing.

Chapter 4 is the first of three empirical papers composing the core of this dissertation. The paper responds to early observations in my work that noted that, when patients and caregivers relayed their experience of HF, they focused extensively on fluid and its management. In fact, patients and caregivers referred to fluid more prominently than to their hearts. This study—in submission to the journal *Sociology of Health and Illness*—delves into the central, sociomaterial role of fluid in the lived experiences of patients and lay caregivers involved with negotiating fluid management in their domestic lives.

Chapter 5—in submission to the journal *Social Science and Medicine*—presents the second of three empirical chapters. The paper asks how our understanding of health care teamwork shifts when ANT prioritizes materials—in this case interstitial fluid—as an actor on the HF team. The paper describes the agency of heretofore taken-for-granted fluid accumulation, a matter of concern at the heart of interprofessional collaboration between cardiologists and nephrologists. The study advances one of the core theoretical insights of my dissertation—the concept of ‘collaborative entanglement’—an innovative and functional construct for understanding and reconceptualizing what are more routinely called ‘interprofessional collaborative tensions’.

In Chapter 6 the ideas and values of palliative care integration for HF are engaged directly. The paper argues that while sociological explanations are crucial to policy programming around palliative care integration, they are insufficient for fully appreciating the challenges faced by HF care teams who are actively trying to integrate palliative care. The paper attempts to answer the question, why does palliative care integration fail even when human roles are clear, local culture is supportive, and team knowledge is accurate? I use ANT to reframe the discussion
about ‘under-utilization’ of palliative care services for patients with HF.

Chapter 7 concludes the dissertation by discussing the implications of these findings for health professional education and ANT research more broadly. I begin with three methodological reflections that emerged from this study, specifically the process of negotiating how to follow the actor, the tensions of adopting a postmodern stance, and the significance of rich descriptions. I then consider three conceptual contributions that arise from my research, including the idea of entangled collaboration, the notion of networked competency, and an approach to HPE that I refer to as sociomaterial pedagogy.
Theoretical framework and methodology

“Inanimate objects are always correct and cannot, unfortunately, be reproached with anything. I have never observed a chair shift from one foot to another, or a bed rear on its hind legs. And tables, even when they are tired, will not dare to bend their knees. I suspect that objects do this from pedagogical considerations, to reprove us constantly for our instability.”

Zbigniew Herbert, Objects, 1957

“Here on the table near the window is a vase of peonies and next to it black binoculars and a money clip, exactly the kind of thing we now prefer, objects that sit quietly on a line in lower case[.]”

Billy Collins, The Death of Allegory, 1991

2.1 Overview

The aim of this chapter is to outline the theoretical and methodological considerations that informed my ANT research project. My primary aim is to discuss ANT as both a theoretical framework and research methodology garnering increased attention in social science. The paper concludes by proposing that in order to use ANT successfully, researchers must be aware of the congruences and tensions inherent in combining ANT with other social science frameworks and methodologies.
Overall, the chapter discusses ANT in detail and is heavily weighted toward describing the theoretical/methodological framework offered by ANT’s central thinker, Bruno Latour (2005). This chapter first describes ANT as a theoretical framework in the social sciences. It then attempts to situate ANT as a ‘theoretical’ versus a ‘methodological’ approach. Lastly, I present the plan I used in my work for working toward theoretical and methodological congruence between my background in social research methods and my interest in what ANT could offer.

Let me first begin by clarifying some of the key terms I will be working with below. I consider myself a social sciences researcher who conducts ‘social research’. I define social research as research that uses social theories in order to understand some aspect of the world (Turner, 2009). In most social research, researchers are asked to clarify the position from which they approach their project and their data. I support the model proposed by Bunniss and Kelly (2010) for this clarification. It consists of a two-tiered theoretical framework comprised of a ‘philosophical position’ and a ‘social theory’ and a two-tiered methodological framework comprised of a ‘methodology’ and a ‘set of methods’ (Bunniss and Kelly, 2010).

To expand on the two-tiered theoretical framework, the philosophical position includes how the researcher understands knowledge—epistemology—and the nature of reality—ontology—while the social theory or theories informs the intellectual decisions involved in designing and implementing social research. From the perspective of this two-tiered methodological framework, methodologies are seen to inform the way data is defined, gathered, structured and analyzed. Methods are viewed as the tools by which researchers gather and structure data (Bunniss and Kelly, 2010). While ANT has been called a methodology, I argue ANT can also be fruitfully employed as a theoretical framework grafted onto other social research approaches—in the case of my study, constructivist grounded theory (CGT).

2.1.1 Reassembling ‘the social’ with ANT

ANT originated alongside the interdisciplinary fields of Science, Technology and Society (STS) and the Sociology of Scientific Knowledge (SSK). It is a theoretical framework and, according

Though its descriptions have varied over the past 35 years (Law, 2007a), ANT is probably best known for exploring how humans and nonhumans interact. In his ANT primer, *Reassembling the Social*, Latour (2005) provides a structured introduction to ANT that includes methodological recommendations and key terminology, including discussions of the ANT approach in relation to other theoretical positions. Latour proposes ANT as a way to enrich social theory and social research. In this work he parallels two contrasting views of society. The first view is that of

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1Defining nonhumans is a challenge for researchers interested in ANT. Frankly, ANT proponents have hesitated to give the term a straightforward definition. What I can say confidently is that the term nonhuman intends to disrupt the philosophical tradition in which a thing, or object, is a priori placed in opposition to a person, or subject. The meaning of nonhuman is meant to be narrower than the term actor, which is intended to include both humans and nonhumans. Similarly, the term nonhuman is clearer than alternative terms used in the ANT oeuvre such as hybrid which is used extensively in some early ANT (esp Latour, 1993). Sayes (2014) provides a thorough summary of how the term nonhuman is used in ANT scholarship, arguing that the term is an umbrella used to encompass a wide range of entities:

In We Have Never Been Modern, Latour (1993: 13) includes ‘things, objects, [and] beasts’ under the heading of ‘nonhumans’; meanwhile, in Reassembling the Social, he includes ‘microbes, scallops, rocks and ships’ (Latour, 2005: 11). More systemically, we can say that the term is used to denote entities as diverse as animals (such as scallops—(Callon, 1986)), natural phenomena (such as reefs—(Law, 1987)), tools and technical artifacts (such as mass spectrometers—(Latour and Woolgar, 1979)), material structures (such as sewerage networks—Latour1998), transportation devices (such as planes—(Law and Callon, 1992)), texts (such as scientific accounts—(Callon, 1986)), and economic goods (such as commodities— (Callon, 1998)).

This elaboration by Sayes (2014) on how the term nonhuman has been used in ANT is extensive, but not exhaustive. Fenwick and Edwards (2010a) have also foregrounded the agency of ‘immaterial’ nonhuman phenomena in ANT, specifically how ideas and memories can be invoked by nonhuman materials (Fenwick and Edwards, 2010a, pp. 36;51)
Chapter 2. Theoretical framework and methodology

Traditional sociology, what Latour calls the “sociology of the social” (Latour, 2005, p. 9), which highlights the social forces influencing human actors. Latour characterized Bourdieu’s concepts of *habitus* and *field* (Bourdieu, 1977) as representative of this type of sociological thinking. Both concepts, according to Latour, are built on a human-centred definition of society that describes ‘the social’ as an omnipresent meta-concept.\(^2\) The second view, the one that Latour offers as a contrasting position to traditional sociology, what he calls the “sociology of associations” (Latour, 2005, pp. 9), posits that local collectives of people, things and researchers form their own ‘sociologies’. According to Latour (2005), sociologists of the social accept a priori ‘the social’ as an organizational ether that dictates human behavior and group formation. ANT, on the other hand, describes the social as comprising the changing activities and associations constantly taking place between human and nonhuman actors, especially the surprising reshuffling of associations that Latour calls controversies or discoveries.

### 2.2 ANT epistemology

ANT is particularly interested in scientific epistemology, the philosophy of scientific knowledge and facts. Epistemology comes from the Greek, *episteme*, meaning knowledge or science, and *logos*, meaning discourse. It is a philosophical approach interested in theories of how knowledge is defined and what it does. Like other approaches to studying science, ANT advocates different knowledge ‘paradigms’ that have been said to influence the capacity for certain groups during certain time periods to produce, possess, use and exploit scientific knowledge (Kuhn, 1962).

ANT is a particularly powerful lens for researchers interested in the dissemination of information and knowledge (Fenwick and Edwards, 2010a; Fenwick, 2010). ANT work requires researchers to pay particular attention to the research enterprise—that is, the collective industry of humans and technologies that generate research outputs such as scientific experiments and scholarly research papers. As authors, scholars from social science consider their work ‘social’ research

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\(^2\)Citing Bourdieu’s study of social scientists (Bourdieu, 1977), Latour calls it a study of “the position of a sociology of *scientists* (as opposed to a sociology of *science*)” (Latour, 2005, pp. 94).
when it uses principals from social science to build new social theories or build on established ones. ANT asks scholars to interrogate what is meant by the terms like *science, social, research* and *theory*. ANT asks, what makes social science different from natural science? How is social research different from scientific research? How and when does theory enter the research process? Outlining some key arguments from ANT’s epistemological position takes us closer to understanding how these important but challenging questions influence ANT work.

### 2.2.1 Foundations of ANT

The history of science has for years acknowledged a fascinating split that occurred in Western epistemology sometime during the Enlightenment—1650 - 1789. It was during this era that the most recognized minds in the history of Western science and mathematics were also the greatest philosophers (Ede and Cormack, 2004). Bacon established the scientific method alongside his career in law, Descartes founded metaphysics while advancing the theory of geometry, Boyle laid the foundations of chemistry while writing extensively about theology, Hobbes used physics as an entry point to founding the field of political philosophy, while Adam Smith and David Hume established the fields of moral philosophy alongside modern economics (Pinker, 2013).

Latour (1993) is one of numerous scholars to have written a monograph on the shift that occurred during the Western Enlightenment that segregated humanistic pursuits such as philosophy from scientific pursuits such as chemistry (Shapin, 2010; Shapin and Schaffer, 1985; Ede and Cormack, 2004; Bazerman, 1988). Particular to ANT is the critical attention it pays to the divide that exists between social science and natural science today. Before the Enlightenment, Foucault (1971) argues, this split in the sciences was impossible; Enlightenment philosophy initiated an important shift in *episteme*—Foucault’s term for accepted knowledge or, rather, what was knowable during a given historical period.

Latour (1993) and Shapin and Schaffer (1985) situate the beginning of this split with the famous debates on the scientific method and the nature of matter that took place between Robert Boyle and David Hume in the mid-eighteenth century (“Hume’s Newtonianism
and Anti-Newtonianism”). This serves as a backdrop for the first epistemological argument from ANT: the split between social science and natural science is a historical development, not necessarily something that should be accepted *a priori*.

### 2.2.2 The social science / natural science divide

More recently, and also of particular interest to ANT scholars, the pursuit of scientific and technical advancement by way of new discoveries has become a lucrative and revered professional role. Research practice has become increasingly professionalized by way of a number of global developments. With the increased application of engineering and scientific research during the Industrial Revolution—1760 - 1830—the economy allowed professional careers for those trained in sciences like chemistry and physics.

As industrialized world economies flourished, especially Great Britain’s, Western scientific practice spread globally by way of public and higher education accompanying the British imperial era—1815 - 1914 (Ede and Cormack, 2004, pp. 223-265). More recently, the war-era (1914 - 1945) and the Cold war era (1945-1980) were characterized by massive investments in post-secondary research institutions’ science and engineering programs (Stokes, 1997). Thus, the second epistemological argument from ANT is that scientific knowledge does not emerge from a vacuum; shared knowledge claims, or theories that inform the sciences are the result of social processes, historic contexts and human motivations.

### 2.2.3 Empirical research

Further to the argument that social processes inform both ‘social’ and ‘natural’ science, the third epistemological argument from ANT is that both social theories and scientific theories are the product of empirical research. In the same way that physicists at CERN utilize their Large Hadron Collider to generate a standard model of particle physics, sociologists and anthropologists spend months observing and surveying groups to understand the patterns of action and understanding that characterize group function. A common critique of such a
comparison of social science theory and natural science theory suggests that the empirical standards of natural science trump social scientists’ subjective observations and correlational assumptions. Perhaps the scholar who most influenced the work of Bruno Latour, Thomas Kuhn, has observed that natural science research and social science research are both evolving processes of testing, justifying and judging theories (Kuhn, 1962, p. 327).

2.2.4 The incommensurability of scientific theories

Kuhn’s argument leads us to the fourth epistemological argument from ANT: that science is often understood as a linear progression from ignorance to enlightenment when it ought to be understood as an ongoing, overlapping set of evolving processes. Kuhn calls this the incommensurability of scientific theories (Kuhn, 1962). The incommensurability of scientific theories is a crucial idea for ANT. Rather than a linear progression, Kuhn argues that paradigm shifts take place in the sciences that lead to fierce periods of posturing on the part of scientists from their respective communities. Paradigm shifts are not just ‘next steps’ in a way of understanding the world. Rather than building necessarily on theoretical predecessors, paradigms replace their predecessors. Paradigms shift. According to Kuhn, paradigm shifts can be found in the social sciences and natural sciences (Kuhn, 1962).

To take one example from popular science, the Higgs mechanism is one of several paradigms purported to explain mass in the universe, yet quantum mechanics is a guiding paradigm in physics that the Higgs mechanism seeks to disrupt (Richard, Schneider, Trines, et al., 2001). To take one example from critical theory, second-wave feminism is one of several paradigms purported to explain patriarchy, yet the Enlightenment shift toward humanism is a guiding paradigm that necessarily informs and complicates some approaches in feminist theory (Johnson, 1994). For Kuhn and others (Feyerabend, 1981b; Feyerabend, 1981a), scientific theories are more akin to strategies in a long battle than steps on a path to intellectual transcendence (Kuhn, 1962).

Through a largely historical and epistemological consideration of the history of science,
Kuhn’s work was itself a paradigm shift. Kuhn’s work, combined with Foucault’s concept of *episteme*, laid the foundations for researchers looking to embark on topics relevant to the hitherto unapproachable, objective world of scientific discovery. Thanks to the early STS and SSK scholarship of thinkers like Thomas Kuhn and Paul Feyerabend, science was made something plainly human and, therefore, worthy of anthropological analysis by researchers (Knorr Cetina, 1995). ANT originates from this intellectual milieu.

2.3 ANT ontology

I have above outlined how ANT finds the dichotomous separation of ‘social’ theories/concepts/sciences and ‘natural’ theories/concepts/sciences unsupportable. Latour characterizes this separation as an ontological one. Consider his description of the the ontology of “social explainers”\(^3\) and the central justification for an alternative:

When I begin to ask naive questions about what is really meant by social explanation, I am told not to take the existence of social forces ‘literally’, since no reasonable sociologists ever claimed that they could really *substitute* society for the object it explains . . . the difficulty comes from the double meaning of social we have already detected: behind the innocuous epistemological claim that social explanations have to be ferreted out, lies the ontological claim that those causes have to mobilize forces made *of* social stuff . . . If they don’t literally replace some phenomenon by some social force, what do social explainers mean when they say that there is some force ‘behind the illusory appearances’ that constitutes the ‘real stuff’ out of which gods, arts, law, markets, psychology, and beliefs are ‘really’ made? . . . I propose to do the same with this great mystery of the social. Everyone seems to know what it means to ‘relate’ religion and society, law and society, art and society, market and society, to have something at once ‘behind’, ‘reinforced’, ‘invisible’, and ‘denied’.

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\(^3\) Latour’s oeuvre refers to users of this ontology as ‘the Moderns’ (Latour, 2013) and ‘sociologists of the social’ (Latour, 2005)
Rather than an epistemological argument, Latour proposes radical new conceptions about our ways of understanding what it means to exist—a ‘counter ontology’ to the social explainers. Latour opens the door for a counter-ontology that refuses to accept ‘the social’ a priori.

Mol (2010) suggests we think of ANT’s ontology not as a microscope but as a kaleidoscope, suggesting ANT is less an approach to studying something in a specific way and more a “repertoire” that includes sensitizing concepts and techniques for looking at issues from alternative perspectives (Mol, 2010, pp. 261). I argue ANT’s ontological sensitivity has eight key premises: actors, networks, symmetry, hybrids, matters of fact / matters of concern, assemblages, network effects and translation. Importantly, these eight premises come from a variety of ANT sources, some with divergent standpoints on the ways and means of social research. For the purposes of cohesiveness, I elected to follow a Latourian, pragmatist version of ANT (Latour, 2005) that, I contend, uses these key premises in terms of their practical function and past successes. From this standpoint, I recognize that ANT has changed over time, and while I selected my approach because of local development of my research, other works—especially Actor network theory and after (Law and Hassard, 1999)—point to a two-way division between older ANT approached and more modern ones.

The first of what I will characterize as three ‘schools of thought’ in ANT has been called “Actor Network Theory 1990” by Law (2007b) and “Early ANT” by Fenwick and Edwards (2010a). This was ANT work from its first appearance in the 1980s that set out to describe, map and generate terminology that would inform the description of actor-networks (Callon and Law, 1982; Callon, 1986; Law, 1987; Latour, 1987). Law and Hassard (1999) call this a period where ANT was “a ruthless application of semiotics” (pp. 3) and “a semiotic machine for waging war on essential differences” (pp. 7). This early ANT work sought to disestablish accepted

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4Interestingly, Peter Hedström (2005) published his treatise on analytical sociology using the title “Dissecting the Social” the same year Latour (2005) published the magnum opus of ANT, “Reassembling the Social”. It remains unclear whether or not this is a coincidence. Latour (2005) does not cite Hedström (2005) in his text, and neither does the Hedström (2005) cite Latour (2005). Either way, the titles of these two books are a metaphorical illustration of each ontological position.
understanding of practices and forms through a networked counter-ontology. According to Law and Hassard (1999), ANT became a *semiotics of materiality*, or a method for exacting meaning systems out of the ways nonhuman objects are arranged.

For a long time, ANT was taken up in this way. The aim of this early ANT work was to deliberately interrogate and disturb leading approaches in the social sciences. Until, according to Law and Hassard (1999) critiques began to roll in about ANT’s gaps. “Easy use of the term ‘actor-network’” state Law and Hassard (1999), “has tended to defuse the [term’s] power” (pp. 8). Feminist critiques argued that ANT was not aware of its own role in discourses of gender politics and the political implications of its agenda (Haraway, 1997). Post-structuralist STS critiques accused ANT of being overly prescriptivist, even directorial (Star, 1990). Sociological critiques positioned ANT as deliberately ignorant of its own role in ‘Othering’ human agency (Lee and Brown, 1994). Law (2007b) argues these critiques came from other social theorists and stimulated the development of a second ANT ‘school of thought’, a body of work now called After-ANT or the ANT diaspora (Law and Hassard, 1999; Fenwick and Edwards, 2010a). These critiques and others have expanded and revised ANT work and ANT ideas. Importantly, as Fenwick and Edwards (2010a) so succinctly affirm, “the *After* in Law and Hassard’s (1999) book title did not signal the end of ANT, but that there was more to be done.” (p. 2)

More recently a third ‘school of thought’ has become more common in discussions of ANT work, especially in HPE. As mentioned in Chapter 1, sociomaterialism, or sociomateriality, is a term associated with recent work incorporating ANT (Fenwick and Edwards, 2010a; Fenwick, 2014a; MacLeod, Kits, Whelan, et al., 2015). While not exclusive to ANT-oriented research, sociomaterialism shares ANT’s drive to unpack and explore the important nonhuman aspects of social activity. Fenwick and Edwards (2011) include complexity theory, activity theory and cultural geography alongside actor-network theory in a recent, expanded discussion of sociomateriality in education research.

What operates across all three schools of thought is the tendency for ANT scholars to emote a playfulness in their work—akin to the postmodernist and poststructuralist ideas that have
influenced ANT’s development. ANT’s progenitive philosopher, Bruno Latour (1999), goes so far as to comment that the word theory is one of the things that “do not work with actor-network theory” (p. 15). Annemarie Mol, another influential scholar associated with ANT, argues that it is less a theory and more a ‘sensibility’ (Mol, 2010); while the well-known poststructuralist sociologist John Law (2007a) argues that actor-network theory is too immutable, with too fractured an intellectual heritage to call a theory.

Like a welcome mat that reads ‘Go Away!’’, Mol’s recent introduction to ANT warns researchers, “beware: as you walk nobody will hold your hand, there are no reassurances.” (Mol, 2010, p. 261) Rather than sidestep this variety and complexity in ANT thinking, my study design immersed itself. The remainder of this chapter outlines the eight key premises from ANT work that influenced my study and then discusses my approach alongside the more common social research methodology of grounded theory.

2.3.1 Actors

ANT rejects broad categories like ‘society’ and the ‘social sphere’ in favor of a zoom-like focus on the actors or actants at work in different situations. For clarity, throughout this dissertation I favor the term actor over actant. Actor is a common term used in the social sciences. It is the core idea behind analytic sociology because, according to Hedström (2005), sociology can “explain a social phenomenon by referring to a constellation of entities and activities, typically actors and their actions, that are linked to one another in such a way that they regularly bring

5Latour (2005) distinguishes between actors and actants. Whereas actors are isolated people, objects and ideas; actants are a semantic role for that which acts on an object. For example, in the sentence ‘The IV bag delivered fluid into the patient’ the IV bag and the patient are both actors, but the IV bag is also an actant because its role could be substituted by another actor also responsible for fluid delivery. The distinction does begin to become cloudy in situations where multiple actors are responsible for similar activities, such as when the same patient received multiple treatments for fluid delivery, like an IV, a bolus and something to drink. To avoid this confusion I use the term actor throughout this dissertation for two reasons.

First, Latour (2005) describes how any given activity involves a framing based on who or what is observing (pp. 192). In this sense, the actant role can sometimes be an interpretation—this is particularly true, I would argue, in qualitative research where the researcher and participants synthesize and analyze observations. Second, Law (2004) articulates a useful rationale for how all research necessarily generates a research presence articulated in a research work, as well as a manifest absence accessible from other worldviews and positions not contained in the ‘present’ work. Both of these layer enough complexity on the decision that such and such an actor is also an actant that I have comfortably dispensed with the term.
about the type of phenomenon we seek to explain” (pp. 2). Scott and Marshall (2009) argue that how the terms ‘action’ and ‘actor’ are understood are crucial underpinning concepts for the field of sociology. The term actor also lies at the heart of one of modern sociology’s most influential works, Parsons’ *The Structure of Social Action* (1937). Importantly, Parsons’ doctoral student Harold Garfinkel would go on to develop the observational approach of ethnomethodology. This may seem mere trivia until one considers that ethnomethodology is the central methodological approach used by Bruno Latour and the source for ANT’s advice to “follow the actor” (Latour, 2005).

Crucial to ANT is the position that actors can be nonhumans. Actor are not always people; the actor position is open to both humans and nonhumans. From this stance, the ANT ontology requires a radical shift in what we consider to be ‘social’ about the activities that surround us and the topics that are of interest to social science researchers. ANT invites us to think about all entities the same way. Rather than immediately assigning people, things and phenomena to taxonomical categories, ANT simply states that if something *acts*, it is real:

> ... everyone knows what an actor is an actor does things it, he, she acts. But no, of course it is not easy, because in different theoretical repertoires an “actor” is made to be different things. Look at these sentences. First, they state that an actor acts and then that an “actor” is made to be. From one sentence to the next there is a shift from a real life actor who acts to the term actor which is made to be and, at the same time, a shift from the active to the passive. Making such shifts and playing with them to see what happens, is one of the pleasures of engaging in “ANT” (Mol, 2010).

Put another way, Mol’s quote reminds us that when we depart from the modern distinction between ‘social’ and ‘natural’ we depart from accompanying dichotomies that include people and things, culture and nature, humans and the world. Actors act, and therein we will find the object of inquiry.
2.3.2 Symmetry

This balanced attention given to ‘social’ and ‘natural’ actors is perhaps the most well-known ontological premise of ANT. Symmetry accounts for the tensions that arise when social phenomena are traditionally considered in relation to humans and natural phenomena are traditionally considered in relation to objects. Symmetry is an approach for disturbing the dichotomous separation of phenomena as either social or natural. It asks researchers to consider how social phenomena are influenced by objects and natural phenomena are influenced by humans.

In one of his best known works, Latour (1996) tells the story of Aramis, a failed personal rapid transit (PRT) system in Paris. PRTs are above- or below-ground subway systems that use smaller scale vehicles meant for 3-10 passengers. By way of background, urban planners theorized PRT systems as a response to the rapid growth of cities following World War II. Pollution and traffic congestion had began to plague urban centres around the world, coupled with a decrease in capital in downtown areas as citizens migrated to the suburbs. Recognizing the need for an attractive commuting option, PRTs started being developed around the world as early as 1950 (Weiner, 2012). From 1969 - 1987, industry sponsors as well as the French government agency DATAR\(^6\) poured over 500 million francs developing and piloting Paris’ Aramis PRT.

After nearly two decades of research and development, though, Aramis failed. For Latour, this projects offered a ripe opportunity to explore the symmetry of human and nonhuman actors. Despite the many groups interested in the Aramis system and the technological advancements supporting its construction, Latour argues, the inability of human and nonhuman actors to form networks caused the project’s failure\(^7\). Latour central thesis is that ‘social’ explanations of Aramis’ failure were unsatisfying. Intangible and difficult concepts like ‘changes in policy’ or the ‘political landscape’ could never full explain what happened to Aramis. It had all of the people, funding, and technology needed to succeed. But still it failed. Finding out how and,

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\(^6\)Translated literally as the Inter-ministerial Delegation for Territorial Planning and Regional Attractiveness.

\(^7\)The term network will be described in the next section.
Latour argues, is a question that can only be answered with symmetry. Neither a group of people nor a group of technologies led to the fall of Aramis. Humans and nonhumans acted together, and they deserved to be treated symmetrically.

Symmetry is a contentious idea. After several years of ANT study, I can commiserate. It is unsettling to reflect on ANT’s claim that nonhuman things negotiate with humans and other nonhuman things to create, assemble, organize and maintain networks. This difficulty accepting the agency of nonhumans is just the point ANT wishes to tease apart. Latour (1996, 2005) argues that we cannot conceive of the agency of a nonhuman actor because we are conditioned by the sociology of the social to think of agency as only a human characteristic. Our a priori conditioning says that nonhuman things cannot take on human characteristics.

Latour describes a scenario where the Aramis engineers were brainstorming the qualities of the automated controller that would ‘drive’ the Aramis personal rapid transit cars. They debated whether or not anthropomorphizing qualities of a human character would be appropriate. Would the Aramis be driven by an omniscient computer system or a physically present artificial, android driver—think of ‘Johnny Cab’ from the film Total Recall (Verhoeven, 1990). The engineers were faced with literally “a matter of defining the human [anthropos] form [morphosis] of a nonhuman and deciding on the limits to its freedom” (Latour, 2005, p. 61). Machines and people work on one another in an ongoing negotiation.

Figure 2.1: Johnny Cab ©Chris Simon CC BY-NC-ND 3.0 US

ANT invites scholars to envision how nonhuman things can be actors. Imagine you are
planning an academic conference. Decorations, colours, signage, furniture and lighting are all nonhuman things that influence a given environment. The confluence of these elements influences the experiences and interactions of people in their environments. Latour describes the influence of these elements as the persuasion and collusion of both human and nonhuman actors in networks. Actors must win over other actors in order to see their networks succeed, and, where possible, these actors will resist new roles in order to maintain their extant agency.

In ANT, a sensitivity toward symmetry requires researchers accept two tenets. First, nonhuman objects have life cycles like humans. Instead of progressing through the human stages of life—being born, growing up and then dying—nonhumans move through stages of production: they begin as concepts, become projects, and eventually become objects. Objects are networks of relations manifested in the ideas, outcomes and needs of other networks. They are built on the projects, objects and institutions that have come before. Like humans, objects also recruit and enroll actors or, in the case of failed technologies like Aramis, degenerate, divide and dissolve into other networks. Second, researchers must accept that, like humans, a nonhuman object’s success is not a given because it fills a ‘social need’ or ‘cultural need’. Networks of people and technologies must be interested in an object for it to thrive and function. Elements “have to be recruited, seduced, modified, transformed, developed, brought on board” (Latour, 1996, p. 57). According to ANT, when social scientists explain the success or failure of people, concepts or objects as caused by social, political or cultural means, they miss important local explanations. The success or failure of human and nonhuman actors means strong or weak networks.

2.3.3 Networks

ANT replaces the typical distinction between phenomena as either social or natural with a networked ontology where reality and truth are comprised and composed through actor-networks, or, for simplicity, just networks. The philosopher Graham Harman (2014) makes this point by arguing that ‘natural’ objects like neutrons and ‘cultural’ concepts like myths are made real not
a priori but through the strengths of their associations with other actors:

Unicorns cannot be excluded from the picture, since they obviously have an effect on the structure of fairy tales and the stuffed animal collections of children. We cannot say that neutrons are more real than unicorns. After all, neutrons simply have more and better animate and inanimate allies testifying to their existence than do unicorns. Truth is primarily a matter of strength in assembling allies, not of immaculate point-for-point correspondence with some external reality. (pp. viii-xi)

An added dimension to this ontological position is that it characterizes people, things and phenomena as networks rather than unified constructs like ideas, people, or objects.

This networked ontology does not render ideas, people and objects as somehow non-existent or ethereal. Instead, while accepting both the physical and conceptual presence of ideas, people and objects, a networked ontology invites us to look to how networks of ideas, people and objects serve to influence and define one another and their constituent parts. Mol makes the useful comparison of ANT to Swiss linguist Ferdinand De Saussure’s version of structural linguistics (Mol, 2010, p. 257). In Saussurian semiotics, words are composed of two parts, signifier and signified. A signifier is the verbal or textual representation of a word. A signified is the concept for which a signifier stands. Taken together, signs are arbitrary in and of themselves. A tree is not called “tree” because the word tree expresses some type of ‘treeness’ (Saussure, 2001). Signifieds, which are cognitive structures, are at the heart of true meaning.

More importantly for thinking about ANT, signifieds gain their ability to relay meaning only in relation to a complex semantic web of conceptual relations. The concept of a tree gains meaning by being a part of a network of other words: roots, trunk, branches, leaves and forest. Mol points out that in ANT this semiotic understanding of language is a useful metaphor for thinking through the networked ontology characteristic of ANT (Mol, 2010). Not only must the concept of tree be seen as a network of relations, so too must the phenomenon of “tree”. A tree depends on the water it requires to live, the soil in which it gains nourishment, the ecological setting that fosters its growth and continued survival. Trees relate to paper as well, or they can
be used symbolically—such as the logo of a municipality like London, Ontario, Canada. ANT asserts that one can only understand ‘tree’ through its networked ontological position.

2.3.4 Hybrids

In a way, everything and everyone are actors in varying, dynamic, overlapping networks. So where does ANT inquiry begin? Latour (1993) argues that ANT is interested in actors that trouble the artificial dichotomy between the social and the natural; he calls these ‘hybrids’. In order to illustrate hybrids, Latour (1993) reflects on newspaper coverage. Take for example the following anonymized scenario shared with me by a colleague. A major teaching hospital’s health technology assessment team was consulted to review a commonly used drug used perioperatively with most surgical patients. After a thorough systematic review of the evidence, the drug product was found to be associated with liver disease and an increase in all-cause mortality. The product was also 11 times more expensive than an available alternative. The hospital had a financial and ethical mandate to stop using this product.

Findings in hand, the health technology assessment team approached the hospital leaders who had contracted the study. The team concluded that the best possible course of action would be to immediately substitute the drug for its safer, less expensive alternative and publish their
study results. While the hospital leaders celebrated the findings, they were hesitant to publish them. In fact, they forbade the team from publishing their findings. The hospital leaders claimed that they did not want to be the first hospital to reveal they had been using such a dangerous drug. The media had been “all over” the hospital for various reasons recently and the leaders didn’t want to give them another excuse for a story. Instead the hospital leaders recommended the team work with another hospital to publish the findings. Once the team published the findings with another group, the hospital would change their policy to follow.

This scenario leaves us with a number of questions. What do the media, surgical procedures and hospital budgets have in common? How could a drug play such an important role in media interpretations of clinical research? Drugs illustrate a hybrid phenomenon, where, as Latour says, “heads of states, chemists, biologists, desperate patients and industrialists find themselves caught up in a single, uncertain story mixing biology and society” (Latour, 1993, p. 2). In my colleague’s scenario, the drug is a hybrid, neither a strictly social nor a strictly natural phenomena. It is a physical thing, a pill, but it is also laden with implications for researchers and organizations like the hospital and the media. Latour sees a ‘proliferation of hybrids’ as characteristic of modern society, and an eye towards hybrids is seen as a key premise of ANT.

### 2.3.5 Matters of fact and matters of concern

Keeping with the drug replacement scenario, we know health care decisions are complex phenomena that involve all kinds of actors. Not only are there human beings and human groups but there are also scientific facts and technical devices, individual needs and institutional reputations. While most work in health care follows routines, like the drug that was standard therapy in the hospital, at times those routines are disrupted by new discoveries, like the new drug found to be safer and cheaper. When routines are changed, the way things are (or matters of fact) become debated issues (or matters of concern). Latour’s oeuvre frequently returns to the problems in climatology related to global warming as an example of matters of fact and matters of concern. Both sides of the global warming ‘debate’ defend their positions with matters of fact
such as study results, charts and graphs. Yet these results, and the ‘debate’ itself, are matters of concern: information produces actor-networks such as corporations, universities and specialty interest groups. From ANT’s epistemological stance, ANT researchers consider matters of fact a facade for the complex networks of matters of concern that define the world around us. Matters of fact are filtered versions of matters of concern, and unpacking matters of concern is the central occupation of ANT research (esp Latour, 2004).

The term *matter of concern* is an organizing term for thinking about the debated meanings and values that often occur when there are hybrid phenomena nearby. Matters of concern are not always as controversial as the scenario described by my colleague. They are phenomena that cause facts and values to be laid bare as evidence. Therefore matters of concern are a primary focus of ANT research because they function as a “a space of conflict and negotiation between actors” (Yaneva, 2010, citing Callon (2001) p. 10).

### 2.3.6 Assemblages

The terms hybrids and hybridity have largely been left behind due to the overlap with postcolonial theory and the term’s semantic connotation toward a seamless blending or spawning (Latour, 2005, p. 43). Instead, researchers using ANT prefer the term *assemblage* to capture an aggregated convergence of disparate components (Fenwick and Edwards, 2010, p. 9). This premise of ANT moves beyond the seeming cohesiveness of hybrids: actors can operate within assemblages, as assemblages or as network effects. The idea of assemblage clarifies the distinction between an actor, an assemblage and a network. Actors act. Actors can be composed of other actors, making an assemblage. This does not mean that all assemblages are networks. For an assemblage to be a network it must generate some type of network effect that allows the network to grow and sustain itself or to dissipate and vanish.

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8According to Fenwick and Edwards (2010a), these quarrels can tend to open up ‘black boxes’—objects and facts that are otherwise taken for granted. One example of a black box could be the position that ‘patients deserve access to the best health care, no matter the cost’. Latour (1987, 1999) identified ANT as a methodology for revealing black boxes. I frankly find the term difficult to work with, a point on which I will expand in my discussion.
One problem for researchers using ANT involves how best to recognize when actors are parts of networks or whether/when they are networks in and of themselves. A smart phone is a common example used to illustrate the actor/assemblage distinction—the YouTube account of Swedish sociologist Simon Lindgren (2014) has a ‘Social Science in 60 seconds’ video on ANT that provides a stimulating example. When my friend sends me a text message our smart phones play a crucial role in how we communicate. The same friend and I may be in a lecture where I pass a note written in pencil to communicate instead of texting. Both scenarios include key nonhuman actors required for communication to take place—the smart phone and the pencil/paper. Yet I would argue that the smart phone is an actor \textit{and} an assemblage, meaning the smart phone is a network of other actors including for example a microprocessor, a touch-sensitive screen, a user-interface/operating system and a receiver connecting to a telecommunications network. I could argue that a pencil and paper form a more rudimentary network, but it would be a stretch to claim that a pencil is an assemblage. Instead, following Fenwick and Edwards (2010a), we might look at how the pencil/paper are actors within the assemblage of a lecture hall (pp. 13).

\subsection*{2.3.7 Network effects}

One central premise clarifies the distinction between an actor and a network: a network must generate some type of network effect that allows it to grow and sustain itself or to dissipate and vanish. For example, a medical student and his/her professors are not simply actors in a medical school. Faculty, students and administrators can also be considered network effects of a broader post-secondary education system. Medical schools are assemblages of both nonhuman and human actors—including but limited to faculty, students, administrators, cadavers, laboratory equipment, hospital rotation schedules, white coats and stethoscopes. Network effects are sometimes planned, but can often be complex and unpredictable as actors and assemblages are members of multiple networks with varying levels of complexity and influence. A physician is not simply a professional role (Fenwick and Edwards, 2010, p. 17). Physicians have personal and
professional responsibilities and communities. Further, physicians can be members of broader actor-networks like clinics or specialty and sub-specialty practice groups. But a physician is also the effect of a broader health care network that situates the physician’s roles and responsibilities within a system of medico-legal regulations.

### 2.3.8 Translation

The final premise of ANT argues that networks are always changing by means of a process called translation. Actors are recruited or dismissed, connected or disconnected, ordered and disordered, all depending on the stability of various networks. Rather than imagining actors as the sprockets of a machine, imagine actors as members of a political party: some actors will never change allegiances, while others change allegiance at the first chance (Latour, 2005). Molecules are transformed into molecular models with mass spectrometry (Latour and Woolgar, 1979); tissues are transformed into diagnoses with biopsies (Mol 2002); children are transformed into citizens with schools (Fenwick and Edwards, 2010).

Translation is a carry-over from Latour’s earliest work in ANT. During his ethnographic study of a scientific laboratory, he observes that the function of the laboratory involves constantly changing statements based on new translations, “adding modalities, citing, enhancing, diminishing, borrowing and proposing new combinations” (Latour and Woolgar, 1979, p. 87). Predominantly, most laboratory tasks are the initial stages in processes of translation that see technical laboratory tasks turned into text. This process of translation involves laboratory animals, chemicals and equipment that flow through a sequential process of work.

At each stage of laboratory work sequences, the results of each translation are recorded and catalogued. For example, tagging and labelling might follow the resection of a laboratory rat’s pituitary gland, while the results of a blood test from the same sample might be recorded in a database. In one example Latour observes laboratory technicians print a graph from a machine. The printed graph is made the object of interest, while the laboratory animals and chemicals that were used as machine inputs are disposed of as waste. “The same tubes which had been
carefully handled for a week, which had cost time and effort to the tune of several hundred dollars, were now regarded as worthless. The focus of attention shifted to a sheet of figures” (Latour and Woolgar, 1979b, p. 50). Transforming material inputs into literary transcriptions is crucial to understanding the process of laboratory research production. Scientific activity builds facts from the interactions of ideas, theories, machines, texts, animals, scientists and techniques—not from a linear series of progressive discoveries about the real world.

### 2.4 ANT as a methodology

With its attention to scientific epistemology and an ontological position that avoids separating society from nature and includes nonhuman entities, ANT is a social theory with its own nuanced terminology and unique focus. I have tried above to explain these focal terms, all of which served as key analytical lenses in my study of team-based experiences of cardiac and palliative care in HF. Some have argued that ANT is not only a theory, it is its own methodology (Bleakley, 2012). I could argue that the ANT methodology is a research process that pays special attention to how labels, signs, notes, slides, posters, blueprints, charts, articles, white papers, policy briefs and legal charters provide descriptions of actor-networks (Latour, 2005). Further, like Latour and Mol, I could look at the ways these objects transfer knowledge and disseminate networks by way of interviews with human stakeholders and other forms of content analysis (Latour, 1996; Annemarie Mol, 2002). But would such an approach elaborate a methodology, or would it be an extension of the ethnomethodological social theory tradition?

Ethnography is the methodological practice of studying social groups and organizations using interviews and participant observation (Atkinson and Pugsley, 2005; Goodson and Vassar, 2011; Hammersley and Atkinson, 2009). The types of ethnographies one might see in our field of HPE research are more akin to the methods of ethnomethodology, an approach developed by Talcott Parsons’ student, Harold Garfinkel. Unlike the top-down imposition of social order on individuals in a society laid out by Parsons’ functionalism, Garfinkel’s contribution to social
2.4. ANT AS A METHODOLOGY

theory involved the counter-argument that social order is a local accomplishment generated by micro-level interactions and agreements between individuals (Heritage, 1984).

ANT does not entirely follow Garfinkel’s ethnomethodology. Whereas Garfinkel often began with mundane accounts of the world and the everyday lived experience of research participants (Heritage, 1984), Latour believes that the philosopher Thomas Kuhn’s focus on sites of scientific controversy offer a better entry point for social studies of science and technology. However, as a follower of Garfinkel’s ethnomethodological tradition and its mandate to ‘follow the actor’, Latour advises researchers that it is implausible for researchers to begin their work with a priori definitions of social groups and their components (Blok and Jensen, 2011).

Documenting an actor-network requires researchers to capture how actors make sense of themselves and other actors (Latour, 1996). Taking a similar epistemological stance as ethnomethodology, ANT takes the position that researchers can elicit descriptions of networks from actors rather than simply describing networks based on observation. Actors themselves define the actors within a given network and their relationship to one another. Does the ever-increasing complexity of networks not render understanding phenomena impossible? ANT argues the contrary: without local understanding of networks and assemblages, we risk slipping back into the false dichotomy of social phenomena and natural phenomena. Therefore, while we can presume to understand the social forces and power relations that impact the networks we study, we cannot understand how those networks influence them without understanding local context.

Unlike ethnomethodology, though, ANT pays explicit attention to nonhuman actors. With this in mind, the role of the ANT researcher changes from ‘elicitor’ to ‘observer’, for nonhuman actors cannot speak for themselves. In this sense, an ANT approach is related to but stands apart from fully ethnomethodological approaches that allow actors to fully define themselves and their relationships.

Latour published his ANT guide (2005) as a way to offer a philosophically informed methodology for researchers interested in producing work that could be meaningful to both the
scientific realists and the social constructionists. Social constructionist arguments had hampered scientific realists’ readiness to accept social studies of science, especially when simplistic versions of the social constructionist epistemology were being taken up to dismiss scientific work in areas such as global warming, evolution and AIDS research (Latour, 2004). ANT was developed to offer a more sophisticated argument for the ways reality is constructed, a way that recognizes social and historical contingency of scientific knowledge and empirical truths, but at the same time gives researchers permission to claim certain versions of knowledge and the truth operate more successfully.

Latour (2005) argues that the points seeking to be made by studying the mundane and by studying controversies are the same: the social researcher’s duty is not to decide a priori and in a group member’s stead how their society is structured. While avoiding preconceived notions that can alter the interpretation of research data is common in chemistry and physics, the same notion, according to Latour (2005), is at odds with the ‘sociology of the social’. ANT’s methodological mandate means to render the social traceable, by giving actors space to outline their own social groups, group activities, accepted knowledge, key objects and controversies. This approach plays out in four steps (Latour, 2005).

First, ANT researchers must identify spokespersons and groups. Key to ANT research is the mandate to identify how actors align themselves with certain groups (e.g., cardiovascular medicine) but not others (e.g., palliative medicine). Instead of ‘research participants’, which conjures the image of a study that has been designed to allow for play, ANT considers the perspectives of actors as spokespersons for heterogeneous networks of people and things (e.g., a heart function clinic). Second, ANT researchers must find nonhuman actors. People are easy to identify, but nonhuman things have a tendency to be stable, motionless and invisible. Third, observing activity allows ANT researchers to identify both human and nonhuman actors. Activity renders objects and people visible for the researcher. While we may not always observe activity, descriptions of activity can do just as well. Fourth, ANT researchers must be sensitive to areas where scientific facts are being contested and, thus, are becoming matters of concern,
which are particularly revealing ways to see how networks function. In Chapter 3, I describe how I operationalised these steps in the present study.

2.5 ANT and CGT

Prior to beginning this study, my training background was primarily oriented within the methodological approach of constructivist grounded theory (CGT). A simple comparison of library search results will reveal that CGT is a far more common health research approach than ANT. Due to the popularity of CGT and its prevalence in the overarching research program in which my doctoral study takes place, I believe it is worth briefly reflecting on some of its key ideas.

Whereas ANT is primarily a European movement with key thinkers emerging from France, the U.K. and the Netherlands, CGT is an approach to social research that has grown out of the U.S. Specifically, American sociologists Glaser and Strauss are credited with developing grounded theory during their seminal study of dying (Glaser and Strauss, 1965). In response to a number of methodological questions they were asked in the time following their study, they published a treatise on their methodological approach (Glaser and Strauss, 1967). The original intent of grounded theory was to generate new theories about complex topics. Unlike research in the quantitative paradigm, grounded theory was a systematic approach for social scientists to develop theories based in rigorous analysis of their social research data.

Charmazian grounded theory shares a view of research not unlike Law’s (2004): research is always the product of a researcher’s or a research team’s interpersonal positions. Charmaz (2006) would argue that research is always an act of persuasion grounded in dynamic social relations, and that it is impossible to separate one’s research from the situatedness of lived experience. Charmaz advocates for an understanding of grounded theory research as something that is not grounded in post-positivist ideals of generating theories to explain phenomena. Instead, her approach embraces the act of interpretation and understanding, welcoming diverse and divergent
perspectives as complex, necessary and meaningful.

ANT does not have a well-established methodological connection to CGT. However, certain CGT practices offered affordances in my ANT research. Specifically, while ANT provides researchers with advice for data collection and research methods (Latour, 2005), CGT offers social researchers a detailed methodology for data analysis. I borrowed four primary techniques from CGT data analysis for my study: sensitizing concepts, reflexivity, theoretical sampling and saturation.

Sensitizing concepts are ideas or worldviews that play a role in data analysis (Charmaz, 2014). These concepts originate in the researcher’s disciplinary background and serve to explain how the researcher’s presence will influence or at least play a role in data analysis. Sensitizing concepts fit well with several exemplary ANT studies. Throughout Latour’s *Aramis* (1996), the author pauses to write a reflexive diary that responds to the ongoing narrative between the professor and student. (Latour, 1996) Similarly, in Mol’s *Body Multiple* (2002) and *Logic of Care* (2008) the personal experiences and training of the researcher as an aspiring medical student and anthropologist are brought to bear on analysis throughout the text.

Reflexivity is a tenet of CGT and ANT. Not unlike sensitizing concepts, reflexivity is a goal for researchers to attain in CGT. The main idea is for researchers to evaluate, re-evaluate and critique their thoughts and assumptions as they analyze their findings. ANT requires researchers to depart from epistemological and ontological assumptions as they go about their work. Reflexivity plays an important role in fostering this process of repositioning. In a similar vein to Latour’s call for ANT researchers to “follow the actor” (Latour, 1996, p. 242), theoretical sampling involves data collection that is responsive to project developments, participant insights and new networking opportunities. Theoretical sampling is an approach in CGT that gives researchers permission to explore emerging insights, even those outside the boundaries of what they may have initially set out to do in their research study.

Saturation is a contested term in CGT. The term originates in positivist grounded theory as a sign that ‘no new insights’ are available from one’s data analysis. Saturation is also used in CGT,
but with the added meaning that the goal of saturation is deep, contextual meaning rather than veracity and reproducibility. Similarly, ANT posits that actor-networks have ‘boundaries’ that can be discovered and described by researchers. Like saturation in CGT, the goal of ’bounding’ an actor-network is rich description rather than cohesiveness and completeness (Latour, 2005).

While ANT primarily informed my study, these four elements of CGT proved useful in data analysis. This integration of the two methodologies is defensible, I would argue, because both ANT and CGT are attempts to rework and rethink existing viewpoints on knowledge. Their arguments are epistemologically compatible. I agree with the ANT scholar, Law (2004), who argues that social research’s theoretical frameworks and methodologies can be mixed as needed, as long as the researcher is knowledgeable and self-reflexive about the position of the work within networks of scientific production.

2.6 Conclusion

This chapter has offered an in depth consideration of the congruences and tensions for employing ANT as a theoretical framework. I have discussed how ANT has been called both a theoretical framework and a methodology (Bleakley, 2012), and I have described eight key ANT terms and how these are informed by different schools of ANT thought.

As both research methods and research topics become intertwined with science and technology, ANT will no doubt continue to be an opportunity for social theorists. In my work, ANT allows me to view health care and society in dynamic ways. As a researcher trained in CGT, I noted that while CGT offers a useful and compatible analytic approach, ANT provides a suite of arguments allowing new insights into phenomena traditionally considered ‘sociocultural’. Using ANT, concepts like power, ideology and discourse are no longer considered outside or beyond health care objects and processes, nor do they emerge as pervasive, all-compelling forces dictating activity. Instead, ANT research posits that local collectives of people, things and researchers form their own ‘sociologies’ that, from this standpoint, are taken as something engrained within
social groups rather than as an ethereal substance accessible and understandable only by social scientists. Building on ANT as a theoretical foundation, Chapter 3 will outline the research study within which my work took place.
This chapter outlines the methodological context, underpinnings and methods of the current study. The research took place within the context of a larger qualitative study focused on HF care teams. The overarching study used constructivist grounded theory (CGT) as a methodology as its theoretical framework. As the larger study’s data collection and analysis progressed, new areas of inquiry emerged that opened the possibility to answer new questions. Therefore, early in the study, the role of materials emerged as a worthwhile area of inquiry for my doctoral project. While CGT informed the study’s methods, subsequent analysis of these data were analyzed from an ANT standpoint.

The following chapter explains what exactly I did. I will begin by describing the design of the larger study, my role in it and how my doctoral project emerged. Next, I will provide an overview of my own study design, attending to the dataset from which I drew my findings and my approach to data analysis. This chapter’s descriptions are an important precursor to my Discussion (Chapter 7), where I reflect on the challenges inherent in designing an ANT study within the context of a CGT research project. To avoid repetition, I will leave the discussion of challenges for the final chapter.
3.1 The larger study: palliative care on the HF team

As mentioned, my doctoral work took place within a larger, CGT study called “palliative care on the heart failure care team: mapping patient and provider experiences and expectations” (Lingard, McDougall, Schulz, et al., 2013). I was the research coordinator and doctoral student for this study, a multi-institutional project featuring collaborators from Ontario, Nova Scotia and British Columbia. By way of review from Chapter 1, the study is a response to growing calls to integrate palliative care for patients with advanced heart failure (HF). When building the study protocol, we identified that most research in the area of palliative care for HF uses interview- and survey-based methods focused on populations of individuals—e.g., a survey of cardiologists or a set of interviews with caregivers. We aimed to develop a team-based methodology that would allow us to both explore patients’ experiences of team-based HF care and incorporate the insights of patients’ team members.

3.1.1 Research ethics

The overarching study was approved by five institutional research ethics boards between 2011 and 2013. All of my data collection and analysis fits within the ethical approval for the initial study from the Western University Health Science Research Ethics Board (Appendix A). An important ethical decision impacted the study’s design that I believe is worth reflecting at the outset: *no mention of palliative care was made during recruitment or during interviews to avoid distressing patients* (Fitzsimons and Strachan, 2011). Although palliative care integration is a central interest of the research team, when designing the study protocol we agreed that introducing palliative care or mortality into patient interviews could potentially put patients at risk for emotional stress in the event that the issue of palliative care had never been broached with them previously, or it had been broached and they had resisted discussing it. This decision had two long-term outcomes: first, much study data does not directly relate to the integration of palliative care; second, palliative care is an explicit part of only one of my three manuscripts.
3.1.2 Study design

This study focuses on patients with advanced HF. To find these patients the study recruited from family practice clinics and heart function clinics—specialized chronic care clinics set up for patients with HF because they often require more frequent medical care such as adjustments to medication and liquid/dietary restrictions. In order to capture how team-based care differs across different Canadian settings, the study took place in heart function clinics and family practice clinics in five different Canadian cities: Vancouver, BC; London, ON; Kitchener, ON; Hamilton, ON; and Halifax, NS. While the clinics in Vancouver and Kitchener had formal palliative care integration in common the others did not.

Patients with New York Heart Association (NYHA) Class III or IV were eligible for participation. This is a classification of patients’ function, where Class III and IV are considered to be patients with “advanced HF”. Patients with Class III HF are considered to display marked limitation of physical activity. While these patients are comfortable at rest they face excess fatigue, heart palpitation, and shortness of breath when they try to do minor activities. The functional gap between Class III and Class IV is substantial. Patients with Class IV HF are unable to carry on any physical activity without some form of discomfort—e.g., pain or nausea. These patients have symptoms of HF such as shortness of breath even when they are at rest (Association, 1994; Broek, Veldhuisen, Graeff, et al., 1992).

Patients were recruited via two routes: the HF clinic and the family physicians’ offices that refer to the HF clinic. A research associate recruited patients in person at the heart function clinic and family physicians were asked to send letters to patients who met the study’s inclusion criteria. Information provided to patients during recruitment indicated that they were being asked to consider participating in an interview to talk about their HF care experiences (Appendix B).

The team-based methodology we have developed involved recruiting and sampling not only patients but their team members. ‘Index patients’ were asked to identify their team
members—which were loosely defined as the individuals who provide them with any type of HF-related care. With index patients’ consent, we invited their team members to also participate in interviews (Appendix C). Interviewees became part of team sampling units (TSUs)—defined as a patient-identified team consisting of the patient plus at least two other members (see Figure 3.1). This approach has been used successfully to gather multi-perspective data in studies of patients with COPD (Pinnock, Kendall, Murray, et al., 2011; Kendall, Carduff, Worth, et al., 2009; Murray, Kendall, Carduff, et al., 2009) but have not been widely used to study HF care teams. Although Kaasalainen, Strachan, Brazil, et al. (2011) interviewed patient and family caregiver dyads recruited through health care professionals, interviews with health professionals did not explore that particular patient’s situation. With the patient’s permission, contact was made with members of the HF care team who emerged as important in the patient’s narrative. This included family caregivers (Appendix E), health professionals (Appendix F), and numerous other unexpected team members with a variety of roles (Ladonna, Bates, Tait, et al., 2015). Interviews were in-person or by phone depending on each participant’s preference.

![Figure 3.1: My illustration of two team sampling units from Understanding Palliative Care on the Heart Failure Care Team (Lingard, McDougall, Schulz, et al., 2013) and Adaptive practices in heart failure care teams (Tait, Bates, LaDonna, et al., 2015)](image)

To ensure confidentiality, participants were assigned pseudonyms during all stages of data collection and analysis. Interview data was not included in the analysis when patients declined
3.1. THE LARGER STUDY: PALLIATIVE CARE ON THE HF TEAM

<table>
<thead>
<tr>
<th>Individual team members</th>
<th>152</th>
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</thead>
<tbody>
<tr>
<td>Patients with advanced HF</td>
<td>50</td>
</tr>
<tr>
<td>Caregiver/supportive person</td>
<td>55</td>
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<tr>
<td>Family physician</td>
<td>25</td>
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<td>Nurses</td>
<td>18</td>
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<td>Nephrologist</td>
<td>5</td>
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<tr>
<td>Other</td>
<td>4</td>
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<tr>
<td>Other health professionals</td>
<td>15</td>
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</tbody>
</table>

Table 3.1: Table 1: Individual team members

referring us to other team members (n=2) or where we were unable to recruit at least two team members (n=10). While 62 patients were recruited for the study, the final dataset consists of 209 interviews from 50 TSUs, including a variety of health professionals, family members, and other caregivers. Because some health care professionals were interviewed about more than 1 index patient, these 209 interviews represent 152 individual participants (see Table 3.2).

Data were collected to create a well-triangulated qualitative dataset. Initial interviews were always conducted with an index patient. From there, members of their HF care team were invited to participate once the patient gave his or her permission.

All study interviews had four aims:

1. To explore the patient’s experiences, main goals and concerns regarding their HF condition and care trajectory, as well as any recent changes in those goals or concerns;

2. To explore the patient’s expectations for their future care trajectory, including the responsibilities of their care team members with regards to palliative care considerations;

3. To identify documents that the patient perceives are relevant and to request permission to collect;

4. To identify members of the patient’s distributed care team who they perceive as central to
their care and to request their permission for the researchers to approach for an interview.

The interview guide was based on widely accepted patient-centered interviewing technique (Stewart, 2003). Each interview focused on three key areas: defining, from the patient’s perspective, their main health problems and concerns, identifying their goals and priorities for treatment, and identifying their expectations regarding the roles of providers on their HF care team. Using variations of the same interview guide (Protocol Appendices C & D), the other researchers and I each requested for patients and family caregivers to be interviewed separately to explore their individual experiences and expectations. As mentioned, because patients and family caregivers may not have had the idea of palliative care introduced to them previously in the care trajectory, or might not have acknowledged its relevance to their situation, interviewers never introduced this terminology (Rogers and Addington-Hall, 2008; Fitzsimons, Mullan, Wilson, et al., 2007). Instead, interviewers used the language of the functions of palliative care to pose broad questions about expectations, hopes and fears for the future, recent changes in their health status (e.g., hospitalizations) and related needs (physical, psychological, social, spiritual or practical), or experience of changes in their treatment plan—such as receiving an implanted cardiac defibrillator device. Should patients or family caregivers explicitly introduce the concept of palliative or end-of-life care, the interviewer would explore their experiences and expectations around that topic. Interviews with caregivers and health care providers were similarly structured but had slightly different aims:

1. To discuss the participant’s expectations and experiences of palliative care in the index patient’s care trajectory, including the responsibilities and involvement of various care team members;

2. To explore health care provider experiences of palliative care for other patients with advanced HF;
3. To identify current communication and coordination practices, including documents in use, that influence the experience and expectation of palliative care in the practice environment.

Where possible, health care providers were asked to consult their patient’s medical record prior to the interview to facilitate discussion of palliative care needs in their particular case. Health care providers were also asked to consider particular communication and coordination issues that influence their expectations or experiences of how the HF care team supports these palliative care needs. Following this, they were asked general questions that afforded the opportunity to talk about the representativeness of this patient case in their professional experience and to consider other, anonymous examples of how palliative care can occur for patients with advanced HF (Appendices B & C).

3.1.3 My study: a sociomaterial analysis of team-based HF care

I have an intimate understanding of every aspect of this project, including data collected by other research assistants in other cities. Importantly, two years ago my role on the project transitioned from ‘research coordinator’ to ‘doctoral researcher’. My focus shifted from supporting the large, grounded theory study, to establishing how to use ANT to study materials at play in the integration of palliative care for patients with HF.

When my doctoral research began, I aspired to use sensitizing concepts from ANT to conduct an analysis of qualitative interview data collected by me in the larger study. At first, I wished to specifically focus on a material technology that fascinated me, implantable cardiovascular medical devices (ICMDs). The most common type of ICMD is the pacemaker, a medical device that uses electrical impulses, delivered by electrodes contacting the heart muscles, to regulate the beating of the heart. But implantable cardiovascular medical devices are often more complex. An implantable cardioverter-defibrillators (ICD), for example, has the ability to treat

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'The study included me and three research assistants collecting data. I read all of the study’s data in my coordinator role. However, for my dissertation I have only included data I personally collected.'
heart rhythm disturbances by means of ‘shocking’ a sudden heartbeat stoppage or slowness. ICDs stop the primary cause of death from heart disease, sudden cardiac death, when a heart rhythm disturbance is unable to be naturally reset.

These devices were laden with medical ethics and health policy implications, and were relevant to the question of palliative care integration. They seemed like a wonderful nonhuman actor on which to focus my analysis. They were a hot topic in the palliative care literature and they were even the subject of numerous critical studies from the social sciences (Kaufman, 2009; Kaufman, Mueller, Ottenberg, et al., 2011; Shim, Russ, and Kaufman, 2006; Palacios-Cena, Losa Iglesias, Las-Penas, et al., 2011; Palacios-Cena, Losa-Iglesias, Alvarez-Lopez, et al., 2011). However, during the first year of my doctoral candidacy I began to realize that a study of ICMDs was not working. ANT calls for researchers to follow the actors, and the patients in my study were simply not talking about their devices. The devices were matters of fact. They existed and functioned in the background for patients. Patients had little to say about their devices and often reported that they rarely thought about them.

This is not to say no patients faced issues of concerns with their devices. Numerous patients expressed concerns over being defibrillated (shocked) or facing technical complications with their ICMD, and two patients in our study were on LVADs while they awaited heart transplantation. But these were largely ‘one-off’ scenarios where a patient had been shocked but was now feeling better, or a patient had been using an LVAD but had since received a heart transplant.

I was left with a choice: foreground devices even though they did not seem as prominent an issue in the data, or reevaluate which materials of interest would be worth studying. The answer emerged during a tense meeting with my supervisor where I confessed that devices were simply not working out. “They’re boring if you just look at what patients report,” I said. “Well what do you suppose is the central controversy in heart failure team care? What is the matter of concern you have seen emerging?” replied my supervisor. The answer was obvious but I had not seen it before: “It’s fluid.”
When patients and caregivers relayed their experiences of HF during my interviews, most had very little to say about ICMDs but they talked a great deal about ‘fluid’. When I say fluid I mean the volume of *interstitial fluid* that accumulates inside patients’ bodies due to the depletion of their heart function. During dozens of interviews with patients, caregivers and health care providers, I noticed in most cases that references to fluid were far more prominent than references to ICMDs.

### 3.1.4 Sampling teams

I was closely involved with data collection at all 5 sites in the larger research study, including reading and auditing dozens of interviews collected by research assistants. However, early on in the design of my ANT analysis I decided that team-sampling units collected by other researchers would not be a part of my dataset. My focused ANT analysis used only teams where I was the primary research associate collecting data. This was in order to align as closely as possible my own experience as a researcher, my reflective memos, and my interview transcripts. Not only did I interview participants, but I consented them for the study, travelled to the heart function clinics and family medicine clinics where they received care, and often travelled to patients homes in both London, ON and Kitchener, ON.

![Figure 3.2: Complete study dataset](image)
Therefore, my study purposefully sampled TSUs that involved patients struggling with fluid from London and Kitchener only\textsuperscript{2}. This complete dataset was made up of 15 teams. While nearly all of the 50 TSUs involved patients struggling with some aspect of fluid management, 14 of those 15 teams featured where fluid management was somehow problematic.

![Figure 3.3: London, ON (red) and Kitchener, ON (purple)](image)

Using this dataset, Table 3.2 summarizes how teams were integrated into each of the analytic papers that compose this dissertation. Paper 1 had the largest sample (n = 14 TSUs) because fluid management is a pervasive issue for advanced heart failure care teams. Paper 2 had a smaller sample, as only 4 teams across the dataset contained interviews with both a nephrologist and a cardiologist. And Paper 3 contained the smallest sample, as only 2 patients in the dataset were actively enrolled in palliative care.

### 3.1.5 Data analysis with ANT

Along with the interview data, observational data is foundational to ANT research. The original study did not include any formal non-participant observation data collection. However, as a

\textsuperscript{2}The only exception is Part 1 of Paper #2, Chapter 5, where quotes from several cardiologists and nephrologists from other cities were used to illustrate key points that were particularly compelling.
3.1. The larger study: palliative care on the HF team

<table>
<thead>
<tr>
<th>Teams in ANT study dataset</th>
<th>50</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teams across larger study that fit Paper 1 sampling criteria</td>
<td>41</td>
</tr>
<tr>
<td>Teams sampled for Paper 1 analysis</td>
<td>14</td>
</tr>
<tr>
<td>Teams quoted in Paper 1</td>
<td>4</td>
</tr>
<tr>
<td>Teams across larger study that fit Paper 2 sampling criteria</td>
<td>14</td>
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<tr>
<td>Teams sampled for Paper 2 analysis</td>
<td>4</td>
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<tr>
<td>Teams quoted for Paper 2</td>
<td>4</td>
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<tr>
<td>Teams across larger study that fit Paper 3 sampling criteria</td>
<td>5</td>
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<tr>
<td>Teams sampled for Paper 2 analysis</td>
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<tr>
<td>Teams sampled for Paper 3 analysis</td>
<td>2</td>
</tr>
<tr>
<td>Teams quoted for Paper 3</td>
<td>2</td>
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</tbody>
</table>

Table 3.2: Sampling strategy for analytic chapters

Founding team member and research coordinator for the study my own incidental observations were captured throughout the work in form of reflective memos and meeting notes. These collective experiences have played a key role in how study data were interpreted.

The data analysis stage is where my project departed from the larger grounded theory study. As I mentioned, my initial goal was to use sensitizing concepts from ANT in a grounded theory analysis. ANT encourages researchers to approach their data in a way that allows study participants to describe their own social context as richly as possible. Along with the key epistemological and ontological concepts highlighted in Chapter 2, my data analysis was informed by ANT’s networked ethnomethodology. This position argues that the researcher’s duty is not to decide a priori how a group member’s society is structured. While the notion of avoiding preconceived notions that can alter the interpretation of research data is common in the basic sciences, the same notion is at odds with technological determinist and social essentialist arguments about technology. Data analysis with ANT aims to render the social ‘traceable’ by giving actors space to outline their own social groups, group activities, accepted knowledge, key objects and controversies. I undertook the analysis process in four analytic steps with numerous

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3Research ethics were not sought for formal, ethnographic observational methods for this project. Observational research was instead incidental, such as through the use of reflective memos, meeting notes and the researchers’ lived experience. While ethnographic methods could have been sought, the team decided that they were not required given the focus on patient centred team-sampling units as well as the possible privacy concerns of patients with advanced symptoms and their loved ones.
pauses for reflection, refinement, and iteration.

**Groups and anti-groups**

Identifying how actors align themselves with certain groups (e.g., a department of cardiology) but not others (e.g., the palliative care team) is an essential first step in ANT analysis. ANT considers the perspectives of actors as spokespersons for heterogeneous networks of people and things (e.g., a heart function clinic). First, an ANT researcher must identify spokespersons, which can be human or nonhuman. Spokespersons can represent their own roles in networks or they can represent other actors’. The majority of spokespersons for this study were people—research participants in an interview-based grounded theory methodology. Latour (esp 1996) frequently reminds readers that spokespersons can be nonhumans. Human actors such as cardiologists as well as nonhuman actors such as clinical documents offered insights for understanding the actor-networks of the heart function clinics in which patients were enrolled.

Anti-groups that spokespersons distance themselves from can be just as important as the groups with which spokespersons identify. ANT analysis involves marking how spokespersons identify areas where they differ from other groups—e.g., a cardiologist told me, “we’re focused on the heart’s function, so we don’t focus on the end-of-life care like the palliative care team.” In this statement the cardiologist is highlighting a distinction between their group and another group—the palliative care team. During this time, ANT encourages researchers to find group definitions—e.g., an electrophysiologist stated “I follow the Heart Rhythm Society guidelines for implanting ICDs in my patients.” As a spokesperson, this physician pointed me to a guideline for identifying an important element of how he practices as a member of a group of electrophysiologists.

**Actions and agencies**

Activity renders objects and people visible for the researcher—although we tend to be more attuned to the activity of human actors than nonhumans. For my study, while I did not use
formal observational methods, descriptions of activity proved useful for providing the history and context of some activities. Forms of activity that are to be particularly noted by ANT researchers include those that pertain to the production of information and those that are described as archaic or obsolete—e.g., a description of why a certain clinical protocol was replaced by a newer, better one. Like the idea of anti-groups, negative descriptions of activities reveal how concepts and actors are understood in a given context.

Alongside this analytic focus on activities and their descriptions, ANT research involves highlighting where actors present their own theories of action to explain network effects. This is a particularly functional analytic technique for studying health care teams. My research identifies situations where patients understood their fluid status quite differently than physicians (Chapter 4), situations where certain specialists understood fluid status quite differently than other specialists (Chapter 5), and situations where fluid management networks were at odds with human intentions (Chapter 6).

**Find objects and, subsequently, more agencies**

ANT invites researchers to attend to the nonhuman things with which human actors engage. Objects can have contested functions and varying meanings depending on which group your spokesperson represents. This was especially relevant in how technologies were found being negotiated between outpatient palliative care teams and inpatient hospice units (Chapter 6). ANT advises researchers to approach even the most innocuous objects with an open mind and to avoid falling into the traps of technological determinism by paying too much attention to powerful, influential objects that may in fact be covering up less obvious ones. This was the situation I found myself in pertaining to ICMDs and fluid. While ICMDs held fascinating implications, it was fluid that emerged as a key object after a close look at the activities of patients and care teams.

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4Despite the use of ethnomethodological techniques in much early-ANT work (e.g., Latour, 1979), Latour also used archival and historical research (e.g., Latour, 1988)
Identify matters of fact and matters of concern

In the search for objects, ANT researchers will often uncover matters of fact being contested and, thus, becoming matters of concern. Identifying matters of fact and matters of concern is a central preoccupation of ANT work (Latour, 2005) because it puts the researcher in a position to see how actors are being negotiated between and within networks. In Chapter 6, for example, I will describe a fundamental division between a fluid management technology as a both a matter of fact and a matter of concern when it involves the interaction of a hospice network and a heart function clinic network.

3.1.6 Coding/diagramming

With these four analytic steps in mind, I undertook a coding process that involved several steps. First, I broke team sampling unit transcripts down into long, composite lists of every actor and activity that was described. Actors were broken down into types based on a close analysis of interview transcripts. Humans, objects, groups, anti-groups and theories were all labelled and assigned a color coding. The aim was to trace the outlines of networks and identify matters of fact and concern.

It should be noted that these diagrams were an iteration of the project’s early interest in cardiac devices. These diagrams allowed me to begin mapping networks of HF care, but they were not used in the final analysis presented in Chapters 4-7. These were a means of analyzing data but were not findings. Nevertheless, the diagramming process was essential for identifying how central the issue of fluid and its management was on HF care teams. Mapping allowed me to identify the passive presence of ICMDs and the relevant and active presence of fluid.

The first diagrammatic approach positioned the patient at the centre of the team and paid attention to how actors were grouped around the patient (Figure 3.2). Groupings included human team members as well as nonhuman actors like devices and documents. Spaces were emerging as important networks for human and nonhuman actors.
The second diagrammatic approach envisioned patients’ trajectories of illness (Figure 3.3). Human actors, nonhuman actors, spaces and things were plotted chronologically as patients described the history of their illness. The use of scenarios by health care providers emerged as a persuasive rhetorical technique where concepts such as risk and prognosis connected with possible futures rather than historical events. These were accounted for as outside of the main diagrammatic trajectory.
Finally, human and nonhuman actors were plotted according to spaces of care and responsibility (Figure 3.4). Each space presented clusters of not only human and nonhuman actors, but also rules, diagnostics, value-systems and group meanings that were representative of a given space. For example, as discussed in Chapter 6, spaces of palliative care such as hospices allowed certain technologies (e.g., drugs) but not others (e.g., dialysis).

**Reflexivity**

ANT requires researchers to engage in researcher reflexivity throughout their data collection and analysis. I frequently wrote reflective memos and discussed my work with colleagues engaged in similar work—such as fellow doctoral candidates and professional colleagues. I also had regular analysis meetings with my doctoral supervisor to ensure that I was conceptualizing key terms correctly and approaching my problem in a manner reflective of ANT research.
3.2 Reflecting on the results

At first glance, it may surprise readers that the first two manuscripts from this study have little to do with palliative care. Chapter 4 describes patients who struggled with self-care and seeks to unpack some of the matter of fact notions about self-care in the HF literature. Chapter 5 describes the entangled collaborative goals of cardiologists and nephrologists aiming to provide care for patients involved in complex networks of health technology. Neither chapter focuses explicitly on palliative care. This dissertation took place within a palliative care research project, but permit me to explain why palliative care only becomes a part of the research in Chapter 6.

In keeping with the ANT practice of following the actors, the patients and their networks that I analyzed revealed insights that often did not involve palliative care. Recall that we sampled patients whose health care providers thought they may require palliative care in the near future. This does not mean patients had thought of or knew much about palliative care. Some had, but most had not. Therefore, palliative care did not feature prominently in their local networks. My network diagrams revealed that palliative care featured in the speculations and prognostications of health care professionals—e.g., “an ICD leads to an uncomfortable drowning death instead of a peaceful death in your sleep.” Yet discussions or considerations about the future were not part of the local network surrounding patients. Chapters 4 and 5 offer interesting analyses of fluid and its management, but only two patients in my dataset were actively receiving palliative care. I saved those patients to discuss in Chapter 6. To be clear, I was looking for insights on palliative care in patient networks but the actors did not lead me there. The actors led me somewhere else, as I discuss in Chapters 4 and 5.
Sodden bodies: a sociomaterial analysis of heart failure self-care networks

“

To One denied the drink / To tell what Water is /
 Would be acuter, would it not / Than letting Him surmise?

To lead Him to the Well / And let Him hear it drip /
 Remind Him, would it not, somewhat / Of His condemned lip?

Emily Dickinson, To One Denied The Drink

4.1 Background

Patient self-care has become a matter of fact in modern health care, fueled by a growing awareness of the need for patients to play an active role in taking care of their bodies rather than on relying solely on health professionals to do this for them. Self-care is an essential strategy in an era of increasingly strained health human resources (Lainscak, Blue, Clark, et al., 2011). Heart failure (HF) is a case in point. HF is “a complex and progressive condition whereby the heart is unable to pump enough blood to meet the body’s demands, resulting in fatigue, shortness of breath and swelling” (Arnold, Liu, Demers, et al., 2006). Strong evidence suggests decreased hospitalizations, lower mortality, reduced health care costs, and increased quality of life are some of the benefits when patients effectively tend to self-care (Michalsen, König, and
4.1. BACKGROUND

Thimme, 1998; Riegel, Moser, Anker, et al., 2009; Clark, Spaling, Harkness, et al., 2014).

The purpose of this paper is to offer a new lens through which to envision how providers can evaluate and intervene in complex, contextually responsive HF self-care factors. HF self-care interventions can include remote patient management (Anker, Koehler, and Abraham, 2011), telemonitoring (Chaudhry, Mattera, Curtis, et al., 2010), or participation in specialized outpatient clinics (Nucifora, Albanese, De, et al., 2006). Despite the extensive attention to the benefits for patients who practice good HF self-care, several recent systematic reviews have noted the ineffectiveness of some HF self-care interventions (Clark, Davidson, Currie, et al., 2010; Savard, Thompson, and Clark, 2011; Clark, Spaling, Harkness, et al., 2014). This research argues HF self-care interventions have been notoriously difficult to implement and have had somewhat successful, but largely inconsistent results. Other reviews posit that current recommendations gloss over HF self-care’s relationship with the notion of complex systems (Harkness, Spaling, Currie, et al., 2014) and context (Strachan, Currie, Harkness, et al., 2014). These findings emphasize that self-care interventions such as patient education initiatives will continue to fail until they attend to complex, contextual factors, including but not limited to home environments, routines and self-care technologies (Harkness, Spaling, Currie, et al., 2014; Clark, Spaling, Harkness, et al., 2014; Strachan, Currie, Harkness, et al., 2014; Currie, Strachan, Spaling, et al., 2014; Clark, Davidson, Currie, et al., 2010; Currie, Strachan, Spaling, et al., 2014). In this paper, we argue that self-care can be conceptualized in relation to networks of people, objects and ideas that enable and constrain patients’ and caregivers’ lives. This ‘sociomaterial’ orientation offers new insights for patients and providers tasked with developing and supporting HF self-care interventions (cf. Fenwick, 2014a; MacLeod, Kits, Whelan, et al., 2015; Fenwick, 2012; Law, 2007b; Latour, 2005).
4.2 Methods

4.2.1 Data collection

This paper draws on data gathered in a larger study of advanced HF care teams (Lingard, McDougall, Schulz, et al., 2013), which was designed in response to calls for better palliative care for patients with advanced HF (Kaasalainen, Strachan, Brazil, et al., 2011; Strachan, Ross, Rocker, et al., 2009; Goodlin, Hauptman, Arnold, et al., 2004; Goodlin, 2009; Carstairs, 2010; Health Information, 2010; McKelvie, Moe, Cheung, et al., 2011; McMurray, Adamopoulos, Anker, et al., 2012; Chattoo and Atkin, 2009). At five sites in Canada during 2012-2014, we interviewed 62 patients with advanced HF and requested interviews with individuals they identified as important to their health care. HF is a complex, problematic condition to define. For this study, advanced HF was delineated according to The New York Heart Association functional Class III or Class IV criteria.

The sampling strategy resulted in 50 team sampling units (TSUs) consisting of a patient and 2 other team members, including health care professionals (e.g., physicians, nurses and allied health professionals), family members, friends or community members. The larger study used constructivist grounded theory (CGT), a qualitative methodology for understanding complex social processes (Charmaz, 2014). The study accepted both a plurality in research findings and the health researchers’ presence in data analysis (Charmaz, 2014; Charmaz, 1990), and drew on five analytic techniques: sensitizing concepts, reflexivity, theoretical sampling, thematic analysis and saturation. The study was approved by 5 different institutional research ethics boards, beginning with Western University. All study data is de-identified and anonymized, including patients’ ages which are expressed as an age range (e.g., ‘Irene is a 50-60 year old woman’).
4.2.2 Sensitizing concepts

Following CGT, sensitizing concepts were used in the iterative analytical process. To analyze self-care data, sensitizing concepts were drawn from Actor-network theory (ANT). In ANT, the dichotomous separation of phenomena as either social or natural is replaced with a ‘networked’ ontology that characterizes all phenomena as networks of actors, rather than constructs like people, ideas, or objects. Crucially, actors includes not just people but nonhumans like ideas and objects. Both human and nonhuman actors are viewed as having agency, through networks. A networked ontology invites us to consider agency as pluralistic and relational (Fenwick and Edwards, 2010). Rather than taking for granted that agency is a human characteristic that excludes nonhuman constructs, ANT invites us to contemplate how networks of people, ideas and objects serve to enable and constrain one another toward or away from intentionality or willful action.

Matters of fact / concern

ANT attends to both the social and the material aspects of experience, particularly experiences or phenomena which have the status of ‘matter of fact.’ In ANT, matters of fact are phenomena or behaviors that are considered normative conduct or accepted knowledge. In health care, patient self-care is such a phenomenon: it is considered a ‘matter of fact’ that patients should adhere to medication regimens and clinical advice. ANT, however, argues that matters of fact are simplifications of more complex ‘matters of concern’. Our approach seeks to describe some of the challenges inherent in taking patient self-care as a matter of fact and illustrate several key ‘matters of concern’.

Material/network effects

One problem for researchers using ANT involves how best to recognize when actors are ‘parts’ of networks or whether/when they are networks in and of themselves. Several interrelated
concepts allow us to parse the multiple and sometimes overlapping roles for actors and their respective networks. Effects are a central premise clarifying the distinction between actors and networks: a network must generate some type of *effect* that allows it to grow and sustain itself or to dissipate and vanish. For example, a patient and his or her caregiver are not simply actors in society. Patients, caregivers and health care providers may also be viewed as network effects of a broader health system, typically an arm of government that designates resources for treating disease and improving quality of life for people with illnesses.

One disadvantage of ANT-informed research involves justifying in the analysis where one network begins and another one ends. On the teams we discuss below, we developed two thematic categories to organize the hundreds of network effects we identified. We distinguished between material effects and network effects. When networks generated new actors, we categorized these new actors as *material effects*. When material effects generated new, additional effects of their own we called these *network effects*. We realize that this generates a cycle of material effects leading to network effects ad infinitum. ANT-inspired research accepts this paradox provided researchers are open and reflective about how and why they elected to categorize their observations. Aside from this categorical practice, we allowed research participants to describe the components of various network effects. The results are structured accordingly.

### 4.2.3 Analytic procedure

This analysis of self-care emerges from the study’s overarching research question asking how materials mediate and influence the integration of palliative and cardiac care for patients with HF? Self-care was an important, emergent issue for this study, and we aimed to study it in relation to networks of people, ideas and objects that enable and constrain patients’ and caregivers’ lives. Following Latour (2005) we used a two-part analytic procedure focused on self-care: studying material, such as actors and objects, and studying attendant networks, such as new actors, activities, matters of fact and matters of concern. Insights gained from this
approach included the identification of several key distinctions between the actor-networks that patients engaged with at home and at hospitals and clinics. While a close analysis of HF health care settings is part of another study (McDougall, Goldszmidt, Kinsella E.A., et al., 2015), the current analysis closely explored patient and caregiver interviews.

An advantage of ANT analysis is considering the perspectives of study participants as members of heterogeneous networks. Following a preliminary analysis of the larger corpus of 50 TSUs, we selected 3 that richly demonstrated networks of patient self-care. Our analysis focused on descriptions by patients and caregivers where the matters of fact of patient self-care revealed themselves as controversial matters of concern. Two analysts completed the analysis, an ANT researcher (AM) and a grounded theory expert (LL). AM closely read 11 interviews (3 patients, 2 caregivers, 2 nurses, 3 specialists, 1 family physician) interview transcripts for these 3 teams and followed an ANT coding structure (Latour, 2005). Coded materials were then read and considered between AM and LL for appropriateness and fit. Findings have been anonymized and de-identified to protect participant confidentiality.

4.3 Results

When patients and caregivers relay their experience of HF, they talk a great deal about ‘fluid’, referring to the volume of interstitial fluid impacted by depleting heart function. In fact, in this study we found that references to fluid are more prominent than references to their hearts. With HF, excess fluid builds up in parts of the body such as the lungs, abdomen, or legs. As a result, people may complain of worsening shortness of breath, abdominal discomfort or swelling in their legs or feet. Self-care to deal with excess fluid can include activities that help to prevent the buildup of extra fluid, monitoring for signs of extra fluid, or finding ways to manage extra fluid when it starts to accumulate.

In these results, we highlight excess fluid as a powerful actor influencing patient self-care. While fluid is a central effect of HF pathophysiology, our results express its material and
network effects as it is encountered and translated in patient self-care. Below we describe fluid management as a collective of groups, objects, activities, facts and concerns, considering how fluid translates into aspects of successful or unsuccessful patient self-care, through these material and network effects.

We found material effects were the immediate, often physical phenomena relating to fluid and its management in patients’ lives. We found network effects often involved the changing space of fluid, the physical areas and relations where fluid enters other spaces for the enrollment of new actors and activities. ANT work uses rich descriptions to illustrate data, and we use three discrete scenarios to describe our means of organizing the information we gained from each team sampling unit. Each of the three scenarios below was selected for its ability to illustrate the material effects of fluid and its management, the network effects of fluid and its management, and the impact of those effects on networks of patient self-care.

4.3.1 Scenario 1: weeping wounds

Irene is a 50-60 year old woman who lives with her spouse, Ivan, in an apartment. Both Irene and Ivan are on social assistance for chronic disabilities: Irene due to a stroke 5 years ago and Ivan due to debilitating back pain. According to her doctors, Irene has advanced HF and kidney disease, she also suffers from osteoarthritis. Irene is overweight to the point where walking causes her difficulty; she requires a mobility assistive device when she leaves the apartment. Ivan is responsible for most of Irene’s self-care, even though he is limited by his back pain. Irene and Ivan receive homecare supported through two local government organizations: one agency arranges for a house cleaner every three weeks, while another arranges a health care aid to dress Irene’s wound once per day. Irene has advanced HF, which in her scenario means that her decreased blood flow has begun to negatively impact some of her bodily tissues.
Material effects

Irene’s HF both results from and perpetuates a physiological network of biological objects and activities. In Irene’s scenario, water retention emerges as a primary material effect of her advanced HF. Excess fluid stretches her skin due to underlying swelling. In some areas her skin has started to thin and break apart. Initially, her skin began to discolor and break down. But her body’s inadequate cardiac output prevents much-needed nutrients from reaching the afflicted area. This results in a chain of material effects Irene translates as a weeping\(^1\) leg wound:

**Irene:** Over the last few years [the fluid] is everywhere. When it’s really bad I feel as though I’m choking and you can actually see me getting bigger. Ivan has on occasion sat in that chair and just watched as I got bigger. And I feel as though I’m being strangled . . . The thing about the wound, if it heals over, if it stops leaking, I go into heart failure because all of the fluid backs up\(^2\).

As Irene’s body becomes increasingly over-saturated, her HF translates into more fluid; the primary material effect of her HF is this steady flow of fluid. For Irene, the wound’s flow can relieve pressure from within her over-saturated body. When Irene’s wound stops flowing, more nefarious material effects manifest themselves in her body:

**Irene:** The thing about the wound, if it heals over, if it stops leaking, I go into heart failure because all of the fluid backs up. And it doesn’t go, you know, the gold standard treatment for that is compression. But what happens with me in compression is it doesn’t go into the circulatory system, it goes up into, you know, around my heart and lungs . . . I can’t breathe, gasping for air.

Irene believes the material effects for leg wound are inversely proportional. On days when her wound weeps profusely, her fluid translates to physical relief; while on days when her wound

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\(^1\)A “weeping wound” is a wound that excretes bodily fluids such as interstitial fluid or blood.

\(^2\)While ANT research encourages openness towards a diversity of research participants’ perspectives, we believe it is important to acknowledge that Irene’s understanding and diagnosis of the function of her leg wound and its relationship to her HF is physiologically incorrect. From a cardiovascular standpoint, a chronic leg wound cannot cause heart dysfunction; but heart dysfunction can make it difficult for a chronic leg wound to heal.
ceases weeping, her fluid translates to acute HF symptoms such as intense shortness of breath. While this process may seem impossible from a clinical standpoint, this is her material reality of her HF.

**Network effects**

Fluid moves outward from Irene’s body into a variety of network effects that impact her and Ivan’s lives. These effects lead to fluid being translated in sometimes unexpected ways that complicate patient self-care. The constant flow of fluid from Irene’s wound requires that the fluid be contained, translating into the network effect of wound dressing. Ivan and the health care aid perform the dressing, sometimes several times a day:

**Ivan:** One of the health care aides come in once a day and changes the dressings on her leg . . . We just hope that it never stops weeping. That’s, you know, sort of like a Catch-22. It’s like, I have to change the dressing sometimes 4 or 5 times a day because the drainage is so heavy, but if the drainage stops, she’s in heart failure.

Wound dressing is a network effect of Irene’s fluid overload, requiring materials such as gauze, tape and scissors. Irene explains that along with these materials, the bandaging activities have been translated into a “protocol” by Ivan for the nurses:

**Irene:** Ivan is very experienced with dressing the wound. He has it down to an exact system. How to undress, clean and bandage the wound properly; which bandages to use and such. Actually he has written out the protocol for the aides and they follow it.

As the wound weeps, the gauze sops it up, stopping the flow from trickling from Irene’s body into her clothes or the furniture. Held fast with tape, according to Ivan’s protocol, the gauze absorbs fluid like a sponge. In relation to the interstitial fluid, wound dressing is a material effect. The dressing has no recourse for the fluid; it simply is a new storage space. Yet recall that the dressing’s gauze has a maximum fluid capacity. Left unattended, the gauze translates to
dirty, saturated dressings. Gauze must be changed, and not only is a stock of materials required but a protocol of activities must be followed. The material effect of the wound now translates to a number of network effects including purchase, retrieval and storage of wound management materials.

An ANT lens shows how self-care recommendations for Irene starkly illustrate the tension between self-care as a matter of fact and a matter of concern. We see fluid literally moving through Irene’s wound into network effects like wet bandages, bed pads, trips to the pharmacy, visits from homecare support staff, or new equipment. Bandaging may not impact the physiology of fluid, but it does require dedicated amounts of time, materials and knowledge that must be routinized and arranged:

Irene: This is a pattern, this is now my life, having to have these bandages changed a few times everyday and sleep with a pad to absorb the overflow at night and, I don’t know what’s going to happen when Ivan’s back condition worsens because the community health care organization simply will not fund the amount of nursing that I require . . . I have had wanted to, had been advised that swimming would be good for me as a low impact exercise and I can’t because of the wound. So that is an issue.

Irene’s weeping wound requires constant activity throughout each day. For Irene and Ivan, bandages, bed pads, tape and gauze are mediators, actors that play a direct role in the translation of fluid. The wound substantially limits Irene and Ivan’s capacity and resources for effective self-care, including HF self-care, wound care and exercise. However, the self-care recommendations Irene reports to her team are matters of fact; she needs to find ways to improve her self-care or the fluid will increase and her heart function will decrease. Irene reports that she has been advised to exercise more—some care providers have recommended she take up swimming. Yet this ‘matter of fact’ advice fails to recognize the agency of fluid as an actor in Irene and Ivan’s patient-caregiver network. Swimming as self-care is a matter of concern for Irene: she cannot swim while she has a weeping wound.
4.3.2 Scenario 2: swelling limbs

David is a 40-50 year old man who lives alone in a one-bedroom apartment. He is divorced. His ex-wife and two daughters live in the same city. David’s HF has come relatively early in life, and at the time of his interview David’s HF symptoms had progressed to a point where he was forced to stop working as a carpenter and take disability leave. David enjoyed his work and cited this early exit from his occupation as causing him some depression, which impacted his self-care. David’s depression left him unmotivated to consult a health professional about his worsening symptoms.

Material effects

Like the weeping of Irene’s wound, David’s swelling limbs have become material effect of his HF. As David’s body grew to make room for excess fluid, the fluid began to collect in his hands and feet, a phenomenon called peripheral edema. According to David, a significant material effect of this swelling was diminished energy and increased discomfort:

**David:** I was losing breath. I couldn’t walk a block . . . I was sleeping on my knees because I couldn’t lay flat anymore. I was all swollen from my ankles to pretty well my chest. I was bloated across my torso. It was just all fluid and that’s what I couldn’t get rid of . . . I had a two bedroom apartment at the time and I couldn’t even go from my living room to the bathroom.

David gained weight, felt heavier and, as a result, became slower and more lethargic. He describes how, his fluid overload caused other material effects such as difficulty walking and poorly fitting clothes:

**David:** I couldn’t wear my work boots; my ankles were swollen so much that I’d actually have to take my work boots off during the day because my feet would just swell up and I would just go home.
The material effect of swollen hands and feet, also called peripheral edema, is both a physiological necessity and a physical reality. Biologically, peripheral edema is a result of fluid retention associated with HF. Physically, gravity causes water to ‘pool’ in the hands and feet.

**Network effects**

As fluid’s material effects manifest themselves in David’s life, network effects ripple outward and begin to impact his capacity for self-care. A key network effect of David’s HF involved the changed social relationship between him and his job. This started as a material effect: David’s swelling made wearing his work boots—required safety equipment—impossible:

**David:** I was a carpenter for a company that did very high-end renovations. We did $30-$40,000 bathrooms, stuff like that and it was a great job. Yeah, actually I loved my job. It wasn’t a hard thing to go to at all. But then I just had to stop six months after the swelling began. I just couldn’t do it anymore.

David’s swelling, the material effect of fluid overload, translated into a major change in his occupation, a network effect:

**David:** I had a job for 14 years and then it was done. Basically, that was it, I couldn’t work anymore. Thought I could; I wanted to go back to work but no, there was no way I could do that I just couldn’t work anymore.

Due to his swelling, David was no longer capable of fulfilling his career as a professional carpenter. External to the material effects of pain and fatigue in David’s life, the fluid generated by David’s HF spread outward as a network effect that altered his relationships with colleagues, customers and the economy. HF also altered his sense of self, resulting in episodes of depression:

**David:** I went through depression. I went through a whole lot of changes during that time. It took probably a good three years to get over all that and start feeling better and taking care of myself I’m not going to lie.
David’s depression was a network effect that interfered with his capacity for self-care. For example he was chronically swollen—“sleeping on his knees”—and fatigued—“couldn’t walk a block”—before finally consulting a cardiologist. Through a series of translations, the material effects of fluid overload influence David’s depression, a state that complicated his capacity for self-care.

4.3.3 Scenario 3: Enrolling technologies

Martin is a 60-70 year old man who lives in a condo down the block from his daughter, Myra. She provides some support for Martin in his home life. A certified health care professional, Myra was instrumental in motivating Martin to see specialists when his tendency to ignore his HF symptoms nearly cost him his life. Around the time of that intervention Martin, an alcoholic, quit drinking. Martin has advanced HF which is being managed partly by peritoneal dialysis, a filtration of fluid. Martin is connected to an automated peritoneal dialysis machine for 8 hours every evening. This fluid management is critical to Martin’s survival.

Material effects

Like Irene and David, Martin’s fluid generated two material effects, weeping wounds and swelling skin. Myra said that by the time she convinced him to seek help:

Myra: His [peripheral] edema had become so bad his legs were so swollen they barely fit in his pants . . . we were in the HF clinic waiting room and we were sitting there and there was a puddle forming by his feet from his legs oozing.

Alongside weeping and swelling, Martin’s scenario offers an example of how fluid’s material effects bring an important self-care technology into Martin’s care, home-based peritoneal dialysis (PD).

In ANT terms, peritoneal dialysis is a mediator that plays a direct role in transferring Martin’s fluid. It greatly impacts how Martin lives. For eight hours each day, the device pumps
dialysis fluid from an IV-bag to the inside of Martin’s abdominal cavity. The dialysis fluid contains electrolytes, which help the dialysis fluid absorb waste out of both Martin’s blood and interstitial fluid. The dialysis machine then removes the fluid from Martin’s peritoneum, a larger volume than what went in now that the dialysis fluid has been translated by the waste and extra fluid. Importantly, PD requires him to be at home each day in order to connect to the device. Both the device and Martin’s body are now material effects. They both involve transferring fluid back and forth, using the device as a mediator for that process. And while the machine mobilizes fluid, its functions, settings and the composition of its dialysis bags are negotiated through an interesting set of network effects, especially realized in descriptions of the health professionals associated with his care.

Network effects

In Martin’s scenario, fluid’s network effects translate into the parts, people, agreements and mandates that compose multiple networks. There is a supply chain keeping Martin stocked with dialysis supplies, and a system of training and monitoring associated with ensuring he correctly runs his peritoneal dialysis. Each network plays its part it mobilizing fluid, maintaining the dialysis device, and keeping Martin comfortable and alive. Many of the material components of dialysis described above are consumables that must be replaced for the device to function successfully again, such as bags of dialysis fluid. Martin must interface with a supply chain actor-network facilitating the process of acquiring these materials from the hospital:

**Martin:** I just pick up what I need from the hospital. Everything is on a tight schedule.

At the time of the interview Martin was able to drive and could pick up the materials himself.

Martin described how, when he joined the local peritoneal dialysis program, he was discharged with temporary orders to receive daily nursing care to help assist him with the device. The nurses visited Martin daily for three weeks. During these visits, experienced
nurses taught him how to use and maintain the peritoneal dialysis machine and the network of components associated with it:

**Interviewer:** The nursing care after your discharge was mostly associated with the dialysis?

**Martin:** Setting up that, right. They just would come in and do it and teach me every day.

Nurses from this clinic taught Martin to set up the machine, run it and clean its parts before each use. Martin learned to connect and reconnect the pumping/heating mechanism to a catheter attached to a fistula in Martin’s torso. The catheter allows for fluid to be flushed into the body and, upon overflowing the body’s peritoneal cavity, returned to the machine. He also learned to operate the device, add a new dialysis bag, and change the waste bag. Finally the nurses would ensure Martin learned how to properly maintain and disinfect the machine and its parts daily. Martin was also required to interface with the local health care network by way of the collection of his vital signs, weight, bodily swelling and measurements of dialysis waste fluid. At the time of our interview, Martin had been tasked with administering his own dialysis and reporting clinical metrics himself by phone:

**Martin:** I see the nurse, Miriam, once a month, As long as I phone in once a week.
If I don’t, then they’ll be coming back in here every day.

**Interviewer:** So, is that because you wanted less nursing?

**Martin:** No, I just don’t need it.

Martin describes his feedback regimen for each day. By phone, Martin provides the nurses with the date and time of day, his weight, sitting blood pressure, standing blood pressure and solution measurement. He also writes down all of these metrics in his "Daily PD record” notebook provided by the hospital. Each day, Martin is required to report this clinical information to hospital-based nurses.
Is Martin’s self-care the byproduct of his education and his capacity to understand direction? The answer partially is, yes. Yet Martin’s discharge with peritoneal dialysis involves him connecting to new, sophisticated fluid management actor-networks. These fluid management networks include Martin, the nurses, infrastructure for Martin to pick up new equipment, training programs, daily monitoring, and a feedback regimen for Martin’s clinical details to be reported back to the local health system. Each part, piece and person must affect the other correctly in order to perform the crucial role of drawing fluid out of Martin’s body. In this sense self-care is influenced by a patient’s understanding of their condition and capacity for care. But self-care is also a network influencing and influenced by human and nonhuman materials, particularly fluid and its management.

### 4.4 Discussion and conclusion

This paper has demonstrated the materiality of HF self-care in light of calls for increasing attention to the contextual and environmental elements that impact it. Our ANT analysis presents three scenarios for theorizing context and environment in HF self-care. Irene’s scenario outlines how fluid management for HF self-care may require a degree of dedicated time and energy which patients and caregivers can find exhausting, if not impossible. David’s scenario highlights how self-care is impacted by the painful physical and psychological realities of the material and network effects of HF. Martin’s scenario depicts the elaborate actor-networks associated with the self-care technology of home-based peritoneal dialysis. For all three participants, fluid is a central actor in self-care. Fluid constrains where patients can go and what they can do. Via network effects, fluid is translated into systems of fluid management that impact patient self-care.

However fluid management is only possible insofar as it can build on, work around, and move through existing material and network effects in patients’ and caregivers’ lives. This insight shifts the characterization of fluid as a matter of fact in HF self-care to a matter of
concern. Seen as a matter of fact, fluid is a passive actor in self-care activities; it is acted upon by patients and governed by their decisions and cognitive abilities. Seen as a matter of concern, fluid has the active capacity to enable or constrain patient self-care, sometimes bedeviling patients’ and caregivers’ best intentions. These insights allow us to usefully extend two ongoing HF self-care discussions: that self-care interventions must move away from a sociocognitive understanding of HF self-care and ‘turn toward context’; and that an ANT approach to context can illustrate material and network effects of HF self-care. We will conclude by describing a call for inquiry into “patient-work systems” from the field of Human Factors / Ergonomics that aligns with our ANT analysis of HF self-care.

4.4.1 The turn toward context

The conversation around self-care has existed for the past 60 years. Patient self-care finds its roots in the turn away from medical paternalism, labelled famously as the “sick role” (Parsons, 1951a; Parsons, 1951b). Prior to the 1960s, patients were discouraged from playing a role in their health care (Armstrong, 2014). Under medical paternalism, physicians were considered technical experts and objective scientists; while patients were considered helpless, technically incompetent and emotionally attached. Patients were not responsible for their health and had minimal involvement in their own care (Armstrong, 2014). This conceptualization of the patient role changed to a focus on self-care after mid-century work from public health (Rosenstock, Derryberry, and Carriger, 1959; Rosenstock, 1961). These studies explored why vaccination campaigns had trouble recruiting the public for pre-symptomatic infectious disease screening. They found people were disinclined to seek medical attention when they exhibited no symptoms—after all, only physicians had the technical expertise to diagnose disease. Pre-symptomatic screening asked patients to play a more active role in self-diagnosis. In order to foster a public responsibility toward disease prevention, the story goes, a societal shift in values was required to instill in patients a sense of self-appraisal and social responsibility (Armstrong, 2014).
The shift to self-care was operationalised in medical practice during the 1970s and 80s (Levin, Katz, and Holst, 1976), especially in the budding field of family medicine, where scholars advanced models of “patient-centred” or “person-centred” care (Fenwick and Edwards, 2012; Stewart, McWhinney, and Buck, 1979). The guiding advice for physicians of this era was to consider the perspective of their patients and evoke their explanatory models of health and illness (Armstrong, 2014). The shift beckoned an era of patient responsibility for managing their health in light of both risk factors and therapeutic advice. The locus of responsibility for health and illness shifted from paternalistic medicine to active patient involvement. Self-care was born.

In heart failure, self-care has traditionally emphasized an individual patient’s ability to care for themselves, including their capacity for understanding consequences and their cognitive response to self-regulation:

> [Self-care] refers to the individual’s ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition, to effect the cognitive behavioral and emotional responses necessary to maintain a satisfactory quality of life, so a dynamic and continuous process of self-regulation is established. (Barlow, Wright, Sheasby, et al., 2002, my emphasis)

Other definitions of self-care are more task-oriented, often focusing on nine self-care practices: measuring one’s weight daily (1), contacting health professionals if weight increases (2), restricting fluids (3), eating a low salt diet (4), taking prescribed medication (5), exercising regularly (6) and contacting health professionals for shortness of breath (7), swelling (8) or fatigue (9) (Jaarsma, Beattie, Ryder, et al., 2009a; Jaarsma, Beattie, Ryder, et al., 2009b). This approach to self-care can be considered ‘sociocognitive’ in that self-care primarily succeeds when patients possess the right abilities and skills. Reviews of the HF self-care literature argue that intervening to improve self-care involves educating patients and caregivers via a curriculum focused on skill development and behavior change (Riegel, Moser, Anker, et al., 2009).
Recent critiques of the sociocognitive approach have argued that self-care over-emphasizes the patient’s role (Mol, 2008; Greenhalgh, 2009). As a response to the gaps in evidence on how to effectively intervene in patient self-care, recent accounts from the HF literature suggest an approach we call the ‘turn toward context’ (Strachan, Currie, Harkness, et al., 2014). As opposed to sociocognitive definitions of HF self-care, the turn toward context argues that HF self-care interventions must address “many factors beyond patient knowledge to support patients, caregivers, and communities” (Clark, Davidson, Currie, et al., 2010). It is a response to sociocognitive approaches that are ill-equipped for the “complexity-driven” nature of HF self-care (Clark, 2013).

Consider Irene’s case: her health care providers focus on self-care as an individual ability that is based in Irene’s understanding. This leads to the provision of logical, linear advice about the benefits of swimming as a self-care activity: its impact on obesity through reduced weight, which make it easier for the heart to work as well as reduce symptoms and eventually reduce her swelling. Irene’s care providers know exercise is challenging for her, and she knows it as well. Operating in the backdrop of this scenario is a network of fluid management activities, including but not limited to a weeping wound, Ivan, a bandaging protocol and nursing schedules. Despite Irene’s awareness that she has been instructed to swim, her willingness to swim and her desire to swim, this network of materials involved in fluid management impacts Irene’s capacity to swim.

This is not to say that Irene’s understanding of her HF is unimportant. The turn toward context reconceptualises HF self-care as deeply embedded in contextual factors beyond simply Irene’s capacity to understand her HF and act out self-care practices—a sociocognitive understanding. This stance is supported by numerous recent systematic reviews of HF self-care literature (Siabani, Leeder, and Davidson, 2013; Clark, Davidson, Currie, et al., 2010; Strachan, Currie, Harkness, et al., 2014; Harkness, Spaling, Currie, et al., 2014; Currie, Strachan, Spaling, et al., 2014). These reviews advocate a shift away from understanding self-care as centering on patients, moving towards self-care as shaped by complex, contextual factors that supersede an
individual patient’s cognitive ability or health literacy. Strachan and colleagues in particular highlight the importance of context and complexity in HF self-care, suggesting that HF self-care programs consider new theoretical models “to identify the main contextual factors and processes that influence patients’ self-care of HF” (Strachan et al., 2014, pp. 448). While these insights are important, we argue that researchers are at risk for missing the agency of important actors, such as fluid, when they consider contextual factors instead of actors.

4.4.2 The sociomaterial turn

Irene, David and Martin’s scenarios demonstrates how HF self-care is formed of parts that “can be material, human, theoretical, social, or procedural in nature, [exercising] power individually, in combination, or as emergent properties” (Clark, 2013, pp. 185). Yet the turn toward ‘context’ can be expanded when considered in light of sociomaterial approaches like ANT. A sociomaterial understanding of self-care requires the concept of context to include material and network effects in HF self-care. One of the main tenets of ANT research is that “actors themselves make everything, including their own frames, their own theories, their own contexts, their own metaphysics, even their own ontologies” (Latour, 2005). From this standpoint, calling for researchers to more closely analyze and understand ‘contextual factors’ reinforces an artificial divide between the researcher and their involvement in research work. ANT sees this as playing into the dichotomous separation of phenomena as either social or natural (Latour, 1993; Latour, 2005). For example, material and network effects provide a rich summary of the actors that play a role in Martin’s self-care. This lens could provide his care team with a new understanding of the different material implications for HF self-care when patients join peritoneal dialysis networks.

A sociomaterial lens foregrounds fluid as a key ‘actor’ in the three scenarios above, illustrating that fluid is a key actor in self-care, with material and network effects that impact patients’ and caregivers’ self-care knowledge, skills and intentions. What does it mean to suggest that the contextual turn seeks to illustrate contextual factors, not actors? While factors
and actors are similar in their etymology, they are different in semantic extension. Factors are the variables, elements or constituents that influence a final outcome, passive agents waiting to be quantified and formulated. Actors on the other hand can be passive, but can also resist and respond to human intentions. Our results illustrate the need to further shift self-care discourse to include a broader array of actors, particularly nonhuman actors such as fluid. Sociomaterialist inquiry expands the turn toward context to consider HF self-care as a pluralistic and relational network.

4.4.3 A way to intervene

In a recent position paper on the current state of ANT, medical sociologist Mol described ANT research as a “way to intervene” (Mol, 2010). We will leave off this discussion with some suggested methodological insights for the direction of future work aiming to explore key actors in of HF self-care. Recent work from the Human Factors / Ergonomics (HFE) discipline offers a sibling approach to this ANT analysis of HF self-care (Holden and Mickelson, 2013; Holden, Carayon, Gurses, et al., 2013; Holden, Schubert, and Mickelson, 2015). The HFE approach of ‘patient-engaged human factors’ foregrounds patients, caregivers, objects and processes as “actors” in systems of health care practices and priorities (Unruh and Pratt, 2007; Vincent and Coulter, 2002). A compelling contribution from HFE comes in the form of several studies that have redefined patient self-care as work for patients and caregivers (Granger, Sandelowski, Tahshjain, et al., 2009; Holden, Schubert, and Mickelson, 2015). These studies have sought to highlight effortful activities of lay care providers, using the work-oriented metaphor of caregiver burden. These studies have identified a gap in our understanding of patient and caregiver work systems, calling for comprehensive, theory-based and methodologically rigorous approaches to fill these gaps. Calls for inquiry into patient-work systems by HFE scholars aligns with our actor-network theory analysis of HF self-care. Though it may appear we are critiquing the turn toward context, we believe that future studies bridging HFE and ANT can fruitfully explore the contextual (f)actors of HF self-care.
4.5 Limitations

Two limitations for this paper involve the focus on patients and caregivers, instead of entire teams that include health care providers. Health professionals were an important part of our study, and their omission from this analysis was a deliberate decision because they are the focus elsewhere (McDougall, Goldszmidt, Kinsella E.A., et al., 2015). Similarly, our close analyses of three patient scenarios may seem patient-centered, not sociomaterial in nature. This was a deliberate methodological decision to provide rich accounts of patients’ and caregivers’ networks of care (Ladonna, Bates, Tait, et al., 2015, forthcoming). We also acknowledge that ANT is a controversial mode of inquiry with key tenets that intentionally disrupt some philosophical and sociological norms, including some generally associated with constructivist grounded theory. Following ANT, the results and discussion we provide in this paper are not written to be generalizable in every setting. Instead, they are meant to intercede on behalf of the groups we have worked with in preparing this study.

4.6 Conclusion

This paper argues that self-care can be conceptualized in relation to networks of people, ideas and objects that enable and constrain patients’ and caregivers’ lives. This “sociomaterial” orientation offers new insights for patients and providers tasked with HF self-care. In an era of calls for an evidence-base to support research health interventions, ANT offers the opportunity to tease out the complex threads that come together to assemble the matters of fact and matters of concern that clinicians, patients and caregivers must work around and navigate.
interdisciplinary collaboration and collaborative entanglement: a sociomaterial analysis of fluid management

“The world is not a solid continent of facts sprinkled by a few lakes of uncertainties, but a vast ocean of uncertainties speckled by a few islands of calibrated and stabilized forms.”

Bruno Latour, Reassembling the Social, 2005

5.1 Background

Heart failure (HF) is a growing burden on the health of patients and the economic viability of health systems. Patients with HF are at high risk for hospitalization and death. Just in North America, an estimated 5.8 million American adults have HF (Heidenreich, Albert, Allen, et al., 2013) and an estimated 500,000 Canadians (Ross, Arnold, Liu, et al., 2006). International rates of HF are expected to increase exponentially in coming years as a result of aging population, improved survival rates after myocardial infarction and the development of new therapies for more effective treatment of those with the disease (Ambrosy, Fonarow, Butler, et al., 2014). Within the last decade all major cardiovascular medical organizations have recognized a
complex chronic condition requiring a multidisciplinary team-based approach guided by the
tenets of interprofessional collaboration (IPC)—including the American Heart Association
(Hunt, Abraham, Chin, et al., 2005), American College of Cardiology (Hunt, Abraham, Chin,
et al., 2005), the National Heart Foundation of Australia (Krum, Jelinek, Stewart, et al., 2011),
the Cardiac Society of Australia and New Zealand (Krum, Jelinek, Stewart, et al., 2011), the
European Society of Cardiology (Jaarsma, Beattie, Ryder, et al., 2009a) and the Canadian
Cardiovascular Society (McKelvie, Moe, Cheung, et al., 2011).

While guidelines reinforce the importance of IPC in HF care, a stable definition of collaboration
eludes the HF literature. International health policy organizations have defined interprofessional
collaboration as occurring when health care professionals from diverse backgrounds work
together with patients, families, caregivers and communities to deliver the best quality of care
(WHO, 2010; Service, 2001; Herbert, 2005). Guidelines argue IPC correlates with improved
patient access to health services and outcomes, better use of clinical resources, and less stress
and higher retention of health care providers (HFO, 2010). IPC research orients us toward
a position we call the sociological understanding of IPC. From this position, IPC is viewed
as the negotiation of values, goals and activities among health care providers, patients and
families. IPC research has argued that local cultures (Hall, 2005) and discourses (Haddara
and Lingard, 2013) influence how we understand and engage with collaboration. Research
using the sociological understanding of IPC has particularly improved our understanding of
important, ongoing *interprofessional collaborative tensions* in health care and administration.
At the health systems level, research has illustrated interprofessional collaborative tensions
such as local mandates that conflict with public legislation (Lahey, 2012), or scope of practice
guidelines (Khalili, Hall, and DeLuca, 2014). At a daily practice level, research has illustrated
interprofessional collaborative tensions in team collaboration such as misunderstanding team
members’ roles (Khalili, Orchard, Laschinger, et al., 2013) or hierarchical professional cultures
and values (Paradis and Whitehead, 2015).

Identifying, describing and ameliorating interprofessional collaborative tensions is a crucial
tie that unites research using the sociological understanding of IPC. Underlying this type of research is the idea that collaboration is a human endeavour. People are presented as the crux of the relationships, interactions, negotiations and forces that lead to interprofessional collaborative tensions. However non-human materials also influence IPC. We use the term materials to mean the objects, things, and parts that play a role in the spaces we investigate. Materials like guidelines, clinics and hospitals play an important role in the described mandates and legislation. For example, a medication adherence document could greatly influence the interactions between physicians and nurses if a policy required nurses to witness physicians signing off on a medication order for patients. A growing body of research has sought to account for materiality in descriptions of collaboration in health care. (Bleakley, 2012; Fenwick, 2014b; MacLeod, Kits, Whelan, et al., 2015) This research can collectively be called sociomaterial inquiry on collaboration, and it informs the disciplinary orientation of this paper.

The term sociomaterial inquiry can be broadly defined as an approach originating from the application of post-structuralism to sociological study (Fenwick, 2014b; Law, 2004). These approaches sought to dispatch a priori models of social structure and cultural groups in favour of local descriptions that sought to illustrate, rather than theorize, the operations of power, knowledge, and capital (Law, 2004; Law, 2000; Law and Singleton, 2013). Like the sociological understanding of IPC, sociomaterial inquiry on collaboration seeks to improve our knowledge of how teams work together. Where it differs, however, is in the deliberate engagement with nonhumans as active agents playing an equal role in human activities.

5.1.1 Sociomaterial inquiry on collaboration with ANT

Our chosen approach to sociomaterial inquiry is actor-network theory (ANT), associated with the work of the philosopher and anthropologist Bruno Latour (Latour and Woolgar, 1979; Latour, 1987; Latour, 1993; Latour, 1996; Latour, 2005). ANT is well-known for its claim that by focusing exclusively on people sociology ignores how materials play a role in human activities. Crucially, ANT puts forward the notion of material agency, also called symmetry,
where people and materials are given equal attention and treated as social actors. Describing something as an actor in sociomaterial inquiry is akin to showing someone is an actor in the sociological understanding of IPC. In each case, actors act. They play a role in relation to other actors. For IPC research on HF care teams, ANT reveals technological and material elements that impact team-based care.

ANT posits that technical fields like science and medicine ground daily practice in “matters of fact.” These matters of fact are reproducible truths about our world (Latour, 2004a). ANT, however, argues that matters of fact are the filtrated, simplified byproduct of more complex ‘matters of concern.’ From this standpoint, facts are the necessary simplification of the catalog of activities taking place between human and nonhuman stakeholders jockeying for position in an ongoing series of political and financial moves coloured by public opinion and media coverage (Latour, 1987; Latour, 1993; Latour, 2004a; Latour, 2005).

A useful analogy for understanding the distinction between matters of fact and matters of concern is riding the bus. We know several matters of fact for riding the bus: the schedule is posted by the bus company, the bus arrives at a set time at your bus stop, you pay the fare or show your bus pass, and the bus stops at destinations along a set route. Despite these facts, riding the bus is influenced by matters of concern: political funding for public transit, unions that negotiate wages and organize strikes, even the choice of vendors for the buses’ tires. ANT studies matters of concern, making the point that it is necessary to focus on matters of fact for many good reasons, but that facts are always informed and influenced by matters of concern.

We studied team collaboration and employed ANT’s key principles of symmetry and matters of concern to guide our inquiry. Our research was conducted with health care teams caring for patients with advanced heart failure (HF), which is a chronic disease characterized by several common symptoms that can negatively impact a patient’s quality of life. Following other work that has used sociomaterial inquiry to study health care contexts (Mol, 2002b; Mol, 2010), one particular symptom is our point of focus in this paper, the abnormal accumulation of fluid within patients’ bodies. Our research question asks: how does our understanding of health care
teamwork shift with a sociomaterial inquiry that prioritizes not the people but the materials engaged in teamwork—in our case interstitial fluid—as an actor on the team? Responding to recent attention to better understanding and representing the complexity of collaboration in health care settings (Cristancho, 2014; Lingard, Vanstone, Durrant, et al., 2012; Fenwick, 2012; Clark, 2013; Selman, Beattie, Murtagh, et al., 2009; Cristancho, 2014) this paper describes the agency of heretofore taken-for-granted fluid accumulation, a matter of concern that influences IPC. Placing fluid at the center of a network of actors brings into focus the negotiations and entanglements that characterize IPC with HF patients. Drawing from our sociomaterial analysis, we hope to advance collaborative entanglement as an innovative and functional construct for understanding and grappling with interprofessional collaborative tensions.

5.2 Methods

5.2.1 The larger study

We conducted a study of interdisciplinary teamwork on complex, distributed health care teams, where patient care is largely outpatient based and health care providers collaborate remotely. The larger study used a qualitative grounded theory methodology. Patients with NYHA Class III or IV were eligible for participation because they were considered to be “advanced” HF patients likely requiring complex team-based care. Patients with Class III HF are considered to display marked limitation of physical activity. Patients were recruited via two routes: the HF clinic and the family physicians offices that refer to the HF clinic. A research associate recruited patients in person at the heart function clinic and family physicians were asked to send letters to patients who met the study’s inclusion criteria. Information provided to patients during recruitment indicated that they were being asked to consider participating in an interview to talk about their HF care experiences. Importantly, no mention of palliative care was made during recruitment or during interviews to avoid distressing patients (Fitzsimons and Strachan, 2012). The study’s sampling strategy took a patient with advanced heart failure as the focal point,
and used each patient’s sense of key members of their care team to build a series of ‘team sampling units’. This approach has been used successfully to gather multi-perspective data in studies of patients with COPD (Pinnock, 2011; Kendall, 2009; Murray, 2009) and each HF team sampling unit consists of at least 3 interviews (the index patient and at least two other team members). Citing recent research on the complexity of providing palliative care for patients with advanced HF (Lemond and Allen, 2011), the study recruited patients with advanced HF, their caregivers and health professionals. Our unit of analysis was the “team sampling unit” (TSU), defined as the recruitment of an index patient, at least one of the index patient’s lay caregivers (e.g., a spouse), and at least one of the index patient’s health care professionals (Lingard, McDougall et al., 2013). Participants were recruited discretely in person. After their interviews, participants were asked for permission for researchers to request interviews with their identified team members. Using this approach, the study took place across five cities in heart function clinics in three Canadian provinces, where researchers conducted 205 interviews with 62 patients with advanced HF, 58 caregivers and 72 health care providers. This study was approved by separate research ethics boards in all five cities.

5.2.2 The cardiology / nephrology interface

We found advanced HF care is distributed across multiple care teams at different clinical sites, with access to diverse clinical diagnostics and technologies. Early in our analysis we found a cohort of 13 recruited patients who had advanced HF as well as kidney disease. As a result, these patients were being seen by both cardiology (heart specialty) teams and nephrology (kidney specialty) teams, along with other care providers such as their family doctor and a family caregiver. Preliminary thematic results suggested that actor-network theory (ANT) could offer a productive orientation for understanding the collaborations between specialist physicians caring for these patients. These 13 TSUs—consisting of 47 interviews: 13 patients, 10 lay caregivers, 5 family physicians, 6 cardiologists, 7 nurses, 4 nephrologists, 1 nephrology nurse practitioner and 1 cardiology nurse practitioner—were reread and analyzed using the ANT lens
to highlight the presence and impact of material elements. In a subset of 4 of these 13 TSUs, we were able to analyze interviews from TSUs featuring a patient, at least 1 lay caregiver, at least 1 cardiologist and at least 1 nephrologist.

5.2.3 Analysis and representation with ANT

ANT uses thick descriptions to evoke detail and meaning. ANT research takes the position that, whether presenting matters of fact or matters of concern, all research findings result from a series of transformations. In his study of an electrospectrometry laboratory, Latour famously traced cyclical transformation of lab mice into tissue samples, and tissue samples into spectrometry readings and research paper (Latour and Woolgar, 1979). ANT research follows how events are made to happen by a heterogeneous set of both people and things, but which people and which things is dependent on the purpose of the description. ANT research products, called accounts, are focused and descriptive, rather than thematically structured like many qualitative approaches such as grounded theory. ANT is a methodologically diverse approach, but if there is one truism across all ANT-informed work it is that the results of an ANT study are always the impressions of researchers or research teams. With ANT, the insights and contributions of participants are foregrounded but do not trump researchers’ interpretations. This is not to suggest researchers have the final interpretive position; on the contrary, ANT suggests research articles are a byproduct of material agency (Law, 2004; Law, 2007b; Mol, 2010; Mol, 2002b).

Within the context of the larger study, the authors recognized the influence of fluid on interprofessional care. Two researchers (AM, LL) began a focused analysis of TSUs featuring fluid management. Both authors wrote frequent research memos and sought guidance from clinical collaborators during research meetings and drafting discussions (MG, AK, SS). Collectively, efforts were made to ‘bracket’ our own predilections and biases in order to let participants speak for themselves—Latour (2005) calls this ‘following’ the actor. While this was challenging, we believe the authors mix of both clinicians and theorists allowed for greater capacity for open and descriptive interpretation.
5.3 Results

The results are structured in two parts. Part 1a and Part 1b draw on the 47 interviews across the 13 TSUs to describe fluid as a key actor on advanced HF care teams. Part 2 focuses on the 4 TSUs where, in separate interviews, cardiologists and nephrologists talk about their approach to patient care. Part 2 illustrates how fluid is a matter of concern as these specialists describe how they negotiate advanced HF care.

5.3.1 Part 1a: fluid is an actor on the HF care team

Our data illustrate how fluid comes to act as a central part of care for patients with advanced HF. Patients with advanced HF constantly fluctuate between periods of relative equilibrium (euvolemia), fluid overload (edema), and fluid deficit (dehydration). Physiologically, fluid increases in patients’ bodies. A key activity of fluid on the advanced HF care team is worsening of a patient’s HF which can contribute to significant amount of physical discomfort and emotional distress:

"Getting dressed in the morning, I’m out of breath [...] I walk a block and I’m just exhausted [...] there’s a lot of fluid build-up that’s causing this. It really holds me back from doing lots of things [...] I’ve been waking up and I’ll be gasping when I’m waking up and I didn’t like that at all. I’d be sleeping for a couple of hours and I’d wake up and then of course you can’t get back to sleep."
(Mr. Benjamin, patient)

Heart Failure physically exhausts patients. Patients are heavier from water retention and physiologically their cardiovascular systems are overloaded:

"As people live with HF, it becomes a salt and fluid issue, and their body loses the ability to regulate the salt and the fluid, and over time they become, what we say, resistant to the fluid medication [...] their hearts aren’t strong enough to pump fluid"
over to the kidneys, then they become like an unprimed pump, their blood pressure falls, their kidney function gets worse, they’re falling down, they feel awful. (Ms. Olivier, heart function clinic nurse)

Fluid also creates concern and effort for caregivers. One caregiver described how difficult her husband’s condition was before a recent medication adjustment:

They’ve cut his medications way, way down. He’s taken an enormous amount of medications [...] That was two years ago, and that’s when he couldn’t walk properly, he looked a hundred years old, his brain wouldn’t work because he didn’t have enough oxygen going to his brain. He behaved almost as if he had had a stroke. (Mrs. Meyers, spouse)

Advanced HF patients often have multiple, competing health issues relating to fluid. A HF nurse practitioner described such a patient:

[Mr. Schmidt] was very sensitive to beta-blockers, we tried him on a beta-blocker and he ended up with a very low blood pressure. He ended up after that with even worsening renal failure [...] they tried dialysis but they couldn’t because of hypotension [...] he ended up having a cardiac arrest in dialysis [...] He’s currently in the intensive care unit.

(Talia, HF nurse practitioner)

Her team took a variety of approaches to managing this patient’s fluid (e.g., dialysis, etc.). Fluid leads patients to emergency room visits, medical procedures and hospital admissions. Fluid is more than simply a passive symptom that patients report; it physiologically, individually, and systemically becomes a central actor for understanding the people, objects and activities that make up collaborative HF care.
5.3.2 Part 1b: care teams react to fluid

ANT research looks at what actors do and how they relationally affect other actors. Participants described a variety of reactions to fluid, often using the verb “manage” (e.g., fluid management, volume management). This verb connotes control over fluid as a “matter of fact” in HF care. However, seeing fluid management as a reaction rather than a controller offers important insight into fluid’s impact on teamwork. In particular, three reactions to fluid were recurrently described by participants: mobilizing, measuring, and teaching.

Cardiologists described how they begin with drug therapies and lifestyle changes to treat fluid overload in patients with advanced HF:

> Fluid compliance issues include the clinical scenario of someone on high-dose diuretics, fully treated with beta blockers, ACE inhibitors [...] with salt and fluid restrictions so those sort of lifestyle changes. As patients’ HF progress, they may become candidates for aldosterone antagonists, other advanced medical therapies and then become candidates for mechanical supports. (Dr. Richards, cardiologist)

Each of these drugs acts to mobilize fluid or support the body to better handle them. ACE-inhibitors to relax blood vessels and decrease blood volume, beta-blockers to block the mechanism for bodily adrenaline, diuretics to promote the production of urine, and aldosterone therapy to inhibit sodium absorption in the kidneys. Alongside drugs, as Dr. Richards alludes, mechanical therapeutic interventions also work to mobilize fluid. A particularly important intervention for the four patients in this study is dialysis.1

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1There are two primary kinds of dialysis: hemodialysis (HD) and peritoneal dialysis (PD). The patients in our study were primarily involved with a local PD program. One author, a cardiologist (SS), felt that because the differences between patients with advanced heart failure on hemodialysis versus peritoneal dialysis were subtle. We therefore refer to “dialysis” throughout the paper with the understanding that may lead to some small ambiguities for area experts.
Dialysis is another strategy our participants highlighted for both mobilizing and measuring fluid:

We would give our patients a target weight, we would teach them how to adjust their diuretics, when we assess them we would reset their target weight, and readjust the diuretics and the medication to control it. But when they’re on dialysis, the nephrologist has to order the change in the solution strength, and change in the exchange times, in order to take more or less fluid off. (Ms. Olivier, heart function clinic nurse)

Both drug therapies and dialysis are examples of patients measuring fluid themselves. One nephrologist characterized these ongoing processes of measurement and mobilization as ‘tinkering’:

Once we established [Mr. Muloney] on dialysis and established what his weights are and his mode of therapy, it’s just more tinkering over time. Does his weight go up or down a few pounds? Is that fluid? Is that actual body mass that he’s gaining or losing? And then adjusting his prescriptions on that basis. (Dr. Ming, nephrologist)

Patients and health care providers evaluate fluid, and patients take more or less diuretics accordingly. Dialysis often requires patients to take a device home or attend an outpatient clinic and connect each day in order to ‘put in’ and ‘pull out’ fluid from their bodies over the course of 6-8 hours. As this language illustrates, balance is the goal of drug and mechanical therapies in fluid management, and each balancing activity is a reaction to fluid. As Dr. Ming’s explanation illustrates, this is not a simple matter of control; this is tinkering responsively, acting with and reacting to the actions of fluid.

In order to effectively act with and react to fluid, patients required intensive education. Our participants described how fluid impacted their home lives. Health care providers required patients to mobilize fluid by following procedures for drug and mechanical therapies, as well as measuring volumes for reporting back to health care professionals:
We teach them what can be helpful in regards to the changes that they can make in terms of their activity or their diet. Going over salt restrictions. And discussing fluid restrictions, sometimes talking to them about reducing the amount of fluids that they’re drinking. (Ms. Rodriguez, heart function clinic nurse)

Drugs, dialysis, salt, glasses of water, nurses, physicians, patients, and caregivers all form a network of actors acting and reacting to keep fluid at bay—ANT uses the term actor-network for these heterogeneous groups. Health care for patients with advanced HF is an actor-network with fluid at its core. Study participants describe fluid management as the processes whereby they mobilize, measure and teach fluid. Yet fluid manages team activity as well. More or less fluid impacts activity at every level of these actor-networks, and in this sense fluid impacts advanced HF care team collaboration. HF team collaboration emerges as the collaboration among fluid, patient, caregiver and health care professionals.

5.3.3 Fluid: matter of fact or concern?

The above examples show fluid and its management being treated as matters of fact by patients, caregivers, nurses and physicians. Yet our analysis of cardiologist and nephrologist interviews suggests that what is a matter of fact about fluid management for one team member may be a matter of concern for another:

Often patients are given a lot of diuretics, and we have to make sure we speak the same language because the kidney doesn’t necessarily like the diuretic and the heart needs the diuretic. (Dr. Golden, nephrologist)

Cardiologists prescribe diuretics for fluid management as a matter of fact, but this action constitutes a matter of concern for nephrologists focused on caring for the kidney. Nephrologists describe being brought into the network of HF care when fluid management was taxing cardiology resources in the form of time in hospital. Patients’ kidneys start failing, often because of HF drugs, bringing them back into hospital:
The more common experience for me is the patient is followed by a cardiologist, is on the revolving door program on the cardiology floor of the hospital. And then, on one of those admissions, I’ll get called and asked if there is anything I can provide to basically keep the patient out of the hospital. They have no quality of life. They’re spending all their time in the hospital. In some cases, they’re sending the patient home on IV lasix [a method of diuretic delivery] but then they lose their kidney function. So they’re back and forth and back and forth.

(Dr. Khan, nephrologist)

For heart patients in this situation, dialysis was a matter of fact approach to fluid management. However, it was also a matter of concern, because dialysis is a fluid mobilization technology typically controlled by nephrologists, and cardiologists described some difficulty accessing this technology.

Frequent negotiations over fluid occur as cardiologists and nephrologists collaborate. One cardiologist explained how some advanced HF patients’ kidney failure is not severe enough to meet the minimum guidelines for dialysis, even though their fluid overload is unmanageable with HF drug therapies:

There are patients who it’s difficult to impossible to manage their HF because they have such a severe degree of renal impairment that it’s altering their response to diuretics, in combination with poor heart function […] I must convince the nephrologist, “I think this person needs to be dialysed for fluid management, not because of kidney failure symptoms […] sometimes fluid management issues alone may dictate the need for dialysis.

(Dr. Edwards, cardiologist)

This explanation reveals that there is a ‘usual’, ‘reasonable’ set of circumstances that ‘dictate the need for dialysis’, and, advanced HF patients may not fulfill these requirements. Nephrologists’ descriptions also reveal a tension between matters of fact and matters of concern regarding
fluid management through dialysis for these patients. In fact, dialysis is “consistent day by day extra fluid removal [which] does a better job of keeping patients out of hospital.” (Dr. Chavez, nephrologist) As a matter of concern, however, it is perceived as both “an underused resource” (Dr. Chavez) and a naively quick fix: “the cardiologists got wedded to the idea of ‘a quick spin of dialysis changes the career of the patients’ and I think that that’s a little flawed.” (Dr. Chavez) Further complicating the picture, one nephrologist perceived that a clinical trial of dialysis for HF was “undervalued” by cardiologists asked to refer HF patients in need of fluid management:

A couple of years ago there was a trial put out by our dialysis provider []in a program where we think we work pretty co-operatively, there were mutterings that cardiologists weren’t going to probably want to have their patients on ‘dialysis.’ We think that the therapy is undervalued by some of the cardiologists. (Dr. Chavez, nephrologist)

Each of these descriptions illustrates fluid being treated as a matter of fact in one specialty while being a matter of concern in the other. What does this say about how fluid is understood by cardiologists and nephrologists collaborating in advanced HF care?

I don’t necessarily need the nephrologist to tell me the dose of diuretics needs to be adjusted or that their renal function is significantly abnormal [...] Most of the time for advanced HF patients I pick up the phone and speak to the nephrologist directly. If you try to do it through notes and stuff like that it doesn’t convey that, ‘I feel quite strongly that this person should be considered for dialysis’. The best way to do that is picking up the phone. (Dr. Edwards, cardiologist)

As this cardiologist expresses, collaboration involves specialists in negotiations regarding fluid as a matter of concern.

This specialist negotiation takes the form of asserting authority over the meaning of and response to fluid. Because nephrologists’ roles “somewhat overlap with cardiologists’ role, in the sense that both look at a patient’s weights, fluid status and blood pressure,” (Dr. Ming,
nephrologist) this negotiation requires both parties to contend with each other’s distinctive definitions of ‘fluid’. Our participants recognize that this contending looks like disagreement:

Patients sometimes get mixed messages from their nephrology team and their cardiac team, so we need to make sure we’re all on the same page. I often hear and see patients feeling quite frustrated that someone is telling them to take less fluids and someone else is telling them to take more.

(Dr. Golden, nephrologist)

While this nephrologist acknowledges that patients can feel frustrated at the apparent contradictions in fluid management directions, another explained how these distinctive approaches to fluid set up complex ‘interspecialty’ relations of authority:

Nephrologists are probably obliged to follow the cardiologist directions about HF patients, although I might tend to whisper in a patient’s ear and tell them to lie to the cardiologist about how much liquid they drink. I think it’s a problem [...] I don’t believe that it’s necessary to restrict fluid water intake.

(Dr. Chavez, nephrologist)

Fluid is such a matter of concern for this nephrologist that she overtly asserts the authority of her definition of fluid, encouraging her patients to disregard their cardiologist’s fluid restriction advice.

Some of the cardiologists and nephrologists in our study used a tug-of-war analogy to characterize the impact of fluid on clinical authority and collaboration. Patients were said to go “back and forth” in a “push and pull” as both groups mobilize fluid in their particular ways:

Diuretics are bad for your kidneys. Well yes, they’re bad for your kidneys, but you’ve heard me say this before, the heart wins the battle, the kidney wins the war. So in order to keep [Mr. Thomson] dry, we have to give him diuretics. We fully know they’re bad for his kidneys, but he won’t be able to breathe or do anything if
he’s wet [fluid overloaded] and he’ll end up back in the hospital. So that’s been one of our sort of push and pull. (Dr. Ohari, cardiologist)

This cardiologist’s war metaphor reveals the central matter of concern pertaining to fluid management in advanced HF care: patients die when their kidneys fail, not their hearts. “The heart wins the battle” by making patients feel better when it functions well—the patient will be able to “breathe [and] do [things]”. The heart also loses the battle when patients are “wet” and “end up back in hospital”. Why then does “the kidney win the war”? The cardiologist appears to indicate that fluid management is a series of “battles” and that a patient’s mortality is the “war”. For this cardiologist, authority for regular symptom management “battles” shifts away from the cardiologists and on to the nephrologists as the “war” for kidney function intensifies.

The descriptions above indicate that the collaboration between cardiologists and nephrologist around fluid management becomes increasingly complex as each patient’s heart function and kidney function deteriorate. One nephrologist describes how authority is renegotiated between her and her cardiology colleagues as standard fluid management stops being effective:

I think my cardiology colleagues see it this way, I of take over their care. They still see their cardiologists occasionally but nowhere near as often once they’re on dialysis because I manage their volume and I manage their medications and I see them on a regular basis. And they don’t get admitted, so the cardiologists don’t get to see them as much.

(Dr. Khan, nephrologist)

The cardiologists in our study expressed as a matter of fact the need to mobilize fluid with standard drug therapies. Nephrologists in our study treated as a matter of fact the need to mobilize fluid with dialysis. While both facts were self-evident in their own disciplines, this ANT analysis reveals how fluid sits at the centre of complicated negotiations around how the pathophysiology of each patient’s HF advances, how the chronic adverse effects of medications should be understood and handled, and how care responsibility and decision-making authority should be shared between specialties.
5.4 Discussion

Our analysis illustrates that fluid is an actor in networks of heart failure care. It is not a passive object. It can generate physical discomfort, pain and poor heart function for patients. It can lead to concern and effort for caregivers. It can direct complex health care work. Fluid sometimes is also, importantly, a different actor for cardiologists and nephrologists. They understand it differently. They perform its management differently. They react to it differently. They mobilize, measure and teach it in sometimes contradictory ways. Fluid is a critical, complicating factor in how they collaborate. This brings us back to the paper’s orienting question, how does our understanding of health care teamwork shift with sociomaterial inquiry?

Were we to look at fluid with the sociological understanding of IPC and its focus on humans acting together, these cardiologists and nephrologists would seem not to agree on fluid. One nephrologist’s description of telling patients to ignore the fluid management advice of their cardiologists would appear to be poor teamwork: “[I] tell them to lie to the cardiologist about how much liquid they drink”. Similarly, the cardiologist’s statement that cardiovascular care trumps renal care at a certain point in fluid management would appear to be a disciplinary culture clash: “you’ve heard me say this before, the heart wins the battle, the kidney wins the war”. In another case, interdisciplinary collaboration would appear to be complicated by different assessments of the best methods for fluid management: “it’s trying to convince the nephrologist, I think this person needs to be dialysed or ultrafiltrated solely for fluid management, not because of kidney failure symptoms”.

It may be tempting to read these situations as dysfunctional collaboration—a position that would align with the notion of interprofessional collaborative tensions. These tensions have attracted growing attention in medical sociology and medical education because they are understood to both threaten quality patient care and influence trainee socialization (Reeves, 2011; Reeves, 2012). For example, sociological analyses of interprofessional collaborative tension highlight professional hierarchies and institutional structures (Paradis and Whitehead, 2015),
both of which are at play in our description of how nephrologists and cardiologists negotiate their shared care of HF patients. Similar work looks at how team collaboration can be impacted by leadership tensions (Lingard, Vanstone, Durrant, et al., 2012) and mutual awareness of team members’ roles (Macdonald, Bally, Ferguson, et al., 2010; Suter, Arndt, Arthur, et al., 2009). And our description of how nephrologists and cardiologists understand their work could add to current considerations of how differences in professional culture influence how collaboration is understood, implemented and assessed (Hall, 2005).

Our sociomaterial analysis is distinct from these conversations because it considers interprofessional collaborative tensions as not happening just between people/groups/cultures, but rather as networks of activities among actors, or actor-networks. In foregrounding the role of fluid as an actor and looking at its network effects, we are able to offer two novel insights regarding interprofessional collaborative tensions. First, that IPC initiatives around interprofessional collaborative tensions involve material agency. And second, that the notion of collaborative entanglement is a means for grappling with overlapping networks and their effects in modern IPC.

5.4.1 Interprofessional collaborative tensions and material agency

Our results describe a number of interprofessional collaborative tensions around advanced heart failure patient care provided by cardiologists and nephrologists. The results suggest that the site of collaboration is more granular, and less stable, than the idea of ‘the patient.’ The site of collaboration in HF care is not even, interestingly, the heart. The site of collaboration is an actor itself: fluid. Fluid is what that other team members are interacting with and reacting to in their work. And while fluid influences IPC for patients with advanced heart failure, it is also prone to being understood in diverse, sometimes contrasting ways.

Our results also describe how material objects, like fluid, emerge multiply (Mol, 2002). Fluid overload as patients experience it, cardiovascular fluid management as cardiologists approach it, and renal fluid management as nephrologists conceptualize it are distinct practices, with sometimes commensurate but sometimes contrasting descriptions and definitions what fluid is.
For a nephrologist fluid may be the cause of a patient’s complaints, while for a cardiologist the same patient’s complaint may be the effect of fluid. The same fluid has different mechanisms, definitions and, subsequently, clinical advice—but mutually exclusive practices. The cardiologist and nephrologist share resources and expertise across actor-networks of cardiology care and nephrology care, but they also access and privilege distinct elements from these networks. In our results, nephrologists used the tools and training at their disposal to enact fluid overload in a way that aimed for more fluid to stay ‘onboard’ the kidneys. Cardiologists, however, enacted fluid overload another way, using specialist expertise with the heart to keep the body as ‘dry’ as possible. As Mol has noted about atherosclerosis plaque, fluid, is multiple: it varies depending on a cardiology or nephrology perspective, featuring different, sometimes overlapping networks of equipment, diagnostics, imaging techniques, schedules, spaces and organ systems (Mol, 2002b).

What does this multiple understanding of fluid imply for how patients are constructed in IPC interactions? In a sense, our results describe cardiologists and nephrologists who are, therefore, not collaborating around a/the/our patient, but are also collaborating around multiple patients with differing fluid problems. This critical insight calls into question one of the standard ‘solutions’ to collaborative tension: the ‘common purpose’ narrative, the adage that interdisciplinary professional collaboration succeeds when providers act with the patient’s best interests in mind. Research on the sociological understanding of IPC invokes the common purpose narrative for understanding interprofessional teamwork in studies of patient safety (Haynes, Berry, and Gawande, 2014), patient and family satisfaction (Kvarnstrom, 2008), and resource expenditures (Schmitt, 2001). Yet if even physiological concepts such as fluid are multiple this calls into question the expectation that improved information sharing, role clarity, and conceptual definitions are the comprehensive solutions to collaborative complexity. In fact, toward our final point, we would argue that collaboration in fluid management for HF is, at its core, a matter of collaborative entanglement.
5.4.2 Collaborative entanglement

We offer collaborative entanglement as a new term for articulating the multiple enactments of materials in IPC, especially in relation to interprofessional collaborative tensions. From our results, one striking example of collaborative entanglement is the interdisciplinary use of dialysis for the four patients from Part 2, patients with advanced HF and moderate kidney impairment. For these patients, the use of diuretics to treat persistent fluid overload has led to a scenario where they face serious kidney injury. One cardiologist described how these patients fall into a grey area where their kidney function is not “at the usual dialysis level [. . . yet] this person needs to be dialysed solely for fluid management.” (Dr. Edwards) The practice of using dialysis and ultrafiltration for HF has taken place since the 1960s (Lemmon, Hironse, O’Connor, et al., 1960). Yet the efficacy and safety of these techniques has recently been challenged as medical science has advanced and patients live longer with advanced HF. A recent trial comparing dialysis techniques with medication management for advanced HF (CARRESS-HF) concluded that medication management was more effective and safer (Bart, Goldsmith, Lee, et al., 2012b). A flurry of critical letters to the publishing journal’s editor led the trial’s authors to admit “uncertainty in clinical practice for patients with acute decompensated HF and kidney disease.” The authors acknowledged that:

Ideal rate of fluid removal, supportive medical therapy, monitoring measures, and the conditions used to determine the best time for discontinuing acute decongestive therapies [. . .] are unknown [. . .] Data are lacking to answer these and many other questions that directly affect the outcomes of patients with volume overload and renal dysfunction. (Bart, Goldsmith, Lee, et al., 2012a)

While definitive knowledge remains elusive, interprofessional care must persist. In the face of clinical uncertainty and multiple matters of fact, cardiologists and nephrologists continue to collaborate with each other and with fluid. This is collaborative entanglement, the continued tinkering and improvisation of therapies like dialysis in the face of uncertainty and multiplicity.
A cardiologist from our study provided the succinct reminder that in the face of trial-based evidence, “sometimes fluid management issues alone may dictate the need for dialysis.” (Dr. Edwards) We take this to mean that sometimes materials and their effects drive care practices in ways that can seemingly defy guidelines and disrupt disciplinary routines.

Collaboration between medical specialties is an important type of IPC that has received little attention (Heldal, 2010; Lingard, Vanstone, Durrant, et al., 2012). We advocate that this inattention may perpetuate the assumption that physicians see patients’ bodies the same way and therefore that their collaborative practices are unified and representative of medical practice trends (Clarke, 2010). Our results suggest this position is enriched by considering the complexity, artistry, and uncertainty of medical practice. Collaborative entanglement is marked by recognition by team members that other disciplines see materials differently, through multiple ontologies where actors like medical conditions, technologies and patients exist in multiple ways. Despite the ways the idea of entanglement disrupts a stabilized understanding of patients and symptoms, collaboration is still possible—in fact we have identified it happening all the time.

Following Fenwick (2014), we propose collaborative entanglement as an ANT informed construct as additive to, not dismissive of, the ongoing sociological understanding of IPC. One of the benefits of the notion of collaborative entanglement is that it begins to attune us to improvisations, of which dialysis is a good example. We know there is conflicting evidence for the efficacy of these treatments, especially when patients’ kidney function is still reasonably good (Tang, 2012; Chung and Meyer, 2014). Yet coming to a decision around dialysis requires the cardiologists to see fluid the way the nephrologists see it and nephrologists to see fluid the way the cardiologists do. In negotiating around fluid, the cardiologists and nephrologists improvise an epistemological understanding of fluid. They agree that fluid is multiple. They agree to acknowledge the other’s perspective of it. They agree on collaborative entanglement. And that allows each of them to improvise, practicing in ways outside their disciplinary conventions: cardiologists referring patients for dialysis and nephrologists treating heart failure.
5.5 Limitations

Our decision to focus on health care providers leaves room for an elaborated description of how interdisciplinary collaborative tensions impact the lived experience of patients and caregivers. Although patients and caregivers were an important part of our overarching study and the focus of a separate analysis of fluid (Lingard, McDougall et al., 2015), we encourage more research to tackle collaborative care from a sociomaterial standpoint. Similarly, though our focus on the interface between cardiology care and nephrology care illustrated a number of key tensions, it also silenced the voices of other allied health professionals. As future work emerges using this lens, it will be important to further consider the notion of ‘collaborative entanglement’ in relation to other health professionals. For example, other research could address how nurses conceptualize and enact fluid or other materialities of care for patients with advanced heart failure.

5.6 Conclusion

Fluid in advanced HF care is only one of the many clinical materials that play a significant role in interprofessional collaborative tensions. In spite of this complexity, we argue that collaborative entanglement offers an opportunity for practice and learning in health care as far-reaching as the vast, overlapping actor-networks that compose modern health systems. We hope this work inspires new ideas for investigating this complexity and stimulates new opportunities for understanding entanglement in health care.
From integration to translation: sociomaterial tensions in palliative care for heart failure

“There seems to be virtually no demand for palliative care beds for patients with cardiac failure . . . [This may be related] to a lack of appreciation of the poor prognosis of this condition . . . Research is needed[.]”

Sarah Jones, *Palliative care in terminal cardiac failure*, 1995

“Our research suggests that deficits in providers’ knowledge and comfort in discussing palliative care for a difficult-to-predict disease present major barriers to referring patients with advanced HF for palliative care.”

Kavalieratos et al., “*Not the Grim Reaper Service*”, 2014

6.1 Background

The two above epigraphs have been selected and arranged to demonstrate the ongoing, decades-long conversation on the challenges of integrating palliative care for patients with advanced heart failure (HF). Within the last decade the American Heart Association (Hunt, Abraham, Chin, et al., 2005), American College of Cardiology (Hunt, Abraham, Chin, et al., 2005), the National Heart Foundation of Australia (Krum, Jelinek, Stewart, et al., 2011), the Cardiac Society of
Australia and New Zealand (Krum, Jelinek, Stewart, et al., 2011), the European Society of Cardiology (Jaarsma, Beattie, Ryder, et al., 2009a) and the Canadian Cardiovascular Society (McKelvie, Moe, Cheung, et al., 2011) have generated official statements and guidelines for the integration of palliative care for patients with heart failure. Palliative care integration has been positively associated with family satisfaction (Gries, Curtis, Wall, et al., 2008), patient satisfaction (Gade, Venohr, Conner, et al., 2008), and decreased health care expenses (Unroe, 2011). Supported by recent research focusing on palliative care integration for patients with heart failure, the recommendations advise more multidisciplinary collaboration (Kini and Kirkpatrick, 2013), earlier communication about palliative care with patients and caregivers (Bekelman, Hooker, Nowels, et al., 2014), earlier integration of palliative care alongside active therapies (Dionne-Odom, Kono, Frost, et al., 2014; Allen, Stevenson, Grady, et al., 2012), more research into predictive models for prognosis (Gadoud, Jenkins, and Hogg, 2013), and more palliative care education for health professionals involved in caring for patients with heart failure (Green, Gardiner, Gott, et al., 2011). The practice and research domains have been increasingly active: federal palliative care funding in both the U.S. and U.K. has increased tenfold since 1997, correlating with three times as many palliative care scientific publications (NIH, 2013). Despite these efforts, there remains limited utilization of palliative care services by patients with heart failure (Greener, Quill, Amir, et al., 2014; Lemond and Allen, 2011).

A noteworthy imbalance in palliative care access for patients with heart failure exists when compared to patients with cancer (Adler, Goldfinger, Kalman, et al., 2009). The majority of patients with HF die in hospital compared with cancer patients (Kaul, McAlister, Ezekowitz, et al., 2010), who often receive in-home palliative care and are more likely to die at home consistent with their expressed wishes (Tolle, Rosenfeld, Tilden, et al., 1999). Cancer does not necessarily mean a poorer prognosis compared to heart failure (Askoxylakis, Thieke, Pleger, et al., 2010), which can be as ‘malignant’ as many common types of cancer (Heyland, Groll, Rocker, et al., 2005; Hupcey, Penrod, and Fogg, 2009; Stewart, Ekman, Ekman, et al., 2010). The percentage of patients with heart failure who enroll with palliative care has been estimated
as low as 10% (NHPCO, 2012). In the U.S., a study of hospice service usage observed an increase in heart failure patient enrollment during the last 6 months of life—increasing from 19% in 2000 to 38% in 2007. However, one third of those patients received palliative care during the final week of their lives or less, compared to 55% of patients with cancer enrolling in hospice and only 15% of those patients being admitted during the final week of their lives (Miesfeldt, Murray, Lucas, et al., 2012).

To date, many discussions around how to improve the integration of palliative care services for patients with heart failure have been sociological in their orientation, emphasizing the social characteristics of integration such as culture, stigma, and gaps in knowledge. Some argue that palliative care integration is challenged by ‘culture clashes’ between cardiologists and palliative care providers (Gott, Frey, Robinson, et al., 2013; Gott, Gardiner, Ryan, et al., 2013), where the former group are interventionists focusing on ‘rescue therapy’ (O’Leary, 2009; O’Leary, Murphy, O’Loughlin, et al., 2009) and the latter group are the “Grim Reaper service” (Kavalieratos, Mitchell, Carey, et al., 2014). Others argue that there is a stigma attached to palliative care that originates in a lack of understanding by cardiologists over what palliative care means and how patients might interpret a palliative care referral (Fitzsimons, Mullan, Wilson, et al., 2007; Fitzsimons and Strachan, 2012). There is also an overall lack of understanding of what services palliative care can offer heart failure patients, and how those services will contribute to current cardiovascular best practices (Chattoo and Atkin, 2009). Finally, research has suggested that confusion over the negotiation of roles and responsibilities between cardiologists and palliative care providers creates challenges for integrated care (Green, Gardiner, Gott, et al., 2011).

While sociological explanations are crucial to policy programming around palliative care integration, they are insufficient for fully appreciating the challenges faced by heart failure care teams who are actively integrating palliative care. Specifically, they do not explain why palliative care integration can fail even when appropriate social components are present—when roles are clear, culture is supportive, knowledge is accurate and stigma has been overcome. We posit
that one reason for integration failure is related to how material elements impact palliative care service utilization, particularly how materials can complicate palliative care integration—even when human actors have it as their main goal.

Our research explores integration from this different stance; from a perspective that seeks to understand how 'material' elements like tools, fluids, measurements, and models impact palliative care service utilization. Using actor-network theory (ANT), this paper illustrates the fundamental importance of materials by describing two narratives, each about a patient who would be clinically identified as having unremitting, treatment resistant advanced heart failure, or end-stage heart failure. Both patients struggle with fluid balance as they are formally provided palliative care. ANT research is a methodology used extensively in the fields of Education (Fenwick and Edwards, 2011), Sociology (Law and Singleton, 2013; Law, 1998), Medical Sociology (Mol, 2002a; Mol, 2002b; Timmermans and Berg, 2003c; Timmermans and Berg, 2003b), and Science, Technology & Society (Latour and Woolgar, 1979; Latour, 1987; Latour, 1993; Latour, 1996; Latour, 2005) to explore how people and materials influence one another in networks associated with some form of unified activity. We hope that ANT can offer insight into how material elements influence integration efforts. In particular ANT brings a theoretical perspective and language that revises characterizations and ways of addressing the under-utilization of palliative care services for patients with heart failure. Without such new characterizations, we risk overlooking the pervasive influence of material elements on palliative care integration.

6.2 Methods

The current analysis is part of a larger, multi-institutional qualitative study of advanced heart failure care teams (Lingard, McDougall, Schulz, et al., 2013). Advanced HF was defined according to The New York Heart Association functional Class III or Class IV criteria (Broek, Veldhuisen, Graeff, et al., 1992). Using these criteria, NYHA Class III includes patients
who experience mild to serious HF symptoms during most activities while NYHA Class IV includes patients who constantly experience mild to serious HF symptoms—both during activity and at rest. The study took place across five sites, in five Canadian cities in three provinces during 2012-2014. 62 patients with advanced HF were interviewed along with individuals they identified as important to their health care. This resulted in 50 ‘team sampling units’ (TSUs), defined as the recruitment of an index patient along with at least one health care professional and at least one lay caregiver. Researchers conducted 205 interviews with 62 patients with advanced HF\(^1\), 58 caregivers and 72 health care providers\(^2\).

The larger study used constructivist grounded theory, a qualitative methodology for understanding complex social processes (Charmaz, 2014). The study’s research coordinator was also a doctoral student (AM) who collected and analyzed data for a sub-analysis focusing on how materials played a role in palliative care integration for patients with advanced heart failure. The current analysis focuses on two TSUs for patients who were sampled from an Ontario heart function clinic in an urban setting. The heart function clinic (HF Clinic) was primarily nurse-led with a rotating group of on-call heart specialists—two cardiologists and a geriatrician. Importantly, HF Clinic team members had established a formal relationship with a local palliative care physician who acted as a liaison to facilitate palliative care integration for patients with advanced heart failure. The two TSUs were selected for a sub-analysis because they were actively receiving palliative care for end-stage heart failure. In total, the two team sampling units comprised eight interviews—two patients, a nurse practitioner, a spouse, a family caregiver, two cardiologists and a nephrologist. Actor-network theory (ANT) was used as a theoretical framework informing data analysis for these two patient cases (Latour, 2005). All data have been de-identified and pseudonyms have been used.

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\(^1\)62 patient interviews generated 50 TSUs due to 12 index patients not leading to additional team interviews and therefore being removed from the total count

\(^2\)Some health care providers were interviewed more than once leading to 15 additional interviews.
6.2.1 Actor-network theory

ANT favors rich descriptions of specific actors at work in situations, as opposed to archetypal analytic frames such as ‘thematic’ analysis. ANT is unique in that it posits three key tenets which have significant implications for research consequences. First, it dismisses any notion that objects and people are essentially different. ANT posits a symmetry of all ‘actors’, both human and nonhuman. Put another way, ANT research generates rich descriptions to illustrate how people and things act together. Second, these descriptions attend to actors entering or exiting ‘networks’; networks are metaphors for collectives such as social groups (e.g., cardiologists), physical spaces (e.g., heart function clinics), and large-scale projects (e.g., health care policy change). Third, actors in ANT are defined by their actions and nothing else, specifically how actions operate as processes of ‘translation’.

This last point on the idea of translation deserves additional attention as it is at the centre of how ANT actors interact in networks. A popular example of translation involves biomedical research taking place in an electrospectrometry laboratory (Latour and Woolgar, 1979). A network of scientists transforms hypotheses into research findings—and published manuscripts—through a series of connected activities. Experiments involving lab mice take place: lab mice are dissected for their tissue samples, the tissue samples are fed through the electrospectrometry device, and a printout of readings is generated. At each step in the process, actors change and interact to transform the hypotheses, mice, slides and printouts into the manuscripts that will be used to inform future hypotheses. In keeping with ANT, we intentionally avoid the word team because it semantically suggests a group of people. In order to foreground how people and things interconnect, we will refer to the three clinical groups involved in this analysis as networks: the Heart Failure (HF) Clinic, the Hospice, and the Home-Based Palliative Care Program.
6.3 Results

Using the ANT focus on both human and material actors, the accumulation of fluid within patients’ bodies, also known as edema, was a key activity for networks engaged in palliative care integration for patients with end-stage heart failure. Fluid was a crucial material element in palliative care integration. It played a direct role in the interactions of physicians, nurses, patients, caregivers, equipment, devices, measurements and schedules. Below we present two ANT ‘descriptions’ (Latour, 2005) that were selected because they illustrated the only two HF Clinic patients with formal palliative care integration.

Description 1 examines how fluid is translated in negotiations between the HF Clinic and the Hospice around the use of a patient’s peritoneal dialysis (PD). Description 2 examines how fluid is translated as it relates to the provision of palliative home care by the local Home-Based Palliative Care Program. Each description focuses on the network of people and materials involved in fluid management as the HF Clinic network integrates palliative care for a patient. A central material concern is at stake in both instances: the distinction of ‘fluid management as palliative care’ and ‘fluid management as life extension’.

6.3.1 Description 1: Mr. Yasuo’s hospice admission

Peritoneal dialysis (PD) for HF patients

Diuretic drugs are the most common approach to treat fluid overload in patients with heart failure. In cases where diuretic drugs are ineffective, some patients begin PD, a home-based fluid removal technology that uses an automated pumping mechanism to transfer a waste-absorbing solution into and, after several hours’ absorption, out of the abdominal cavity. PD was originally developed for patients with kidney failure but has since been adapted for patients with heart failure due to its highly effective fluid management functionality (Blagg, 2007).

PD is a sophisticated device made possible by many people and materials. The device is
6.3. RESULTS

a network of interworking material actors including a computer, a pump, tubes, gauges, bags, and three different types of fluid: interstitial, dialytic and waste. A network of human actors also support and operate the device: a nephrologist to prescribe the device’s use and fluid composition, interpret its feedback and adjust its function; an outpatient nurse to visit patients’ homes and set up each device; and patients and family caregivers to follow clinical advice while ensuring the consistent operation of devices in patients’ homes. These people and materials form networks that are formalized under names like ‘peritoneal dialysis clinic’ or ‘PD program’ to buy, store, lend, and maintain devices to support patients who need them.

PD as palliative care

PD can have a therapeutic function for patients with kidney failure, meaning it can stabilize and replace a patient’s failing kidneys. The same cannot be said for PD for patients with heart failure. PD has a ‘palliative’ function for patients with heart failure, meaning it serves to reduce symptoms by reducing fluid overload. At the onset of our study, we were told that a strong collaboration had been formed between a local PD program and the HF clinic. Numerous patients with heart failure were receiving PD to ameliorate fluid overload. Due to its primary goal of symptom relief and improvement of quality of life, PD was considered by health professionals at the HF clinic to be a form of palliative care for HF patients.

Mr. Yasuo is in his 60’s and has end-stage heart failure. He has been an inpatient followed by the HF Clinic for over a month due to a recent, rapid and difficult to manage progression of his heart failure. The HF Clinic integrated palliative care with Mr. Yasuo after they determined he was not a heart transplant candidate. Palliative care integration involved two steps: first focusing Mr. Yasuo’s care on fluid management; second supporting his choice on a location to come to the end of his life. Each step though would reveal how fluid translates differently in the HF Clinic than the Hospice.

The first step of Mr. Yasuo’s palliative care integration is symptom management. Fluid has become a central actor that is translated throughout a broader clinical network for him.
Fluid overload impacts almost every aspect of his life, including his breathing and energy levels. Dr. Garen, the lead physician of Mr. Yasuo’s local PD program, describes how the HF Clinic brought in PD as ‘palliative care’ because its focus is not on ‘curing’ but rather on ‘quality of life’:

For patients like Mr. Yasuo, peritoneal dialysis is palliative care. They’re having trouble breathing. They’ve got no energy. The dialysis helps them feel better. The patients know we’re not going to cure them. We’re trying to provide the best quality of life for them for the duration of their life, which may be months, as it was for Mr. Yasuo, or may be years, for other patients. (Dr. Garen)

The HF Clinic translates fluid overload through PD. The PD translates fluid overload into ‘palliative care’. One way this latter translation can be illustrated is by focusing on how fluid overload impacts breathing for Mr. Yasuo. Fluid overload makes breathing painful. Yet fluid’s physical impact on his body is only translated as symptoms after 1) he complains about his breathing or 2) a health care provider hears ‘crackly’ breathing through a stethoscope. These symptoms translate into metrics of evaluating fluid overload—more or less ‘crackly’ breathing is a measure of how successful PD has been. Fluid is a crucial actor in Mr. Yasuo’s care, and the HF Clinic interacts with it by way of a series of translations that lead to symptom reduction, not the improvement of heart function. In this sense fluid is translated as palliative care.

**PD as aggressive measure**

Mr. Yasuo’s prognosis is poor and he expresses that the end of his life is coming. He also states he is worried he cannot cope at home while dying. The second step of his palliative care integration is working with his health care team to establish where he will come to the end of his life in a way that supports his goals of care. Mr. Yasuo, after consulting with his health care providers and family members, explains the deeply personal decision he made to enter the Hospice rather than choosing to die at home:
I got thinking, if I die at home, what’s that going to do to my wife? I know it tore her up when her father died at home, so we talked about that one night and I said, ‘Would it bother you if you woke up in the morning and I [died at home]?’ She said, ‘Yeah it would. I still see my father.’ I said, ‘Well, then that’s the end of that. I’ll go to the Hospice. I won’t put you through that.’ (Mr. Yasuo)

Going to the Hospice, however, requires Mr. Yasuo to abide by their admission criteria. As Ms. Janna (HF Clinic nurse practitioner) reflected, although the HF Clinic considered PD ‘palliative care’, the Hospice admission criteria did not:

Hospice felt that peritoneal dialysis was an ‘aggressive measure’, and that he would have to stop peritoneal dialysis in order to get to the inpatient palliative care program. We felt that was a little bit more difficult to handle because we said, ‘Peritoneal is not saving his life, it’s just for symptoms.’ We said, ‘This is a palliative measure.’ So he had to stop peritoneal in order to get to the inpatient palliative care program.

(Ms. Janna)

Dr. Garen provides some detail on the central tension between how PD is framed in each clinical network:

The Hospice is pretty adamant that they will not accept patients onto the palliative care ward who are on dialysis. But, see, the problem is these patients on PD, it is palliative but it does extend their lives and their problem is that they have a bed management issue like the rest of us. And if they’re still on dialysis, then their prognosis for survival is often more than three months and then they’re not eligible. So that’s where we run into problems. (Dr. Garen; emphasis added)

Like the HF Clinic, the Hospice translates fluid through PD, but unlike the HF Clinic the hospice extends this translation from PD into ‘life extension’. For example, an admission criterion for patients at the Hospice is a prognosis of less than three months. In its capacity to effectively reduce fluid overload, PD can also extend patients’ lives. For the Hospice, an
extended lifespan translates into material arrangements such as beds, meals, pain medications and the hospice waiting list. In this way, the same fluid and the same fluid management technique are translated differently across two networks. And this translation is crucial in that it creates tensions impacting a core palliative care element: supporting Mr. Yasuo’s choice of where to reach the end of his life. If his health care providers truly wish to make space for his choice to die in the Hospice it will require him and HF Clinic to relinquish receiving PD for managing his fluid overload. The two translations of fluid put Mr. Yasuo into a dilemma: he can die in the Hospice with potentially more acute fluid overload symptoms, or he can die at home with his fluid overload managed well by PD. He cannot do both. At the end, he elected to relinquish his PD and enter the Hospice.

6.3.2 Description 2: Mr. Vincent’s home care

Integrating home-based palliative care for a patient with end-stage HF

As mentioned, a core component of palliative care is attempting to support patients to reach the end of their lives in a location they choose. (McKelvie, Moe, Cheung, et al., 2011). While some patients with end-stage heart failure, like Mr. Yasuo, elect to come to the end their lives in an inpatient hospice setting, other patients prefer to die in their own homes. In order to provide outpatient palliative care for patients with end-stage heart failure, palliative care programs require a distributed network of people and materials capable of attending to fluid overload. Home-based palliative care requires physicians who can make house calls and, often, nursing care two or more times per day. These health care provider visits are required to manage the material elements of home-based palliative care like the hospital beds, health care devices, prescription medications, wound dressings and, for patients with end-stage heart failure, fluid management materials like catheters, IVs and dialysis equipment. Clinical documentation and record-keeping practices are also an important component of home-based palliative care. In cases of end-stage heart failure patients with fluid overload, these practices generate metrics
such as fluid records, daily weights, respiratory assessments, and records of any patient and family symptom complaints. These people and materials often amalgamate into networks that are formally or informally called ‘palliative care programs’ or ‘home-based palliative care teams’.

Like hospice care, this complex form of patient care is expensive for health care systems to support (Unroe, 2011). As a result, palliative care programs traditionally require a formal assessment of patient prognosis in order to offer these home-based benefits. Palliative care programs will not offer palliative care benefits to a patient who has more than a 3 or 6 month prognosis. This can be tricky for patients with heart failure, because their prognosis is both difficult to predict and liable to change. In this sense, prognosis is a powerful actor for palliative care integration.

**Integrating home-based palliative care for a patient with end-stage HF**

Mr. Vincent’s description reveals how prognosis acts as an influential element of home-base palliative care services. Mr. Vincent is a member of a subgroup of HF clinic patients whose heart failure originates with a condition called amyloidosis, an abnormal multiplication of cells in the heart. He receives home-based palliative care that is managed through a regional palliative care program. After months of struggling with fluid overload from his heart failure, the HF Clinic network introduced Mr. Vincent to the local palliative care physician, Dr. Vo, who explains that while in hospital for his most recent heart issues, “[Mr. Vincent] really wanted to go home . . . [and] we tried to make his choice real because it was very important for him [to] get home.” (Dr. Vo) Along with having a number of adult children living nearby to help with his care, Mr. Vincent receives daily home nursing support from the regional palliative care program.

The Home-Based Palliative Care Program is composed of activities for both health care providers and family caregivers, as described by Mr. Vincent’s son, Van:

> You have to make sure you use the wipes to clean the IV line, and you’ve got to make sure you flush it and don’t get the air in the line . . . the nurse trained me and
one of my sisters, and then I trained, showed my brother and my other sister how to
do it . . . I think what it boils down to is you have to make sure there’s somebody
available to do it, so there’s a whole scheduling and time management thing that
you have to take into consideration. (Van)

Van’s description outlines activities and materials associated with home-based palliative
care for his father’s end-stage heart failure. In addition to Mr. Vincent having a very supportive
family, he relies on twice-daily nursing visits to support his care. When he was initially assessed
for palliative care by the Home Based Palliative Care Program this schedule of nursing was
recommended; however, recently a palliative care program case manager asked Dr. Vo to
re-assess Mr. Vincent because he has outlived his initial prognosis of 3 months. When his time
comes, Mr. Vincent wants to be at home and not in a hospital, but until then his daily nursing
has been reduced to one visit per day even though his care needs have not changed.

Outliving palliative care

Given the network of support that has been established for Mr. Vincent, how is it that his daily
nursing care has been reduced? Dr. Vo, explains that Mr. Vincent has “behaved in an unusual
way”:

Like when he went home, he was very, very sick at [local cardiac care hospital], we
did not expect him to do well . . . And so I was able to say, ‘Okay, yes, you can go
home because we’ll continue to provide service for you in the community.’ Then
he’s actually been remarkably stable. (Dr. Vo)

Dr. Vo also explains the position of the Home-Based Palliative Care Program who decreased his
care:

What happens is the patients, like Mr. Vincent, they come out of the hospital,
they’re looking like they’re going to die, they go home and if they stabilize I get
a lot of pressure from the case managers at ‘Home Care’. They say, ‘Okay, we
should discharge this patient, he’s not appropriate because he’s not behaving in the expected way.’ (Dr. Vo)

Between his nursing staff and his family, Mr. Vincent’s fluid overload has been so effectively managed that he has outlived his 3-month prognosis. Across the network of people and materials providing care for Mr. Vincent in his home, fluid management has translated into life extension. Paradoxically, this is problematic because it has resulted in decreased daily nursing care for Mr. Vincent and added caregiving responsibilities for his children.

6.4 Discussion

To date, studies focusing on the challenges to palliative care integration have emphasized sociological dimensions such as conflicting goals and role confusion. However, as our results suggest, even when the heart failure care network and the palliative care networks share the goal of palliative care integration and roles are relatively clear, they may nevertheless struggle with a basic sociomaterial issue: the tension between ‘fluid management as palliative care’ and ‘fluid management as life extension’. This tension has real impacts: it shapes where patients die and what treatments they have access to in those places. In this section, we argue that the integration of palliative care for patients with heart failure is not just a sociological issue but also a sociomaterial one: it depends on specific translations of fluid management between different networks of human and nonhuman actors. Further, we contend that the integration of palliative care for patients with heart failure is multiple: more than one ‘integration’ exists. Based on these two claims, we conclude that clinicians and policymakers should think of integration not only as bringing networks together but also as translating actors between networks.

The descriptions of Mr. Yasuo’s and Mr. Vincent’s palliative care integration networks reveal the centrality of material actors—like fluid—as they become involved in networks of fluid management. Despite the patient, team members, and family all agreeing in these cases that palliative care integration is appropriate and necessary, materials like PD and prognostic
algorithms interfere with human intentions and complicate integration efforts. This resonates with other sociomaterial analyses in health care settings. For instance, Ackerman and colleagues used ANT as a lens to study challenges integrating electronic patient ‘check in’ kiosks in a local emergency department (ED) waiting room (Ackerman, Tebb, Stein, et al., 2012). Despite overall agreement between hospital staff that kiosks had improved wait times in local urgent care clinics, the software programming was unable to account for the diversity and complexity of patient populations in an ED. Ackerman and colleagues use this tension between human goals and material realities to challenge what they call the “myth that a priori qualities and meanings” exist in health care technologies regardless of context (Ackerman, 2012, p. 2378). This notion resonates with the tension around Mr. Yasuo’s PD, which does not have an a priori meaning but exists as ‘palliative care’ in the heart function clinic network and ‘life-extension’ in the hospice network.

This shift in meaning is what ANT understands as ‘translation’. Used by ANT, translation means more than transmitting a message from one language to another. The Latin root of translation literally means ‘move across’ or ‘move to the other side’ of something. ANT scholars describe translation as implying the collected activities that make up a network (Blok and Jensen, 2011). Our analysis demonstrates how things, not just people, translate as well. Mr. Vincent’s prognostic algorithm translates lifespan in a way that leads the Home-Based Palliative Care Program to reduce home nursing care. Broer and colleagues have also explored how measurements and algorithms translate actors in networks (Broer, Nieboer, and Bal, 2010). Their ANT analysis of two mental health quality improvement projects found that measurements, such as ‘network circle’ assessments, not only generated data but reconfigured how patients and care providers conceptualized each other’s roles. Similarly, McCarthy and colleagues used ANT to explore how the Comprehensive Geriatric Assessment (CGA) algorithm had both intended and unintended consequences (McCarthy, Cook, and Yates, 2013). While the CGA did translate into care that was in line with patients’ and family members’ goals, the algorithm also created false expectations when those interests were in tension with the local
6.4. DISCUSSION

health care network’s broader interests and constraints for providing therapies to aging adults with cancer. Similarly, our finding that prognostic algorithms translate lifespan in ways that alter care practices illustrates first that even lifespan has no a priori meaning; it is translated differently in different networks and second that these translations have both intended (conserve resources) and unintended (undermine patient’s ability to choose their place of death) consequences.

The implication of our finding that material actors such as PD and prognostic algorithms are translated differently in different networks is that such materials are not single and unified: they are multiple. And therefore integration, too, is multiple: it has neither a priori meaning nor stable enactment. This notion of multiple ontologies comes from the medical sociologist Anne-Marie Mol, who developed the idea in her ethnography of atherosclerosis care in a Dutch hospital (Mol, 2002a). Her work shows how physiological objects such as blood vessels and atheromatous plaque are multiple, because health care providers from different specialties see, understand and use the same objects differently. This notion helps to explain our finding that the heart function clinic network and the palliative care networks each translate material objects such as fluid, fluid management technologies, and lifespan differently, and this impacts the activities those objects can perform in each network. What results from these translations is multiple, competing versions of integration. These competing versions of integration appear to have the same aim—palliative care integration—yet they are conceptually multiple—existing as both ‘palliative care’ and ‘life extension’ across different networks.

Importantly, these multiple versions of integration do not ‘integrate’. They disrupt and disturb the possibility of integration. When materials exist as both ‘palliative care’ and ‘life extension’ our analysis shows the necessity of negotiation and selection that fits the Hospice and home-based palliative care networks. This forced decision-making around palliative care preferences runs counter to one of the main premises of palliative care: that all reasonable attempts should be made to support a patient’s desire for how to end his or her life. In both descriptions the palliative care networks permit certain models of integration but not others. Mr. Yasuo can enter a hospice according to his wishes but his peritoneal dialysis cannot; Mr.
Vincent can receive home-based palliative care, but his prognostic algorithm limits how much.

Competing versions of each patient’s palliative care integration are in tension and materials are at the core. In both cases, the resolution to integrate palliative care involves selecting and negotiating for material resources in the form of PD and home-based nursing services. Mr. Yasuo’s PD will be left behind for the new network with the new actors: hospice staff, a hospice bed, pain management drugs, etc. Mr Vincent’s prognostic algorithm will limit nursing services but the home-based palliative care network will permit palliative care actors in his home: fluid management drugs, IV poles, physician home visits, etc. This process of tension, selection, and negotiation is the material reality of palliative care ‘integration’. Far from true integration, this process actually demonstrates translation. More than ‘bringing things together’, integration as Mr. Yasuo and Mr. Vincent experienced it is a disturbance of existing arrangements, a disconnection of actors that gives us pause when considering the calls for improved palliative care service use for patients with end-stage heart failure. Such disturbances, disconnections and reconnections challenge the conventional notion of “integration” of palliative care, as represented by the Canadian Cardiovascular Society’s recommendation that palliative care be provided “in conjunction with other therapies that are intended to prolong life” (McKelvie, Moe, Cheung, et al., 2011). The ideal of ‘in conjunction with’ is not realized when the Hospice will not allow Mr. Yasuo to be admitted with PD, or the Home-Based Palliative Care Program reduces funding for Mr. Vincent’s home-based nursing hours. Health care providers from the HF Clinic could have decided to delay palliative care service use given that important actors from their network require disruption and cancellation in order for patients to transition to a palliative care network.

Both materials and people influence palliative care integration efforts in end-stage heart failure care, suggesting the relevance of further research into the tools, technologies, algorithms, measurements and admission criteria composing heart function clinics and palliative care teams. Mr. Yasuo’s and Mr. Vincent’s descriptions offer a window into how material translations can disrupt palliative care integration even when the people on the team agree to integrate palliative
care. The current integration rhetoric of best practice guidelines is unaware, or pretends, these tensions are not there. Current literature and current guidelines position sociological elements such as ‘role clarification’ at the heart of integration efforts when attention should be paid to sociomaterial elements like networks and their various translations. By focusing on areas where palliative care integration leads to disruption, research with a sociomaterial focus can inform future guidelines, policies, and practices at the intersection of HF and palliative care.

6.5 Limitations

Our decision to focus on only two patient descriptions is a contrast from more inclusive qualitative analytic techniques, such as ‘coding for saturation’. While we were limited in our dataset to only these two patients who were receiving integration palliative care, a broader ANT-framed study with a larger patient group would contribute more voices to the developing dialogue around sociomateriality in palliative care research. The ANT component of this study was a secondary analysis to an overall methodological framework of CGS. While this was an iteration of the research team’s interest, it is also a limitation insofar as some ANT ethnomethodological techniques like participant observation and photographic data collection were not used. This is a productive gap that would be well served by future research tackling palliative care from a sociomaterial standpoint. As future work emerges from this study and other similar ones, it will be important to further consider the notion of ‘translation’ in relation to palliative care integration.

6.6 Conclusion

Both Mr. Yasuo and Mr. Vincent desire to have their lives come to an end in a place of their choosing, which necessarily involves moving equipment, travelling health care providers, abiding by new eligibility criteria and applying new algorithms. Despite the best efforts of the health care providers, patients and caregiver involved integration is still problematic partially
because of sociomaterial elements. Instead of an ending, we hope this work offers a jumping off point for future sociomaterial inquiry into the disruptive translation of material elements in palliative care integration and other complex health care systems.
We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time.”

T.S. Eliot, *Four Quartets*, 1943

“**It is not the slumber of reason that engenders monsters, but vigilant and insomniac rationality.**”

Deleuze & Guattari, *Anti-Oedipus: Capitalism and Schizophrenia*, 1899

In this concluding chapter, I begin with my methodological reflections on the research, including the process of negotiating how to follow the actor, the tensions of adopting a postmodern stance, and the significance of rich descriptions. I discuss the dissertation’s three major contributions to health care and the field of HPE. These are *entangled collaboration*, a theoretical construct for describing team-based health care; *networked competency*, a sociomaterial approach to HPE assessment; and *sociomaterial pedagogy*, an educational philosophy for preparing trainees for disturbance and disruption. Finally, I highlight the limitations of the study and present my summary conclusions.

The primary research question for my work has evolved throughout this study. In the first four chapters of this dissertation, I state that my primary research question asks: how do
materials mediate and influence the integration of palliative and cardiac care for patients with HF? In my dissertation’s three articles, the question takes on some added specificity, asking how our understandings of patient self-care (Chapter 4), health care teamwork (Chapter 5), and palliative care integration for patients with advanced heart failure (Chapter 6) shift when we use sociomaterial inquiry to prioritize not just the people but also the materials engaged in teamwork—in my case interstitial fluid—as actors on the team? In order to explore this, I explore the integration of palliative and cardiac care for patients with advanced HF. The articles each contribute novel insights into some of the challenges facing team-based care for patients with heart failure. In the first article, fluid emerges as a matter of concern enabling and constraining how patients and caregivers follow medical advice. When fluid acts, health care providers may frame it as ‘ineffective self-care’, despite the lived reality that the material effects and network effects of an unpredictable, physiological material complicate patients’, caregivers’ and health care providers’ best intentions. In the second article, actor-networks of people and things lead to interprofessional collaborative tensions around fluid management. The manuscript theorizes how collaborative entanglement offers a means for understanding the role fluid plays in complex, overlapping networks of interprofessional collaboration between cardiologists and nephrologists. In the third article, translations of fluid are at the core of difficulties integrating palliative care for patients with heart failure in different care networks. Because three programs—the heart function clinic, the hospice and the community palliative care program—translate fluid in multiple ways, I theorize that clinicians and policymakers should think of palliative care integration not only as ‘bringing networks together’ but also as ‘translating actors between networks’. With these findings from each of my dissertation’s three empirical manuscripts in mind, this Discussion chapter creates a space for additional reflection on, and theorisation of, my work.
7.1 Methodological reflections

Methodologically, I faced several challenges during the progress of this dissertation. The first challenge was procedural. While Latour’s early ANT projects were methodologically prescriptive (Latour, 1988; Latour, 1987), offering researchers a toolkit for building ANT projects of their own, contemporary ANT research offers little in the way of procedural guidelines. ANT invites researchers to ‘follow the actor’, but guides on what to do next can be cryptic and dense. The second challenge was theoretical. ANT in many ways is a deeply critical methodology. It asks researchers to become suspicious of sociological explanations and interpret meaning from nonhuman sources. Such an intense attention to non-speaking, nonhuman elements can at times be disorienting and leave one feeling quite alone. ANT is distinct from other critical perspectives in that it considers itself in opposition to the ontology of postmodernism and critical theory, and yet it takes on a critical position of its own. The third challenge was methodological. ANT was developed by an anthropologist. It builds on the tradition of ethnomethodology. Yet my research took place in the context of a constructivist grounded theory study. Bridging these two approaches was challenging and remains a productive tension in my work. Below, I expand on how I took this position into consideration as I designed my study. I provide three methodological reflections and insights regarding the use of ANT in HPE research: following the actor, taking a postmodern stance, avoiding social explanations, using rich description, and describing instead of explaining.

7.1.1 Negotiating how to follow the actor

Negotiating which actors to follow was a central tension I faced early on in my study. I knew that early choices when designing a study have important implications. Some influential early readings on studying health technology showed me that social research focusing on material elements in health care often falls into one of three approaches: technological determinism, social essentialism, and ANT (Timmermans and Berg, 2003a). Technological determinism often
focuses on groundbreaking new technologies that offer implications for health that are morally or ethically charged. Implantable cardiovascular medical devices (ICMDs) are a good example. Kaufman (2010b) argues that evidence-based medicine contributes to standards of care that shape the ethical necessity for physicians offering and patients accepting device therapies late in life. From this standpoint, while extending patients’ lives ICMDs also prolong the process of dying from heart failure and increase the span of a decreased quality of life. ICMDs had fascinating implications for my work, yet despite my early enthusiasm to study them, the data I was gathering pointed elsewhere.

ANT doctoral study required me to ‘follow the actor,’ and like any good chase, this dissertation had detours. While I started with an interest in ICMDs, the further I went in my ANT analysis the more I realized that the presence of ICMDs did not emerge in the daily networks of care delivery for patients with advanced heart failure. Following the actors did not lead to ICMDs. To force the issue of ICMDs into the analysis would be technological determinism: putting my own interest in the moral or economic implications of a given material over and above the actual activities and materials identified through study. Once I became attuned to the presence of fluid, it seemed to be everywhere. It was a central actor for team-based HF care impacting most of the patients, caregivers and health professionals with whom I spoke.

This is not to say that fluid is the single most important material element impacting these networks. Fluid is one of many actors that play a role in the care experiences of patients with advanced HF. Other researchers doing ANT health research highlight other actors. McCarthy and Martin-McDonald (2007) used ANT to explore the implementation of peritoneal dialysis care in rural Australia focusing on how contrasting networks create sociomaterial tensions. Moreira (2004) conducted an ethnography of surgical fluid management techniques in neurosurgery to describe how sociomaterial components impact the negotiation of patient agency. What remains more important than the actors being studied is that researchers do not presume to know which materials powerfully influence social values, nor do they presume that only the most sexy or novel materials are the ones worthy of study. ANT tells researchers to ‘follow the actor’, which
requires leaving behind a technology or object that they personally find compelling if it does not strongly feature in the data.

7.1.2 Taking a postmodern stance

One of the elements of an ANT approach is its postmodern stance which requires that the researcher deliberately critique modernity. With ANT, I was invited to work from a position that attempts to break down the dichotomies of individual/society, nature/culture, and humans/objects. In my study, a central finding is that a physiological object, fluid, plays an overlooked role in team-based care. My research puts a nonhuman actor at the centre of patient self-care (Chapter 4), interprofessional collaboration (Chapter 4), and palliative care integration (Chapter 5). I ask health professional educators and HPE researchers not just to consider but to actively engage with the idea that physiological components, considered by some as the object of medicine, may in fact be just as important, influential and communicative as the patients and health care professionals who are involved in team-based care.

Surely this is ludicrous, a skeptic might claim. Yet, why is it ridiculous to say that fluid is just as important as people when we study team-based care? Because, might come the rejoinder, fluid cannot speak, it cannot make decisions, and it certainly cannot impact patient outcomes. It is just stuff.

In the event that such debate occurs—and I hope it does!—I have succeeded in making my work impactful in HPE. The postmodern stance succeeds when a work is so unsettling it leads those entrenched in fixed ways of seeing to question their taken for granted assumptions. As I worked through the shift in thinking the postmodern stance requires, I debated whether or not my work was actually postmodern. Will it succeed in forcing readers to reconsider the ontological dichotomy between people and things? Will it disrupt the epistemological divide between nature and society? The answer remains to be seen. What I can claim for certain is that I have scrutinized any phenomena and practices that were described as ‘standard’ or ‘matters of fact’ throughout my analysis—from the accepted truism that patient self-care research requires a
better understanding of context (Chapter 4), to the challenging premise that team communication improves when care providers have a shared understanding of patients (Chapter 5), to the claim that unsuccessful palliative care integration is based in clashes in clinical culture (Chapter 6). Patients, caregivers, nurses, specialists, wounds, dialysis devices, hospices—these were all considered not as standalone facts in my research, but as networked relations. The postmodern stance made space for me to leverage the artful and somewhat liberating acceptance of ambiguity in my work.

### 7.1.3 Using rich descriptions

Instead of explanations that rely on ‘social ideas’, the third analytic consideration for ANT is its use of rich descriptions. While I knew the term rich description to originate in ethnography, it has a privileged place in ANT as a method reflective of modesty and openness. During my project, I challenged myself to write reflective memos that paid close attention to how labels, signs, notes, slides, posters, blueprints, charts, articles, white papers, policy briefs, and physiological objects—like fluid—provided descriptions of actor-networks. Following Latour (1996) and Mol (2002a), I looked at the ways these objects transferred knowledge and disseminated networks by way of interviews with patients, caregivers and health care providers.

I’m an HPE researcher, but Latour and Mol are anthropologists. ANT’s roots are in the ethnographic tradition characteristic of anthropology and the later ethnomethodological tradition of sociology. Ethnography was the approach used by the classic anthropologists who traveled to remote cultural communities in order understand other cultures and our own, for example, Margaret Mead’s canonical Coming of Age in Samoa (Mead, 1928). Ethnomethodology uses ethnographic methods, but instead of applying these methods in remote locations it applies them to ‘everyday’ settings. It describes the local practices of groups and organizations using a combination of interview methods and informal, incidental observations.

Ethnographic methods were not feasible for my study, despite the fact that in a perfect world I would have preferred to use them. My work took place within the context of a broader study
using constructivist grounded theory. At the time of this research my position as a researcher was much different than an ethnographer. My research collaborators were well aware that ethnographic methods would not be appropriate in the spaces in which we conducted our work—primarily outpatient clinics and primary care clinics. My data, therefore, were primarily composed of interview transcripts as well as incidental observations that were written after each interview in the form of reflective memo.

This raises the question of whether interview transcripts can effectively document the actor-networks in which I was interested. I would argue that they can, because they were not simply text documents analyzed out of context. As I have described in Chapter 3, I was tasked with coordinating the larger study within which my work takes place. I was involved in planning the study, acquiring ethical approval from five research ethics boards across Canada, collaborating with our clinical stakeholders, presenting our study to the clinics where we were recruiting, and participating in grand rounds presentations. Most importantly, I went to heart function clinics, I met patients there, I met their companion caregivers, I interviewed patients in their homes, I observed the way they lived, I observed the structure of the clinics, I observed the material arrangements in patients’ homes. I debriefed with mentors and collaborators throughout the process, discussing the role and agency of fluid with various physicians before deciding it would be my focus. Therefore, I would argue that, like the other materials in my study, interviews are networks. They can be seen as translations in a chain of activities that compose the research process. They did not begin as text documents and they did not end there. Instead they represent artifacts of numerous activities in which I was directly engaged and where various materials influenced my study.

Notwithstanding this defense of interviews as a primary data source for my inquiry, I would endeavor to design this study to allow for ethnographic methods were I to do it again. My data collection took place in fascinating environments filled with human and nonhuman actor-networks. I would have liked to have the ability to not only observe health care providers at work but also patients as they engaged in fluid management techniques at home or at the
Ethnographic research also affords the opportunity for researchers to conduct short, ad hoc interviews in real time. I would have used these to enquire about the agency of nonhumans and the network and material effects relating to the people I was observing. The collection and analysis of artifacts is another important factor that often plays a role in ethnography. I would have liked to use photography and document analysis to bring to light otherwise invisible aspects of the networks I was observing.

The primary methodology informing my work required recruiting patients and asking them to identify who they considered to be on their care teams (Lingard, McDougall, Schulz, et al., 2013). During interview analysis I endeavored to compose rich descriptions that depicted the ways my participants traced their care networks. And while ethnographic methods could have added important dimensions to the study, I believe that my interviews allowed me to explore in useful ways how these actors define the actors within a given network and their relationship to one another.

### 7.2 Contributions to health care and the field of HPE

Within the clinical domain of heart failure where my study took place, my dissertation’s three articles shed light on the powerful role fluid plays in care for patients with heart failure. My results offer several key implications more broadly, for health care and the HPE field. Recognizing ‘broad implications’ appears antithetic to ANT’s aim for local insights grounded in research participants’ networks, I nevertheless will attend in this section to what my work mean more broadly for my field. First, I describe how team collaboration scholarship and teaching can benefit by integrating entangled collaboration as a theoretical frame; second, I advocate for the inclusion of a networked competency in HPE practice guidelines; third, I provide a rationale and early description of a sociomaterial pedagogy for future development in HPE curricula.
7.2.1 Entangled collaboration

Overall, this dissertation became a study of a physiological object, fluid. I have analyzed fluid’s complexity to understand how it plays a role in team-based HF care. This study led me to more deeply consider what Mol calls multiple ontologies of the body (Mol, 2002b; Mol, 2008). Specifically, like Mol, my work is underpinned by the argument that diseases are enacted and re-enacted with each clinical encounter between patients and care providers. One of Mol’s more prominent studies focuses on atherosclerosis (Mol, 2002b), a buildup of plaque in the body’s arteries often manifesting in the legs. She points out that a person with leg pain does not become a ‘patient with atherosclerosis’ until their physician enacts their complaint as a diagnosis by way of practices like physical examinations and cardiac stress tests (Mol 2002b, p. 23).

Mol traces the different ways atherosclerosis is enacted: it starts nameless as leg pain, and then family physicians and specialists enact it as a disease before it is acknowledged to be atherosclerosis. Enactment happens in stages, but Mol pushes us to imagine pathological epistemology as imbricated alongside complementary yet alternative clinical interpretations. Mol studies how physicians enact atherosclerosis in clinical and surgical environments, and a particularly salient example of disease enactment is one of Mol’s conversations with a pathologist. While sitting at the microscope with Mol, the pathologist says, “Look. Now there’s your atherosclerosis. That’s it. A thickening of the intima. That’s really what it is. . . Under a microscope” (Mol 2002b, p. 30). Mol’s point is that pathologists are often the only physicians who identify atherosclerosis by seeing it. Pathologists enact a ‘pathological’ atherosclerosis, an interpretation of the disease that both complements and diverges from the ‘clinical atherosclerosis’ enacted by family physicians and, later, the ‘surgical atherosclerosis’ enacted by vascular surgeon. Clinical atherosclerosis requires a patient to come to their physician and complain about leg pain. Surgical atherosclerosis requires a patient who meets the criteria for surgery. But pathological atherosclerosis requires postmortem analysis either from a deceased patient or an amputated appendage. The only way to actually see atherosclerosis is when health
care is no longer necessary. From this standpoint many medical objects like atherosclerosis are often composites of images, symptoms, and exams.

Taken cumulatively, the three articles of my study argue that not only do teams understand fluid in multiple ontologies, but so too do they encounter fluid as entangled in networks of human and nonhuman activity. I borrow the term entangled from the medical sociologist Margaret Lock (2013), whose study of Alzheimer’s disease contrasts a localized theory of disease with an entangled theory of disease. Lock argues that in the neurological sciences, a localized theory of disease understands diseases as empirical entities waiting to simply be discovered, controlled, and, hopefully, treated. An entangled understanding of disease includes both predictable and unpredictable interactions between persons, life events, aging and environmental factors to precipitate pathological conditions. In Chapter 4, patients and caregivers navigate the material and network effects of fluid overload; in Chapter 5, nephrologists and cardiologists debate the quantity and agency of fluid for patients seen as possessing too much or too little fluid; and in Chapter 6, network effects of fluid management complicate the integration of palliative care for patients. Throughout these articles, fluid is shown to be entangled in practices of team collaboration.

Like ANT’s argument that knowledge and information (matters of fact) are the product of layered networks of humans and nonhumans (matters of concern), an entangled theory of disease considers disease in light of chains of multiple, overlapping enactments. From this standpoint, diseases are not always physiological entities awaiting interpretation and evaluation. They are multivalent conditions; they are dynamic, complex and variously interpreted. They are networks.

Here I wish to return to the concept of entangled collaboration introduced in Chapter 5, a concept for health care team researchers and educators to describe how seemingly stable concepts such as professional roles and clinical objectives often exist in tension. My articles have described how the HPE literature to date remains ‘human-centred’, focusing on cognitive processes like behavior and understanding (Lingard, Mcdougall, Levstik, et al., 2014; Hodges
and Lingard, 2012). For example, collective competence is a concept that is growing in popularity in medical education (Kitto, Marshall, McMillan, et al., 2014; Hodges and Lingard, 2012). The term builds on the idea that physicians must demonstrate competence, not only in order to be certified as professionals but also throughout their careers. Collective competence draws on social learning theories of the professions that counteract individualist, ‘acquisitional’ education models (Lingard, 2009). Instead of defining learning as ‘sending’ information from expert to student, contemporary social learning theories of the professions shift focus to the role of environments, communities, activity, self-realization and work in learning processes. Collective competence fits within a theoretical milieu that includes situated learning theory, which generated foundational insights on apprenticeship-based education (Lave and Wenger, 1991) and the concept of communities of practice (Wenger, 1999; Wenger, McDermott, and Snyder, 2002); practice-based professional education theories (Brown and Duguid, 2001; Orlikowski, 2002; Gherardi, Meriläinen, Strati, et al., 2013), which influenced approaches such as reflective practice (Kinsella, 2010; Kinsella, 2007; Kinsella, 2007) and situated/distributed cognition (Brown, Collins, and Duguid, 1989; Eraut, 2000; Nardi, 1996).

Collective competence responds to the rhetoric of competency pervading contemporary medical education. Lingard (2009) illustrates how clinical errors or gaps in care are frequently not individual decisions or mistakes but lapses in collective competence. Thus, collective competence attempts to characterize competence not only as an individual state but also as a distributed capacity of a social system (Goldszmidt, Dornan, and Lingard, 2014; Lingard, 2011). As an educational theory, collective competence is claimed by Kitto and Grant (2014) to have three aims: building collective understanding in the workplace; building and using collective knowledge resources; and developing interdependency amongst team-members. While collective competence represents an important shift in HPE discourse from the individual to the group dimensions of competence, it is limited by its focus on humans and its inattention to materials.

Research on collective competence remains primarily sociocognitive in its orientation.
Should it continue to treat competence as something exclusively human, the collective competence movement runs the risk of drifting too far away from the local environments and practice-based theories in which it originates. These environments and practice-based theories have materials as core components. I contribute collaborative entanglement as a theoretical construct that is consonant with collective competence’s focus on interactions among actors, but adds materials explicitly and discourages sociocognitive primacy. Collaborative entanglement adds an additional dimension for teamwork researchers, health professional educators and education researchers to consider. It invites teams to highlight not only how they invoke and use competence, but how networks of humans and nonhumans build toward competence. Building on ANT, collaborative entanglement focuses on local collaborative scenarios, on the networks of actors that make up team-based care. Rather than extrapolating collective competence to the level of health systems, institutional cultures, or government policy, collaborative entanglement brings nonhuman actors to the fore in local contexts.

My work is highly relevant to discussions about collective competence, and illustrates the benefits of foregrounding nonhuman elements of the ‘collective’. In Chapter 4, my analysis has described how, despite shared goals amongst team members, material and network effects negatively impact patient self-care. In Chapter 5, interdisciplinary debates between cardiologists and nephrologists situate fluid and its management in contrasting ways, sometimes leading to patients receiving opposing pieces of advice from physicians. In Chapter 6, technologies become materials that intervene in the shared goals of team members seeking to integrate palliative care for patients with advanced heart failure. My analysis illustrates how gaps and lapses in patient care reside not only in the realm of human cognition but also in sociomaterial networks.

7.2.2 Networked competency

While my aim is not to dismiss collective competence, an additional contribution of my work is the proposal that decision-makers structure educational programs around a definition of competence that acknowledges the influence of actor-networks. Instead of collective competence,
which is strongly oriented toward sociocognitive conditions, we might call a sociomaterial approach ‘networked competency’. While my work has concentrated primarily on care for complex heart failure patients, this insight applies more broadly. Health care operations at every level are networked, and nonhuman elements deserve recognition for the influential roles they can play in team-based care. I offer the following suggestions for future efforts to integrate networked competency in HPE.

First, I argue networked competency requires a shift in current HPE assessment strategies and practices. HPE training systems focus on individuals. Individual students are selected for programs, individual students are taught and trained, individual students are assessed, rewarded and sanctioned (Hodges and Lingard, 2012). This approach to training fails to capture the reality of a networked ontology in health care work. My work has presented numerous scenarios in health care work where nonhuman actors play an active role in clinical outcomes. How then can individual approaches to assessment be justified as the final say in trainee assessment? It might be useful for HPE assessment to consider the place of networks, and to imagine how it might move from individual, to collective, to networked competencies. This, as I have argued above, might begin with curriculums that prepare trainees to understand disruption, prepare for disturbance, and encourage critical speculation.

Second, I argue that competencies are not just about humans, they are also about materials. Yet current competency frameworks continue to encourage a ‘human-centred’ understanding of professional learning. Fenwick and Edwards (2014b) pull no punches when they state, “Large amounts of policy and curricula for professionals’ learning and assessment continue to be generated using models long since debunked and abandoned by educationists: de-contextualized individual competency, disembodied cognitive decision-making, and de-materialized knowing and practice” (p. 1). To use the CanMEDS framework for Canadian specialist physicians as an example (Frank, 2005; Frank, Snell, and Sherbino, 2014), HPE as a field requires competency frameworks to ensure benchmarking and collaboration are possible across disciplines, regions and institutions. Consider the ‘Collaborator’ competency: could my characterization of
the influence of technologies and spaces of care on human decision-making expand our understandings of what collaboration might mean? Note the ‘Leader competency’: could my depiction of influential nonhumans, like dialysis, refine our view of how care providers’ best intentions sometimes fail?

Third, I argue that competencies are not individual, they are networked. Consider the ‘Medical Expert’ competency: could my description of the multiple ontologies of fluid highlight the networked reality of how health care professionals understand pathophysiology? Are there implications for how we might rethink our understandings of such competencies? As competency-based education continues to evolve in HPE (Frank, Snell, Cate, et al., 2010; Nasca, Philibert, Brigham, et al., 2012), a sociomaterial perspective has the potential to offer assessors a new language for integrating complementary assessment strategies that are not completely human-centred. I argue that future research more fully consider competency frameworks in light of a sociomaterial perspective?

### 7.2.3 Sociomaterial pedagogy

If we accept that competency is networked, then movements like interprofessional education (IPE) are challenged to consider how collaboration and collaborative tensions are actor-networks. Much IPE literature displays a tendency to represent collaboration as something stable and straightforward. Take the study by Molyneux (2001) of ‘successful collaboration’ of a health care team in North England. The author argues that the ability of team members to be ‘supportive, cooperative, egalitarian and communicative’ lay at the heart of successful IPC. In a similar vein, the prevailing WHO definition of interprofessional collaboration refers to collaborative practice as when “multiple health workers from different professional backgrounds work together with patients, families, carers and communities to deliver the highest quality of care” (WHO, 2010, p. 7). This deceptively simple definition fails to respond to work that has served to complicate IPC, such as the review by D’Amour, Ferrada-Videla, San Martin Rodriguez, et al. (2005) that found significant inconsistencies in how the terms interprofessional, interdisciplinary, multidisciplinary
and transdisciplinary were used in the literature. This review concludes that IPC requires a deeper level of analytic consideration because “the dynamic established between professionals is as important as the context of collaboration. Collaboration needs to be understood not only as a professional endeavour, but also as a human process” (D’Amour et al., 2005, pp. 128). However, as the final two words of this quote reveal, even in this review complicating the discourse of interprofessional collaboration, the presence of materials is left tacit. I argue instead that IPE initiatives must consider a pedagogy of networked collaboration - a sociomaterial pedagogy.

What would it mean to propose a sociomaterial pedagogy in HPE? This pedagogy would be a branch of a substantial, historically-situated literature focused on postmodern pedagogies. Critical and pedagogical theorists like Howard Zinn (2004), Paulo Freire (1970), bell hooks (1994), and Henry Giroux (2004, 2006) have recognized that the influence of systems of power and domination are not simply economic, political and judicial. Power operates at a sociocultural and pedagogical level as well. Educational practices and perspectives that become entrenched and accepted impact how people think, what transformations and translations become possible, and how resistance is conceptualized. While ANT work attempts to avoid explanations of phenomena that rely on an overarching model of ‘power’, its approach is inherently postmodern in its attempts to describe how actor-networks create powerful or disempowered networks.

While much of my work has situated ANT as a methodological and theoretical construct, ANT has pedagogical possibilities for HPE as well. Bleakley (2012) for example encourages that medical education should invest in networks that promise collaboration, trade, dialogue and translations that will fuel innovation in learning organizations. Fenwick (2014) goes further, suggesting HPE curricula that teach learners to attend to both major and minor fluctuations and perturbations in practice; attune to emerging ideas instead of only fixed ones; notice one’s own and others’ impacts on what emerges in different networks; ‘tinker’ amidst complex situations sometimes involving uncertainty; and, most importantly, interrupt ‘black boxes’ of practice to reveal matters of concern and opportunities to intervene.

For my part, I propose two components of a sociomaterial pedagogy that run alongside
and interweave with those offered by Bleakley (2012) and Fenwick (2014). First, I propose a sociomaterial pedagogy in HPE that teaches translation as a form of disturbance. Translation as disturbance is a key epistemological and ontological tenet of ANT that has emerged in my work. Physiology, diagnostics and data are not disconnected, value-free objects. They operate as parts of actor-networks that connect and reconnect in predictable and sometimes unpredictable ways.

As actors move and transform through networks, the term *transformation* is used to represent these stages of change. A sociomaterial pedagogy would encourage trainees to consider how each new stage of a chain of information transfer is a disturbance and reassembly of things that have come before. Take, for example, the uptake of peritoneal dialysis by the hospice described in Chapter 6. Despite the acknowledged goal of palliative care integration by the patient, caregiver and health care providers, competing translations of fluid management by the heart function clinic and the hospice disrupt integration. This example is not meant to critique the actions and decisions made by my participants; rather, it is meant to suggest that it is worth asking whether strategically accepting and planning for disturbance might create possibilities for alternative outcomes.

The idea of disturbance leads to the second component of sociomaterial pedagogy: preparing for disruption. While the terms *disturbance* and *disruption* are similar, the former term refers to processes of reorganization and relocation, whereas the latter term pertains to outright barriers to the continuation of a given activity. Competency-based models encourage HPE programs that generate trainees who are ‘navigators’, ‘advocates’, and ‘leaders’ (Frank, 2005; Frank, Snell, Cate, et al., 2010; Frank, Snell, and Sherbino, 2014). However, the lived reality of practice is often a swampy morass, to use Donald Schön’s metaphor (1983, 1987). This metaphor positions HPE programs as guiding from a plateau overlooking a vast mire. While navigation and leadership are important to move through the swampy realities of practice, the current research raises the question of how to prepare trainees for disruption as well. My description of self-care in Chapter 4 is one such example. Despite care providers’ best efforts, self-care is out of their control and, as I have described, sometimes out of patients’ and caregivers’ control as
well. A sociomaterial pedagogy would encourage a willingness to attend to such disruption of planned care activities, and would explore how both human and nonhuman elements are factors in this disruption.

As the author of a dissertation for the HPE field, I speculate about other core components of what a sociomaterialist pedagogy might look like. In an effort to inspire future HPE researchers and educators, I offer the following suggestions. Strategies to promote a sociomaterial pedagogy in HPE include:

1. Examine ways in which a networked collaboration framework could reflect themes linked to actor-network theory and sociomateriality (e.g., intra-group collaboration);

2. Guide the development of networked learning environments by involving students, patients, caregivers, educators and administrators (e.g., community workshops).

3. Generate research that aligns with networked collaboration to support future activities (e.g., local ethnographies);

4. Build seminars for undergraduate and postgraduate students to explore human-centred paradigms of learning and their impact on teaching and learning contexts (e.g., sociomaterial education rounds).

My hope is that this, and future work, will contribute to the integration of sociomaterial theories in health care and HPE. My work points to this as an important and under-attended area, for future theorizing, investigation and practical application.

7.3 Limitations

ANT research has its shortcomings. Its postmodern epistemology largely marks conclusions as fractured and relativistic. Its intellectual heritage is informed by a few highly prolific authors who frequently adjust and change the definitions of key terms and concepts. Its inclusion of nonhuman actors disrupts the commonly held principle of human agency from fields like
sociology, anthropology and critical theory. Its networked ontology inverts our understanding of society and the social sphere. Its empirical approach disavows itself of the major traditions of qualitative data analysis, such as thematic abstraction and induction. In short, readers of ANT are asked to leave behind many of the central tenets commonly used to orient themselves within groups and institutions. I have struggled with each of these issues as I have developed and implemented this ANT-informed study. This dissertation’s structure primarily follows insights I could glean from the relatively few seminal works that seek to instruct potential ANT users (Latour, 2005; Law, 2004; Mol, 2002b). Readers will find my approach drastically different than other, recent ANT-informed work (CF Booth, 2004; Fenwick and Edwards, 2010b). Another ANT scholar may potentially find fault in how I privileged certain concepts over others—such as my emphasis in Chapters 4 and 6 on matters of fact/concern but my lack of any discussion over ‘black boxes’. While my approach to both study design and analysis were unique, I contend this speaks to the need for more diverse ANT resources and toolkits for the growing field of health professional education—Fenwick and Richards provide illustrative examples (2010, 2014).

While grappling with diverse opinions on how to conduct ANT-informed work, I was also required to consider the fierce oppositions to ANT research that exist in the literature. ANT’s central thinker Bruno Latour was a main character of the infamous “science wars” of the late-90s—a fierce period of academic debate between scholars in science studies and critics from the ‘natural’ sciences. These events culminated with the infamous Sokal Affair (Latour, 2004b; Markley, 1999). Physicist Alan Sokal submitted a fake article to the postmodern cultural studies journal Social Text (Sokal, 1996b). Despite Sokal’s claim that the article was “liberally salted with nonsense,” it was indeed published in Social Text (Sokal, 1996a, p. 62). Sokal revealed his hoax in the now defunct academic magazine, Lingua Franca, stating, “nowhere in [the article] is there anything resembling a logical sequence of thought; one finds only citations of authority, plays on words, strained analogies, and bald assertions” (Sokal, 1996a, p. 63).

Bruno Latour’s work was cited heavily in Sokal’s paper, especially Latour’s treatment of Einstein’s special theory of relativity in one of his early papers (Latour, 1988).
Sokal would debate in several articles and editorials that graced the pages of the French daily *Le Monde* and the French popular science magazine *La recherche* (Latour, 1997; Sokal, 1997; Sussman, 1998; Latour, 2004a). Ultimately, Sokal accused Latour of radical relativism that threatens to undermine the reality of scientific thinking:

> Every scientist knows perfectly well that our knowledge is always partial and subject to revision – which does not make it any less objective. In the same way, Latour reduces relativism to a banal “ability to change one’s point of view”, as if this were not a long-standing characteristic par excellence of the scientific attitude. (Sokal, 1997)

The deeper I read into these vociferous attacks on Latour’s work, the more concerned I became about the issue of working with and around epistemological relativism at every stage of my project. I often asked myself whether critics of ANT, like Sokal, had a point. Does ANT lead researchers toward making novel claims? Am I making other social research approaches into straw figures to burn?

Through reflective memoing, frequent discussions with mentors, and consultations with area experts, I came to realize that accusations of relativism in ANT are slightly misplaced. Eminent scholars like Michael Bérubé (2006) and Stanley (Fish and Durham, 1996) called Sokal’s attacks on Latour “crabbed,” “ungenerous,” (Bérubé, 2006) and “a bad joke” (Fish, 1996). In preparing to begin my study I recognized that relativism is in fact a term embraced by ANT, just not in the way that Sokal intended when he accused Latour and others of radical relativism. Sokal intended the term relativism to mean the belief that points of view have no truth or validity. ANT uses the term relativism in a manner more akin to Einstein’s special principle of relativity (Latour, 1988). Einstein built on the work of Galileo to demonstrate that different systems in motion are different relative to one another but are independently stable.\(^1\) ANT relativism argues

\(^1\)To illustrate this, imagine someone watching a plane at cruising altitude and someone sitting on the same place; despite the fact that a plane is moving hundreds of kilometers per hour faster than someone on the ground each individual experiences gravity in the same way. Special relativity explains why an item, like a pen, doesn’t fly to the back of a plane when accidentally dropped. The pen behaves the same on the plane and it does on the ground when dropped.
that epistemologies, ontologies, sociologies, and cultures are like so many systems acting and moving in different ways in our world. The physical nature of each system is consistent despite the fact that systems appear in motion to other systems. ANT embraces relativist perspectives and encourages rich descriptions of as many systems as possible, but this does not mean that anything goes. Systems are bounded by networks and actors, and the responses that various disruptions entail. In this way, I believe that relativism can be seen as a strength and opportunity of ANT research instead of a fault.

Another well-known limitation of ANT originates from the intellectual debate in education scholarship between proponents of ANT and proponents of cultural-historical activity theory—also called CHAT. In many ways these approaches are complementary, but in others they are quite opposed—with powerful critiques coming from the CHAT community. The first main critique against ANT is that while foregrounding nonhuman actors it simultaneously backgrounds human intentionality and the true asymmetry between people and things (Kaptelinin and Nardi, 2006). Activity theorists take the position that people have goals and needs that are not accounted for by ANT’s symmetrical, networked ontology. Furthermore, they argue, ANT creates docile networks that have trouble explaining activity, the main unit of analysis in activity theory. This is true: ANT beckons its proponents to give a voice to objects, processes and ideas so that they can be brought to equal footing with human actors. I struggled with the simultaneous humanizing of objects and depersonalizing of people during the analysis and writing phases of this work. While I would argue that there is no clear solution to navigating the tension between these activities, I believe that CHAT is an analytic model that offers its own strengths and weaknesses. From an ANT ontological point of view, CHAT approaches would be considered distinctly ‘modern’ due to the acceptance of a social fabric (the cultural-historical sphere) binding together human and nonhuman activities. My study could have been a CHAT study, but I believe that ANT allowed me to foreground the role of fluid in ways that differ from what a CHAT approach would have considered as an ‘object’ within an activity system (Engeström, 2008). CHAT looks for the social, cultural and historical properties of objects rather than the ways objects participate in the
7.4. Conclusion

The three empirical articles in this dissertation, informed by ANT, present different dimensions of the processes involved in team-based care for patients with advanced heart failure. Each article demonstrates an ANT ‘account’ of the activities, actors and networks involved in the management of patients with advanced heart failure, an area of health care that is garnering increased attention in the face of an aging population (Latour, 2005). Chapter 4 identified how patient self-care became complicated by material and network effects of fluid and its management. Chapter 5 described the collaborative entanglement of fluid in ontologies of cardiology care and nephrology care. Chapter 6 found that palliative care integration for advanced heart failure involved sometimes competing translations of material fluid management techniques, such as dialysis. The findings are not exhaustive, nor do they present a novel social theory of palliative care integration. The goal of an ANT study is rich, contextual and particular descriptions that look at something and how it unfolds through specific cases. Each article is intended to ‘intervene’ in some way, to capture and illustrate activities through rich description that may bring to light insights on how material and social elements blend and interweave. These insights are also meant to illustrate core assumptions and categorizations that can be sometimes left tacit in integration work and in health care work more generally. The articles present several findings that serve as lenses in the kaleidoscopic assemblage of this dissertation. Centrally, fluid emerged as a central material actor through the course of many analytical steps and each article offers its own account of fluid and its management. The extent to which these results have
intervened remains to be seen, but I hope that they will enrich the policy and practice debates around heart failure care in general, and palliative care integration in particular.


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Appendices
Appendix A

Research Ethics Approval

Office of Research Ethics
The University of Western Ontario
Room 5150 Support Services Building, London, ON, Canada N6A 3K7
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website:  www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. L. Lingard
Review Number: 17665E
Review Date: December 15, 2010
Protocol Title: Healthcare team experience in caring for patients with advanced chronic illness
Department and Institution: Medicine-Dept of, University of Western Ontario
Sponsor:

Ethics Approval Date: January 14, 2011
Documents Reviewed and Approved: UWO Protocol, Physician Letter to Patient (Recruitment), Letter of Information and Consent (sent by GP), Letter of Information and Consent (sent by researcher), Letter of Information and Consent (given to family member).

Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICCH Good Clinical Practice Practices: Consolidated Guidelines, and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REBs as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB’s periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly report any adverse events to the HSREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected events or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

NOT FOR PUBLIC RELEASE
Appendix B

Sample Letter of Information / Consent for patients

Project Title: Healthcare team experiences in caring for patients with advanced heart failure

Dear X,

A physician currently providing care for you has indicated that you have agreed to speak with a research associate regarding a study you may be interested in participating in. This study is exploring the experiences of patients with heart failure (HF). You are being asked today to consider participating in this study.

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time. Your decision about whether or not to participate in this study will have no impact on your current or future care at The London Health Sciences Centre. Your doctor has not supplied any of your personal information to the research team.

This study of health care teams is funded by the Academic Medical Organization of Southwestern Ontario. The researchers involved in this study hope to interview the members of 12–16 health care teams from your region.

Description of this Study

This is a study exploring the experiences of health care teams involved in the care of individuals with heart failure (HF). As someone receiving care for HF, this study would like to find out your insights. Health care team research traditionally uses surveys studies to discover patients, caregivers and healthcare providers individual knowledge, needs, and attitudes regarding HF care. But this information about individual elements is insufficient to capture the complex nature of the teams on which HF care is provided.

We are asking that you participate in a single, in-person interview discussing your past, present and anticipated healthcare experiences. If you are interested in participating in this study, a researcher will need to make an appointment with you to arrange for the interview. We anticipate that the interview will take about one hour of your time. You will be asked to discuss
your experience with HF, your experience with the health care system, and your role in relation to others who provide HF care. You can decline answering any question(s) you are asked.

We would also like to interview healthcare professionals involved in caring for patients like you. During your interview we will ask you if we can retain your name so that we can interview health professionals you feel are important in your care (such as your cardiologist). We will also ask you if we can retain your phone number so that we can contact you for a follow-up interview. You can still participate in the study without having any of your personal information retained. You are under no obligation to have your personal information retained.

The interview will be audio-recorded by the research associate during your appointment. The time, date, and location of the interview appointment will be determined by you. Potential locations for an interview include your home, a public place such as a meeting room in a local library, or a private room at St. Marys Hospital. If you are more comfortable having another person be present during your interview, such as a family member, this will be accommodated for you.

You will receive a $25 gift card as an honorarium for your time and the cost of your parking will be reimbursed to you during your appointment.

The interview will be typed out into written copy from the audio-recording by a professional transcription service. Any reference to your identity will be removed. Your name will not appear in the written interview transcript and neither will any personal information. For example, if you named one of your relatives it would not be transcribed. If you feel that an adult family member(s) involved in your care may be interested in potentially participating in this study, please consider forwarding this letter to them.

**Potential Benefits and Risks**

This study involves no known risks. If you are uncomfortable with the idea of being audio-recorded, you should participation in this study.

There are no immediate benefits to participating in this research. At the individual level, a potential benefit would be your contribution to research aimed at better understanding how the healthcare team cares for patients with chronic illness.

**Confidentiality**

In order to preserve the confidentiality of participants, all collected data will be anonymous. Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your future care. Representatives of The Tri-Hospital Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

All data will be stored on a password-protected, secured network server. Only the members of the research team and the Tri-Hospital Research Ethics Board will have access to the
information collected by this study. Any identifying information will be retained for approximately 2 months after your interview, when it will be erased permanently.

Any presentation of the results obtained from this study will only appear in de-identified form. You have the right to ask the study doctor about the data being collected about you for the study and about the purpose of this data. You also have the right to ask the study doctor to let you see your personal information and to make any necessary corrections to it.

**Research Team**

This study is being conducted by

Dr. Lorelei Lingard of the Centre for Education Research & Innovation at the Schulich School of Medicine & Dentistry (SSMD),

Dr. Stuart Smith, St. Marys General Hospital Heart Function Clinic,

Dr. Joshua Shadd, Department of Family Medicine, SSMD, Dr. Valerie Schulz, Department of Anaesthesia & Perioperative Medicine SSMD,

Mr. Allan McDougall, Research Associate, Centre for Education Research & Innovation, SSMD.

**Contact information**

If you are potentially interested in participating in this study, please call Mr. Allan McDougall at [Redacted]

Additionally, please feel free to ask any questions that you may have regarding this study by phoning Dr. Lorelei Lingard at [Redacted]

This project has been reviewed and received ethics approval through the [local] Research Ethics Board, and if you have concerns or questions about your rights as a research participant in the study you may contact the [local] Research Ethics Board at [Redacted]

You will be presented with a copy of this Letter of Information for your own records.

With regards,

Dr. Lorelei Lingard

Centre for Education Research & Innovation [Redacted]

**Consent**

I have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction.
In the event you agree to be interviewed, please indicate your preference for being audio-recorded:

☐ Yes, in the event I agree to an interview, I agree to having it audio-recorded
Sample Letter of Information / Consent for health professionals

Project Title: Healthcare team experiences in caring for patients with advanced heart failure

Dear X,

We are interested in interviewing you because you have been identified as a healthcare professional involved in the care of X. You are being asked to today to consider participating in a study exploring your experience as a health professional involved in the care of an individual with advanced heart failure (HF).

Participation is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time. Your decision about whether or not to participate in this study is anonymous and will have no impact on your institutional or professional status. This study of health care teams is funded by the Academic Medical Organization of Southwestern Ontario. The researchers involved in this study hope to interview the members of 12 16 health care teams from your region.

Description of this Study

This is a study exploring the experiences of health care teams involved in the care of individuals with heart failure (HF). As someone providing care for individuals with HF, this study would like to find out your insights. Health care team research traditionally uses surveys studies to discover patients, caregivers and healthcare providers individual knowledge, needs, and attitudes regarding HF care. But this information about individual elements is insufficient to capture the complex nature of the teams on which HF care is provided.

We are asking that you to consider participating in a single, in-person interview that should involve about fifteen or twenty minutes of your time. The time, date, and location of the interview appointment will be determined by you. The interview will be audio-recorded by the research associate during your appointment. Potential locations for an interview include your office or a private room at [Redacted]. You will be asked to discuss your experience as a health care provider for individuals with HF, your experience in the health care system, and your role in relation to others who provide care to individuals with HF.
You will receive a $25 gift card as an honorarium for your time and if you incur any parking costs related to your interview, the cost of parking will be reimbursed to you during your appointment.

The interview will be typed out into written copy from the audio-recording by a professional transcription service. Any reference to your identity will be removed. You name will not appear in the written interview transcript and neither will any patient information. We will ask you to review your records on X before the interview. The interview will not focus on X, but will use this case to facilitate a broader conversation around health systems in this region.

**Potential Benefits and Risks**

This study involves no known risks. If you are uncomfortable with the idea of being audio-recorded, you should decline participation in this study.

There are no immediate benefits to participating in this research. At the individual level, a potential benefit would be your contribution to research aimed at better understanding how the healthcare team cares for patients with chronic illness.

**Confidentiality**

In order to preserve the confidentiality of participants, all collected data will be anonymous. Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research. All data will be stored on a password-protected, secured network server. Only the members of the research team will have access to the information collected by this study. Any presentation of the results obtained from this study will only appear in de-identified form.

**Research Team**

This study is being conducted by

Dr. Lorelei Lingard of the Centre for Education Research & Innovation at the Schulich School of Medicine & Dentistry (SSMD),

Dr. Stuart Smith, St. Marys General Hospital Heart Function Clinic,

Dr. Joshua Shadd, Department of Family Medicine, SSMD, Dr. Valerie Schulz, Department of Anaesthesia & Perioperative Medicine SSMD,

Mr. Allan McDougall, Research Associate, Centre for Education Research & Innovation, SSMD.
Contact information

If you are potentially interested in participating in this study, please call Mr. Allan McDougall at [Redacted]

Additionally, please feel free to ask any questions that you may have regarding this study by phoning Dr. Lorelei Lingard at [Redacted]

This project has been reviewed and received ethics approval through the [local] Research Ethics Board, and if you have concerns or questions about your rights as a research participant in the study you may contact the [local] Research Ethics Board at [Redacted]

You will be presented with a copy of this Letter of Information for your own records.

With regards,

Dr. Lorelei Lingard
Centre for Education Research & Innovation [Redacted]

Consent

I have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction.

________________________________________________________________________
Participant Date

________________________________________________________________________
Person obtaining consent Date

In the event you agree to be interviewed, please indicate your preference for being audio-recorded:

☐ Yes, in the event I agree to an interview, I agree to having it audio-recorded
Appendix D

Interview protocol for patients

Introductory script

Thank you for your time. I work with a group that is studying how care for patients with heart problems is delivered and who delivers it. We are interested in you, your family, and the health care professionals (like your family doctor, cardiologist, nurses, etc.) involved in your care. We are trying to figure out how people can get the supports they need, when they need them, in the course of their illness. I just want to remind you that this interview is 100% anonymous and confidential. Don’t hold back your opinions and don’t worry that anyone involved in your care will hear what you say. The results of this interview and other like it will contribute to an ongoing campaign that will affect health care in Canada and the world. The interview is in two parts. First, I’m going to ask you to tell me the story of your illness. Second, I’m going to ask you about the system of care you are involved in—I’ll ask about people, places, and how information is relayed.

Part 1: Lived experience

- Tell me the story of your heart problem, start at the beginning.
- What’s a day like for you?
- Are there any problems you wish you could help with but can’t?
- Has anything changed in the way you get care or how you access care over time? Imagine 1 year ago? What about 2 years ago? What has changed?
- What do you expect will happen if there is (another) life-threatening crisis?

Part 2: Team

- Who is on the team involved in caring for you?
What roles or functions do team members play?

What are your relationships like with the team members? Does that play a role in the type of care you receive?

Tell me about the people who help you. Who are they? Where are they?

How many clinics are you involved in? Describe a day when you're coming to the X clinic. What has to happen for that to occur? How does that work?

Is the clinic accessible? Is it easy to get to? What would make it better for you? How do you get an appointment? How convenient is parking/transportation?

Have you ever experienced a situation where everyone seemed to work together very well?

Has there been a situation where a person or the system went “above and beyond your expectations?"

What about the opposite? Have you ever experienced a situation where everyone hasn't seemed to be on the same page? Where you had hoped for more from the system?

What do you feel is missing in the care you receive?

Can you tell us about any obstacles you have encountered in seeking the care you need?

**Part 3: Agency**

Who makes your health care decisions?

Are there factors that assist you in providing care/making decisions? Have you ever felt “powerless or unable to make health care decisions or care for yourself?

**Part 4: Care system**

With my research group, we are interested in hearing about the people who help you and how that happens. I'm going to use my notepad to track things as you tell them to me.

Have you gotten better on your current care plan?

How has the group of people who care for you changed?

When have you met or been involved with new people involved in your care? Who might they be? Why did you meet them?

Who helps you if you have a sudden change in your health? How?

Describe a day when you do not have any appointments, but you need help from someone, what do you do then?
– Why would you call that person? Is that their role?
– Are there any other options available?

• How do the health professionals / people who take care of you (your doctors, nurses, etc) let each other know about what's happening with you?

• Do they talk to each other? How do you understand information and/or care decisions to be communicated between them? What do you or your family do to make sure the health professionals have the information they need about you?

• Do the people involved in your care seem to have the same idea about what's going on and what kind of care you need? Tell me more about that.

– Do you ever need to relay information about what someone else has done?

**Part 5: Communication**

• When you need to communicate with your health care providers, how does that happen? What about when the need to communicate with you?

• Have you been in a situation where the discussion has been about bad news?

– Who held those discussions with you? How did they happen?

**Part 6: Meaning**

• How has living with this illness affected the way you look at life, what is important to you, the people you want to see? How you plan for the future?

• What or who brings meaning or purpose to your life?

• Where do you draw your strength? What keeps you going despite difficult times?

• What are your hopes for the future?

• If appropriate: Do you have a spiritual or religious practice? Is that helpful for you?
Part 8: Opportunities

Your input will provide important information for the care of patients like you. If you had to identify your most important opportunities for change in this setting, what would they be? Are there any potential improvements for providing care?

Request for permission to contact other healthcare team members

We're interested in talking to others that you have identified as important in your care. Would you be comfortable with us retaining your name so we can contact those people about how they provide care for people with heart problems? And do you mind if we retain your phone number in case we want to follow up with you?
Appendix E

Interview protocol for caregivers

Introductory script

Thank you for your time. I work with a group that is studying how care for patients with heart problems is delivered and who delivers it. We are interested in talking with you, your loved one, and the health care professionals (like your loved ones family doctor, cardiologist, nurses, etc.) involved in your loved ones care. Were trying to figure out how people can get the supports they need, when they need them, in the course of their illness. I just want to remind you that this interview is 100% anonymous and confidential. Dont hold back your opinions and dont worry that anyone involved in your loved ones care will hear what you say. The results of this interview and other like it will contribute to an ongoing campaign that will affect health care in Canada and the world. The interview is in two parts. First, Im going to ask you to tell me the story of your loved ones illness. Second, Im going to ask you about the system of care your loved one is involved in Ill ask about people, places, and how information is relayed.

Part 1: Lived experience

• Tell me the story of your loved ones heart problem, start at the beginning.

• Whats a day like for your loved one?

• What physical problems bother your loved one? (probes: breathing? energy level? diet? sleeping? mood?)

• Are there any problems you wish you could help your loved one out with but cant?

• Has anything changed in the way you get care or how you access care for your loved one over time? Imagine 1 year ago? What about 2 years ago? What has changed?

• What do you expect will happen if there is (another) life-threatening crisis?

Part 2: Team

• Who is on the team involved in caring for your loved one?
  
  – What roles or functions do team members play?
What are your loved one’s relationships like with the team members? Does that play a role in the type of care you receive?

• Tell me about the people who help your loved one. Who are they? Where are they?

• How many clinics are you involved in? Describe a day when you're going to the X clinic. What has to happen for that to occur? How does that work?
  – Is the clinic accessible? Is it easy to get to? What would make it better? How do you get an appointment? How convenient is parking/transportation?

• Have you or your loved one ever experienced a situation where everyone seemed to work together very well?
  – Has there been a situation where a person or the system went “above and beyond your expectations”?

• What about the opposite? Have you ever experienced a situation where everyone hasn't seemed to be on the same page? Where you had hoped for more from the system?

• What do you feel is missing in the care your loved one receive?

• Can you tell us about any obstacles you or your loved one have encountered in seeking the care you need?

**Part 3: Agency**

• Who makes your loved one’s health care decisions?

• Are there factors that assist your loved one in providing care/making decisions? Have you or your loved one ever felt “powerless or unable to make health care decisions or care for yourself”?

**Part 4: Care system**

With my research group, we are interested in hearing about the people who help you and how that happens. I'm going to use my notepad to track things as you tell them to me.

• Has your loved one gotten better on your current care plan?

• How has the group of people who care for your loved one changed?

• When have you met or been involved with new people involved in their care? Who might they be? Why did you meet them?

• Who helps you if your loved one has a sudden change in your health? How?
• How do the health professionals / people who take care of your loved one (doctors, nurses, etc) let each other know about what's happening?

• Do they talk to each other? How do you understand information and/or care decisions to be communicated between them? What do you or your loved one do to make sure the health professionals have the information they need about you?

• Do the people involved in care seem to have the same idea about what's going on and what kind of care you need? Tell me more about that.
  – Do you ever need to relay information about what someone else has done?

**Part 5: Communication**

• When you need to communicate with health care providers, how does that happen? What about when the need to communicate with you?

• Have you been in a situation where the discussion has been about bad news?
  – Who held those discussions with you? How did they happen?

**Part 6: Meaning**

• How has living with this illness affected the way you look at life, what is important to you, the people you want to see? How you plan for the future?

• What or who brings meaning or purpose to your life?

• Where do you draw your strength? What keeps you going despite difficult times?

• What are your hopes for the future?

• If appropriate: Do you have a spiritual or religious practice? Is that helpful for you?

**Part 8: Opportunities**

Your input will provide important information for the care of patients like your loved one. If you had to identify your most important opportunities for change in this setting, what would they be? Are there any potential improvements for providing care?
Appendix F

Interview protocol for physicians

Introductory script

I am part of a team conducting a research project studying health service provision for patients with advanced congestive heart failure. In particular, we are interested in understanding patients’ and providers’ experiences and expectations of palliative care in advanced heart failure.

One of your patients is a research participant in this study. This patient has identified you as an important healthcare professional involved in their care and that’s why we’re here to talk to you.

• From your perspective as their [family physicians, cardiologist, etc], what are the needs of [Patient’s Name] as they deal with advanced heart failure

• Have this patients needs changed as their illness course has advanced? In what ways?
  – Are there other needs aside from clinical needs?

• How do you address these needs as their [family physicians, cardiologist, etc]?
  – Is your role different than a physician in another setting [e.g., a local hospital, a local family practice?]
  – Are there others on this patients care team who address these needs? How do you think they do that?

• What factors come into play when deciding to follow or not follow a patient?

• How do you discuss prognosis with your heart failure patients?

• Do you think that[Patient’s Name] has palliative care needs?
  – Has this patient had a palliative consult?
  – Do you think that should happen? When?
  – Do you/would you play a role in the process of integrating palliative care for this patient? What is that role?
  – Who communicates that to the patient?
  – Who else do you think will play a role in this?

• Once you determine a patient is nearing the end-stage of CHF, who are the key players that need to be involved in a conversation on that topic?
– Can you give me an example of how you would communicate around this issue?
– Can you ensure uptake of the information you provide?

**Part 5: Communication**

- What are the services currently available to this patient to assist with palliative care if/when they require it?

- In an ideal world, if we could introduce something to these patients what would it be?
Curriculum Vitae

Name: Allan McDougall

Post-Secondary Education: University of Waterloo
2007 - 2009 M.A.
Western University
2011 - 2015 Ph.D.

Honours and Awards: CIHR - HCTP Strategic Training Fellowship
2012-2014
Ontario Graduate Scholarship
2013-2014

Related Work Experience: Research Coordinator
Palliative Care on the HF Team Research Study, 2011-2014
Writing Instructor
Huron University College Writing Centre

Related Volunteer Experience: Community Palliative Care Volunteer
Victorian Order of Nurses, 2010-2012
Hospice Volunteer
Parkwood Hospital, 2010-2012

Selected Publications:


