**Who Pays the Cancer Tax?**
**Patients' Narratives in a Movement to Reduce their Invisible Work**

Many studies show that the division of labor between professions is contested and dynamic. Yet there is also a division of labor between professionals and their clients, which research to date has tended to ignore or has treated as static and easily accepted by both parties. Do clients ever successfully change their expected division of labor with professionals, and if so, how? We developed this question while studying an academic cancer center (ACC), where patient activists led such a movement. Their main influence tactic was to tell personal stories about the burdensome invisible work they and their families had to do, simply to receive treatment. Their storytelling practices included telling stories to build the movement, creating channels to collect more stories, and broadcasting the stories widely. These practices mobilized and resourced a powerful cross-occupational coalition of staff allies who both used their own resources to support change, and created new resources. Coalition members drew on the patient stories to develop a new *diagnostic* framing of the "Cancer Tax" that ACC placed on patients. They also developed a new *prognostic* frame for how ACC could help, which inspired a new administrative program that took on some of the patients' coordination tasks. In this way, the patients' storytelling practices created new awareness of the problem and provided new resources for staff allies as they made the case for redirecting ACC's formal resources towards lessening the patients' expected division of labor.

**Keywords:** professions, invisible work, narratives, social movement theory, organizational change

# INTRODUCTION

Large bureaucratic organizations structure the institutional, spatial, and legal arrangements in which professionals provide socially-valued services such as health care or education to clients (Briscoe, 2007; Freeland, Sivan, & Ezra, 2018; Huising, 2015). Initially, researchers studying such services focused specifically on understanding the professionals themselves and their work (e.g., Abbott, 1988), but this research area has recently undergone several significant shifts. Most relevant to this paper, scholars have begun to argue that clients and professionals actually *co-produce* these services; this view is in contrast to the traditional view of professionals *delivering* services in a one-way set of activities (see Anteby, Chan, & DiBenigno, 2016, pg. 41; Okhuysen & Bechky, 2009, pg. 495). Clients co-produce professional services though activities such as coordinating and participating in the service encounter, recording the data that the professionals rely on to make their judgements, taking action to carry out recommendations, sharing learnings, and piecing together different services to meet their own desired service experiences (e.g., Bettencourt, Ostrom, Brown, & Roundtree, 2002; Eyal, 2013; Huising & Silbey, 2011; Joshi & Moore, 2004). Studies that explicitly recognize clients' involvement in the co-production of services better account for the ways that services are defined and evolve over time (e.g., Eyal, 2013) as well as for variation in service effectiveness (e.g., Blustein, Borden, & Valentine, 2010; Brandsen & Pestoff, 2006; Huising, 2015; Joshi & Moore, 2004).

In this paper, we argue that the idea that professionals and clients collaborate to co-produce professional services also opens up the idea that professionals and clients have an expected division of labor – they share an implicit agreement about the tasks that the professionals are expected to do and the tasks that the clients are expected to do as they interact to co-produce the service. In this way, clients can be understood as being responsible for certain tasks in their division of labor with professionals. This connection is interesting in light of the many studies that have documented political battles and organizational maneuvers between different professions to claim or avoid different tasks. Tasks come to hold significance such as "prestige, influence, and compensation," and various professions and

occupations will protect their jurisdiction over some tasks or avoid tasks seen as dirty work or "scut" work (e.g., Anteby et al., 2016; Bechky, 2003; Kellogg, 2014). The division of labor between various professions and occupations has been shown to be dynamic and contested, but our research to date has either ignored the division of labor between professionals and clients or treated it as static and easily accepted by both parties. But do clients ever successfully contest and change the expected division of labor between themselves and professionals as they co-produce services? And if so – how?

We developed this research question when studying a multi-year organizational change process at an academic cancer center (ACC), where patient activists led such a movement. Their primary influence tactic involved telling stories about the burdensome "invisible work" they and their families had to perform simply to receive treatment (Daniels, 1987). The patient activists continuously shared their own stories with supportive ACC staff, developed formal channels for collecting more stories, and worked to broadcast the stories across ACC. We analyze the influence of these storytelling practices on the change process using the lens of social movement research, and especially stories and narratives in social movements (e.g., Olsen, 2014; Polletta, 1998a). Consistent with prior research on narratives in social movements, the patient activists storytelling practices helped mobilize a small but powerful cross-occupational coalition and provided a key resource for the coalition; coalition members, in turn, used their own resources and developed new coalition resources to press for change (e.g., Howard-Grenville, 2007; Wang & Soule, 2012). Coalition members drew on the stories to develop a *diagnostic* framing of the "coordination burdens" and "cancer tax" that ACC was placing on patients and mobilize awareness that ACC should help. Ultimately, changes to task structures occurred only after one of the coalition members, the palliative care team, drew on these accumulating resources to also develop a new *prognostic* frame for how ACC could help. They proposed a new administrative program that would take on some of the patients' coordination tasks – thereby changing the expected division of labor. These findings demonstrate that the patients' storytelling practices successfully changed the division of labor with professionals by mobilizing and resourcing a coalition of supporters in the organization.

**RELATED WORK**

Research on professional services now increasingly argues that clients and professionals *co-produce* services and service encounters, this view is in contrast to traditional research that suggests that professionals *deliver* services in a one-way set of activities (see Anteby et al., 2016 pg. 41; Okhuysen & Bechky, 2009, pg. 495). The idea of co-production first became popularized in the 1970s, when a group of economic theorists developed new "production functions" that reflected the nature of service work (Ostrom, 1972; Ostrom, Parks, & Whitaker, 1978; Ostrom & Whitaker, 1973; Parks et al., 1981). In contrast to classic production functions that modeled production as organizations uni-directionally transforming inputs (e.g., labor) into a set of outputs (e.g., services), these new "*co-production* functions" modeled service organizations and users *together* transforming inputs into service outcomes (Bovaird, 2007; Brudney & England, 1983; Percy, 1984; Whitaker, 1980). This idea has now gained interest among sociologists and organizations researchers, who focus more on the social interactions and activities whereby clients co-produce services. Clients co-produce professional services through activities such as coordinating interactions, collecting data, and carrying out recommendations (e.g., Bettencourt et al., 2002; Eyal, 2013; Huising & Silbey, 2011; Joshi & Moore, 2004). Scholars now propose that explicitly recognizing clients' involvement in the co-production of services can better account for how the services are defined and evolve over time (e.g., Eyal, 2013), as well as for variation in how effective the services are (e.g., Blustein et al., 2010; Brandsen & Pestoff, 2006; Huising, 2015; Joshi & Moore, 2004). As a key example, Eyal (2013) analyzes how a new diagnostic criteria for autism was created and argues that the key actors in assembling this new network of expertise were "*not* child psychiatrists, but the parents of children with autism" (pg. 868). The paper importantly advances the idea that clients can arrange a different network of expertise than the one recognized by the professionals, and that clients can do so in ways that change the professionals' work over time.

In this paper, we aim to build on these ideas. We argue that the idea that professionals and clients collaborate to co-produce services also opens up the idea that professionals and clients have an expected

division of labor.  They share an implicit agreement about the tasks that the professionals are expected to do and the tasks that the clients are expected to do as they co-produce the service.  Highlighting this point is interesting because many studies have shown that the division of labor or expected task structures between professions is always contested and dynamic (Anteby et al., 2016, pg. 25).  Our paper connects these ideas by asking whether and how clients similarly challenge and change their expected division of labor with professionals.  To develop this new understanding, we first review prior research on how professions and occupations contest and change task structures in bureaucratic organizations, and then ask how such processes might look different for clients.

**Changing Task Structures in Bureaucratic Organizations**

Bureaucratic organizations structure the institutional, spatial, and legal arrangements under which professionals provide services to clients (Briscoe, 2007; Freeland et al., 2018; Huising, 2015).  The majority of professionals are now employed in large bureaucratic organizations, rather than in solo practices as modeled in older research (Briscoe, 2007; Noordegraaf, 2011; Poley, Newkirk, Thompson, & Ricketts, 2009).  Understanding this common employment relationship and related authority structure is particularly key for understanding how change unfolds in these organizations (Empson & Langley, 2015; Huising, 2016; Kellogg, 2019).  Organizations can be understood as "socially constructed arenas" wherein different occupations, professions, and other stakeholders interact both to accomplish shared purposes, and to compete for resources, legitimacy, and status (e.g., Bechky, 2003; Bechky, 2011; de Bakker, den Hond, King, & Weber, 2013; Fligstein & McAdam, 2011; Freidson, 1976).  Synthesizing this literature, we can identify the barriers and tactics related to changing task structures in organizations for three relevant groups:  peer occupations, subordinate occupations, and managers (see Table 1).

------------------------------------------------------------
Insert Table 1 about here
------------------------------------------------------------

*Peer and subordinate occupations and workroom interactions.*  One overarching theme in these

5

related studies is that different groups have access to different kinds of organizational interactions, and this differential access shapes their barriers and tactics for changing task structures. One point of differential access involves workroom interactions. Only some groups have access to workroom interactions, wherein the day-to-day activities and interactions of organizational work are carried out (e.g., Barley & Kunda, 2001; Brown & Duguid, 2001; Feldman, 2004; Orlikowski, 2002). This kind of access is important because research has exhaustively shown that various professionals and occupations can effectively resist or co-opt the attempts of policymakers, managers, or activists to control or change their tasks simply by how they carry out their daily activities (e.g., Edwards, 1979; Kellogg, 2011; Prasad & Prasad, 2000). Members of target, peer, and subordinate occupations accomplish changes to task structures simply by how they negotiate their task jurisdiction in daily work. Some of those changes arise from members of a target occupation interacting with each other to alter their tasks as they carry them out, often working to better align their activities with their desired meaning, identity, or status (e.g., Anteby, 2008; Fine, 2006; Wrzesniewski & Dutton, 2001). Many changes also arise through jurisdictional battles between adjacent occupations in shared work and work spaces (Bechky, 2003; Kellogg, Orlikowski, & Yates, 2006; Lamont & Molnar, 2002; Lingo & O'Mahony, 2010). This contestation arises at the moment of work when people explicitly articulate and negotiate "who should do what" and "what [tasks] should *not* be done by whom" (Anteby et al., 2016, pg. 25). Prior research offers many examples of this process (Dobbin & Kelly, 2007; Kellogg, 2014; Kellogg, 2019; Zetka, 2003). Typically, only members of the target occupation, or members of peer or subordinate occupations, have access to the daily tasks of targeted occupation. Clients will rarely have access to workroom interactions, and this lack of access will shape their tactics and influence.

   ***Boardroom interactions and changing task structures.*** Changes to task structures are also accomplished through boardroom interactions, wherein managers allocate formal resources that structure jobs, groupings of individuals, space, communication, trainings, and technologies in ways that reconfigure task structures (e.g., Bower, 1986; Fligstein, 1987; Greenwood & Hinings, 1996; Pfeffer &

6

Salancik, 1974). Boardroom interactions also involve privileged access, but for different groups –

typically only managers or leaders of high-status professional groups (Table 1). For example, managers

might decide to fund new jobs, or to invest in new technologies that reconfigure tasks, or might decide to

formally redesign teams or workflows in ways that reconfigure task structures (e.g., Adler & Borys, 1996;

Fligstein, 1990; Hackman & Katz, 2010; Lewin & Stephens, 1993; Valentine & Edmondson, 2015). Of

course, managers' formal resource allocation decisions are then subject to the front-line staff agency and

resistance (e.g., Hodson, 2001; Morrill, Zald, & Rao, 2003; Roscigno & Hodson, 2004), but the formal

resource allocation process does influence later events and subsequent task structures (e.g., Valentine,

2018; Vallas, 2003; Wiedner, Barrett, & Oborn, 2016). Research studies in this area characterize this

formal design, allocation, and change process as involving issue selling, framing contests, and coalition

formation (e.g., Dutton & Ashford, 1993; Dutton, Ashford, Lawrence, & Miner-Rubino, 2002; Kennedy

& Fiss, 2009). Managers' attempts to "sell" new procedures, technologies, or work designs often involve

framing strategies and formal communication to make a case for change (Covaleski & Dirsmith, 1988;

Kaplan, 2008; Lounsbury, 2001; Zald & Berger, 1978). Prior research has not yet explained whether and

how clients access these kinds of boardroom interactions or how they might engage.

**Narratives in Collective Action**

Taken together, this prior research reveals two main paths of influence leading to changed task

structures: managers with formal authority allocate resources in ways that change task structures (e.g.,

Burns & Wholey, 1993; Vallas, 2003), and members of different occupations interact to claim, delegate,

and avoid particular tasks as they go about their daily work (e.g., Bechky, 2003; Kellogg, 2014). This

perspective emphasizes that clients do not have easy access to the kinds of interactions that lead to change

in task structures. Moreover, clients are engaging the professionals and the organization from a different

kind of role: as service recipients, they do not have a basis of professional expertise or formal authority

from which they can frame and legitimate organizational change. How, then, do clients effectively

engage issues pertaining to the organizational division of labor, and how does their engagement bring

about change to task structures?

During our study, we observed patient activists lead a movement that successfully changed their expected division of labor with staff at an academic cancer center (ACC).  Their primary influence tactic was to *tell stories* during meetings with ACC staff about the burdensome invisible work they did to coordinate their cancer care.  Stories or narratives are "accounts of a sequence of events in the order in which they occurred" to "project a desirable or undesirable future," thereby making a moral or normative point (Labov & Waletzky, 1997, pg. 111; Polletta, Chen, Gardner, & Motes, 2011; note following this review we also use stories and narratives interchangly).  Researchers recognize stories to be a distinct influence tactic used in collective action, and have analyzed their advantages and disadvantages (e.g., Davis, 2002; Polletta et al., 2011).  In terms of advantages, stories provide marginalized groups a form of persuasive communication in formal professionalized forums where they would typically be silent because they do not approach those formal discussions with technical, scientific, or expert discourse (Naples, 2003; Polletta, 1998a, b).  As an example, Nolan (2012) analyzed a social movement focused on making the court system more therapeutic, and found that clients told personal stories over and over about how a new Drug Court model had helped them overcome drug addiction.  Second, stories as persuasive communication allow people to narrate their personal experiences as "members of a legitimately aggrieved group," meaning they speak with a sense of "efficacy, even entitlement" to ask for injustices and suffering to be addressed (McAdam, 2010; Nepstad, 2001).  Iedema et al. (2011) illustrated how patients' collective storytelling allowed them to speak up about grievances without feeling like they would be dismissed simply as "difficult patients."  Finally, stories of injustice or suffering allow marginalized groups to "draw empathy" and "stress similarities" between themselves and those who have the authority to make needed changes (Bernstein, 1997; Fajer, 1991; Olsen, 2014, pg. 249; Sarbin, 1995).  As an example, Olsen (2014) analyzed discursive strategies used by proponents of a legislative bill legalizing same-sex marriage and found that in the hearings, gays and lesbians told stories about their loving families to demonstrate the "overwhelming similarities between gay and straight couples and

8

families" (pg. 249). In contrast, the opponents only used ideological frames in their testimonies. This body of research illustrates how marginalized groups use stories to mobilize support, attention, and action for their desired changes. However, even though narratives are well-suited for conveying emotion and morals, they are less powerful in debate-style forums that require 'ideological maneuvering' (Nepstad, 2001, pg. 136; Polletta, 1998b; Tatum, 2002). Groups thus tend to use narratives with other frames or with other persuasive communications within an overall collective action effort, and for certain purposes. Narratives tend to substantiate broader movement frames about needed change.

Much of this prior research has focused on movements external to bureaucratic organizations. Less is known about how clients might use stories and narratives as influence tactics in intra-organizational change efforts, and with what effects. In this paper, we draw on and extend general findings about narratives in social movements to develop this understanding. Our iterative review of the literature and our data produced three key themes. First, stories are often used to develop and cohere the communal identity and coherence of a movement (e.g., Benford, 1993; Fine, 1995; Hunt & Benford, 1994; Loseke, 2007; Polletta, 1998b), and of coalitions that form to produce the movement (McCammon & Moon, 2015; Van Dyke & McCammon, 2010). These studies show that stories and the cohering identities they help develop can sustain diverse groups' involvement in the movement. Second, stories also mobilize and sustain attention and support from stakeholders external to the movement (e.g., Nolan, 2012; Olsen, 2014; Rothenberg, 2002; Tatum, 2002). Third, stories told as part of a movement become resources that inspire, inform, and strengthen later influence tactics. This perspective aligns with both social movement and organizational change theories, which argue that influence tactics such as storytelling become resources for later influence attempts (Howard-Grenville, 2007; Wang & Soule, 2012). Similarly, as clients use narratives to mobilize support and attention, they are also developing and accumulating resources that they and coalition partners can use and draw on to support later "moves" (Feldman, 2004; Howard-Grenville, 2007; Pentland, 1992). As one specific example of this positive spillover effect, or "resourcing" of later influence attempts, stories can help different groups recognize a

new problem, develop a diagnostic frame for the problem, and possibly innovate a new prognostic frame with specific solutions (Snow, 2013). *Diagnostic* frames refer to interpretive frames that persuade that social change is needed, and *prognostic* frames persuade that social change is possible given specific remedies (e.g., Cress & Snow, 2000; Snow, Vliegenthart, & Corrigall-Brown, 2007). Cress and Snow (2000) argued that without a coherent frame that "specifies the problem, identifies culpable agents, and offers a specific remedy for the problem," a movement is unlikely to succeed. Our findings draw together these ideas to show that in our research setting, supportive staff allies were not commonly aware of the patients' task burdens so were not likely to mobilize a movement, and that patients did not have the access or influence to accomplish change alone. But the patient activists' storytelling practices mobilized and resourced a new internal coalition of supporters. Coalition members had new understanding and resources because of the patient stories, and then in turn brought their own occupational resources to bear and together with the patient activists created new resources to help change the expected division of labor.

## METHODS

### Research Context: Cancer Care Delivery System in the United States

We conducted this study at an academic cancer center in the United States (ACC). Cancer care in the U.S. is an opportune setting for studying the changing relationship between patients, professionals, and bureaucratic organizations, because of two broad trends in this care delivery system. First, the U.S. health care system is undergoing a well-established cultural shift where "patient-centered" care models and approaches are becoming more expected and valued (Mead & Bower, 2000; Stewart et al., 2013). This cultural change reflects a new expectation that "patients know best how well their health providers are meeting their needs" and that to be effective, providers need to hear much more from patients about their experiences (Rickert, 2012). Patient-centered care models involve many new ways that patients engage the health care delivery system, including through patient satisfaction surveys, patient and family advisory councils, focus groups, and participation in quality improvement work (e.g., Armstrong, Herbert, Aveling, Dixon-Woods, & Martin, 2013; Wiig et al., 2013). A leading medical journal described this

cultural shift as involving changes to "the traditional roles of patients and their families" – shifting them from passive 'order takers' to active 'team members'" (NEJM Catalyst, 2017).

Second, these emerging patient-centered frameworks and their corresponding engagement are coming at a time that the cancer care delivery system is seen to be "in crisis" (Bylander, 2013; Institute of Medicine, 2013). One main issue is that cancer patients and their families encounter a considerable burden in coordinating many professional services as they seek care in the cancer care delivery system (Institute of Medicine, 2008, 2013). Often, a patient will have a team of specialists who all provide specialized components of their care, including a medical oncologist, a surgeon, and a radiologist who oversees radiation therapy (Fleissig, Jenkins, Catt, & Fallowfield, 2006; Junor, Hole, & Gillis, 1994). Each of these physicians has a large support staff including medical fellows, nurses, clinical trial coordinators, schedulers, and billing agents (Pruitt & Sportsman, 2013; Thygesen, Pedersen, Kragstrup, Wagner, & Mogensen, 2012; Wagner et al., 2014). Most patients also require the services of additional specialties such as in-patient hospitalists, dermatologists, cardiologists, or palliative care specialists, as well as non-medical specialties such as nutritionists, financial counselors, or social workers (Bernabei et al., 1998; Buzaglo, Karten, Weiss, Miller, & Morris, 2014; Del Ferraro, Ferrell, Van Zyl, Freeman, & Klein, 2014; Hurria et al., 2007; Rock et al., 2012).

These two trends intersected in the events that we observed at our field site. We began studying ACC's formal change process aimed at improving cancer care outcomes. We observed that the patients were influential actors in the change process in ways not yet accounted for in organizations research so focused our data and analysis there. To set the stage for our data, analytic approach, and findings, we first describe the research context, focusing on the initial task structuring that changed during the study.

**Research Context: Initial Task Structuring at ACC**

The initial task structuring at ACC reflected the dual-authority structure between doctors and managers typical of most academic medical centers (e.g., Empson & Langley, 2015; Pool, 1991; Tap & Schut, 1987), the peripheral status of the palliative specialty compared to oncology (e.g., Del Ferraro et al., 2014; Lorenz et al., 2008), and the invisible coordination work of patients and families, which was

11

"relegated to the background of expectation" and not part of anyone's job description (Daniels 1987; Nardi and Engestrom 1999, pg. 1; Star and Strauss 1999). To co-produce their cancer care, each patient interacted with a medical oncologist and also a variety of other professionals and specialists; this network of professionals involved both professionals that the main medical oncologist referred the patient to, and also additional services that the patients wanted to include. Understanding this network is helpful for understanding the patients' work coordinating their care. In some cases, the additional specialists became involved because the medical oncologist referred the patients to them during oncology clinic appointments. In some cases, the patients sought out the specialists on their own. These appointments wherein an oncologist and her team would interact with patients to develop a diagnosis and a treatment plan are central to the care delivery process and the task structuring of oncologists, auxiliary services, and patients and families. To establish the research context, we will first describe these appointments in detail. The data used to develop this description are described immediately below and in Table 2.

*Oncology Clinic Appointments.* Oncology clinic appointments were a main interface between oncologists and patients and were the occasions during which the oncologists made diagnostic decisions and treatment plans. One of the doctors explained to us in an interview that he worked within a "curative" paradigm, meaning he always focused on information relevant to whether and how a patient could be cured from their cancer. He said that given the stakes, not just for one patient but for the entire population of patients whose lives might be saved, he focused on distilling the patients' descriptions of their experiences to the information relevant to their ultimate prognosis. He expressed empathy about side effects and other concerns but emphasized that his specialized service was to cure people from their cancer; other aspects of patients' experience were extraneous to his specialized expertise.

This specialization is relevant to the task structure both because of how it played out during appointments, as well as because of how it created a need for patients to coordinate many specialists. Many of the patients' needs and concerns fell outside of the oncologists' "curative" specialization. Some of the patients' concerns were resolved by the oncologist directly, but many others were referred out to

12

other professionals, or pushed back to the patient to handle without professional support. When a patient's concerns fell into the oncologists' specialized expertise, they offered prescriptions, tests, scans, or counseling about behavior change. The most common example we observed involved the hematologists interpreting lab test results and adjusting the patients' treatment plans based on those values. In such interactions, the patients' issues fell squarely in the oncologists' service paradigm and they offered diagnostics, treatments, or counseling during the appointments. Table 2, column 1 illustrates examples of patients' needs that fell in the curative paradigm.

------------------------------------------------------------
Insert Table 2 about here
------------------------------------------------------------

However, another common response was for the oncologist to respond to patients' descriptions of their lived experiences by referring them to other professionals with a more relevant service domain. As an example, during an appointment, a patient showed the doctor a huge bruise and rash that had developed on his chest, and the doctor said he wanted someone from interventional radiology to look at it, and then put in a referral to that service. Another patient described being sensitive to the sun, and the doctor said he should consider seeing dermatology. Another patient said he was having somewhat regular chest pain, and the doctor asked if he was seeing a cardiologist. The doctors recognized how these particular aspects of the patients' lived experiences could be addressed within the service paradigm of another professional. Patients had to then go seek services from the other professionals. Table 2, column 2 gives illustrative examples of the many issues that the doctors referred to other professionals.

Finally, the oncologists also frequently pushed concerns back to the patient to handle without professional support. One patient described developing severe diarrhea after her chemotherapy, and the doctor responded that it was very common and not something to worry about. Clearly the patient would continue to worry about and deal with this symptom, but the oncologist's comment – working within his "curative paradigm" – meant that this symptom did not impact her cancer prognosis. The patient learned she would have to deal with this symptom outside of this service relationship. During the many visits we

observed, the doctors gave this response of "normal" or "common" or "expected" to patients' descriptions of leg cramps, fatigue, difficulty getting out of bed, diarrhea, weight gain, pinching pain under the ribs, vaginal itchiness and pain, numbness, back pain, swollen lymph nodes, and headaches, among others. As another example, after leaving an exam room where the patient had complained about strained bowel movements, an upset digestive system, and deep anxiety over an abnormal CT scan, the doctor commented to residents and other observers, "Nothing really wrong with her; her tumor is doing great." This comment illustrates how this specialized professional interpreted the information relevant to his service: his service was to cure cancer, and he was pleased with the information relevant to that particular service – he deemed that this patient was progressing towards what he hoped might be a cure. But of course, in her lived experience, it did not feel like "nothing was really wrong." Table 2, column 3 lists illustrative examples of the experiences that the doctors judged normal or expected – implying the patient was supposed to deal with them without the oncologist or referred professional supporting them.

*Patients and families coordinate multiple services.* The patients' and families' tasks therefore evolved to include coordinating the complex, multi-specialty, multi-site network of services they felt they needed and wanted when dealing with their cancer diagnosis. The dynamic illustrated above from the clinic appointments reveals in part why the patients and their families interacted with many different medical and other specialists as they coordinated their cancer care, which included getting help with the many side effects of treatment. They also sought additional help with other needed services such as mental health support, financial planning, survivorship, pain management, and nutrition. Interacting with this network of specialists involved calling or going to different offices with different administrative staff, learning about and accommodating different referral and scheduling practices, learning about and managing different paperwork, and IT systems, and navigating different financial and insurance policies.

*Initial task structuring of administrators.* The tasks of administrators can also be understood in relation to these formal service appointments. The oncologists made decisions about diagnoses and treatments during those appointments. They typically had large teams of nurse coordinators,

administrators, and schedulers who did the administrative coordination work of setting up those appointments, documenting decisions, and carrying out whatever plans had been made, for example by inputting referrals into the electronic health record.  The administrative/operations group carried out the work of scheduling appointments, registering new patients, checking patients in for the clinic appointments, and billing patients or insurance companies for thousands of appointments a year.

*Initial task structuring of palliative specialists.* The palliative specialists were involved with offering decision support or pain management plans, mostly for patients and families confronting the need for an end-of-life care plan.  The palliative care service was dependent on referrals from the oncologists. The palliative specialty was more developed in the main hospital (versus at ACC, the outpatient cancer center, the focus of this study), and this small specialty team was struggling to increase understanding and adoption of their services.  They were aware of oncologists' and patients' perceptions that palliative care was only useful in end-of-life scenarios, when all other treatment options were exhausted, and they felt that oncologists and patients were often reluctant to engage with them for that reason.  This struggle was common for palliative specialists at the time of this study (Boldt, Yusuf, & Himelstein, 2006; Del Ferraro et al., 2014; McIlfatrick et al., 2014; Zimmermann et al., 2016)  At the main hospital, this service was often offered at the bedside, but appointment structures were more variable in outpatient cancer care.

**Research Context:  Formal Change Process at ACC**

At the start of our study period, a group of patient-family donors sponsored a formal change process at ACC. The center leaders were asked to prepare a proposal outlining needed changes and plans for change.  The proposal began with a summary of the nation's 40-year "War on Cancer."  It framed the need for change around the lack of translation of basic research into improved clinical care.  Under this broad problem framing, several major initiatives were proposed, broadly relating to operations, scientific advance, and supportive care.  Important for this study's focus:  none of the problem framings and none of the proposed changes were focused specifically on dealing with the patients' and families' administrative work coordinating their care across multiple medical and non-medical specialists.

***Administrative groups propose new programs for operational excellence.*** The administrative groups framed their needed changes as system "re-engineering" efforts. These included efforts whose goal was "applying proven operational concepts" such as the Toyota Production's Lean methods, as well as programs focused on training administrative staff to be compassionate, effective communicators when interacting with patients. Initiatives in this section were focused on identifying promising quality improvement programs, lowering their costs, and "scaling" learnings from these programs.

***Oncologists propose advancing science for new cures.*** In contrast, the oncologists and other medical specialty groups framed their needed changes in terms of advancing scientific discovery and then translating those discoveries into clinical care. These initiatives included "pushing the frontier on cancer prevention" or "developing novel diagnostics and therapeutics based on science" or "incorporating various genomics, proteomics, etc. into the standard of care." These initiatives also included funds for recruiting additional physician-scientists who could lead basic science discovery studies.

***Palliative specialty peripheral in the original plan.*** Palliative care was barely touched on in the proposal. It was mentioned once, in a short phrase, listed together with survivorship and supportive care. The proposal defined palliative care as "providing specialized symptom management to patients nearing the end of life." The proposal earmarked funds to "expand the breadth of services" and recruit staff "for continual improvement of the clinical services, research, and dissemination."

***Patients and families formally involved in the process.*** Patients and families were included in the original plan for change in several ways. First, the patient-family donor requested the proposal, requested revisions, and approved the final framing and plan. The proposal also paid for and required both patient activists and health services researchers to join the change process and further develop more ways of hearing about patients' experiences at the cancer center.

**Data Sources**

We proposed to study ACC's formal change process. Very soon after we began our data

collection, we realized that a major interaction pattern playing out in most meetings that we observed involved patients and families telling stories to describe the enormous coordination burdens that they faced while seeking care. We expanded our data collection to focus specifically on understanding the nature of the patients' coordination work, and to understand whether and how the patients were influencing the change process. We collected data over a three-year period (Table 3).

-----------------------------------------------------------
Insert Table 3 about here
-----------------------------------------------------------

*Observation of patient-doctor encounters.* We observed a full month of clinic visits for 5 different oncologists in two different clinical areas. Each clinic session usually lasted about 4 hours and consisted of between 8-16 visits. We used a standard chart to record much of the interaction, jotted free-form notes immediately after the visits, and recorded fuller notes after the clinic session. We observed considerable variation in how physicians responded even to similar complaints (Table 3). Practice variation is a common pattern in medical care (Corallo et al., 2014; Davis, Gribben, Scott, & Lay-Yee, 2000) and our main point in illustrating these data is that all of these physicians commonly responded to many patient complaints by using referrals to other specialists. These appointments provide key context, but these data are not analyzed as part of the findings on the change process.

*Observation of patient participation in formal change process meetings.* The main data that support analyses related to changes over time were the formal change process meetings. We observed many meetings at the cancer center for over eighteen months. These meetings were organized around several initiatives aimed at improving patients' experiences, eventually including the development of the new integrative program that they called CarePoint. We also observed Patient-Family Council meetings.

*Observation and interviews with patients in their homes or at the cancer center.* As the change process developed, ACC staff and patient activists created opportunities to hear from more patients about their experiences. Members of the author team helped support this data collection. We either interviewed or accessed interview transcripts of 52 patients; 28 were conducted at the cancer center and 26 during home visits. These interviews took several hours and were conducted in the patients' homes, often with

17

their family members also participating. These interviews were recorded and were supplemented with many de-identified photographs of the settings and tools. These interviews were open-ended and focused on asking the patients to show and demonstrate their activities involved in co-producing their cancer care. The questions and transcripts were created with the patient activists and their staff allies, even though we as the author team sometimes helped collect these data. We were participant observers doing work directed by different actors that allowed us to understand interactions and events as they played out.

*Patients' handwritten comments.* As part of the change process, the patient activists and health services researchers also developed and collected thousands of surveys about patients' experiences and satisfaction. The surveys used standard questions to assess patients' satisfaction with their care. Patients often filled in handwritten comments on the backs of the forms. During one six-month period, over 3000 patients wrote handwritten comments on the backs of the surveys. We obtained access to these de-identified free-form comments and analyzed them as participant observers. Some of the handwritten comments included stories of coordination burdens which the patient activists used in their work.

**Analytic Approach**

Using the data described above, we focus in this paper on analyzing how the patient activists used stories in ways that influenced the structuring of a new cross-functional program referred to as "CarePoint" which was newly funded from the cancer center's operating budget. We conducted a longitudinal analysis of key events that unfolded between the formal change process beginning and the first several operational meetings of CarePoint, which represented a change in the task structuring between patients, professionals, and ACC administrative staff. We also conducted several other analyses that shaped this study. We coded all of the patient stories to develop a comprehensive understanding of patients' invisible work in coordinating their cancer care (e.g., Daniels, 1987; Oudshoorn, 2008; Parks et al., 1981; Star & Strauss, 1999). Through these analyses, we realized that a key way that patient activists were engaging the ACC staff was specifically by telling stories about their coordination burdens. We turned to prior research on stories and narratives in collective action (e.g., Polletta, 1998a; Polletta et al., 2011) to help us understand the use and influence of stories during this change process.

***Analytic use of comparisons.*** To explain how the patient activists' use of stories influenced the formal change process, we used two forms of comparison. Our first analytic use of comparisons relates to comparing how plans changed over time. The formal change process involved many documentation requirements, so we are able to closely analyze how the plans for change evolved over time, even into new program implementations. The issue of "coordination burdens" or the "Cancer Tax" was not framed in the original plans. And, the cross-occupational coalition that formed around that issue also emerged during the study period, and was not included in original plans. Second, we also compared the influence of different kinds of patient engagement that we observed during the study period. This approach holds constant the source of the persuasive communication, allowing us to loosely rule out arguments that the process we observed was independent of the mode of patient engagement. This analytic choice allowed us to focus on how patients' *stories* in particular were used, and to what effect. We compared the patient activists' use of stories to two other forms of patient engagement. One we characterize as "patient voice" which is an emic but broadly used term to refer to patients' proactive feedback and ideas about quality improvement initiatives. The second is patient complaints. We included complaints because they have negative valence and prior research has shown that "bad" is stronger than "good" in organizational decision-making (Rafaeli & Sutton, 1991; Sutton, 2010). These two comparisons – between original and changing plans and between different patient engagement initiatives – allow us to illustrate a process theory accounting for how and why patient activists' use of stories successfully changed the task structuring between them and ACC staff.

**FINDINGS**

The patient activists and their families were struggling under the amount of work they had to do to coordinate their cancer treatment. During the formal change process, they engaged with ACC staff to make this problem visible and illustrate its harmful consequences. Over the course of the study period, they effectively persuaded ACC to take on some of the coordination work that they had previously done themselves; ACC created and funded a new administrative program run by a new staff member. Her

tasks involved coordinating referrals to multiple auxiliary services on behalf of patients, as well as coordinating the cross-specialty management of some complex cases that would benefit from extra auxiliary service support. These coordination tasks had previously been done by patients and their families at home, through unpaid and invisible work.

How were the patient activists able to successfully challenge and change the division of labor between themselves and ACC staff? We observed that the patient activists employed a common social movement tactic: they told stories that illustrated the collective suffering caused by their coordination burdens (see Figure 1). Similar to what has been observed in prior research, their use of stories was an action-oriented tactic in this movement that "built a shared movement community" and "incited and sustained mobilization" (Hunt, Benford, & Snow, 1994; Olsen, 2014, pg. 250; Polletta, 1998b). We observed three related storytelling practices: the patient activists continuously shared their own stories with staff allies, developed formal channels for collecting more stories, and worked to broadcast the stories across ACC. As illustrated in Figure 1, over time, these storytelling practices mobilized a small but powerful cross-occupation coalition that consisted of senior administrators, multiple oncologists, nurses, administrative staff, and palliative care physicians who had all been attending the formal change meetings; this group developed a shared commitment to change. The patients' narratives preceded the cohering of this coalition, and over time helped the coalition develop a new framing for their issues illustrated in the stories. The members of the coalition began to refer to "coordination burdens" as well as the "Cancer Tax" that ACC was putting on patients.

```
-----------------------------------------------------------
                Insert Figure 1 about here
-----------------------------------------------------------
```

Still, at this point the patient activists had only mobilized a coalition around a new problem, and a *diagnostic* frame for that problem – the diagnostic frame persuaded that social change was needed and that ACC as the coordination system was the source for needed change (Snow, 2013). At this point there was still no *prognostic* frame that change was possible given the right remedy. It was challenging for

patient activists themselves to provide the prognostic frame; as outsiders to the daily work of ACC, their ideas were often seen as too radical or infeasible within the current jurisdictional truce between administration and medicine. Ultimately, changes to task structures only came when the palliative care team, a group in the coalition, drew on coalition resources to alter their typical influence moves. In the past, the palliative care doctors had been working on changing perceptions among both oncologists and patients about palliative care services. But over time, their involvement in the cross-occupational coalition and in the development of the "cancer tax" diagnostic frame provided them new resources.

They developed a new *prognostic* frame that offered a new idea for how to address some of the patients' coordination burdens. They developed the idea of a centralized administrative program called "CarePoint" that would bundle and coordinate access to auxiliary services (see Table 4). Their proposal expanded the scope of the issues for which they were typically responsible. Senior administrators agreed to fund the administrative jobs that would run the new program out of the cancer center operating budget.

------------------------------------------------------------
Insert Table 4 about here
------------------------------------------------------------

**Client Storytelling Practices**

The patient activists engaged in three related storytelling practices. They continuously shared their own stories with staff allies, they developed formal channels for collecting more stories, and worked with staff allies to broadcast the growing set of stories across ACC. This set of storytelling practices was a deliberate influence tactic focused on making the case for change. Several times we heard the patient activists urgently use the phrase "the case for change has not been made" as they discussed creating the channels for collecting more stories and the formalized presentations for broadcasting the stories more widely. Table 5 summarizes these three storytelling practices and illustrates each with data.

------------------------------------------------------------
Insert Table 5 about here
------------------------------------------------------------

21

*Stories as persuasive communication.* To explain the influence of these practices, it is useful to first explicitly unpack the narrative structure of patient stories as persuasive communication. As Polletta et al. (2011) notes, telling stories involves describing a sequence of events with ambiguous or implied causes, therefore inviting the listeners to interpret the events, the causes, and the moral of the story. As an example, consider the following story told by one of the patient activists:

> When I was in treatment, I was down. My wife was in a new country with essentially no husband; she was taking care of our two-year old, and all of this paperwork, and appointments, and scheduling, and medication. It was a full-time job. We need to have in mind that family member is also a main actor in this while the patient is down. The family member does most of this coordinating.

With this short story, the patient activist introduced a sympathetic set of actors and described them going through a set of events that the sympathetic ACC staff could interpret: "*Wait, It's like a full-time job? That shouldn't be happening*" because of the role incongruence of being a beleaguered spouse while doing full-time coordination work. The story structure also encourages the next interpretive move to resolve the feeling of wrongness and dismay at the incongruence, "*Why is that wrong outcome happening to the sympathetic actors?*" Hearing so many similar stories, from so many patients and family members, the ACC staff were confronted with a sense of systemic but preventable suffering among the populations they were supposed to be caring for. In interpreting "*why is this happening*?" the ACC staff – whose professional identities were as caregivers – had to reconcile the interpretation that the ACC "system" was contributing to the patients' burden, even though their moral obligation as caregivers was to relieve suffering. Table 6 summarizes the narrative elements of emplotment, sympathetic actors, implied moral, and identity implications of stories as persuasive communications.

---------------------------------------------------------
Insert Table 6 about here
---------------------------------------------------------

*Telling stories to build the movement.* One of the patient activists' main storytelling practices was to share their own personal stories with each other and with supportive ACC staff allies, especially during informal interactions. A key setting for this informal personal storytelling was the change

22

meetings, patient activists attended these meetings and shared their own stories in most of these meetings. The same narrative elements are seen in each of the patients' stories during change meetings. Another patient activist told this story:

> It's a big challenge for patients. They have to navigate through very cumbersome web sites, the phone numbers that might not be providing the information that they need. It takes a tremendous amount of time. I can tell you organizing an imaging study for myself, it took me four weeks to get an appointment and many phone calls to find the person that does that. It turned out to be right next to my other clinic. I shouldn't have to go through the maze of people I need to call.

As another example of a story told in a change meeting, a patient activist recounted this narrative, "Once I was sitting in my doctor's office, and we discovered (an emergency situation). They told me that scheduling with (the specialist who would help with the emergency situation) was an entirely different system—it was different scheduling. They couldn't help me." She said she had to separately contact the other specialist and wait until they called her back at 10pm, and rearrange several appointments.

*Creating channels to collect more stories.* In addition to sharing their own stories many times in in meetings with other patients and supportive staff, the patient activists also worked with ACC staff to create more ways for patient stories to be heard. One of these new channels included interviews conducted at the center and in patients' homes. Every patient interview collected new stories of patients' coordination burdens, and all of those included these same narrative and persuasive elements as above. The stories described both how many different professionals the patients ended up seeing, and also how much work was involved in coordinating the care with these professionals. A patient told this story,

> I must have seen 50 different people here, and I'm not exaggerating. I mean, between ... I had 13 different doctors, and that's not counting anesthesiologists. They were great about… like if I had something (a side effect of treatment), they'd send me to a specialist, and the specialist would try to fix it… But it also just scattered me more.

Another patient told a similar story in an interview: "What happened was I had the plastic surgeon. And then I had a surgeon that cut off everything. Then I had an oncologist. Then I was going to dermatology because I had this thing on my face [a side effect related to the treatment]. Then I was going to the podiatrist because my toes got infected. Then I was going to bariatrics because I had surgery in 2005, so I couldn't take anti-inflammatories." During a home visit, following his wife's description of how many

23

specialists she had seen, one spouse explained that he had quit his job to provide care for his wife during her cancer treatment. He said, "Part of my job is home health aide, paper pusher, errands on demand, and whatever else was required." In an interview, another patient said, "I let my wife go back to work and I would stay home during the day, and she'd come home after work and we'd take my meds and we'd do all the forms and tests and everything at home. She was still the primary caregiver after a full day's work." While telling these stories in their homes, the patients and family members also showed the tools they created to keep track of all of the medical and non-medical specialists with whom they coordinated their care (Figure 2). These are pictures of notebooks with many business cards of medical and non-medical specialists taped to them, with additional phone numbers handwritten in the margins.

------------------------------------------------------------
Insert Figure 2 about here
------------------------------------------------------------

The patient activists and an ACC staff member also created a specific "Patient Stories" initiative. They created a dedicated phone line and advertised it to patients as a way to "Tell Your Story." Many patients called and left their stories. Like the shorter stories told by patient activists in change meetings or by other patients in interviews, the recorded stories left on this phone line took the listeners through the series of events with the sympathetic patient. Like other stories, these recorded stories laid out a sequence of events that illustrate the complexity of the system and the work required to navigate it.

*Broadcasting stories to broader audiences.* A third related storytelling practice included the patient activists working to broadcast their stories and the additional patient stories they collected. The work of broadcasting stories was more formalized than the interactions during smaller change meetings wherein the stories were woven throughout the smaller group discussion. The patient activists worked with staff allies to prepare formal presentations for either ACC leaders or large groups of ACC staff. During these formal presentations, they worked to emphasize the sheer number of stories, for example sharing that "thousands of patients" had "turned their surveys over and handwritten comments." They also selected and shared specific stories that were particularly emotionally evocative. For example, the

24

patient activists and ACC staff together decided to include the images from Figure 2 in presentations to the oncologists. Examples of broadcasting practices are also described in following sections.

**Clients' Storytelling Practices Mobilize a Cross-Occupational Coalition and New Diagnostic Frame**

In the next three sections, we analyze how patient activists storytelling practices influenced the structuring of the CarePoint program, which was not included in the original formal change proposal. We were onsite at the cancer center for over 30 hours a week and observed many initiatives after the ACC leaders launched the formal change process. One change initiative was notable in our observations, because it was at their weekly meetings that we and many ACC staff first interacted with the patient activists and heard their stories. This initiative was tasked with reimagining the oncologist clinic team structure to be more patient-centered. The initiative began with a series of weekly meetings, including participants from many different occupational groups (see Figure 3) and senior leaders in administration, nursing, and medicine. It was at these particular meetings that the patient activists first and then quite consistently told the stories of their coordination burdens and invisible work.

------------------------------------------------------------
Insert Figure 3 about here
------------------------------------------------------------

This weekly meeting involved a common interaction pattern related to the patient activists' stories. The group would discuss a particular plan or intervention, and one of the patient activists would respond with a story that illustrated how a related issue had affected them. As a representative example, the group was discussing the scope of their plan and whether it should include coordinating with the main hospital. One of the patient activists told a story about finishing a harrowing 14 week stay at the hospital where he had been receiving aggressive chemotherapy treatments. His discharge from the hospital meant he was transitioning to outpatient care for the remainder of his treatment. He had not been able to see his young son during this period of time, so his wife brought their son to pick him up after he was finally released. He recounted the moment, standing in the hospital lobby, when his wife and little son ran up to him, and how they felt collective relief at finally being together again. He said that soon, after a few

minutes, his wife said, "OK, now where to?" and they were both dismayed and afraid to realize they did

not know where they were supposed to go for the next steps of his treatment or who even to call.  His

wife began to research – again – how to arrange the next part of this treatment.  Having told that story, he

reminded the meeting participants, "The hospital and cancer center seem like they aren't the same

organization, but they are the same to us. The transition is chaotic. It should be one entity for us."  Later,

one of the consultants found a similar shorter narrative shared in a handwritten survey comment:

> The most difficult part of our experience at the cancer center was when my husband transitioned
> from inpatient care at the hospital to outpatient here. We felt they did not do a good job
> explaining the continuum of care offered at the cancer center and how all the different areas
> operate and support one another.

The above example is representative of this meeting dynamic. The consultants or staff would discuss

different plans and the patient activists often responded with personal stories about their experiences.

Over time, the set of stories expanded to include the many patient story interviews and initiatives

described above. And, more meeting participants began to refer to the events and themes in these stories.

*Cross-occupational coalition.*  This weekly meeting was notable because of the continuing

attendance and active participation of the diverse members of many different occupations, as shown in

Figure 3. Even though the formal initiative that was the focus of these meetings was delayed and

redirected, the powerful cross-occupational group spent a year interacting with patient activists. Our

analysis suggests that this group can be understood as an informal cross-occupational coalition that

developed in support of the issues raised in the patient stories.  Members mobilized support and other

changes throughout the cancer center, eventually including the creation of the CarePoint program.

We interpret this group as an informal cross-occupational coalition that cohered around the issues

illustrated by the patient stories for three main reasons.  First, this group developed a sense of shared

movement community that was new and was inspired by their desire to help address the suffering

illustrated in the patient stories, consistent with prior research on shared movement forming around

movement narratives (e.g., Polletta & Jasper, 2001).   Second, the group together created new resources in

26

support of change that were distinct from any occupation's original resources, which is consistent with prior research on resourcing and coalitions (e.g., Howard-Grenville, 2007; McCammon & Moon, 2015; Wang & Soule, 2012). Third, members of this group each used their distinct occupational resources in support of this new sense of needed change, thereby sharing resources in ways that were similar to what has been observed in movement coalitions (e.g., Van Dyke & McCammon, 2010).

With regard to the first theme, the group that met at these meetings developed a sense of shared movement community that cohered across all of the occupations. When each member first engaged at these meetings, they had specific interests related to their occupation that were not immediately aligned with the issues raised by these stories. In the past, each had been pursuing their own interests as illustrated in the original change proposal. Over time, they began to recognize this cross-cutting issue represented in the patient narratives, and to express interest in that issue during these change meetings. In so doing, they were compromising their singular focus on their own occupation issues in ways their broader occupation's members were not doing. One of the oncologists represents a striking example of a change over time. During one of the first meetings, a consultant referred to a published academic study about needed improvements in care coordination, and an oncologist responded by saying, "Is this really about care coordination? It seems we need more to build *trust* with the patients from the start." Several staff members weighed in, and then a patient activist said, "For us, we didn't know what to expect and there were so many discrepancies between team members' knowledge of the plan. There were lots of calls that needed to be made, and we had to do it." After many such interactions, ten months later that same oncologist said in that weekly meeting,

> I think that when it comes down to care coordination, too much is put onto the patient nowadays, meaning that the patient has to make effort to understand the system, and get consolidated opinions from everyone. I think that a key point of care coordination is to help the physicians talk to each other to exchange information and plans that are necessary for each of them to know.

Over time, the other group members began to refer to these care coordination issues, even when not responding to one of the patient activists telling a story. For example, during a meeting when none of the patient activists were present, a nurse responded to a consultant's idea by saying, "But that does place the

emphasis on the patient doing the work. We don't want that. We don't want the patient doing the work."

As another example, one of the staff members said in an off-hand hallway conversation before a meeting,

"There's all of this kerfuffle like, 'Oh, this is so complicated for us!' I'm like 'Yes, but we were right now

making it really complicated for the patient, and *they are absorbing all of our chaos*.'"

As more evidence of the shared movement community, group members also began to respond to

patient activists' stories and comments in supportive ways that indicated solidarity. As an example, one of

the patients began a comment by saying, "Not to be devil's advocate, but…" and a nurse leader replied, "I

don't see that as playing devil's advocate!  It reflects those human values.  We're not building cars, we

are dealing with people here."  As another example, a patient activist acknowledged the inefficiency of an

idea but concluded, "At the same time I want someone to hold my hand.  It is really, really scary."  An

oncologist responded, "Yes.  Multidisciplinary care coordination.  [David], (the patient activist) is making

a good point.  We're on the same page."  Another time, a patient activist described a compassionate nurse

who had been helpful, saying she was "a hovering angel – protecting patients and family members while

they do all these other things" (i.e., as they go through the experience of treatment).  It was unusual

language for the boardroom, but the senior executive administrator met the comment by replying, "You

need those angels on the ground walking with you and watching you from above when you go into other

groups" (i.e., as the patient moved between hospital and cancer center, or between the clinic and

chemotherapy center).  As Figure 3 illustrated, this cross-occupational group met actively for almost a

year, discussing specific issues and hearing patient stories. Over time the group felt cohesive and

interacted in ways that demonstrated that they were all on the same page in their support for their issues.

The following interaction, described in our field notes in month 11 (Figure 3), illustrates the cohesion and

shared understanding of the group that had developed:

> A social worker visited the group and explained yet another helpful program that they were
> thinking of developing.  Doctor [Steele] (a new doctor to the initiative) who had just joined the
> group meeting late joked, "Another one?  It will be a fulltime job to become a patient!" At the
> same time, most everyone else in the room shouted, "It already is!" and then everyone laughed.

28

The group members also began to refer to their shared "principles".   A nurse leader summed up a meeting by saying, "This meeting is great.  [These ideas] will be our guiding light."

The second reason for interpreting this group as an informal cross-occupational coalition was that together they created new resources in support of change that were distinct from any occupation's original resources (e.g., Howard-Grenville, 2007; McCammon & Moon, 2015; Wang & Soule, 2012).  With regard to this second theme, after interacting with patient activists and hearing their stories in this meeting, this group also developed a new *diagnostic* framing for the problem illustrated in the stories (Snow, 2013).  The members of the coalition developed specific language that they used to frame the "coordination burdens" as well as the "Cancer Tax" that ACC was putting on patients.  This diagnostic frame was a new resource developed during interactions among coalition members around the patient narratives. This diagnostic framing was not developed by the patient activists, who engaged more by telling stories.  In reviewing our data, we found evidence of ACC consultants using the phrase "patients and family members take on the *burden* of coordinating their care" early in these meeting agendas; over time many meeting participants began using the language of "coordination burden".  The first time we heard someone use the phrase the "Cancer Tax" was during month six of these meetings; that phrase does not appear in change proposals or written meeting materials before that.  The "Cancer Tax" phrase became more common in this meeting group later in this and the following year, and it also began appearing in many other organizational settings.  This theme exemplifies how the coalition, interacting around the patient stories, developed new resources for change, grounded in the now visible suffering and implied moral of the patient stories.

The third reason for interpreting this group as an informal cross-occupational coalition was that members of this group each used their distinct occupational resources in support of this new sense of needed change (e.g., Van Dyke & McCammon, 2010).  Each coalition member had different resources because of their occupations, and over time, each coalition member brought their various occupational resources to bear in mobilizing support for this issue, which is also consistent with prior research on coalition formation and resourcing (e.g., McCammon & Moon, 2015; Van Dyke & McCammon, 2010).

We note this point here because it supports the interpretation of this core group as a coalition, but we use the full next findings section to illustrate how each member brought their distinct occupational resources to bear in support of the coalition interests mobilized by the patient stories.

**Cross-Occupational Coalition Mobilizes a New Value Commitment across the Organization**

The change meeting described above provided occasion for the patient activists to share stories with a powerful cross-occupational group; over time, through these interactions, the group cohered, mobilized, and developed resources as an informal coalition responding to the issues made visible in the stories. The cross-occupational coalition members then used their various resources and memberships to broadly communicate this new diagnostic frame that change was needed to their various occupational groups at ACC, helping change the sense of the "value commitments" for which ACC was accountable (Greenwood & Hinings, 1996, pg. 1039). Recall that coalition members included senior administrators, senior nursing leaders, oncologists, palliative care physicians, front-line nurses, many administrative staff, consultants leading the change efforts, and the patient activists (as illustrated in Figure 3). Senior administrators and nursing leaders contributed resources related to formal communications, staff time, and meeting spaces and agendas. Oncologists contributed resources related to their status and professional autonomy; their opinions were often solicited in meetings, and oncologists publicly voicing support in favor of change carried weight.

One senior executive who was involved in this coalition and attended almost every meeting began including the issue of patients' coordination burdens on the agenda of other meetings that he controlled, including with his direct reports, with other executives, with oncologists, and with the entire staff of the cancer center. For example, after several months of attending the change meetings, he newly introduced these themes in his routine weekly operations meeting with all of his direct reports, which included the mid-level managers of every ACC function. He used the phrase "Cancer Tax" when describing the change efforts of this coalition group, which was the first time one of us heard an ACC leader use the phrase outside of the coalition meetings, though it became more common later.

30

He and one of the medical directors also facilitated the monthly meeting of all of the oncologists at ACC. This meeting was in the evening and was a formal invite-only meeting, where issues of interest to all ACC oncologists were discussed. The executives and directors frequently reported on the formal change process, because it was impacting many aspects of ACC, including basic science grants and oncology faculty recruiting. Notably, one of the oncologists who later became an advocate for care coordination issues vocalized opposition to the idea at this meeting at the start of the formal change process. He said that he thought an internal administrative change focused on clinic flow was a "great improvement" but that he "did not care" about the proposed design processes related to care coordination, which "did not add value that [he] could see."

After several months of attending the coalition meetings, the executive and medical director again dedicated more of this oncologist meeting time to the Cancer Tax issue. They invited the patient experience design team to present based on all of the home visits and interviews that we described above. They showed pictures in Figure 1 of the patients' handcrafted coordination notebooks to the oncologists during this evening meeting in the formal board room and shared some of the stories the patients had told. The presentation was evocative and was referred to many times later. The presentation included an archetypal storyboard for each patient "type" the researchers had met, telling the story of how each "type" of patient responded to their diagnosis and treatment, including their coordination burdens. We heard an oncologist later refer to that presentation with other oncologists. She said, "No remember – we heard that – it is important to give the patients permission to ask more questions – remember from that study – some of them wanted to be "The Good Patient" who did not bother anyone. Sometimes they are trying to take care of us by not asking for what they actually need." This executive and the medical director continued to structure the agenda of the oncologist meeting to include discussion of patients' coordination burdens and collective attempts to address that problem.

This executive and other senior administrators also then later sponsored an ACC-wide meeting dedicated to the formal change efforts. They approved time away for all the staff, secured a large formal

31

ballroom at a nearby center, and structured the agenda. Notably, the executives structured the meeting agenda to begin with the patient activists making their case for change. The coalition executives continued to mobilize their resources, including sponsored access to an ACC-wide agenda setting event. The executive made the case for change and introduced two patient activists who introduced themselves by telling their stories. One told about his own treatment experience but emphasized how much his wife had struggled trying to care for him and coordinate the details of his treatment. The other activist told about her husband who was currently in treatment and the amount of work she and her family were having to do to coordinate his care, emphasizing the dehumanizing aspects of trying to interact with a bureaucracy on behalf of a sick loved one. One of the staff allies, and a coalition member, then presented a formal powerpoint presentation that shared related themes from the patient interviews. Throughout this event, the nurse leaders and oncologists who were involved in the coalition also voiced their support for the patient activists and various initiatives that were developing to respond to the care coordination issues.

A senior nurse director was another coalition member who actively attended and participated in meetings with patient activists and later used her own position and resources to mobilize awareness and support for these issues. She also structured many of her meeting agendas to include issues related to the Cancer Tax, and publicly spoke about the importance of the issue. She was also in charge of training the ACC nurse workforce, and often brought up issues of care coordination in training meetings. For example, she told her direct reports that it was their job and a priority to "make things more seamless for the patients." As another example, in another meeting with clinic nurses, she elaborated,

> We do work, but we don't communicate. Now we need to understand what processes stand in our way. We need to fix things that don't work. This can be accomplished with simple things: calling one day post-hospital discharge to ask about meds and upcoming appointments. Help get them support in dermatology, infectious disease, palliative care, finance.

In these meetings, she attributed the cause of the patients' coordination burdens to "broken processes." She said several times that to "fix patient care, we need to fix broken processes."

*Evidence of broader mobilization of Cancer Tax framing.* Over time, we observed that many

32

other staff members regularly used the Cancer Tax problem framing, even in meetings where the patient activists and coalition members were not presenting or leading the conversation.  As another example, in a large staff meeting, someone from the digital tools design team came and presented some research and design ideas for tools that might be useful to patients.  She showed an application that would let patients upload documents and images.  Staff in the audience asked about the use case for the app.  As she brainstormed a few, she mentioned that it would allow the patients to upload images at home (something that the nurses or medical assistants were often doing before).  Someone in the audience mentioned that there was a "fine line" between making patients' lives easier and "adding to their Cancer Tax."  That staff member continued, "we are outsourcing more and more work onto the patient, this might just add to their work."  As another example, when a high-level manager was launching an unrelated program, he brought up the idea in front of a large group of staff.  He talked about how doctors do really well with their specialized work, but there are so many other players including "medical assistants, residents, nurses, physicians' assistants," and sometimes the patients end up being the "human glue" between all of those team members who come and go.  He said that all of these players ended up adding to the patients' Cancer Tax.  As another example, an oncologist heard about some patient feedback and responded to it in a workshop meeting: "It really is our job as clinicians to take the patients' experience and turn it into an integrated service.  If we have a young woman who is pregnant, who is not going to die, who has postpartum depression after her chemotherapy, it is our job to get her to survivorship or psych-oncology."  These are representative examples of the broadening awareness about the coordination burdens that the complex ACC system was putting on patients and families and evidence of the changing sense of value commitments for which ACC was accountable (Greenwood & Hinings, 1996).

**Peripheral Professional Group Draws on Coalition Resources to Develop a New Prognostic Frame**

The data above illustrate that the patient activists and other coalition members had mobilized a new *diagnostic* frame for the problems illustrated in the patient stories (Snow, 2013).  At this point, even though there was a changing sense of support and of the value commitments for which ACC was

accountable (Greenwood & Hinings, 1996), there was still no *prognostic* frame that change was possible given a specific 'remedy' (Snow, 2013). The palliative care team, who had been a somewhat peripheral group at ACC in the past, drew on these accumulating resources to develop a new *prognostic* frame that offered a specific idea for how to address some of the patients' coordination burdens.

They developed the idea of a centralized administrative program called "CarePoint" that would bundle and coordinate access to auxiliary services – including palliative care. Their idea for this program was not included in any of the original change plans, was responsive to the patient stories, and expanded the scope of the issues for which palliative care was typically responsible. Their framing of the proposal acknowledged and claimed this expansion. They said they used to be narrowly focused on "big P" palliative care, meaning their own profession as a capitalized proper noun, but that they proposed to now also develop and offer patients "little p" palliative care – meaning any care focused on relieving patients' suffering, including their coordination burdens. They framed "little p" palliative care as providing comprehensive care for everything the patients needed, including all auxiliary services, and including helping the patients access and coordinate all of those auxiliary services.

The palliative care team developed this broader framing for their program after participating in the coalition meetings where they interacted with the patient activists and heard their stories. Their involvement and participation in the coalition allowed them to draw on the developing resources of the coalition, including seeing which diagnostic frames resonated in this setting at this time (Howard-Grenville, 2007; Wang & Soule, 2012). They also benefited from their affiliation with other coalition members. As they began to scope the idea of CarePoint and socialize the idea with various groups, they received help selling the issue from other coalition members. As an example, the nurse director introduced the palliative care team and their idea at several meetings, lending her position and authority to their ideas. During one such introduction, the nurse director described the "Cancer Tax" motivation and described the developing plans for an integrated care program like CarePoint. The palliative care doctor then introduced the main idea, saying, "We, the care teams, are good at curing and treating cancer, but

34

that is only one component of care." The nurse operational director then added,

> As a (cancer center) team, we have the resources here to improve these other aspects of care; but we need to operate as a team to create a foundation for patients and families. We want to provide the whole experience for the patient. Anything they need, we find it for them. It would be wonderful if they walk through the door and everything they need [is] addressed... from financial issues to nutrition to aging/geriatrics... palliative care, derm(atoloy), nutrition, psycho-oncology

She ended by saying, "What does this look like? We're not entirely sure yet." A patient activist summarized: "We're saying we have the services, there is just no connection. And this brings it together." The palliative care team thus reimagined the scope of their program design together with the other coalition members and patient activists, and received their helping selling their vision.

**Managers Allocate Resources to Change Task Structure**

All of these influence moves culminated in a key event, when ACC leaders formally agreed to allocate specific resources to fund the CarePoint program. The palliative doctors had formalized a pitch deck and successfully pitched the senior executive, medical director, and nursing director during a boardroom interaction. Each of these leaders had also participated in the cross-occupational coalition meetings. These leaders agreed to fund and structure the administrative jobs that would run the 'little p' program in collaboration with the palliative care doctors. We observed the meeting where this palliative care team presented a slide deck outlining the newly envisioned CarePoint program:

> 11:30am meeting. Sonali, a palliative care physician, and Beth, her intern, are meeting with the vice president, medical director, and nursing operations director. Beth brought five copies of a presentation that she and Sonali perfected last night. Sonali carefully talks through the slides, which lay out a case for better integrating more of the center's services. The senior leaders nod along "yes yes yes" – they've heard this framing many times.
>
> The ACC leaders become animated and concretely solution-oriented after the pitch. They brainstorm how to structure an integrative program: who will run it? – a new dedicated FTE (full-time employee) will be needed; – who will she report to? – probably "up through" nursing operations; – where will she sit? – an empty desk outside the directors' office; – what budget line? – again, nursing operations. Within 30-minutes, the decisions have been made. A new FTE has been resourced with space and budget and structured into an existing reporting line.

They agreed to newly funding and structuring CarePoint. They discussed how to structure it, which involved politically complicated issues including reporting relationships, where staff were located, and

the configuration of supporting IT and phone systems. The senior vice president took responsibility for routing the funding to the program and for changing the reporting relationships. The four also agreed to create a new role: a dedicated CarePoint program manager. The nursing operations director took responsibility for creating that hiring line and for hiring a new staff member.

We observed the first several meetings of the new integrative CarePoint program. A large group of physicians, nurses, administrators, and patients met in a large conference room. Their first meeting involved designing an integrated referral form that created a "work around" for the lack of direct referrals from oncologists. The group also ceremoniously handled their first patient case: multiple diverse service-providers discussed how they could each support a patient whose disease and social situation were both particularly complex. Several weeks after this first meeting, the medical director sent out this description to the entire ACC staff:

> CarePoint is a new single-point-of-contact program that connects patients to many services and programs at ACC such as: Palliative Medicine, Integrative Medicine, Pain Management, Cancer Supportive Care, Adolescent and Young Adult Program, Survivorship, Social Work, Psycho-Oncology, Neuropsychology, Nutrition, Spiritual Care, Financial Counseling, Resource Library with translation services, Ostomy/Wound care, Genetics and Genomics, to name a few.

CarePoint was thus launched, and ACC staff began to bring it to life through their ongoing activities.

The CarePoint program structured a new expected division of labor. Previously, much of the expected division of labor in informing, referring, scheduling, and coordinating auxiliary services involved patients' and families' invisible work. At the end of the study period, a full-time program manager answered calls to CarePoint and helped coordinate those auxiliary services. Some referrals could come directly from CarePoint or patients themselves; other referrals still had to come from the oncology care teams, but the CarePoint manager educated and informed patients and families about those programs and helped them know how to get referrals. The CarePoint team also directly coordinated complex patient cases during their meetings, where different specialties discussed how they could contribute to whatever patient cases were being discussed that day.

It is useful to explicitly note the specific division of labor that the CarePoint program addressed. The changes related to the ways that patients got referrals to, appointments with, and coordinated services from auxiliary services and programs. Before the CarePoint program, any referrals and scheduling came from the oncology care teams at their discretion, so they were idiosyncratic across the center. Patients could ask for referrals and would manage integration across referrals and services. Thus, much of the expected division of labor in informing, referring, scheduling, and coordinating auxiliary services involved patients' and families' invisible work. When our research ended, these groups were now bundled in CarePoint and met monthly to discuss how to integrate care for some patients. The design and structuring of the CarePoint program was a more expansive program than the original palliative plans and was shaped by the patient activists' storytelling practices and the coalition they mobilized. However, this change was also more limited in scope than the changes envisioned in the patient stories. The patient stories had illustrated the burdens they faced coordinating between inpatient and outpatient services and between medical specialties in addition to these auxiliary services. Their storytelling practices had a concrete but modest influence on their expected division of labor with ACC in the short-term.

**Contrasting Patient Stories to other Forms of Patient Engagement**

To conclude the findings section, we contrast the influence of the patient storytelling practices with the influence of other forms of patient engagement (see Table 7). Another kind of patient engagement we observed during the study period involved a patient activist promoting the idea of incorporating 'Goals of care' into patients' treatment encounters. The patient activist explained that the idea was to ask patients for a more holistic account of who they are as a person and what they were trying to accomplish with cancer care, instead of ignoring other parts of patients' lives and assuming every patient wanted the most aggressive curative treatment possible. 'Goals of care' was a recognized idea with support in the wider medical community (e.g., Secunda et al., 2020) The patient activist who most actively promoted this idea participated in the coalition meetings, and shared this idea many times in the same meetings where the patient stories were shared that illustrated the suffering created by coordination

37

burdens. We remember hearing this idea shared in the meetings and do not recall any active conflict or resistance to this idea; it just did not garner much attention or mobilize any cross-occupation support. In re-analyzing our data on these meetings, we saw that the idea would be shared by a patient activist or by one physician who was also interested in the idea because of her research area, but then the discussion would move on without the idea getting either resistance or traction. As an example, in one of these coalition meetings, they were discussing a few ideas about how to improve care for patients. This physician said, "Another topic is Goals of Care" and explained what they were. The patient activist illustrated with an example, "What if a patient wants to attend her daughter's wedding in a few months (i.e., and not be sick from chemotherapy treatment at that time); that Goal can be incorporated into the treatment plan." The physician posed the question, "How do we integrate Goals of Care into oncology clinic visits? We think this can be a clear process." One of the consultants enthusiastically replied she had read an article about Goals of Care that she would send around to the team. The discussion then moved on, and this topic was not revisited for many meetings. Most mentions of this idea were similar – it was not resisted but also not extensively discussed. The main barrier seemed to be a lack of attention and sustained interest, which contrasts with the attention and sustained interest mobilized by the patient stories. We were at ACC almost full-time during the first year and involved in many change meetings and were not aware of any cross-occupation meetings or building support related to patient voice.

The second useful contrast is patient complaints, which we include to compare other patient engagement with negative valence, consistent with research showing that "bad" is stronger than "good" in organizational decision-making (e.g., Rafaeli & Sutton, 1991; Sutton, 2010). Some of the patient handwritten comments were stories of coordination burdens, and these were used by patient activists and coalition members during presentations described above. However, ACC also received other patient complaints through other channels. Typically, ACC would respond to patient complaints through a process of "service recovery" which meant that the local manager would contact the patient about their complaint and discuss what had happened and offer a gift card. Common complaints involved rude staff

interactions or late clinic appointments. Local managers were accountable for negative trends in patient satisfaction scores that were related to these complaints, but there was not a forum were the individual complaints were synthesized and channeled into a compelling set of persuasive communications. ACC was frequently undergoing "process improvement" efforts and "service recovery", meaning there were standard ways of addressing expressions of negative patient experiences. But there was not a forum or a way for the patient complaints to mobilize a movement as did the patient activists' stories of their invisible work. Instead, patient complaints were addressed through local relationships and interactions but did not mobilize any broader movement for change.

**DISCUSSION**

This paper explores whether clients successfully challenge and change their expected division of labor with professionals. Drawing on a multiyear field study, we show how patient activists led such a movement and successfully changed some of the coordination work they were expected to do to receive treatment at an academic cancer center. Their primary influence tactic was to use stories to bring visibility and awareness to the burdensome administrative work they and their families had taken on simply to receive treatment. They engaged in deliberate storytelling practices to make the case for change, which included telling stories to build the movement, creating channels to collect more stories, and broadcasting the stories to many large or powerful ACC audiences. Their storytelling practices built awareness and support among sympathetic staff allies, who became an informal cross-occupational coalition. The coalition members contributed their own occupational resources and together developed new resources. They developed a new *diagnostic* frame of the "Cancer Tax" which resonated with many occupational groups. These accumulating resources enabled a peripheral group that participated in the coalition, the palliative specialists, to develop a new *prognostic* frame that offered a specific remedy to the "Cancer Tax." When senior leaders funded the program inspired by the prognostic frame, they committed formal resources to pay an administrator to take on some of the tasks that the patients and families had been doing. With their storytelling practices, the patients engaged as new political actors in

39

the "socially constructed arena" of the cancer center, bringing in new resources that shifted the jurisdictional balance between groups (Fligstein & McAdam, 2011). These findings contribute to research on co-production, professions, and change in organizations.

**Contributions to research on co-production**

These findings contribute to the research literature on the co-production of professional services which recognizes that clients collaboratively co-produce services together with professionals (Anteby et al., 2016; Okhuysen & Bechky, 2009). The 'co-production' idea was introduced by economists in the 1970s (e.g., Ostrom, 1972; Ostrom, 1996), and is now more actively recognized and explored by organizations researchers and sociologists as well. Research in this area has importantly "decentered occupations as the singular unit of analysis and shifted our focus to the network of relations connected to occupations that collectively contribute to building and sustaining their influence" (Anteby et al., 2016, pg. 34). Examples include studies that show that finance professionals, accountants, and lawyers coproduce their work with their networks, including with their clients (Jarzabkowski, Bednarek, & Spee, 2015; Lawrence, 2004; Sandefur, 2015). Our paper contributes new understanding to this stream of research on co-production. Our study is one of the first to demonstrate that clients work to deliberately challenge and change their expected division of labor with professionals. After we observed the patient activists lead this movement, it made sense that clients might directly challenge and seek to change their expected division of labor, given that task jurisdictions between professions are known to be contested and dynamic (Anteby, 2010; Bechky, 2003), but this insight was previously missing from the literature. Sometimes a professional group's clients are other professionals (e.g., Huising, 2014; Sandefur, 2015), so their task dynamics might look similar to other studies of jurisdictional dispute. In contrast, our study examined the co-production practices of clients whose work was not really seen or considered to be work, which might explain some of the new insights uncovered by our study. This finding emphasizes that some of clients' co-production work is "invisible work" and so is unacknowledged and "relegated to the background of expectation" (e.g., Daniels, 1987; Nardi & Engestrom, 1999; Oudshoorn, 2008; Star & Strauss, 1999). Our data show how clients seek to change their division of labor with professionals when

40

their co-production work is not even considered work but is burdensome and creating adverse outcomes.

In addition to newly showing that clients sometimes work to directly change their expected division of labor with professionals, our findings also contribute to the co-production research related to the "sociology of expertise" (Eyal, 2013). The Eyal (2013) study showed how parents constructed an alternative network of expertise that eventually produced a professionalized criteria for diagnosing autism. We similarly found that non-experts, in this case, patients and their family members, had an understanding of the services that should be well-integrated into their desired cancer treatment that differed from the expectations of the professionals at ACC. Although we do not use actor-network theory to conduct our analysis, our findings contribute to this theory of expertise by showing some ways that the non-experts understood and engaged with ACC as an organization as they constructed their desired cancer treatment experience. Bureaucratic organizations such as ACC bundle the institutional arrangements through which professionals provide services and so reflect and structure the professionals' expectations of what their specialized services entail. As Eyal (2013) showed, and as our data show, clients may have a different desired service experience than those provided by professionals and their employing organizations. In such circumstances, clients work to weave together and coordinate the services of many diverse professionals both inside and outside of single organizations. Because the specialized professionals' work experiences are bundled in their focal organization, they may not easily understand the clients' broader network of service experiences, and may inadvertently create significant friction for clients trying to weave together these alternative networks of expertise. The inpatient-outpatient transition for cancer patients is an example from our data. Our findings suggest that these misalignments in understanding, and these growing frictions at organizational boundaries that only the clients have to navigate might be occasions for direct, collective action from clients.

Second and relatedly, our findings also show that clients might focus on organizations as specific targets for collective action in such situations. Social movement scholars argue that organizations offer a readymade "socially constructed arena" wherein political actors negotiate interests (Fligstein & McAdam, 2011), so may be a salient setting wherein clients attempt to directly challenge and change their invisible

work.  This idea resonates with the Freeland and Zuckerman (2018) argument that currently our society

tends to consider and treat organizations as unitary "accountable actors" even as they bundle many

complex professions, occupations, and systems.  Our findings similarly show that not only was ACC a

social arena wherein clients engage in collective action, it was also their target for change.  The patient

activists engaged in direct action to push ACC staff to take responsibility for better integrating some of

the network of services within the intuitional and spatial arrangements that ACC structured. The timescale

and changes in our study are small compared to the historical analysis in Eyal (2013), but our findings

offer a useful real-time account of issues and tactics at play when "non-experts" influenced the

understanding of the relevant network of expertise for which ACC was accountable.

Our study also contributes new understanding about professionals based on their work being

structured in a bureaucratic organization (Briscoe, 2007; Noordegraaf, 2011; Poley et al., 2009).  Our

findings characterize an undertheorized problem that arises from professionals' specialization in these

organizational settings.  As professionals become hyper-specialized in organizations, it can increase the

complexity of care and related coordination work for clients.  To some degree, the organization itself is

expected to provide the coordination and bundling work that integrates across the many interdependent

professionals, but our study reveals that this is often not the case, and the patients themselves are playing

an extensive but often invisible coordination role.   Future research can build on this finding by exploring

the conditions under which complex service organizations take on or outsource coordination work to their

clients.  Complex medical care, including high-needs children or patients with comorbidities might

impose these high coordination burdens and expectations of invisible work on clients.  Higher education

may be another setting where this finding might generalize.  Elite research universities might outsource a

coordination burden to students if faculty are expected to hive off teaching, administration, or mentoring.

**Contributions to research on organizational change**

This study also contributes to the research literature on organizational change.  Greenwood and

Hinings (1996) frame organizational change processes in terms of internal power balances and external

forces such as market and institutional pressures shifting the balance of power among groups (see Figure

1, pg. 1034). Our findings provide a case of clients, as new political actors in the organizational arena, bringing new institutional pressures directly into the negotiations and plans during a change process. This shifting institutional pressure can be understood in terms of the well-established cultural shift in medicine where "patient-centered" care models and approaches are becoming more expected and valued (Mead & Bower, 2000; Stewart et al., 2013). This cultural shift involves changing expectations of "the traditional roles of patients and their families" – shifting from passive 'order takers' to active 'team members'" (NEJM Catalyst, 2017). The patient activists brought this changing expectation into the boardroom discussions and negotiations in ways that influenced the change process.

Our overall account of the patient activists' influence on the change process builds on the Howard-Grenville (2007) idea of influence attempts as "resourcing" that accumulates over time. That idea and our findings also resonate with social movement theory that shows how different groups draw on each other's influence tactics as resources (Wang & Soule, 2012). This resourcing is especially characteristic of coalitions whose members contribute their own resources and together develop new resources (McCammon & Moon, 2015; Van Dyke, 2003). Our study draws together these perspectives to theorize an organizational change process that included clients as new political actors bringing new resources into the organizational arena. Their influence tactics involving storytelling practices reflect their position as non-professional "outsiders" in the organizational change process.

Our study shows that the patients' primary influence tactic was to tell personal stories that made visible their coordination burdens. This characterization of the patients' use of stories is similar to prior research on the use of narratives in social movements (e.g., Coley, 2015; Olsen, 2014; Polletta, 1998a; Polletta et al., 2011). Similar to prior research (e.g., Nolan, 2012), the patient activists used stories as a way to speak persuasively in formal change meetings. Without the storytelling tactic, they would struggle to make their case persuasively because they could not draw on technical, scientific, or expert discourse. Also similar to prior research (e.g., Iedema et al., 2011), their use of stories allowed them to narrate their personal experiences as "members of a legitimately aggrieved group," meaning they could speak with a

sense of "efficacy, even entitlement" to ask for problems to be addressed. Our findings thus substantiate these well-established uses of narratives as persuasive communication, and now also newly link this literature on narratives to research on organizational change.

The specific content of the stories is also important for organizations research – the patient activists specifically told stories about their experiences carrying out invisible work. Their efforts to render their work visible was similar to Daniels (1987, pg. 405) argument that one way that people draw attention to and challenge undervalued invisible work is to show "how it is constructed and what effort it involves." These stories of invisible work constructed a description of a complex set of services that the patients considered comprising their cancer care. Prior research recognizes that *narratives* can more effectively hold complex problems than *frames* because narratives can draw together diverse, complex, dramatic elements and make them coherent (Tatum, 2002). The patients' narratives opened awareness of the poorly integrated services across many different ACC locations and events, thereby making their invisible work visible to ACC staff.

Our study theorizes these storytelling practices as a new resource introduced to the ACC change process. The storytelling practices mobilized and resourced a new informal coalition. Our data show that the cross-occupational group that regularly convened in the meetings where patient activists first and most actively shared their stories developed and cohered into a shared movement community, which is consistent with prior research on narratives and social movements (e.g., Benford, 1993; Fine, 1995; Hunt & Benford, 1994; Loseke, 2007; Polletta, 1998b). The patients' storytelling practices helped cohere the interests of the diverse occupations involved in the developing coalition (McCammon & Moon, 2015; Van Dyke & McCammon, 2010). The coalition members then drew on these stories to develop new diagnostic frame that could sustain attention and support from stakeholders external to the movement (e.g., Nolan, 2012; Olsen, 2014; Rothenberg, 2002; Tatum, 2002). The palliative team, who had been peripheral in prior change efforts, drew on coalition resources to develop and offer the needed prognostic frame for how some of the patients' invisible work could be lessened.

**Boundary conditions**

ACC patients came from many different backgrounds and circumstances, but ACC itself was located in an affluent community. The patient activists themselves had considerable personal and professional capacity and resources to draw on when engaging ACC staff. These are boundary conditions for understanding the influence that these clients had when challenging and successfully changing their expected division of labor. These conditions exemplify specific ways that surrounding communities contribute to the effectiveness of service organizations providing health care or education. Economic geographers have shown that the effectiveness of service organizations often correlates with the human and social capital of the surrounding communities (e.g., Blustein, 2008; Blustein et al., 2010; Ryan, Blustein, & Casalino, 2012). Relatedly, the co-production literature in public administration journals has shown that professional services are more effective when clients are closely involved, including in municipal services (e.g., Percy, 1984), global development (e.g., Ostrom, 1996), and health services (e.g., Hibbard, Mahoney, Stock, & Tusler, 2007). Our research complements these various co-production research streams by illustrating some of the specific activities underpinning those results. Variation in service effectiveness is likely influenced by the available resources in families and communities to do the invisible coordination work depicted by the stories in our paper. And patients' capacity to lead movements to change their expected division of labor with professionals likely also depends on community resources. Future research can explore how clients' co-production activities are constructed in different communities, as well as how clients' collective action to reduce their invisible work plays out.

**REFERENCES**

Abbott, A. 1988. *The System of Professions: An Essay on the Division of Labor*. Chicago: University of Chicago Press.

Adler, P. S., & Borys, B. 1996. Two types of bureaucracy: Enabling and coercive. *Administrative Science Quarterly*, 41(1): 61-89.

Anteby, M. 2008. *Moral Gray Zones: Side Productions, Identity, and Regulation in an Aeronautic Plant*: Princeton University Press.

Anteby, M. 2010. Markets, Morals, and Practices of Trade: Jurisdictional Disputes in the US Commerce in Cadavers. *Administrative Science Quarterly*, 55(4): 606-638.

Anteby, M., Chan, C. K., & DiBenigno, J. 2016. Three lenses on occupations and professions in organizations: Becoming, doing, and relating. *The Academy of Management Annals*, 10(1): 183-244.

Armstrong, N., Herbert, G., Aveling, E. L., Dixon-Woods, M., & Martin, G. 2013. Optimizing patient involvement in quality improvement. *Health Expectations*, 16(3): e36-e47.

Barley, S. R., & Kunda, G. 2001. Bringing work back in. *Organization Science*, 12(1): 76-95.

Bechky, B. A. 2003. Object lessons: Workplace artifacts as representations of occupational jurisdiction. *American Journal of Sociology*, 109(3): 720-752.

Bechky, B. A. 2011. Making Organizational Theory Work: Institutions, Occupations, and Negotiated Orders. *Organization Science*, 22(5): 1157-1167.

Benford, R. D. 1993. "You Could Be the Hundredth Monkey": Collective Action Frames and Vocabularies of Motive within the Nuclear Disarmament Movement. *The Sociological Quarterly*, 34(2): 195-216.

Bernabei, R., Gambassi, G., Lapane, K., Landi, F., Gatsonis, C., Dunlop, R., Lipsitz, L., Steel, K., Mor, V., & Grp, S. S. 1998. Management of pain in elderly patients with cancer. *Journal of the American Medical Association*, 279(23): 1877-1882.

Bernstein, M. 1997. Celebration and suppression: The strategic uses of identity by the lesbian and gay movement. *American Journal of Sociology*, 103(3): 531-565.

Bettencourt, L. A., Ostrom, A. L., Brown, S. W., & Roundtree, R. I. 2002. Client co-production in knowledge-intensive business services. *California Management Review*, 44(4): 100-+.

Blustein, J. 2008. Who is accountable for racial equity in health care? *Jama-Journal of the American Medical Association*, 299(7): 814-816.

Blustein, J., Borden, W. B., & Valentine, M. 2010. Hospital Performance, the Local Economy, and the Local Workforce: Findings from a US National Longitudinal Study. *Plos Medicine*, 7(6).

Boldt, A. M., Yusuf, F., & Himelstein, B. P. 2006. Perceptions of the term palliative care. *Journal of palliative medicine*, 9(5): 1128-1136.

Bovaird, T. 2007. Beyond engagement and participation: User and community coproduction of public services. *Public administration review*, 67(5): 846-860.

Bower, J. L. 1986. *Managing the Resource Allocation Process: A Study of Corporate Planning and Investment*: Harvard Business School Press.

Brandsen, T., & Pestoff, V. 2006. Co-production, the third sector and the delivery of public services - An introduction. *Public Management Review*, 8(4): 493-501.

Briscoe, F. 2007. From iron cage to iron shield? How bureaucracy enables temporal flexibility for professional service workers. *Organization Science*, 18(2): 297-314.

Brown, J. S., & Duguid, P. 2001. Knowledge and organization: A social-practice perspective. *Organization Science*, 12(2): 198-213.

Brudney, J. L., & England, R. E. 1983. Toward a definition of the coproduction concept. *Public Administration Review*: 59-65.

Burns, L. R., & Wholey, D. R. 1993. Adoption and abandonment of matrix management programs: effects of organizational characteristics and interorganizational networks. *Academy of Management journal. Academy of Management*, 36: 106-138.

Buzaglo, J. S., Karten, C., Weiss, E., Miller, M. F., & Morris, A. 2014. The Financial Costs of Chronic Myeloid Leukemia and Implications for Quality of Life and Adherence: Findings from the Cancer Experience Registry. *Blood*, 124(21).

Bylander, J. 2013. Confronting a crisis in cancer care delivery. *Health Affairs*, 32(10): 1695-1697.

Coley, J. S. 2015. Narrative and frame alignment in social movements: Labor problem novels and the 1929 Gastonia strike. *Social Movement Studies*, 14(1): 58-74.

Corallo, A. N., Croxford, R., Goodman, D. C., Bryan, E. L., Srivastava, D., & Stukel, T. A. 2014. A systematic review of medical practice variation in OECD countries. *Health Policy*, 114(1): 5-14.

Covaleski, M. A., & Dirsmith, M. W. 1988. An institutional perspective on the rise, social transformation, and fall of a university budget category. *Administrative Science Quarterly*, 33(4): 562-587.

Cress, D. M., & Snow, D. A. 2000. The outcomes of homeless mobilization: The influence of organization, disruption, political mediation, and framing. *American Journal of Sociology*, 105(4): 1063-1104.

Daniels, A. K. 1987. Invisible work. *Social Problems*, 34(5): 403-415.

Davis, J. E. 2002. *Stories of Change: Narrative and Social Movements*: State University of New York Press.

Davis, P., Gribben, B., Scott, A., & Lay-Yee, R. 2000. The "supply hypothesis" and medical practice variation in primary care: testing economic and clinical models of inter-practitioner variation. *Social Science & Medicine*, 50(3): 407-418.

de Bakker, F. G. A., den Hond, F., King, B., & Weber, K. 2013. Social Movements, Civil Society and Corporations: Taking Stock and Looking Ahead. *Organization Studies*, 34(5-6): 573-593.

Del Ferraro, C., Ferrell, B., Van Zyl, C., Freeman, B., & Klein, L. 2014. Improving Palliative Cancer Care. *Journal of the advanced practitioner in oncology*, 5(5): 331-338.

Dobbin, F., & Kelly, E. 2007. How to Stop Harassment: Professional Construction of Legal Compliance in Organizations. *American Journal of Sociology*, 112(4): 1203-1243.

Dutton, J. E., & Ashford, S. J. 1993. Selling Issues to Top Management. *Academy of Management Review*, 18(3): 397-428.

Dutton, J. E., Ashford, S. J., Lawrence, K. A., & Miner-Rubino, K. 2002. Red light, green light: Making sense of the organizational context for issue selling. *Organization Science*, 13(4): 355-369.

Edwards, R. 1979. *Contested terrain : the transformation of the workplace in the twentieth century*: New York : Basic Books, c1979.

Empson, L., & Langley, A. 2015. Leadership and professionals. In L. Empson, D. Muzio, J. Broschak, & C. R. Hinings (Eds.), *The Oxford Handbook of Professional Service Firms*: 163-188. Oxford: Oxford University Press.

Eyal, G. 2013. For a sociology of expertise: The social origins of the autism epidemic. *American Journal of Sociology*, 118(4): 863-907.

Fajer, M. A. 1991. Can Two Real Men Eat Quiche Together-Storytelling, Gender-Role Stereotypes, and Legal Protection for Lesbians and Gay Men. *U. Miami L. Rev.*, 46: 511.

Feldman, M. S. 2004. Resources in emerging structures and processes of change. *Organization Science*, 15(3): 295-309.

Fine, G. A. 1995. Public Narration and Group Culture: Discerning Discourse in Social Movements. In H. Johnston, & B. Klandermans (Eds.), *Social Movement and Culture*: 127-243: University of Minnesota Press.

Fine, G. A. 2006. Shopfloor cultures: The idioculture of production in operational meteorology. *Sociological Quarterly*, 47(1): 1-19.

Fleissig, A., Jenkins, V., Catt, S., & Fallowfield, L. 2006. Multidisciplinary teams in cancer care: are they effective in the UK? *Lancet Oncology*, 7(11): 935-943.

Fligstein. 1990. *The Transformation of Corporate Control*. Cambridge, Mass.: Harvard University Press.

Fligstein, N. 1987. The intraorganizational power struggle: Rise of finance personnel to top leadership in large corporations, 1919-1979. *American Sociological Review*, 52: 44-58.

Fligstein, N., & McAdam, D. 2011. Toward a General Theory of Strategic Action Fields. *Sociological Theory*, 29(1): 1-26.

Freeland, R., & Zuckerman, E. W. 2018. The Problems and Promise of Hierarchy: Voice Rights and the Firm. *Sociological Science*, 5(7): 143-181.

Freeland, R. F., Sivan, Z., & Ezra, W. 2018. The problems and promise of hierarchy: Voice rights and the firm. *Sociological Science*, 5: 143-181.

Freidson, E. 1976. The division of labor as social interaction. *Social Problems*, 23: 304-323.

Greenwood, R., & Hinings, C. R. 1996. Understanding radical organizational change: Bringing together the old and the new institutionalism. *Academy of Management Review*, 21(4): 1022-1055.

Hackman, J. R., & Katz, N. 2010. Group behavior and performance. In S. Fiske (Ed.), *Handbook of Social Psychology*, Vol. 5th ed. New York: Wiley.

Hibbard, J. H., Mahoney, E. R., Stock, R., & Tusler, M. 2007. Do Increases in Patient Activation Result in Improved Self-Management Behaviors? *Health Services Research*, 42(4): 1443-1463.

Hodson, R. 2001. *Dignity at work*. Cambridge ; New York: Cambridge University Press.

Howard-Grenville, J. A. 2007. Developing issue-selling effectiveness over time: Issue selling as resourcing. *Organization Science*, 18(4): 560-577.

Huising, R. 2014. To Hive or to Hold: Producing Relational Authority through Scut Work. *Administrative Science Quarterly*: 1-37.

Huising, R. 2015. To Hive or to Hold? Producing Professional Authority through Scut Work. *Administrative Science Quarterly*, 60(2): 263-299.

Huising, R. 2016. From Adapting Practices to Inhabiting Ideas: How Managers Restructure Work across Organizations, *The Structuring of Work in Organizations*: 383-413.

Huising, R., & Silbey, S. 2011. Governing the Gap: Forging Safe Science through Relational Regulation. *Regulation & Governance*, 5(1): 14-42.

Hunt, J. G., & Benford, R. D. 1994. Identity talk in the peace and justice movements. *Journal of Contemporary Ethnography*, 22: 488-517.

Hunt, S., Benford, R., & Snow, D. 1994. Identity fields: Framing processes and the social construction of movement identities. In L. Johnston, & J. Gusfield (Eds.), *New social movements: From ideology to identity*. Philadelphia, PA: Temple University Press.

Hurria, A., Lichtman, S. M., Gardes, J., Li, D., Limaye, S., Patil, S., Zuckerman, E., Tew, W., Hamlin, P., Abou-Alfa, G. K., Lachs, M., & Kelly, E. 2007. Identifying vulnerable older adults with cancer: Integrating geriatric assessment into oncology practice. *Journal of the American Geriatrics Society*, 55(10): 1604-1608.

Iedema, R., Allen, S., Britton, K., Piper, D., Baker, A., Grbich, C., Allan, A., Jones, L., Tuckett, A., & Williams, A. 2011. Patients' and family members' views on how clinicians enact and how they should enact incident disclosure: the "100 patient stories" qualitative study. *Bmj*, 343.

Institute of Medicine. 2008. Cancer care for the whole patient:  Meeting psychosocial health needs. In N. Adler, & A. Page (Eds.). Washington DC: National Academies Press.

Institute of Medicine. 2013. Delivering High-Quality Cancer Care:  Charting a New Course for a System in Crisis. Washington DC: National Academies Press.

Jarzabkowski, P., Bednarek, R., & Spee, P. 2015. *Making a market for acts of God: The practice of risk-trading in the global reinsurance industry*: Oxford University Press, USA.

Joshi, A., & Moore, M. 2004. Institutionalised co-production: unorthodox public service delivery in challenging environments. *Journal of Development Studies*, 40(4): 31-49.

Junor, E. J., Hole, D. J., & Gillis, C. R. 1994. Management of Ovarian Cancer:  Referral to Multidisciplinary Team Matters *British Journal of Cancer*, 70(2): 363-370.

Kaplan, S. 2008. Framing Contests: Strategy Making Under Uncertainty. *Organization Science*, 19(5): 729-752.

Kellogg, K. 2011. *Challenging Operations: Medical Reform and Resistance In Surgery*. Chicago: University of Chicago Press.

Kellogg, K., Orlikowski, W., & Yates, J. 2006. Life in the Trading Zone: Structuring Coordination across Boundaries in Postbureaucratic Organizations. *Organization Science*, 17(1): 22-44.

Kellogg, K. C. 2014. Brokerage Professions and Implementing Reform in an Age of Experts. *American Sociological Review*, 79(5): 912-941.

Kellogg, K. C. 2019. Subordinate activation tactics: Semi-professionals and micro-level institutional change in professional organizations. *Administrative Science Quarterly*, 64(4): 928-975.

Kennedy, M. T., & Fiss, P. C. 2009. INSTITUTIONALIZATION, FRAMING, AND DIFFUSION: THE LOGIC OF TQM ADOPTION AND IMPLEMENTATION DECISIONS AMONG US HOSPITALS. *Academy of Management Journal*, 52(5): 897-918.

Labov, W., & Waletzky, J. 1997. Narrative analysis: Oral versions of personal experience.

Lamont, M., & Molnar, V. 2002. The study of boundaries in the social sciences. *Annual Review of Sociology*, 28: 167-195.

Lawrence, T. B. 2004. Rituals and Resistance: Membership Dynamics in Professional Fields. *Human Relations*, 57(2): 115-143.

Lewin, A. Y., & Stephens, C. 1993. Desgining postindustrial organizations: Combining theory and practice. In G. P. Huber, & W. H. Glick (Eds.), *Organizational change and redesign : ideas and insights for improving performance*: xiii, 450. New York ;: Oxford University Press.

Lingo, E. L., & O'Mahony, S. 2010. Nexus Work: Brokerage on Creative Projects. *Administrative Science Quarterly*, 55(1): 47-81.

Lorenz, K. A., Lynn, J., Dy, S. M., Shugarman, L. R., Wilkinson, A., Mularski, R. A., Morton, S. C., Hughes, R. G., Hilton, L. K., Maglione, M., Rhodes, S. L., Rolon, C., Sun, V. C., & Shekelle, P. G. 2008. Evidence for improving palliative care at the end of life: A systematic review. *Annals of Internal Medicine*, 148(2): 147-159.

Loseke, D. R. 2007. The study of identity as cultural, institutional, organizational, and personal narratives: Theoretical and empirical integrations. *The Sociological Quarterly*, 48(4): 661-688.

Lounsbury, M. 2001. Institutional sources of practice variation: Staffing college and university recycling programs. *Administrative Science Quarterly*, 46(1): 29-56.

McAdam, D. 2010. *Political process and the development of black insurgency, 1930-1970*: University of Chicago Press.

McCammon, H. J., & Moon, M. 2015. Social movement coalitions. *The Oxford handbook of social movements*.

McIlfatrick, S., Noble, H., McCorry, N. K., Roulston, A., Hasson, F., McLaughlin, D., Johnston, G., Rutherford, L., Payne, C., & Kernohan, G. 2014. Exploring public awareness and perceptions of palliative care: a qualitative study. *Palliative medicine*, 28(3): 273-280.

Mead, N., & Bower, P. 2000. Patient-centredness: a conceptual framework and review of the empirical literature. *Social science & medicine*, 51(7): 1087-1110.

Morrill, C., Zald, M., & Rao, H. 2003. Covert political conflict in organizations: Challenges from below. *Annual Review of Sociology*, 29: 391-415.

Naples, N. A. 2003. *Feminism and method: Ethnography, discourse analysis, and activist research*: Psychology Press.

Nardi, B. A., & Engestrom, Y. 1999. A Web on the Wind: The Structure of Invisible Work. *Comput. Supported Coop. Work*, 8(1-2): 1-8.

Nepstad, S. 2001. Creating transnational solidarity: The use of narrative in the US-Central America peace movement. *Mobilization: An International Quarterly*, 6(1): 21-36.

Nolan, J. 2012. *Drug Court Stories: Transforming American Jurisprudence*: SUNY Press.

Noordegraaf, M. 2011. Risky Business: How Professionals and Professional Fields (Must) Deal with Organizational Issues. *Organization Studies*, 32(10): 1349-1371.

Okhuysen, G. A., & Bechky, B. A. 2009. Coordination in Organizations: An Integrative Perspective. *Academy of Management Annals*, 3: 463-502.

Olsen, K. A. 2014. Telling our stories: Narrative and framing in the movement for same-sex marriage. *Social Movement Studies*, 13(2): 248-266.

Orlikowski, W. J. 2002. Knowing in Practice: Enacting a Collective Capability in Distributed Organizing. *Organization Science*, 13(3): 249-273.

Ostrom, E. 1972. Metropolitan reform: Propositions derived from two traditions. *Social Science Quarterly*: 474-493.

Ostrom, E. 1996. Crossing the great divide: coproduction, synergy, and development. *World development*, 24(6): 1073-1087.

Ostrom, E., Parks, R. B., & Whitaker, G. P. 1978. *Patterns of metropolitan policing*: Ballinger Cambridge, MA.

Ostrom, E., & Whitaker, G. 1973. Does local community control of police make a difference? Some preliminary findings. *American Journal of Political Science*: 48-76.

Oudshoorn, N. 2008. Diagnosis at a distance: the invisible work of patients and healthcare professionals in cardiac telemonitoring technology. *Sociology of health & illness*, 30(2): 272-288.

Parks, R. B., Baker, P. C., Kiser, L., Oakerson, R., Ostrom, E., Ostrom, V., Percy, S. L., Vandivort, M. B., Whitaker, G. P., & Wilson, R. 1981. Consumers as coproducers of public services: Some economic and institutional considerations. *Policy Studies Journal*, 9(7): 1001-1011.

Pentland, B. T. 1992. Organizing moves in software support hot lines. *Administrative Science Quarterly*, 37(4): 527-548.

Percy, S. L. 1984. Citizen participation in the coproduction of urban services. *Urban Affairs Review*, 19(4): 431-446.

Pfeffer, J., & Salancik, G. 1974. Organizational decision-making as a political process - the case of a university budget. *Administrative Science Quarterly*, 19(2): 135.

Poley, S., Newkirk, V., Thompson, K., & Ricketts, T. 2009. Independent practice becoming increasingly rare among surgeons. *Bulletin of the American College of Surgeons*, 96(3): 40-41.

Polletta, F. 1998a. Contending stories: Narrative in social movements. *Qualitative sociology*, 21(4): 419-446.

Polletta, F. 1998b. "It was like a fever...": Narrative and identity in social protest. *Social Problems*, 45(2): 137-159.

Polletta, F., Chen, P. C. B., Gardner, B. G., & Motes, A. 2011. The Sociology of Storytelling. *Annual Review of Sociology*, 37(1): 109-130.

Polletta, F., & Jasper, J. 2001. Collective identity and social movements. *Annual Review of Sociology*, 27: 283-305.

Pool, J. 1991. Hospital management: Integrating the dual hierarchy? *The International journal of health planning and management*, 6(3): 193-207.

Prasad, P., & Prasad, A. 2000. Stretching the iron cage: The constitution and implications of routine workplace resistance. *Organization Science*, 11(4): 387-403.

Pruitt, Z., & Sportsman, S. 2013. The Presence and Roles of Nurse Navigators in Acute Care Hospitals. *Journal of Nursing Administration*, 43(11): 592-596.

Rafaeli, A., & Sutton, R. I. 1991. Emotional contrast strategies as means of social influence: Lessons from criminal interrogators and bill collectors. *Academy of management journal*, 34(4): 749-775.

Rock, C. L., Doyle, C., Demark-Wahnefried, W., Meyerhardt, J., Courneya, K. S., Schwartz, A. L., Bandera, E. V., Hamilton, K. K., Grant, B., McCullough, M., Byers, T., & Gansler, T. 2012. Nutrition and Physical Activity Guidelines for Cancer Survivors. *Ca-a Cancer Journal for Clinicians*, 62(4): 243-274.

Roscigno, V. J., & Hodson, R. 2004. The Organizational and Social Foundations of Worker Resistance. *American Sociological Review*, 69(1): 14-39.

Rothenberg, B. 2002. Movement Advocates as Battered Women's Storytellers: From Varied Experiences, One Message. In J. E. Davis (Ed.), *Stories of change : narrative and social movements* Albany: State University of New York Press.

Ryan, A., Blustein, J., & Casalino, L. 2012. Medicare's Hospital Pay-for-Performance Demonstration:  Did Rewarding Improvement Accelerate Improvement Among Low Performing Hospitals? *Health Affairs*, In Press.

Sandefur, R. L. 2015. Elements of professional expertise: Understanding relational and substantive expertise through lawyers' impact. *American Sociological Review*, 80(5): 909-933.

Sarbin, T. R. 1995. Emotional life, rhetoric, and roles. *Journal of Narrative and Life History*,

5(3): 213-220.

Secunda, K., Wirpsa, M. J., Neely, K. J., Szmuilowicz, E., Wood, G. J., Panozzo, E., McGrath, J., Levenson, A., Peterson, J., Gordon, E. J., & Kruser, J. M. 2020. Use and Meaning of "Goals of Care" in the Healthcare Literature: a Systematic Review and Qualitative Discourse Analysis. *J Gen Intern Med*, 35(5): 1559-1566.

Snow, D. A. 2013. Framing and social movements. *The Wiley-Blackwell Encyclopedia of Social and Political Movements*.

Snow, D. A., Vliegenthart, R., & Corrigall-Brown, C. 2007. Framing the French riots: A comparative study of frame variation. *Social Forces*, 86(2): 385-415.

Star, S. L., & Strauss, A. 1999. Layers of Silence, Arenas of Voice: The Ecology of Visible and Invisible Work. *Comput. Supported Coop. Work*, 8(1-2): 9-30.

Stewart, M., Brown, J. B., Weston, W., McWhinney, I. R., McWilliam, C. L., & Freeman, T. 2013. *Patient-centered medicine: transforming the clinical method*: CRC press.

Sutton, I. 2010. Bad Is Stronger Than Good: Evidence-Based Advice For Bosses. *Harvard Business Review. https://hbr. org/2010/09/bad-is-stronger-than-good-evid (Luettu 6.2. 2015.)*.

Tap, H. J., & Schut, F. T. 1987. Escaping from the dual organization: physician self-governance. *The International journal of health planning and management*, 2(3): 229-242.

Tatum, J. D. 2002. Compassion on Trial: Movement Narrative in a Court Conflit over Physician-Assisted Suicide. In J. E. Davis (Ed.), *Stories of Change: Narrative and Social Movements*. New York: SUNY Press.

Thygesen, M. K., Pedersen, B. D., Kragstrup, J., Wagner, L., & Mogensen, O. 2012. Benefits and challenges perceived by patients with cancer when offered a nurse navigator. *International Journal of Integrated Care*, 11: 12.

Valentine, M. 2018. When Equity Seems Unfair: The Role of Justice Enforceability in Temporary Team Coordination. *Academy of Management Journal*, 61(6): 2081-2105.

Valentine, M. A., & Edmondson, A. C. 2015. Team Scaffolds: How Mesolevel Structures Enable Role-Based Coordination in Temporary Groups. *Organization Science*, 26(2): 405-422.

Vallas, S. P. 2003. Why teamwork fails: Obstacles to workplace change in four manufacturing plants. *American Sociological Review*, 68(2): 223-250.

Van Dyke, N. 2003. Crossing movement boundaries: Factors that facilitate coalition protest by American college students, 1930-1990. *Social Problems*, 50(2): 226-250.

Van Dyke, N., & McCammon, H. 2010. *Strategic alliances: Coalition building and social movements*. Minneapolis, MN: University of Minnesota Press.

Wagner, E. H., Ludman, E. J., Bowles, E. J. A., Penfold, R., Reid, R. J., Rutter, C. M., Chubak, J., & McCorkle, R. 2014. Nurse Navigators in Early Cancer Care: A Randomized, Controlled Trial. *Journal of Clinical Oncology*, 32(1): 12-U85.

Wang, D. J., & Soule, S. A. 2012. Social Movement Organizational Collaboration: Networks of Learning and the Diffusion of Protest Tactics, 1960-1995. *American Journal of Sociology*, 117(6): 1674-1722.

Whitaker, G. P. 1980. Coproduction: Citizen participation in service delivery. *Public administration review*: 240-246.

Wiedner, R., Barrett, M., & Oborn, E. 2016. The Emergence of Change in Unexpected Places: Resourcing across organizational practices in strategic change. *Academy of Management Journal*.

Wiig, S., Storm, M., Aase, K., Gjestsen, M. T., Solheim, M., Harthug, S., Robert, G., & Fulop,

N. 2013. Investigating the use of patient involvement and patient experience in quality improvement in Norway: rhetoric or reality? *BMC health services research*, 13(1): 206.

Wrzesniewski, A., & Dutton, J. E. 2001. Crafting a job: Revisioning employees as active grafters of their work. *Academy of Management Review*, 26(2): 179-201.

Zald, M., & Berger, M. 1978. Social movements in organizations: Coup d'etat, insurgency, and mass movements. *American Journal of Sociology*, 83(4): 823-861.

Zetka, J. 2003. *Surgeons and the Scope*. Ithaca, NY: Cornell University Press.

Zimmermann, C., Swami, N., Krzyzanowska, M., Leighl, N., Rydall, A., Rodin, G., Tannock, I., & Hannon, B. 2016. Perceptions of palliative care among patients with advanced cancer and their caregivers. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne*, 188(10): E217-E227.

**Table 1.  Different Groups' Access and Tactics Related to Changing Task Structures**

|  | **Members of target or peer occupations** | **Members of lower-status occupations** | **Managers** |
|---|---|---|---|
| **Access** |  |  |  |
| Access to formal resourcing decisions | Sometimes | Rarely | Common |
| Access to workplace interactions | Common | Common | Rarely |
| **Tactics** |  |  |  |
| Related to formal resourcing decisions | Framing contests<br>Issue selling<br>Coalition formation | Framing contests<br>Issue selling<br>Coalition formation | Framing contests<br>Issue selling and formal communication<br>Coalition formation |
| Related to workroom interactions | Delegating tasks<br>Avoiding tasks<br>Claiming tasks<br>Resistance | Co-opting tasks<br>Direct helping or workarounds<br>Resistance | Resource allocation<br>Subordinate activation<br>Control attempts |

**Table 2. Data on Interactions Illustrating Consequences of Oncologists' Specialization**

| Example issues for which oncologist provided direct service | Example issues referred to another professional | Example issues patients expected to handle without professional support ("normal" or "expected") |
|---|---|---|
| Abdominal pain (Urine test) | Anxiety (Social work) | Abdominal pain |
| Abnormal lab values (Ordered tests) | Anxiety (Palliative care) | Anxiety |
| Abnormal lab values (Prescription) | Anxiety about lab values (HIV doctor) | Back pain |
| Biopsy showed cancer (Ordered tests) | Bruise (Interventional radiology) | Bruising |
| Bleeding (Ordered test) | Chest pain (Cardiologist) | Clumsiness |
| Bleeding (Prescription) | Concerns about a virus linked with throat cancer (Head/neck oncologist) | Depression |
| Bloating (Ordered scans) | Declining health (Hospice care) | Diarrhea |
| Constipation (Advice: stool softener) | Depression (Social work) | Difficulty getting out of bed |
| Cough (Advice: smoking cessation) | Fear of falling (Physical therapy) | Dry skin |
| Fatigue (Ordered test) | Fertility concerns (Fertility specialist) | Enlarged lymph node |
| Fatigue (Prescription) | Fever (Hospital inpatient) | Fatigue |
| Feeling worse (Discussed treatment options) | Financial concerns (Financial counselors) | Fingers stick when holding things |
| Genetic test results (Ordered ultrasound) | Kidney Stone (Urology) | High blood pressure |
| Muscle atrophy (Advice: Physical therapy) | Questions about protein powder (Kidney specialist) | Itchiness |
| Nausea (Ordered tests and scans) | Rash (Dermatology) | Leg cramps |
| Nose bleeds (Prescription) | Transportation concerns (Social work) | Memory loss |
| Pain (Ordered laparoscopic surgery) | Weight gain (Nutritionist) | Nausea |
| Pain (Physical exam) | | Numb knees |
| Pain in hands (Advice: ice) | | Poor appetite |
| Poor appetite (Advice: exercise) | | Redness and swelling of skin |
| Possible allergic reaction (Advice: keep trying medication) | | Rib cage pain |
| Rare cancer second opinion (Advice on treatment options) | | Shortness of breath |
| Reduced activity (Advice: Increase activity levels) | | Stiffness; joint pain |
| Swelling (Ordered ultrasound) | | Stomach pain |
| Swelling in legs (Ordered test) | | Strained bowel movements |
| Ulcer in mouth (Prescribed artificial saliva) | | Vomiting/nausea |
| Unable to urinate (Ordered catheter) | | Weight gain |
| eight gain (Switched prescription; Advice: diet and exercise) | | Weight loss |

**Table 3. Data Collected and Use in Theory Development**

| Data | Collection Process | Use in Theory Development |
|---|---|---|
| **18 months of field notes** based on in-depth participant observation in the formal change process | We attended all weekly meetings related to the formal change process and regularly interviewed participants. These included design meetings, report outs, patient family council meetings. | • Used to analyze the change process over time<br>• Used to analyze the context and consequences of patient stories |
| **54 interviews** with patients and family members at the cancer center or in their homes | We conducted these interviews on behalf of the ACC staff (as part of our participant observation) or got access to the transcripts if a staff member had conducted the interview. | • Used to analyze influence on the change process over time<br>• Used to characterize the narrative structure and persuasive message of the patient stories |
| **3000+ handwritten patient comments** on the backs of quality improvement surveys | We got access to quality improvement surveys where patients had handwritten freeform comments describing their experiences. We scanned these comments to include in our dataset. | • Used to characterize the narrative structure and persuasive message of the patient stories<br>• Used to distinguish stories from complaints |
| **Structured field notes based on observation of 125 clinic appointments** | We observed a full month of clinic visits for 5 oncologists in two different clinical areas. | • Used to characterize the research setting<br>• Analyzed to show how often patients' main medical oncologists were referring them to other specialists and why<br>• Used to demonstrate a systematic pattern related to the complexity of the disease and professional specialization |

**Table 4. Summary of the CarePoint section in the UHC patient guide**

CarePoint is your connection to personalized, supportive services before, during, and after your treatment.

Our team of doctors, nurses, social workers, spiritual care providers, nutrition experts, financial counselors, and others work with your oncology team to provide comprehensive and specialized care. We provide symptom management, therapeutic counseling, and more to help you and your family during your cancer experience.

With just one call to CarePoint, you and your loved ones can speak with a nurse to access services that are right for you.

UHC Cancer Center
555-555-5555—ask for the CarePoint team

| | |
|---|---|
| Clinical Cancer Genetics Program<br>*Program description* | *Program referral checklist* |
| Integrative Medicine<br>*Program description* | *Program referral checklist* |
| Neuropsychology Clinic<br>*Program description* | *Program referral checklist* |
| Nutrition<br>*Program description* | *Program referral checklist* |
| Occupational Therapy<br>*Program description* | *Program referral checklist* |
| Pain Management<br>*Program description* | *Program referral checklist* |
| Palliative Medicine<br>*Program description* | *Program referral checklist* |
| ….<br>11 more pages of programs and descriptions<br>… | *Program referral checklist* |

**Table 5.  Clients' Storytelling Practices**

| Practices | Definition | Examples from field site and representative data |
|---|---|---|
| **Telling stories to build the movement** | Sharing personal stories during less formal interactions<br>• with allies<br>• with each other in the aggrieved characteristic | **Telling stories at formal change meetings**<br>During the discussion, a patient says:  The first time I needed major help with side effects was in year 2. The medication at that time was creating ulcer…, but the communication between different specialists… it was lacking… and we have to do it<br>*(excerpt; field notes)* |
| | | **Telling stories at patient family council meetings**<br>During the discussion, a patient tells a story of when his oncologist asked how he was feeling because 'he looked depressed'. The oncologist then made an informal mention of a referral, but the patient thought it should be integrated because he hadn't known whether he "truly needed help or how to get it".  He declares to the staff in the room: "you tell me!" *(excerpt; field notes)* |
| **Creating channels to collect more stories** | Creating ways to recruit others in aggrieved characteristic and encourage them to tell their stories | **Patient Stories Initiative**<br>David and Barb (patient activists), and Joan (staff ally) are meeting in Joan's office to discuss the patient stories initiative.  The main issue in the last month was making sure the phone line is secure and compliant with privacy regulations.  They started advertising the phone line in the clinics and are excited they already have three stories.  They listen to one during the meeting. *(excerpt; field notes)* |
| | | **Conducting Interviews**<br>David and Barb (patient activists) are encouraging ACC staff to continue the interviews with patients.  Staff are responsible for recruiting patients during their clinic visits and have slowed their efforts.  David and Barb brainstorm how to phrase the invitations, where to put fliers, where in the workflow to include the ask. *(excerpt; field notes)* |
| **Broadcasting stories** | Creating and delivering formal presentations, or supporting allies' presentations<br>• to large or powerful groups<br>• emphasizing or visualizing sheer number of stories<br>• emphasizing emotionally powerful stories | **Meetings with ACC Leaders**<br>Six administrators and oncologists meet with patient activists, who present a powerpoint. It reports number of patient interviews and themes. Each themes is illustrated with quoted patient stories. David reads one out loud: "I had significant problems with handling the insurance paperwork. Because of the chemo brain that hit like a ton of bricks, it was very overwhelming and challenging.  The treatment was bad, but it was one of the most devastating parts."<br>*(excerpt; field notes)* |
| | | **Large ACC-wide Meetings**<br>The large ballroom is full, several large screens display the speakers at the podium.  An ACC consultant motivates her talk by sharing with permission a patient story.  Somehow two clinical groups kept struggling to coordinate the patient's appointments, one day she had physically walked the needed information herself between the groups in her hospital gown, crying. *(excerpt; field notes)* |

58

**Table 6. Narrative Structure of a Stories used as Persuasive Communication**

|  | Elements of narratives | Invites interpretive participation from listeners |
|---|---|---|
| **Emplotment** | Sequence of events with ambiguous or implied causes, invites interpretive participation from listeners | "What happened?" |
| **Visibility** | Sequence of events that unfold outside of the persuasive context, creates new awareness | New awareness: "This happens?" |
| **Actors** | Sympathetic victims enduring systemic, seemingly preventable suffering | Sympathy and dismay: "This should not be happening." |
| **Moral** | Ambiguous causal claims, resistant to negation, engages listener in less defensively considering cause of suffering | Moralizing: "Why is this happening?" |
| **Identity implications** | Organizational impact in conflict with identity as caregivers | "We should fix this for our patients." |

**Table 7. Influence of Different Kinds of Client Engagement**

|  | Patient stories<br><br>Example:<br>Coordination burdens | 'Patient voice'<br><br>Example:<br>Goals of care | Patient complaints<br><br>Example:<br>Rude treatment |
|---|---|---|---|
| **Case for change** | Collective suffering, moral accountability | Better and preferred service | Individual grievances, solo bad actors |
| **Coalition forms** | Broad cross-occupational coalition focused on new issue | No new coalition | No new coalition |
| **Coalition creates new resources** | Inspired new diagnostic framing (the Cancer Tax) and new prognostic framing ('Big P, little p', CarePoint) | No | No |
| **Coalition mobilizes attention and support** | Ongoing statements of support from administrators, oncologists, nurses, palliative team | Not publicly expressed | Not publicly expressed |
| **Formal resource allocation** | Administrative, medical, nurse leaders agreed to fund CarePoint led by palliative care | No | No |

**Figure 1.  Conceptual Framework Illustrating How Client Stories Influenced Task Structure**

**Clients: new political actors**

Barriers to influencing change
• Lack of access
• Lack of authority to engage
• Professionals' lack of awareness

**Professional group**

Barriers to influencing change
• Dual authority structure, lack of control of some formal resources

Tactics and resources
• Stories that make a persuasive case for change: needless suffering among sympathetic actors

**Occupational group**

Barriers to influencing change
• Dual authority structure, professionals' autonomy

**New cross-occupational coalition develops**

Tactics and resources
• New resource: shared movement community mobilizes around stories
• New resource: coalition develops new *diagnostic* frame – (the "Cancer Tax")
• Members use existing positions and resources to mobilize broader awareness and support

**New prognostic frame, successful bid for formal resources to change task structure**

Tactics and resources
• New resource: Peripheral professional group draws on coalition resources to develop a new *prognostic* frame
• Leaders use positions and resources to formally fund a new program that takes on some of clients' invisible work

Baseline truce in jurisdiction and task structure

**Peripheral professional group**

Barriers to influencing change
• Low use and misperceptions
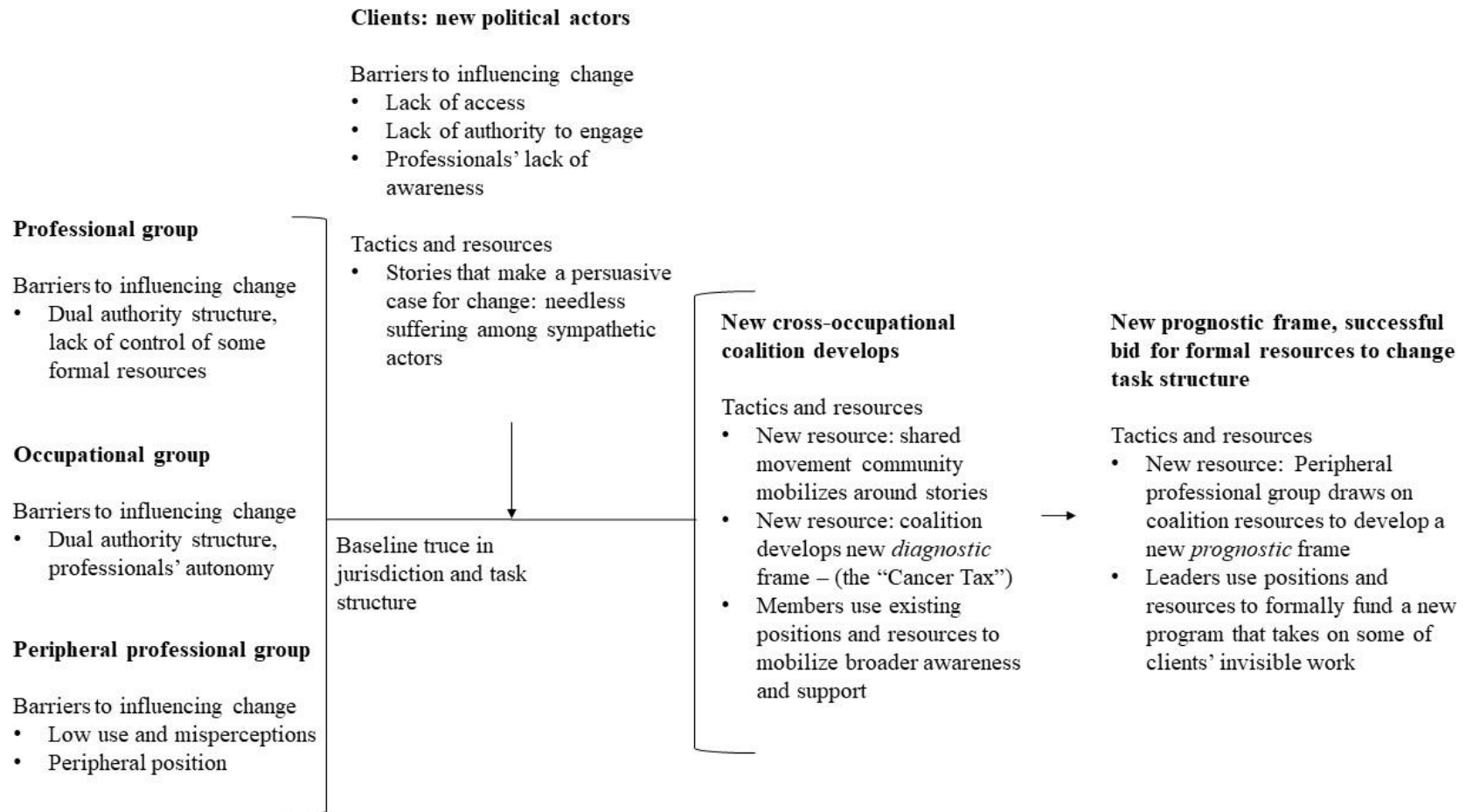• Peripheral position

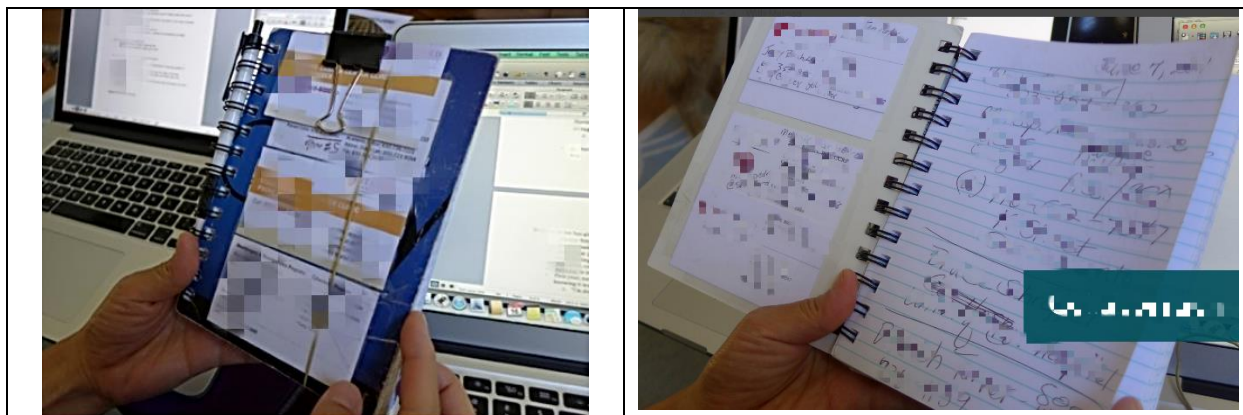**Figure 2a.  Picture of Patients' Work Constructing and Coordinating Networks of Service Providers**



**Figure 2b.  Picture of Patients' Work Managing and Coordinating Information**
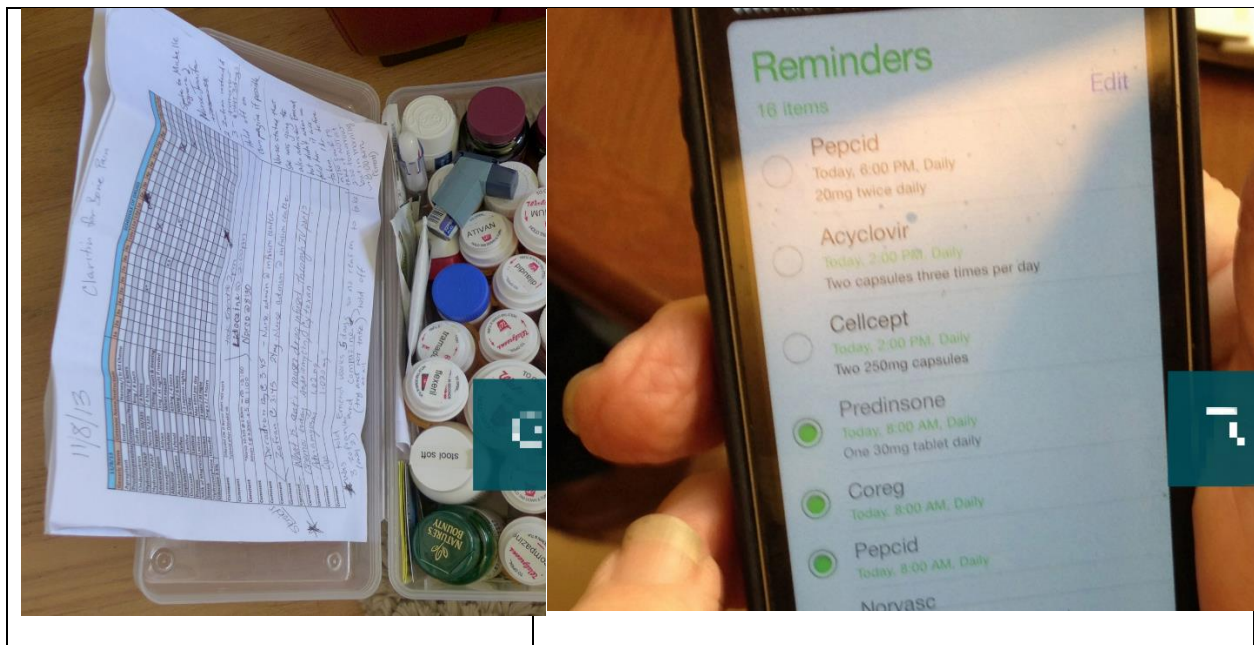
**Figure 3.  Meeting Attendance of Cross-Occupational Coalition Members**

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Senior administrators | ▓ | ▓ | ▓ | ▓ | | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | | |
| Medical director | ▓ | ▓ | ▓ | ▓ | | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | | |
| Nurse director | ▓ | ▓ | ▓ | ▓ | | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ |
| Front-line Managers | ▓ | ▓ | ▓ | ▓ | | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ |
| Process consultants | ▓ | ▓ | ▓ | ▓ | | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ | ▓ |
| Oncologists | ▓ | ▓ | ▓ | ▓ | | ▓ | ▓ | ▓ | | | * | ▓ | | |
| Palliative care | | | | | | ▓ | ▓ | ▓ | | | ▓ | $ | ▓ | ▓ |
| Patient activists | x | x | x | x | | x | x | x | x | | x | x | ▓ | ▓ |

x - indicates a patient story told during a meeting this month
* - indicates a new set of oncologists began attending
Gray cell indicates that participant(s) attended at least one meeting during this month
Notes: Senior leaders agreed to fund CarePoint in month 12; it began operating in month 16