

Who Pays the Cancer Tax?

Patients' Narratives in a Movement to Reduce their Invisible Work

Many studies have shown that the division of labor between different professions is dynamic and contested, but research to date has either ignored the implicit division of labor between professionals and their clients or has treated it as static and easily accepted by both parties. Do clients ever dispute their expected division of labor with professionals as they co-produce services, and if so – how? We developed this question during a three-year study of a formal change process at an academic cancer center. The center's patients and their families were influential actors in the change process. Over and over, they told stories about the invisible work they did to coordinate and co-produce their cancer care. They used these narratives to persuade staff that they should be able to “hive off” their invisible work burdens to the cancer center. The patients' narratives eventually broadened the framing used by administrative and clinical professionals to include the idea of helping patients with the “Cancer Tax” -- i.e., their burden of invisible work. The patients' visibility narratives also inspired changes to the structuring of tasks at the center. Palliative specialists developed a new multi-service program that took on the administrative work of coordinating auxiliary services. This program had not been envisioned at the start of the change process. Administrative staff also reconfigured their work to attempt to help patients' coordination burden. The oncology professionals' task structure did not change. We discuss implications for research on professions, co-production, and organizational change.

Keywords: professions, invisible work, framing, narratives, organizational change, ethnography

INTRODUCTION

The socially valuable services required in well-functioning societies, including health care, education, markets, and public administration, are often provided by large bureaucratic organizations. These organizations structure the institutional, spatial, and legal arrangements under which professionals provide the services to clients (Briscoe, 2007; Freeland, Sivan, & Ezra, 2018; Huising, 2015). These socially valuable services are intended to help the people who use them, as with education or health care, or to improve their environments, as with public administration (Betts, 1992; Cutler, 2004; Hage, 1999; Leape & Berwick, 2005; Merton, 1990; Sagar & van der Zwaan, 2006). Initially, researchers focused specifically on understanding the professionals 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 explicitly describe and analyze how clients and professionals actually *co-produce* these services, rather than the 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 through 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 goals in ways that change the way professionals understand their expertise (e.g., Bettencourt, Ostrom, Brown, & Roundtree, 2002; Eyal, 2013; Huising & Silbey, 2011; Joshi & Moore, 2004). These studies show that explicitly recognizing clients' involvement in the co-production of services can better account for both how the services are defined and evolve over time (e.g., Eyal, 2013) as well as variation in how effective the services are (e.g., Blustein, Borden, & Valentine, 2010; Brandsen & Pestoff, 2006; Huising, 2015; Joshi & Moore, 2004).

In this paper, we explore how this 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 – that they share an implicit agreement about the tasks that the professionals are expected to do and tasks that the clients are expected to do as they interact to 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). In particular, many studies have documented ways that professions or occupations “hive off” undesired tasks, typically work that is seen as dirty, boring, low value, or low status (e.g., Hughes, 1958; Huising, 2014; Nelsen & Barley, 1997). The division of labor between various professions and occupations has thus 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. Do clients ever dispute the expected division of labor with professionals in their co-production of services? More specifically – can clients “hive off” undesired work – and if so, how?

We developed this research question when studying a multi-year organizational change process at an academic cancer center. We observed a series of interactions that played out over several years between the professional staff at the cancer center and the patients and family members who received care at the center; we saw that these interactions can be understood as a kind of dispute that has been undertheorized in prior literature—a dispute about whether certain tasks and activities should be part of a profession’s or organization’s paid work or whether they should be part of the recipients’ unpaid contribution to the service. We observed that the patients and families developed and used narratives in these interactions to make their case for change. Narratives are distinct from framings in social movements but are similarly developed and mobilized in attempts to change social arrangements (e.g., Benford & Snow, 2000; Coley, 2015; Ewick & Silbey, 2003; Olsen, 2014).

The patients and families told stories about their work coordinating their care. These narratives helped their invisible work become visible to the professional staff at the cancer center, work which had

previously been rendered to the “background of expectation” (Nardi & Engestrom, 1999). To demonstrate the influence of these stories, we analyze how relevant professional groups framed the need for the change overtime and document changes to the groups’ task structures. Our data show that the patients’ narratives broadened the framing used by administrative and clinical professionals to newly include the idea of helping patients with the “Cancer Tax,” their burden of invisible work. The patients’ narratives also inspired new programs that changed the task structures of palliative and administrative groups. The oncology professionals’ task structure did not change. We discuss implications for research on professions, co-production, and organizational change.

RELATED WORK

In the contemporary division of labor, bureaucratic organizations structure the institutional, spatial, and legal arrangements under which professionals interact with clients during service encounters (Briscoe, 2007; Freeland et al., 2018; Huising, 2015). Although the classic research in this area began with a focus on “paradigmatic freestanding professions” such as doctors and lawyers (Abbott, 1988; Huising, 2015, pg. 264), research that is focused on understanding professions’ work and related social implications has undergone several shifts in recent years. The first major shift involved scholars recognizing that 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). These scholars show that new research is needed to analyze the consequences of that employment structure for professionals’ task jurisdiction, power, influence, and effectiveness (e.g., Groysberg, Lee, & Nanda, 2008; Huising, 2015; Tilcsik, 2010; Valentine, Barsade, Edmondson, Gal, & Rhodes, 2014).

Second, scholars also now explicitly theorize that clients and professionals actually *co-produce* services and service encounters, rather than the professionals *delivering* 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).

Third, and relatedly, Eyal (2013) argued for expanding beyond a study of professions to a “sociology of expertise” when accounting for how services are produced in society. That paper proposes using expertise as a framework for explaining what arrangements must be in place for particular tasks to be accomplished in a society, and for considering the processes through which these arrangements were created. That study provides a historical analysis of the creation of a new diagnostic criteria for autism 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. Together, these new ideas linking professionals, bureaucratic organizations, and co-production allow researchers to better account for the contemporary division of labor in society and its consequences.

Disputing Task Areas and Hiving off Tasks

In this paper, we aim to build on these ideas. Specifically, we explore how 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 – i.e., that 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. Highlighting this point becomes interesting because of the many studies characterizing how dynamic and contested task areas or jurisdictions often are. The expected division of labor between professions and occupations in an organization tends to be characterized as a “truce,” a “jurisdictional settlement,” or a “political coalition” (Abbott, 1988; March & Simon, 1958; Nelson & Winter, 1982; Stevenson, Pearce, & Porter, 1985). Different occupations in organizations have power and autonomy tied up in how the work is structured, which means that the process of changing task areas is politically and practically complicated (Astley & Sachdeva, 1984; Contu & Willmott, 2003; Salancik & Pfeffer, 1977). Some tasks may hold significance such as “prestige, influence, and compensation” that different occupations want to protect; alternatively, other tasks may signify a lower status that different groups want to avoid (e.g., Anteby et al., 2016; Kellogg, 2014).

One set of maneuvers whereby groups dispute and change task areas involves established professions “hiving-off” tasks seen as undesirable (e.g., Hughes, 1958; Huising, 2014; Nelsen & Barley, 1997). Hiving-off refers to ways that a typically higher-status occupation delegates or hands off routine tasks or dirty work to others, often to protect their own power and expertise. In some cases, this hiving-off leads to the creation of a new occupation such as paralegals or technicians; in other cases tasks are allocated to members of an existing adjacent occupation (Kellogg, 2014; Whalley & Barley, 1997). The dynamics of hiving off are complex: Huising (2015) found an example of an occupation keeping ‘scut’ work in ways that increased their influence and effectiveness. Nelsen and Barley (1997) note that hiving-off is prevalent in our research setting of health care, where “licensed nurses, medical technologists, respiratory therapists, and an expanding array of technicians have coalesced into occupations around tasks jettisoned by physicians and registered nurses” (e.g., Brown, 1973; Freidson, 1974).

Prior literature thus helps us understand the complex division of labor in contemporary society, including how and why different professional and occupational groups seek to hold on to or hive off different tasks. But we do not yet have an account of whether or how *clients* might attempt to hive off certain tasks in their co-production relationships with professionals and their employing organization. We developed this question during our field study of a formal change process at an academic cancer center. We observed that the patients and families were disputing whether certain tasks and activities should be part of the organizations' task mandate or whether those tasks should be part of their unpaid contribution to the service. As we observed the patients and families engage in this collective action focused on the cancer center, we began to understand that they were using stories or narratives as persuasive communication to make the case that the organization should help with their coordination work, which they argued was burdensome and a problematic division of labor. Through these interactions, they made the case for hiving off some of their tasks to the cancer center. We develop this idea by next reviewing research on framing and narratives in collective action.

Framing and Narratives in Collective Action

Many studies relevant to how professions, occupations, and organizations are changed over time have drawn on the idea of persuasive social discourse, and especially framing. Groups strategically develop and mobilize different frames or interpretations of a situation in attempts to mobilize the interpretations of a proposed change most politically resonant and most favorable to them (e.g., Dutton & Ashford, 1993; Dutton, Ashford, Lawrence, & Miner-Rubino, 2002; Kennedy & Fiss, 2009). Researchers draw on two different but not contradictory conceptualizations of frames and framing to analyze persuasive communication and institutional change. One conceptualization of framing comes from Goffman's (1974) theory of symbolic interaction and offers the idea that frames are "schemata of interpretation" through which different groups come to understand and interpret the ambiguities and uncertainties in their work (e.g., Dougherty, 1992; Fayard, Gkeredakis, & Levina, 2016; Howard-Grenville & Hoffman, 2003). Over time, groups engage in "framing contests," where they compare and

contest various interpretations of situations, in attempts to negotiate their interests (Kaplan, 2008).

Framing contests are pervasive during periods of uncertainty or change, such as when managers or other groups engage with new issues or possible changes, as was the case in our study (Covaeski & Dirsmith, 1988; Kaplan, 2008; Lounsbury, 2001; Zald & Berger, 1978).

The second conceptualization of framing comes from the Benford and Snow (2000) body of research on framing processes in social movements. Social movements often have political or policy goals (e.g., Snow, Rochford, Worden, & Benford, 1986; Snow & Benford, 1992), but some sociologists or organizations researchers have theorized how social movement theory is relevant to organizational processes (e.g., Campbell, 2005; McDonnell & King, 2013; Rao, Morrill, & Zald, 2000) – including internal change processes (e.g., Kellogg, 2009; Morrill, Zald, & Rao, 2003). This social movement research on framing, discourse, and change is relevant for our study because the actors making the case for change were not part of a formal occupation, and thus, social movement research is useful for understanding their engagement and tactics, including their use of narratives. We note both of these research streams on framing because the patients' use of narratives was similar to discourse tactics theorized in collective action research (e.g., Feldman, Skoldberg, Brown, & Horner, 2004; Fine & White, 2002), but also played out in an organization with dynamics similar to Kaplan's (2008) framing contests.

Our aim in this paper is to conceptualize how patients attempted to change their expected division of labor with the professionals at a cancer center. We observed a distinct kind of engagement throughout the change process related to how the patients and their families used stories or narratives to make their case for change. Within the larger set of persuasive communications used in collective action, researchers recognize narrative or stories as distinct from frames (Davis, 2002; Polletta, Chen, Gardner, & Motes, 2011; note following this review we also use stories and narratives interchangeably). A narrative is “an account 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 et al., 2011). Narratives offer distinct advantages and disadvantages as a persuasive device. Narratives are well-

suited for conveying emotion and resolving contradictions because they rely on ‘emplotment’ rather than ‘explanation’ (Polletta, 1998b; Tatum, 2002, pg. 139), but they are less powerful in debate-style forums that require ‘ideological maneuvering’ (Nepstad, 2001, pg. 136).

Groups thus tend to use narratives with other frames or with other persuasive communications within an overall collective action effort, and for certain purposes. First, marginalized groups often use personal stories of injustice 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). In this way, the narratives substantiate broader movement frames about needed change. As an example, Olsen (2014) analyzed discursive strategies used by opponents and proponents of a legislative bill legalizing same-sex marriage and showed that “proponents’ testimonies combined frames with personal narratives” wherein “gays and lesbians told stories about their loving families” meant to demonstrate the “overwhelming similarities between gay and straight couples and families” (pg. 249). In contrast to opponents who only used frames in their testimonies, proponents also shared personal stories of discrimination, for example when they were kept from a loved one during their illness. Second, stories also provide marginalized groups a form of persuasive communication in formal professionalized forums where they would typically be silent because they could 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 less oriented towards criminality, and found that clients told personal stories over and over about how a new Drug Court model had helped them overcome drug addiction. Finally, 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). For example, Iedema et al. (2011) illustrated how patients’ collective storytelling allowed them to speak up with complaints without feeling like they would be dismissed simply as “difficult patients.” Thus, narratives as persuasive communication can transform

individual experiences into a sense of collective empowerment. We observed that patient narratives served many of these purposes during the formal change process at the cancer center as well.

Narratives of Invisible Work. As we examined the patients' narratives in the formal change process, we came to recognize that they were telling stories about the many and burdensome activities they had taken on to coordinate their own cancer care. We also saw that the activities they were describing were classic "invisible work". Daniels (1987) introduced the idea of invisible work to critique the gendered way that work is valued in accountings of modern societies: she argued that "real" work is compensated with wages, while invisible work is completed without monetary validation or verbal acknowledgment. Generally, invisible work refers to work that is "relegated to a background of expectation" and may involve "informal work processes that are not a part of anyone's job description" but are crucial for the functioning of the service or product (Daniels 1987; Nardi and Engestrom 1999, pg. 1; Star and Strauss 1999). Patients and families' co-production work was similarly relegated to a background of expectation, with consequences for how their work was valued and understood. Their efforts to get their work seen reminded us of this argument by Daniels (1987, pg. 405) that one way that people draw attention to invisible work is to show "how it is constructed and what effort it involves." In the rest of the paper, we present an analysis of how the patients used narratives to make their invisible work visible to the cancer center staff. The staff developed a new awareness of the patients' burdens; this new awareness changed how they framed the need for change and what specific changes they proposed and pursued, ultimately leading to changes in the division of labor between clients and the organization.

METHODS

Research Setting

In the past decade, many stakeholders have noted that cancer patients often have poor experiences with the cancer care delivery system, beyond the difficulties of the disease itself (Institute of Medicine, 2008, 2013). One of the problems that has been identified is the burden that cancer patients and their families face in coordinating many professional services (Bylander, 2013; Ganz, 2014; Thygesen,

Pedersen, Kragstrup, Wagner, & Mogensen, 2012). During treatment, patients interact with many professionals because of the complexity of the disease (Mukherjee, 2010). Often a patient will have 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 et al., 2012; Wagner et al., 2014). Many patients also require the services of additional specialties such as dermatology, cardiology, or palliative care, as well as non-medical specialties such as nutrition, financial counseling, or social work (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).

We first learned about and began studying these issues during a field study of an academic cancer center located in the United States. We refer to the field site as University Healthcare Center (UHC). We began our engagement with UHC by proposing to study their formal change process. Early in that study, we quickly realized that a major theme emerging in every meeting we observed involved patients and families describing the coordination burden that they faced. They and UHC staff came to frame to this coordination burden as the “Cancer Tax.” We expanded our data collection to focus on patients’ coordination work and over time began to understand how these patient activities “outside” of UHC were influencing the work of UHC staff. We focus in this paper on how the patients influenced the design of a new cross-functional program referred to as “CarePoint.”

Data Sources

We conducted an observational field study of how patients and families co-produced their care and influenced the creation of CarePoint. We collected data over a three-year period. Our data included observations of patient involvement in the formal change process meetings, observations of doctor-patient encounters, interviews with patients at the cancer center and in their homes, and patients’ free-form handwritten responses to surveys (Table 1).

Observation of patient participation in formal change process meetings. We attended weekly meetings at the cancer center for over eighteen months and recorded the meeting discussions. These meetings were organized around several initiatives aimed at improving patients' experiences, eventually including the development of CarePoint. Attendees included oncologists, administrators, consultants, and representatives from the patient-family council (PFC). We recorded all of the PFC representatives' comments during the meetings and interacted extensively with the PFC members before and after the meetings. We also observed monthly PFC meetings.

Observation of patient-doctor encounters. We also 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.

Observation and interviews with patients in their homes or at the cancer center. We conducted interviews with patients or accessed the interview transcripts conducted by UHC staff. The interviews included 26 home visits. These interviews took several hours and were conducted in the patients' homes, often with 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. We also either interviewed or accessed interview transcripts of 28 additional patients at the cancer center.

Patients' handwritten comments. UHC cancer center collected thousands of surveys about patients' experiences and satisfaction. The surveys used standard questions to assess patients' satisfaction with their care. Survey responses were discussed during many management, clinic, and quality improvement meetings. During one six-month period, over 3000 patients wrote handwritten comments on the backs of one set of surveys. The patients addressed these comments to UHC, and included stories, compliments, or complaints that elaborated on the questions. We scanned and analyzed those de-identified free-form comments.

Insert Table 1 about here

Analytic Approach

After we finished data collection and early analysis, we conducted an inductive coding analysis. First, based on our understanding of general themes in the data, we coded every piece of data to develop an exhaustive list of patients' activities involved in co-producing their cancer care and in shaping the design of CarePoint. This first round of coding was focused on developing a comprehensive understanding of what patients did, not on reflecting the theoretical salience or representativeness of the themes (Pratt, 2009; Strauss & Corbin, 1990). This understanding that patients did considerable work to coordinate their care led us to the theories of co-production and invisible work (e.g., Daniels, 1987; Oudshoorn, 2008; Parks et al., 1981; Star & Strauss, 1999). During a later round of coding, we realized that patients primarily told stories in their interactions and engagements with UHC staff. We analyzed the content, use, and influence of these stories. To develop this understanding, we drew on prior research on stories and narratives in collective action (e.g., Polletta, 1998a; Polletta et al., 2011). Our final round of coding focused on developing an understanding of how the narratives influenced the formal change process. Following an analytical strategy laid out in Shestakofsky (2017), we divided the three-year study period and the formal change process into three major Phases using "break-points" when decisions were made that allocated resources in a new way. Phase 1 lasted from the start of the change until CarePoint was funded (about 15 months), Phase 2 was from CarePoint being funded until the first meeting of CarePoint (about 5 months), and Phase 3 was from the first meeting until the end of the study period. We analyzed the framing and task structure of each involved group (administrative groups, oncology groups, palliative care groups, and patients and families) at the beginning and end of each of these Phases (as illustrated in Table 2, introduced below).

FINDINGS

Patients and their families were involved and influential actors in the UHC formal change

process. Their involvement was different from the professional groups because they tended to show up and engage by “telling their stories.” Through their storytelling, the patients and families helped many of the UHC professionals develop new awareness, new program ideas, and new political will to push UHC to take responsibility for coordination work that the patients and families had been doing. To present this account, we first describe the established task structure at UHC before the formal change process began. The relevant groups include the administrative-operations groups, the oncologists and their clinical staff, a small palliative care group, and the UHC patients and their families. We then describe the initial plan for change. Patient donors funded the change process and required a formalized proposal and consistent reporting, which makes it possible to analyze how the formal plans were initially conceived and changed over time. We will show how each group began with a plan for change that was separate (“siloed”) from other groups and consistent with their own specialized group tasks and values. Importantly, this initial plan did not include the programs or changes that were later developed to address the burdensome coordination work that the patients’ stories would reveal and emphasize throughout the change process.

We then describe how the change process unfolded in three Phases (see Table 2). Our analysis shows how the administrative, oncology, and palliative groups framed the need for change and structured their tasks at the beginning and end of each Phase. These comparisons show new awareness and new program ideas developing over time that were inspired by the patients’ stories of their invisible work. For this analysis, it will also be important to differentiate the roles that patients took on. Patients and families engaged UHC with their narratives in three key roles: 1) as *patient donors* who provided funding for the change programs and who structured their funding offer around an archetypal patient story; 2) as *patient activists* who engaged staff during formal change process meetings by telling stories; and 3) through *patient feedback* in interviews and surveys which the patient donors required and the patient activists helped collect and amplify. Notably, when the broader patient population was asked to provide feedback through interviews and surveys, they still engaged by telling specific stories, either in the interviews or by writing comments on the backs of the surveys. Those stories, though sometimes shorter, were remarkably

consistent with the patient donors' and patient activists' stories.

We will show how these stories created new awareness among the professional groups by showing how they broadened their discourse over time about what needed to change. We will also show how the patients' stories inspired new program ideas that the siloed groups had not proposed before hearing the patients' stories. Our data also show that although the patients' stories created new awareness and program ideas, these resources for change were influential only in how administrative and palliative groups structured their tasks; the oncologists' task structure did not change during the study period.

Insert Table 2 about here

Initial Task Structuring at UHC

The initial task structuring at UHC reflects the dual-authority structure between doctors and managers typical of most academic medical centers (e.g., Pool, 1991; Tap & Schut, 1987), and also of the peripheral status of the palliative specialty compared to oncology (e.g., Del Ferraro et al., 2014; Lorenz et al., 2008). The patient donors and activists engaged this political landscape as new political actors trying to accomplish change (versus engaging the system as service recipients). Each of the professional groups expressed sympathy rather than opposition to the patients and their plight; a key difficulty the patients encountered as they engaged this complex jurisdictional settlement was the lack of explicit understanding or engagement from UHC staff about their burdensome coordination work. Another key difficulty was the strong inertial expectations of “the way things had to be” to accommodate the powerful oncologists, who were seen as offering the most high-value services through “life-or-death” diagnoses and treatments.

UHC staff's collective work was to provide cancer diagnoses and treatments to a large patient population. Some critical aspects of this work were accomplished during oncology clinic appointments, where an oncologist and her team would interact with patients to develop a diagnosis and a treatment plan. Many of the tasks of patients, oncologists, administrators, and palliative specialists can be

understood in relation to these formal service appointments. The oncologists made decisions about diagnoses and treatments during those appointments. They typically had large clinical teams of medical fellows, residents, nurses, nurse coordinators, 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 the service encounter.

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 UHC hospital (versus in 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. At the main hospital, this service was often offered at the bedside, but appointment structures were more variable in the outpatient cancer care setting.

Oncology Clinic Appointments. In characterizing this initial task structuring at UHC, we want to use our data to illustrate an interaction pattern that played out during the clinic appointments because of its relevance for understanding the patients' stories. These 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 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 in our data involved the hematologists interpreting lab test results and adjusting the patients' treatment plans during the appointments based on those values. As another example of direct service, one patient who had just started chemotherapy developed mouth sores, could not eat for a week, and lost significant weight. The doctor interpreted this as medicine intolerance, stopped the prescription, and prescribed medical marijuana. In another instance, a patient had developed benign polyps, and the doctor performed an ultrasound and a pap smear and interpreted the results of the scan and the test for the patient, meaning she did not need to be seen again for three months. In these cases, the patients' issues fell squarely in the oncologists' service paradigm and they offered diagnostics, treatments, or counseling during the appointments. Table 3, column 1 illustrates the patients' needs that fell in the curative paradigm.

Insert Table 3 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 3, 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.” To be clear, this comment is not reported to show a lack of compassion, it 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 was glad that this patient, whom he cared about, 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 3, column 3 lists illustrative examples of the experiences that the doctors judged normal or expected – meaning the patient was supposed to deal with them without a professional supporting them.

Patients and families coordinate multiple services. The patients' and families' tasks (according

to the accounts we will report below) 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 specialists as they coordinated their cancer care, which included getting help with the many side effects of treatment. And, as the patients' stories reported below reveal, they also wanted and sought additional help with other needed services such as nutrition, mental health support, financial planning, survivorship, or pain management. Interacting with this broad 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 kinds of paperwork, learning about and interacting with different IT systems, and navigating different specialists' financial and insurance policies. This administrative coordination work may in theory sound simple, but the patients' stories revealed that this coordination work was so burdensome that in most cases, someone in the patients' families had to take it on as full-time endeavor.

Beginning Plan for the Formal Change Process

Now that we have characterized the initial task structure at UHC, we can examine a multi-year process where many stakeholders attempted to change it. At the start of our study period, a group of patient-family donors asked UHC to create a written proposal outlining needed changes at the cancer center. The written proposal that eventually secured funding began with a summary of the nation's 40-year "War on Cancer." The proposal argued that many research advances had been made, but that a main over-arching problem was the lack of translation of learnings into improved clinical care. Under this broad problem framing, several major initiatives were proposed, broadly relating to operations, scientific advance, and supportive care. 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 original proposal. This service was mentioned only once, in a short phrase in the twelve-page proposal, listed together with survivorship and supportive care. The proposal defined palliative care as “providing specialized symptom management services to patients nearing the end of life.” The proposal earmarked some funds to be used 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 proposal in a few ways. First, of course, is the behind-the-scenes anonymous patient-family donor who requested the proposal, requested revisions, and approved it. Patient-family actors thus created the overall event for the formalized change process. The written proposal also included a patient story. After the “War on Cancer” description and framing around lack of translation, the proposal laid out the story of “Gemma” who was supposed to represent an archetypal patient. Gemma’s story began with a brief vignette of her diagnosis and her discussion with family members about her goals for care. Her story then included a longer storyboard, where she as an archetypal patient went through ten mini-

vignettes, each about 50 words long, which followed her entire experience of care, giving stories of experiences she had long the way. The vignettes include interactions within different silos – i.e., in story one she is in the exam room, and in another story, samples of her blood are being stored for genomic analysis. The “Gemma” story thus weaves together many complex separated parts of the organization into a narrative whole. This use of stories to weave together disjoint organizational areas was a common theme throughout the change process, though this initial archetypal story was still separated into organizationally-relevant interactions, rather than into events as they would unfold in a patient’s life. The proposal also included a team of researchers to measure changes in patient satisfaction scores and conduct qualitative assessments of patient experiences. These began to structure the channels wherein many patients could tell their stories.

Phase 1: Patient Narratives Create New Awareness and New Program Ideas

The beginning plan for change reflected each professional group’s understanding of how they needed to change to help patients – for example, by improving operational excellence or by advancing scientific discovery. We now turn to examining how patients and families influenced the change process by helping professional groups develop new awareness and new program ideas related to their burdensome invisible work coordinating their care.

Patient activists tell their stories in design workshops. Some of the key actors in this process were a small group of about six patient activists who participated in formal change meetings at UHC. They were either patients who had been through cancer treatment and were in remission or relatives of patients who were in active treatment or remission. The six patient activists were white, professional, over 50 years old, and were cis-identified men or women. The administrators, physicians, and change consultants with whom they interacted tended to also be professional, cis-men or women, over 50, and white or of Indian or Asian descent. These demographics were never discussed, but they are relevant for later discussions of boundary conditions. The patient activists attended weekly or bi-weekly change design meetings, where consultants who were responsible for designing and implementing various change

programs presented their ideas and progress, and also solicited input from managers, oncologists, the patient activists, and other attendees. We directly observed patient activists engaging in two series of highly-attended redesign meetings, one focused on an administrative program that did not take hold (or evolved considerably over the change process) and one focused on the small palliative care teams' program. These two series of design meetings took place throughout Phase 1 and both of them involved over a year of active engagement.

The interaction pattern in these meetings typically involved the consultants giving an idea or update and the patient activists responding with stories of how they had been affected by situations relevant to that idea or update. These stories tended to describe negative situations and to assign UHC responsibility for them. But they also often contained ideas for resolving these situations. We will give examples of three patient activists telling their stories over time. The first example involves a patient activist who was in remission. During an administrative redesign meeting, he shared this story:

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. So 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. The patient is recovering from the physical trauma, so the spouse carries all the psychosocial trauma.

He continued the story by telling the group that the coordination burdens had been so heavy that his wife was not able to work while helping him manage the complexities of his care. He told the group that there was a “kind of PTSD that all families and survivors share of that experience. You’re not the same after it.” He told his family’s story many times throughout this year of design meetings, emphasizing different events or experiences, depending on what was being discussed. For example, later, during a redesign workshop, he recognized an opportunity for the staff to better understand the complexity introduced by the divide between inpatient and outpatient – the patients and families had to deal with that complexity, and he thought the administrative redesigns could help. He made that point by telling this story:

I was 14 weeks in the hospital which is like a closed circuit, they take care of everything because it is all right there. And then the rest of my care was all outpatient, which is a completely different system. I remember standing in the hospital lobby with my wife and our little kid was

running around and realizing we did not know what to do next (after discharge). The hospital and cancer center seem to think they aren't the same organization, but they are the same to us. The transition between them is chaotic. It should be one entity.

These stories helped the staff develop new understanding about what the patients experienced and inspired ideas for specific ways that new programs might be able to help. This patient activist often pushed the program designers both to be more thoughtful about recognizing and including family members as those who are heavily impacted by the coordination burdens put on patients, as well as to recognize and help with the transitions between inpatient and outpatient services.

The second example involves another patient who was very recently out of her active treatment, which she had received at UHC. She told this story in one of the administration redesign meetings:

It's a big challenge for the patients. They have to navigate through very, at times cumbersome web sites, the phone numbers that might or might not be providing the information that they need. I know this myself personally, being a patient at UHC. It takes a tremendous amount of time. I can tell you, for myself, 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 that I need to call.

In a later meeting, she shared a story with similar themes. She said, "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 could not help me do it." She said she had to separately contact the other specialist and wait until they called her back at 10pm that night, and then rearrange several appointments. A theme across her stories was a desire for a "single point of contact" or a single point of help. For example, when she was hearing early discussions of the palliative care team's ideas for a single supportive care program with automated referrals, she said some of the ideas would make her uncomfortable. She said "The coordination piece would obviously be so huge. But – the relationship with the referring person is also huge. I was pregnant when I was finishing up chemo and was just so stressed. If a Psych Doc had just automatically dropped in at that point, it just would have made it worse. I just needed to cry."

The third representative example of how one of the patient activists engaged in these design workshops involves a woman whose husband had a type of chronic cancer, which refers to any type of

cancer that cannot be cured but that can be controlled for years with extended treatment. She engaged in both the administrative program redesign meetings and also sometimes the palliative team's design meetings. Here is an example of a story that she shared in one of those workshops, and how it shaped the conversation. She said:

Remember that my husband has chronic cancer. We are trying to live our lives and cancer is just one part of it. Something that we keep encountering is him being seen as his disease, instead of as a whole person with a whole life, that cancer is one part of... When I am here, I work with the palliative team, and I work with the survivorship team, they are both relevant to his goals for his care, which is more of a life spectrum. But the survivorship program and supportive care and palliative care... they are so separated here.

This patient activist shared specific stories and experiences to illustrate how cancer care services needed to better recognize that patients were whole people and that the various programs offering help were too disjoint. One specific set of stories this patient activist told on several different occasions revealed the need that patients and their families have to be able to access different kinds of support at different times; without this access, they ended up in the emergency department (ED), which was not well-suited to provide the many different kinds of multi-disciplinary help that were needed. She told this story:

There was a time when he had neutropenia (a side effect of chemotherapy where patients have abnormally low number of white blood cell and are at risk for life-threatening infection) and we ended up having to go the ED. He was treated just like any other patient (implication being, putting him at risk for infection), which was so traumatizing. We vowed to do anything we could to avoid that situation in the future.

An administrative staff member responded to this story with one of her own. She said, "I have a woman staying with me who has stage 3 breast cancer. Often she needs some sort of support at like 6:30pm after the clinics are closed, so you should really think of the timing of when they can access (your program) otherwise, yeah – they end up having to go to the ED" The patient activist agreed, and shared this reflection, "Yeah, there are those moments when it's 30 seconds after 5pm and you have that moment of panic because no one is answering the phone." The staff discussed how they could support patients so they would not have to use the ED as the stop gap when other programs were not available as an integrated supportive network, again collectively emphasizing the idea that supportive cancer care was not fitting into a paradigm of the single-site 9-5pm oncology clinic.

Patient activists shape collection of patient feedback stories in interviews and surveys. Another way that patients engaged in and influenced this formal change process was by responding to UHC's invitations to provide feedback through interviews and surveys. The patient activists helped create and approve many of the materials and processes used to collect this feedback, which often took the form of stories. The patient activists also later helped synthesize the stories collected from the interviews and surveys and communicate them to the UHC managers and oncologists.

For the purpose of analytical clarity, we present a synthesized account of all of these stories. They include interviews solicited as part of the change process as well as hundreds of hand-written comments, some of which included specific stories, and some of which included complaints that were not structured around specific stories. We synthesized the stories into themes around coordinating the network of medical specialists, coordinating a network of non-medical specialists, and a lack of integration among the services. These themes were representative and also reflect the themes the activists reported to managers and oncologists.

Stories about coordinating medical specialists. First, many of the patients' stories about their cancer care experience included the story of coordinating a network of medical professionals. These included specialists to help with side effects, primary care doctors, and ER doctors, in addition to the "traditional" set of radiologists, radiation therapists, surgeons, and oncologists. These stories reflect the implications of the specialized service encounters described in the first section. One patient recounted,

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 said, "I saw lots of specialists. In the last year, I've seen probably a dozen specialists... I saw the neurologist, the rheumatologist, the hand specialist, and the hand surgeon." Another patient told this story: "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." Another patient described coordinating with many specialists to seek help with a common side effect known as "trigger finger":

I got trigger finger in almost all my fingers, so at the worst point, I could barely open a water bottle which was already open, it was so horrible. I ended up chasing that rabbit and I went through three weeks of acupuncture. That didn't work. I went through six weeks of physical therapy two to three times a week. That didn't work because it wasn't treating the right thing. I saw specialist after specialist.

Another patient told this story: "I did at one point develop a rash. And it was quite awkward to get an appointment with a dermatologist." Another patient described developing a rash and having to go to a nearby city to see a dermatologist: "The person I saw in dermatology was like, 'Well I don't know. This could maybe have something to do with chemo, I really don't have any idea.' I'm like, 'Great.' They didn't feel very well-connected." As another example, one patient explained how unmanaged side effects sent her to the ER, introducing another set of professionals she needed to coordinate. She said, "I got very constipated after surgery and had to go to the ER."

Stories about coordinating non-medical specialists. Patients also told stories in their interviews and surveys about the extensive work they did to develop and coordinate networks of non-medical professionals to help create a better cancer care experience. Examples of non-medical professionals with whom many patients developed relationships included nutritionists, financial counselors, social workers, mental health therapists, occupational therapists, and yoga instructors. For example, one patient explained, "We got a dietitian to explain what kind of food I should eat. That helped a lot." Another patient agreed, "UHC did an amazing job I think because they set us up with a nutritionist." One patient told a story about how her wife had to step in and learn nutrition for cancer care because they had not received that essential support from UHC. She said:

We just had to develop a routine for everything. Days during the treatment cycle where I was not in the hospital, I was fairly weak, so I'd crash, and Patty would cook some food for me. I had a kind of a set meal that I would eat every day that I got out of the hospital. We had kale because that was supposed to help. We didn't know, but we made a bunch of kale with some garlic in it.

Another patient agreed, "One thing that is lacking here is nutrition focus and support. You can ask for a

nutrition consultation in the middle of treatment, but it is too focused, it isn't enough. My husband had to do a lot of research and find an outside nutritionist to help us."

In addition to help with nutrition, most patients also wanted help with financial planning as well. One patient told this story:

I had significant problems with the insurance issues and financial issues and because of the chemo brain, that hit like a ton of bricks; it was very overwhelming and challenging. It was one of the things ... the treatment was bad, but the financial aspect was one of the most overwhelming devastating parts. Dealing with it on my own, the finances, the insurance issues, the calls, not understanding what they were saying.

Another patient shared a similar story, "I've maxed out my insurance out of pocket, \$5-7,000 a year, which I'm grateful for the insurance. I'm so grateful for it, but it's like it's been really challenging. The finances and paperwork - it's just another challenge."

Patients also told stories about mental health issues related to their cancer diagnosis. One patient said, "I got very depressed, so I was referred to a psychiatrist to deal with my depression, and... that was really helpful for me." Another said, "I got anxiety, so my primary care doc is prescribing me Zoloft to help with that. It did help." Another patient explained how overwhelming the process had become: "As a very healthy person, and socially well-balanced, this is very shocking. Going from only having to see my doctor once a year, to now I have 6 different doctors that I'm juggling... it's overwhelming."

Stories and complaints about lack of integration. These stories reveal the patients' and families' understanding of all of the services that were relevant to them as part of their cancer care. This "alternative network of expertise" comprising cancer care was broader and more multi-faceted than any one group at the cancer center recognized at the start. The above stories were important for the staff to develop new awareness of how patients were cobbling together medical services and also more holistic and supportive cancer care at great personal effort. A final key theme from the interviews, and especially the surveys, involved stories and complaints about ways in which all of these services were poorly integrated. As one example, a patient wrote about this experience on the back of her survey:

I was told that my doctor is only my surgeon and he does not care about anything else but my reconstruction. I didn't know that I was going to take longer to heal from the reconstruction because I had chemotherapy. I liked him and was happy to have him as my surgeon until he

dismissed my questions about other aspects of my care. The way I was treated felt dehumanizing. Patients also wrote the following comments on the backs of their patient satisfaction surveys (which did not directly ask about these issues): “I would appreciate help with addressing my social and emotional issues as a result of my breast cancer and surgery” and “I would appreciate more involvement and help about some personal issues or questions I might have currently having problems with, perhaps from a case worker” and “I don't feel like I have been seen as a whole person who is in survivorship and still working at job, caring for family.” A strongly-worded complaint about the lack of integration came from another handwritten comment: “We are getting great treatment options but this place is very disorganized. We feel like we are floating out on our own... Get it together, UHC!”

Patient activists amplify patient feedback and stories in meetings with UHC leaders. The patient activists had a regular monthly meeting with executive-level administrators and director-level oncologists. At these meetings, the patient activists shared synthesized accounts of the patients’ stories and feedback. Often these reports were shared with a sense of a collective movement with a lot of energy in it. One of the patient activists said to the executives: “This is the opportunity for UHC to take the lead on integrated cancer care that includes families. There is very little protocol or policy or proven approaches out there.” At one meeting, for example, the patient activists developed and presented a formal presentation of the patient interviews using similar themes to those reported in the last section.

The executive administrators and medical leaders then shared these ideas in other forums. For example, an executive administrator shared these themes in his weekly meeting with all of his direct reports, which included the mid-level managers of every UHC function. He used the phrase the “Cancer Tax” when describing the formal change efforts of this group, which was the first time we personally heard a UHC leader use the phrase, though it became more common later. He and one of the medical directors also facilitated the monthly meeting of all of the oncologists at UHC. This meeting was in the evening and was a formal invite-only meeting where issues of interest to all UHC oncologists were discussed. The executives and directors frequently reported on the formal change process, because it was

impacting many aspects of UHC, including basic science grants and oncology faculty recruiting. At the end of Phase 1, an update included explicit discussions of patients' coordination burdens and collective attempts to address that problem. The patients' stories were thus shared first with executives and oncologists, and then broadly across UHC.

Evidence for increasing awareness. The patient activists engaging UHC staff with these various ways of telling their stories helped the UHC staff develop a new understanding of the patients' burdensome invisible work and also inspired and helped the staff develop new program ideas. Towards the end of Phase 1, we observed that many other staff members regularly used the Cancer Tax problem framing, even in meetings where the patient activists and senior leaders were not presenting or leading the conversation. As one example, an oncologist heard about some negative patient feedback and responded to it in a design workshop meeting: "It really is our job as clinicians to take the patients' experience and turn it into a service. For example, 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 (two auxiliary services offered in ad-hoc ways at UHC)." 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. These are representative examples of the broadening awareness about the coordination burdens that the complex UHC system was putting on patients and families.

Evidence for new program ideas. By the end of Phase 1, the patients' stories had also helped shape the design and funding of a new program. The original proposal did not include a program like CarePoint. We observed several meetings where the patients' stories helped the palliative care team evolve their program idea into the CarePoint program. The palliative care team heard many patient stories in the larger redesign meetings, and they also read the synthesized reports of the patients' stories and feedback from interviews and stories. They began to expand and evolve their sense of the program they should be developing – this can be illustrated by two kinds of meetings towards the end of Phase 1. One involved the palliative care team inviting some of the patient activists who had been more focused on the administrative programs to brainstorm with them about their program. In one of those meetings, the patient activist told them, “(Cancer care) has been really too focused on appointments and visits. We have not mapped out the journey. There are some more quadrants that all people should have addressed as a part of their journey.” She later clarified that such quadrants might include psychosocial support (including help with financial management and mental health), curative support, palliative support, and even spiritual support. As we will describe below, the program they proposed and received funding for represented this kind of broader approach.

A second example of the palliative care team broadening their approach can be seen in their meetings with oncologists. The team was trying to figure out how the palliative specialty could interface with both patients and oncologists. The meetings demonstrate how their questions were no longer focused specifically on growing the palliative specialty, but rather on how to holistically support patients. In one such meeting, a member of the palliative design team asked a doctor, “What other supports beyond active treatment would you say are most relevant to your patients?” He replied, “Dermatology... Supportive transfusions.... Social work, again, is a big one. And nutrition—there are not enough

resources in nutrition, but this is a huge deal.” It is interesting to note that there was a seeming latent awareness that patients needed all of these services, but no active attempts to integrate them for patients or to actively help patients access them.

The palliative design team purposefully evolved their program ideas. Instead of focusing on palliative care, they changed over time to focus more broadly on integrative cancer care, and eventually on developing CarePoint. The palliative care doctor who led this team described this change as going from “Big P” palliative care to “little p” palliative care” (as in a capital letter: “P” and lower-case letter: “p”). She used “Big P” palliative care to refer to an end-of-life medical sub-specialty that had become Board Certified by the American Board of Medical Specialties in 2007 (Schneider 2007). She and her team started contrasting this kind of “Big P” palliative care with any sort of patient-centered integrative care aimed at providing patients with support. They called this “little p” palliative care. Eventually, “little p” palliative care came to mean integrated cancer care that responded to the Cancer Tax problem.

This palliative care doctor and a few members of her team presented the idea of an integrated cancer care service to the Patient and Family Counsel, where several oncologists and high-level leaders were in attendance. At that meeting, the nurse operational director described the “Cancer Tax” motivation and described plans for the integrated care program plan. The palliative care doctor first introduced the idea, saying, “We, the care teams, are good at curing and treating cancer, but 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(atology), 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 evolved the scope of their redesign together with the patient and family members, and the CarePoint design began to integrate more groups to address the Cancer Tax.

At the end of Phase 1, we observed the meeting where this palliative care doctor and intern presented a slide deck outlining the newly envisioned CarePoint program to the medical director, clinical operations director, and a senior vice president:

11:30am meeting. Sonali, a physician, and Beth, her intern, are meeting with the vice president, medical director, and operations director. Everyone is in suits, in leather chairs in a conference room. 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 directors 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.

(Excerpted from field notes)

They agreed to naming and funding CarePoint. They also 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 clinical operations director took responsibility for creating that hiring line and for hiring a new staff member. Note that although CarePoint was responsive to patient feedback, it did not integrate inpatient and outpatient services. Patient activists had given feedback that integrative designs needed to include inpatient services. Despite this consistent feedback, the CarePoint program did not address that integration during our study.

Phase 2: Patient Narratives Continue to Increase Awareness but Encounter Political Limits

In the second Phase of our study, the CarePoint program had been designed and resourced, but not yet launched. The launch of CarePoint came about five months later and marks the start of Phase 3. During Phase 2, the patient activists continued to tell their stories in formal change process meetings, continued to support channels for the broader patient population to tell their stories, and continued to amplify patient stories to professional groups. They had new a coalition in the CarePoint program, and

some of their work continued there. They saw new momentum around administrative changes. These continuing interaction patterns were similar to those in Phase 1, so we will not present new data for them. Instead, we focus on developments that were new in Phase two. These include two new initiatives related to patient stories as well as the CarePoint program encountering and adjusting to political limits, especially in terms of changes that the oncology clinic teams would accommodate.

Patient activists continue to support collection of patient feedback stories. As described above, the patient donors and activists had helped create formal channels for patient feedback to be collected and shared with UHC staff. During Phase 1, these efforts focused on interviews and surveys; two new efforts were created to invite and share patient stories in Phase 2.

‘Sharing Your Story’ Initiative. One of the new efforts was referred to as the “Sharing Your Story” program. Two of the patient activists and a staff ally were frustrated by their perceptions that UHC was continuing on with business as usual, even though there was so much evidence that patients were really struggling under their coordination burdens. This group met regularly in the staff member’s office, continuing to brainstorm ways that they could bring patients’ voices and stories into conversation and planning. One of the patient activists summed up their intent: “We need them (the UHC staff) to understand what it’s like... [pausing]... In fact, maybe we even call this effort... ‘What It’s Like to be Me’.” They talked about how the surveys, and even the interviews, were too limiting in what they asked. They felt that stories told more “naturally” – that is, told the way that a patient would tell a friend or fellow patient – would more powerfully make the case for change. They created a new initiative that they called “Sharing Your Stories,” where patients were invited to call into a secure phone line and share their stories. One patient activist talked about answering standard patient satisfaction surveys and thinking “They are asking the wrong questions” and hoping the storytelling program might help.

In the first few weeks of the program, thirteen patients and family members called in to tell their stories. The stories were poignant. One woman called in twelve days after her husband had passed away and read four poems she had written during his treatment. Another patient called in after a hospital stay

and left the story reported in full in Table 4; we report it in full to be consistent with the patient activists' sense that unstructured stories would be a powerful persuasive communication. This story reflects many consistent themes from all of the stories, but the themes are situated in an overall holistic story of this one patient's experience. Themes from these stories continued to be shared with different UHC groups.

Insert Table 4 about here

Home visit stories. Another UHC team raised awareness that the interviews and surveys were not quite capturing the emotionality and poignancy of the patients' experiences. They were part of the patient experience design team and proposed a new kind of data collection that included going to patients' homes to interview them and observe their work coordinating their care. The themes that emerged from the home visit interviews were similar to the themes from the center interviews, but with added detail and also concrete examples of coordination practices and tools.

During the home visits, the patients and their families sat together with the patient experience team and shared more of their stories of their work coordinating their care. One man told the story of leaving his job to care for his wife during her cancer treatment, concluding with the note that "my job now is home health aide, paper pusher, errands on demand, and whatever else is required." Another patient told of the conversation he and his wife had trying to decide if she should quit her job to coordinate his care. He ended the story by saying, "I let my wife go back to work and I stay home during the day. But 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 my primary caregiver after a full day's work."

Sitting in their homes, the patients and families also told about their work to track information for all of their medical and non-medical specialists. One patient described, "I took my vitals every day. I tracked all the medications I was on. I was taking up to eight pills a day, twice a day." Another said, "This is like a full-time job to manage. Lots of rinses and skin care... and the stress of remembering all these things to do." Another patient listed, "Also... drinking water, so drinking eight glasses of water a

day. I had to write it down so I could tell the nutritionist. I had to do like hash marks on water every day because of the chemo brain.” Another patient showed her tracking binder, explaining,

I did so much research and kept so many copious notes on my meds and my symptoms. I mean, this is my second binder. There were times where I actually had to call and say, "Okay, I've been on this medication for so long, I think now it's time to wean off of it." I knew, from talking to the doctor earlier, that that's what was supposed to be happening.

Figure 1 shows tools that some patients and families created to keep track of the medical and non-medical specialists with whom they interacted for their cancer care. These are pictures of notebooks covered with the business cards of medical and non-medical specialists, with additional phone numbers handwritten in the margins. Figure 2 shows tools for tracking information. These stories and images were shared with the oncologists at their monthly evening meeting.

Insert Figure 1 and 2 about here

Patient activists continue to amplify patient feedback stories in meetings. The “Sharing Stories” and home visits thus produced more stories and more insights that were broadly shared through the cancer center. For example, the patient experience design team created a presentation based on all of the home visits that created an archetypal storyboard for each patient “type” they had met. They were invited to present those storyboards in the formal evening meeting of all of the UHC oncologists, which was a large audience. They later gave that same presentation to many other stakeholder groups across UHC. We heard an oncologist reference that presentation later in a meeting 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.”

During this period, the patient activists attempted to further amplify the case for change. One of the patient activists said that he thought that “The case for change has not been made. We need a stronger case for change.” They began to plan a presentation at a large event where they could “make the case for change.” The two patient activists asked for a presentation slot at the beginning of the meeting. One of

the patient activists divided the room into two sides, with people sitting at many round tables on each side. Each side was prompted with a question and everyone on their side quietly shared their answers, which were written on an easel. At the end, the patient activist turned the two easels around. The list on one easel read: “Bored, hurried, distracted, busy, hangry, busy, dedicated, stressed” and the list on the other easel read: “Terrified, lonely, afraid, confused, worried, don’t know what to do, don’t speak the language, don’t understand what’s going on, I want my mom.” He explained that one group had been prompted to answer “Imagine that it is 3 o’clock on a work day. How do you feel?” The other group had been prompted to answer “Imagine that you find yourself standing in a crowded foreign place that you have never been to before; everyone is running around speaking a different language, you do not know how to read the signs or speak the language, you do not know anyone, and you do not know what you needed to do to get out of there. How do you feel?” The point he was making was clear: when UHC staff met with patients, they were at their place of work. They were at the same office or clinic that they go to every day, with the same colleagues, doing the same thing. When patients met UHC staff, they are in a new place, where they do not “speak the language” or know anyone, and they are often in need of help getting around. Note how urgently the activists continued to make the case for more help and empathy for patients and families, trying to get the staff to put themselves in the patients’ shoes.

Evidence for increasing awareness and also political limits to envisioned changes. During Phase 2, there was continued evidence for broad awareness of the Cancer Tax problem. Many groups continued to talk about the Cancer Tax and the patients’ coordination burden, even when patient activists were not present. For example, one executive said to other administrative staff members 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.’”

This similar pattern was seen among oncologists as well. This pattern is illustrated by an interaction where a new doctor joined one of the design workshops. Someone was explaining yet another helpful program that they were thinking of developing. This doctor joked, “It will be a full-time job to

become a patient!” At the same time, most everyone else in the room including several other doctors shouted, “It already is!” and then everyone laughed at their shared enthusiasm. As another example, one of the oncologists observed during a design workshop meeting:

I think 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 the key point is care coordination. We need to help physicians talk to each other to exchange information and plans that are necessary for each to know.

Some oncologists made similar comments in their monthly meeting, in support of presentations about the administrative changes and the CarePoint program. More oncologists also volunteered to have their clinics do administrative redesigns which were intended in part to help patients’ coordination burdens.

At the same time, what became clear during this period was that there were limits to the changes oncologists were willing to support, especially in how tasks were structured in their clinics and in how referrals were handled. About ten oncologists were willing at this point to support the administrative redesign which was supposed to standardize and streamline all of the “hived-off” work done by administrative staff in their clinics. However, several of these generally supportive oncologists actively blocked a program that could have helped patients with their coordination work because it required taking dedicated clinical staff away from the oncologists. Additionally, many oncologists blocked changes to how referrals were done, in ways that lessened the scope of CarePoint. The oncologists’ reasoning, as explained to us in interviews, was that they were accountable for the patients’ care, so they needed to approve and be aware of all other specialties’ prescriptions and treatments; changes to the referral system were seen as threatening that accountability and introducing unnecessary risk into the patients’ treatment. The oncologists were able to block changes to the referral procedure directly or by simply not adopting CarePoint’s new referral procedures. As an example of the first dynamic, in one design workshop, an oncologist was contending that referrals to other specialists had to happen in an established way. One of the patient activists tried to explain how patients experienced the oncologists’ favored process, but the doctor refused to budge and kept explaining why his preferred way was better. The tension became awkward, someone changed the subject, and the group moved on.

The second dynamic played out in one of the last design workshops that we observed. One of the patient donors and activists hosted the design workshop in her home, in partnership with the palliative specialists and larger CarePoint coalition group. This design meeting took place during the month that CarePoint was holding its first formal meeting at the cancer center. At this day-long design workshop, the main discussion was about how to restructure the referral process, and how to get oncologists to more actively use the referral process to CarePoint. They brainstormed ways to increase interest and adoption among oncologists or, alternatively, ideas for who else in the clinic workflow might take over a survey that might automate the referral procedure to CarePoint. At the time that CarePoint formally launched, this problem had not been solved. Instead, the CarePoint materials for patients instructed them on how to *ask* their oncology clinic team for referrals to any of the programs now bundled into CarePoint.

Phase 3: Broad Awareness of Problems and (Scoped) Programs Take Hold

We sat in on 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 and discussions about whether a few seemingly-redundant services were distinct. The group also ceremoniously handled their first patient case; diverse service-providers discussed how they could each support that patient who had a very complex social situation and complex disease. Several weeks after this first meeting, the medical director sent out this description to the entire UHC staff:

CarePoint is a new single-point-of-contact program that connects patients to many services and programs at UHC 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 UHC 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. Table 5 is a summary of the patient resource guide that is now given to every patient at UHC and is available for download on their web site.

Insert Table 5 about here

This resource offers patients a single point of contact so that patients can access, schedule with, and coordinate all of these multi-disciplinary auxiliary services. When our research ended, these groups that were now bundled in CarePoint continued to meet monthly to discuss how to integrate care for some patients. When considered in the light of the many patient stories reported above, it is clear that the CarePoint program was responsively designed, and became more expansive than the original palliative care design. At the same time, the patient stories reported above show that there remained many opportunities for cancer care services to better help patients with their desire for a more integrated, multi-specialty network of services.

DISCUSSION

The main contribution of this paper is to show how patients' narratives influenced the formal change process at an academic cancer center. The patients used the narratives as part of a movement to hive off burdensome administrative work they and their families had taken on in order to navigate highly specialized and complex cancer care services. Patients' stories about their experiences with this burdensome coordination work created a new awareness among administrators, oncologists, and palliative specialists, who over time broadened their framing of change to include the problems narrated by the

patients' stories. The patients' stories also inspired new multi-service program ideas, which the disjoint groups had not considered before hearing the stories throughout the change process. Despite the new awareness and new program ideas generated by the patients' stories, only the administrative and palliative groups re-configured their task structure, taking on the burden of some of the patients' administrative work; the oncologists' task structure did not change. These findings contribute to research on professionals and framing processes in organizational settings.

Contributions to research on professions, co-production, and bureaucratic organizations

Our findings contribute to the research literature on professions and their work, which has been interested in the division of labor in society and its consequences (Abbott, 1988; Anteby et al., 2016). As noted earlier in the literature review, this literature has recently undergone important shifts, and our findings respond to and contribute to each of these developing areas.

Professionals and co-production. One key shift in the professions literature involves new models of “co-production” activities replacing conceptual models that centered professionals unilaterally delivering services (Anteby et al., 2016; Okhuysen & Bechky, 2009). Our paper contributes new ideas and understanding to this stream of research. To start, our study is one of the first organizations studies to closely examine what clients do to co-produce their services. These new data on co-production reveal key themes that we explored more in depth throughout the paper. The first theme relates to the insight that clients' contribution to co-production work is likely to be invisible work and therefore unpaid, unacknowledged, and relegated to the background of expectation (e.g., Daniels, 1987; Nardi & Engestrom, 1999; Oudshoorn, 2008; Star & Strauss, 1999). This insight has implications for *how* co-production arrangements might be challenged and changed – for example, using narratives. The second insight is that clients' invisible work might reveal a different definition or expectation of the service or task than experts or professionals hold. The final insight that our data revealed is that clients might challenge or attempt to change the expected division of labor in a co-production relationship, an insight we have not seen fully explored in prior research.

Beyond these direct contributions to research on professionals and co-production, our findings have implications for a related research area – the relationship between organizations and their surrounding environments (e.g., Grant, 1996; Jansen, Van den Bosch, & Volberda, 2006). 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 ties together and 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 in our paper. UHC patients and families coordinated what they perceived as better networks of cancer care through great personal effort. They also persuaded UHC staff to make changes to better support them. UHC patients came from many different backgrounds and circumstances, but the patient activists themselves had considerable personal and professional capacity and resources to draw on when engaging UHC staff. These are all specific ways that surrounding communities like contribute to the effectiveness of human service organizations providing health care or education. Future research can explore how patients' co-production activities are constructed in different communities, as well as how collective action to reduce patients' invisible work might play out in different communities.

Professionals and networks of expertise. Another shift in the professions literature, for which our paper offers new implications, is the more general model of “expertise” developed in Eyal (2013). That study showed how parents constructed an alternative network of expertise for addressing behaviors in their children that eventually came to be understood as “autism” rather than as “mental retardation,” which was a broad indiscriminant category with poor treatment options and outcomes. Although we do not directly use actor-network theory to conduct our analysis, our findings resonate with this theory of

expertise. We found that non-experts, in this case, patients and their family members, had a different expectation of the cancer services that were important and useful for their desired lived experiences than the network of services the experts at the cancer center easily integrated. At the beginning of our study, the non-experts were constructing and coordinating this multi-specialty, multi-site network of expertise themselves, through considerable invisible work. Then, a group of the non-experts engaged in direct action to push the experts to take responsibility for better integrating some of that network of services within the intuitional and spatial arrangements of the UHC center. Though the timescale and changes in our study were relatively small, these findings offer a useful real-time account of issues and tactics at play when non-experts influenced the construction of a new network of expertise.

Our findings also introduce new ideas for exploring this framework of expertise. The first relates to discovering some of the direct tactics whereby non-experts might contest experts' understanding of a task, such as treating children with autism or treating patients with cancer. Future research can explore the generalizability of our findings, but the idea of personal stories as a persuasive communication in these collective actions seems promising. Many of the patients' stories seemed to contrast the emotionality and humanity of their lived experience with the dehumanizing ways they felt the bureaucratic systems ended up treating them. To the extent that established networks of expertise favor experts' view of expertise, non-experts' personal stories might be a common and powerful tactic for change, possibly within large movements. This conjecture reminds us of uses of stories in movements for more humane court systems or medical systems (e.g., Nolan, 2012; Polletta, 1998a; Polletta et al., 2011).

Our study design also ended up foregrounding the organizational setting for the place this movement played out. This setting for our study revealed some of the implications of the organization in the activities involved in constructing new networks of expertise. For one, UHC ended up structuring the spaces and events wherein patients could directly dispute their coordination burdens. Instead of being the target of an external social movement, UHC offered the spatial and institutional arrangement for a "formal change process" in which the patients were legitimate and welcome participants. This arrangement may have influenced the patients' collective action and the effectiveness of their movement.

They engaged mostly through stories, stressing similarity with staff and evoking empathy. It is interesting to consider what a social movement to reduce patients' coordination work might have looked like if it had played out in public spaces instead of in these formalized change meetings, where the patients had a formal and legitimized role – and in some cases a continuing dependency on UHC for care.

Relatedly, our findings also demonstrate that patients as non-experts trying to construct a new network of expertise interacted with UHC as a socially “accountable actor” (Freeland & Zuckerman, 2018). We found it interesting that this idea of UHC as a singular accountable actor was never questioned by patients, families, staff, or medical professionals. In every meeting and interaction, it was taken for granted that UHC was an accountable actor; any disagreements that arose were about what tasks and problems UHC should be accountable for. This finding suggests that not only are organizations an important setting wherein people engage in collective action and change, organizations also end up taking on an important social role. As an “accountable actor,” UHC provided a simple focal target for change, even though the actual network of expertise constructed within the organization often seemed so complex as to be intractable. Future research examining networks of expertise might explore this actor role for organizations, and its implications for change.

Professions in bureaucratic organizations. A final shift in the professions literature recognized that most professionals now work in bureaucratic organizations, rather than as “paradigmatic freestanding professions” such as doctors and lawyers (e.g., Briscoe, 2007; Huising, 2015). Research that examines this specific employment arrangement has provided new understanding of both contemporary professionals and their managers (Huising, 2015). Our study similarly provides new understanding about professionals based on their work being structured in a bureaucratic organization. Our first contribution here is the characterization of an undertheorized problem that arises from professionals' specialization in these organizational settings – a trend which seemed to increase the complexity and related coordination work for clients. At UHC, this problem arose from ways that high-status professionals specialized – for example, the division of labor between oncologists and dermatologists around prescribing chemotherapy and then dealing with the side effects of chemotherapy. And, this problem also arose from ways that

high-status professionals “hived off” supportive services and administrative work to other staff. These ways of structuring work created complexity and lack of integration for patients, even though the services were all co-located and appeared to be integrated by the UHC brand. 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. For example, higher education offers an example of a setting where this finding might generalize. Elite research universities might similarly outsource a high coordination burden for students if high-status faculty researchers are expected to and encouraged to hive off teaching, administration, mentoring, or social support. News media have recently explored the rise of mental health services on college campuses, especially in response to high-profile stories of students who did not receive the help they needed within their college bureaucracies.

Our second contribution to this body of research relates to the changes in task structures of different professional groups over time. Our study design leverages comparisons between the initial codified plans and the implemented programs to show that no professional group planned a program like CarePoint. Our data also show how different professional groups responded to the patients’ stories over time. Only the administrative groups and palliative care teams changed their task structures, but the oncologists did not (as was illustrated in Table 2). Thus similar to Huising (2015), our findings uncovered an active role for managers and administrators in the changing task structures of the other professional groups. The administrative groups took on the most new tasks, attempting to relieve some of the patients coordination burdens, even though the palliative care team designed the new CarePoint program, and even though the oncologists’ specialized jurisdiction contributed to the patients’ challenges. Our findings suggest that “hiving off” work to administrative groups may be more accepted and seen as easier than disputing professionals’ task jurisdiction. Future research could explore this pattern further, as well as related implications for increasing bureaucratization and workforce trends.

Our final contribution to this research area about professionals in organizations relates to the patterns we found in how clients held professionals and organizations accountable. Our findings showed that patients and families seemed to hold different expectations of accountability for staff and

professionals than for UHC itself. Negative feedback focused on interpersonal offenses from staff and professionals (e.g., Holdsworth et al., 2019). But as stated above, patients addressed UHC itself, as the whole organization, as an “accountable actor” (Freeland & Zuckerman, 2018). They held the complex organizational system accountable for coordination burdens in a way that they did not hold the professionals accountable. Future research could explore differences in how people hold professionals and bureaucratic organizations accountable, and how these differences explain variation in social movement tactics and consequences.

Contributions to research on framing and narratives in organizational settings

Our findings also contribute to research on organizational change, particularly research on how framings are developed and mobilized in organizational change. Prior research describes various framing activities involved in changing the expected division of labor between different professional groups in organizations (e.g., Kaplan, 2008; Lounsbury, 2001; Vallas, 2003). Our findings similarly showed that patients and families engaged in framing activities to change the accepted division of labor between them and the UHC staff. They deliberately worked to develop an interpretation of the situation that had urgency, salience, and broad appeal (e.g., Dutton & Ashford, 1993); their framing of the “Cancer Tax” supported that kind of mobilization. However, our study also adds new insight to this area of research. To our knowledge, this is the first study focused on how clients were involved in framing a formal change. As clients are a different sort of political actor in organizational change, it is perhaps unsurprising that they engaged in tactics for collective action that have been undertheorized in organizational change research. Specifically, we found that the patients tended to use stories as persuasive communications when engaging UHC staff.

In this way, our characterization of the patients’ use of stories is similar to prior research that theorizes the use of narratives in social movements (e.g., Coley, 2015; Olsen, 2014; Polletta, 1998a; Polletta et al., 2011). First, the patients’ stories substantiated frames about needed change by using personal experiences of suffering and injustice to draw empathy from the UHC staff. Second, the patients’ stories allowed them to speak persuasively in formal organizational forums where they would

typically be silent, because they could not approach those formal workplace discussions with technical, scientific, or expert discourse. Third, the stories allowed the patients 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. Similar to the patients speaking up in Iedema et al. (2011), these patients were not being “difficult patients” – they were telling the story of a legitimately aggrieved group that was entitled to more humane service.

Our findings thus substantiate these well-established uses of narratives as persuasive communication, thereby linking this research on organizational change. But our data also reveal another use of stories in this organizational change process, which extends the prior research focused on narratives in movements focused on policy and law (e.g., Coley, 2015; Davis, 2002; Olsen, 2014; Polletta, 1998b). During our study, we saw that the UHC patients and family members told stories about their experiences carrying out invisible work. These stories reminded us of Daniels (1987) argument that one way people draw attention to, dignify, and emphasize the value of 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 involved the other elements of narratives described above – drawing empathy from authorities, allowing patient participation in formal workplace discussions, and allowing personal experiences to represent a legitimate position of grievance and entitlement – but the persuasive aims of the stories focused specifically on making the invisible work more visible to make the case that UHC should take responsibility for the burdens it was inadvertently placing on patients and families.

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Table 1. Data Collected

Observation of Patient and Staff Activities
<ul style="list-style-type: none">• 18 months of participant observation. We attended weekly meetings involved in the formal change process improvement initiatives aimed at improving patients' experience. We also attended monthly PAC meetings of a large group of patients, former patients, and family members.• 125 clinic appointments. We observed a full month of clinic visits for 5 different oncologists in two different clinical areas.
Interviews with Patients and Family Members
<ul style="list-style-type: none">• 28 interviews with patients at the cancer center• 26 interviews with patients and their families in their homes, observation of their tools and practices
Archival Data
<ul style="list-style-type: none">• 3000+ handwritten patient comments collected on freeform areas on quality improvement surveys

Table 2. Timeline of Major Events, Framing Changes, and Task Changes among Patients and Staff during Study Period

	Year 1	Year 2	Year 3
Major Events	Formal change efforts begin	+ Integrated care program funded	+ First CarePoint meeting
Patients and Families			
Framing change	Visibility Narratives	+ “Cancer tax”	
Task structure	Coordinate “curative” care, research and coordinate auxiliary services		+ Coordinate with CarePoint instead of each auxiliary service
Oncology Clinic			
Framing change	Scientific evidence in curative paradigm	+ “Cancer tax”	
Task structure	Diagnosis, treatment		
Palliative Clinic			
Framing change	Decision support outside curative paradigm	+ “Big ‘P’ vs. Little ‘p’” (Integrated Care)	
Task Structure	Decision support, pain management	+ Support integrated care program	
Administration			
Framing change	Re-engineering systems	+ “Cancer tax”	+ “Big ‘P’ vs. Little ‘p’” (Integrated Care)
Task Structure	Scheduling, billing, operations		◇ Reconfigured administrative work for efficiencies + Run integrated care program, bundle referrals and information for auxiliary services + Provide cross-service case management

Table 3. 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”)
<p>Abdominal pain (Urine test)</p> <p>Abnormal lab values (Ordered tests)</p> <p>Abnormal lab values (Prescription)</p> <p>Biopsy showed cancer (Ordered tests)</p> <p>Bleeding (Ordered test)</p> <p>Bleeding (Prescription)</p> <p>Bloating (Ordered scans)</p> <p>Constipation (Advice: stool softener)</p> <p>Cough (Advice: smoking cessation)</p> <p>Fatigue (Ordered test)</p> <p>Fatigue (Prescription)</p> <p>Feeling worse (Discussed treatment options)</p> <p>Genetic test results (Ordered ultrasound)</p> <p>Muscle atrophy (Advice: Physical therapy)</p> <p>Nausea (Ordered tests and scans)</p> <p>Nose bleeds (Prescription)</p> <p>Pain (Ordered laparoscopic surgery)</p> <p>Pain (Physical exam)</p> <p>Pain in hands (Advice: ice)</p> <p>Poor appetite (Advice: exercise)</p> <p>Possible allergic reaction (Advice: keep trying medication)</p> <p>Rare cancer second opinion (Advice on treatment options)</p> <p>Reduced activity (Advice: Increase activity levels)</p> <p>Swelling (Ordered ultrasound)</p> <p>Swelling in legs (Ordered test)</p> <p>Ulcer in mouth (Prescribed artificial saliva)</p> <p>Unable to urinate (Ordered catheter)</p> <p>Weight gain (Switched prescription; Advice: diet and exercise)</p>	<p>Anxiety (Social work)</p> <p>Anxiety (Palliative care)</p> <p>Anxiety about lab values (HIV doctor)</p> <p>Bruise (Interventional radiology)</p> <p>Chest pain (Cardiologist)</p> <p>Concerns about a virus linked with throat cancer (Head/neck oncologist)</p> <p>Declining health (Hospice care)</p> <p>Depression (Social work)</p> <p>Fear of falling (Physical therapy)</p> <p>Fertility concerns (Fertility specialist)</p> <p>Fever (Hospital inpatient)</p> <p>Financial concerns (Financial counselors)</p> <p>Kidney Stone (Urology)</p> <p>Questions about protein powder (Kidney specialist)</p> <p>Rash (Dermatology)</p> <p>Transportation concerns (Social work)</p> <p>Weight gain (Nutritionist)</p>	<p>Abdominal pain</p> <p>Anxiety</p> <p>Back pain</p> <p>Bruising</p> <p>Clumsiness</p> <p>Depression</p> <p>Diarrhea</p> <p>Difficulty getting out of bed</p> <p>Dry skin</p> <p>Enlarged lymph node</p> <p>Fatigue</p> <p>Fingers stick when holding things</p> <p>High blood pressure</p> <p>Itchiness</p> <p>Leg cramps</p> <p>Memory loss</p> <p>Nausea</p> <p>Numb knees</p> <p>Poor appetite</p> <p>Redness and swelling of skin</p> <p>Rib cage pain</p> <p>Shortness of breath</p> <p>Stiffness; joint pain</p> <p>Stomach pain</p> <p>Strained bowel movements</p> <p>Vomiting/nausea</p> <p>Weight gain</p> <p>Weight loss</p>

Table 4. Representative Story shared as part of Patient Storytelling Initiative

I have now been out of the hospital for a little more than a week. I had skin melanoma. I had three surgeries, two to remove the tumors off my back and one for skin graft. Now, a week later, things have calmed down. The phone calls and all the prayers and thoughts from others have died down. Now I'm kind of sitting here thinking about the reality of what I just went through.

I'm going to have to get a lot of motivation and I think I can do this and pull it off. I do want to say that each new patient, whether it's at UHC or anywhere, I think, needs an advocate or a person they can turn to for the emotional part of the diagnosis, when you first hear about it, because it is very scary and you're following everybody else's decisions, pretty much, about what time you need to be here, what time's surgery, what we're going to do, da, da, da.

A lot of appointments, and there's just quite a bit to have on your plate. Luckily I have my wife who's done a tremendous job, but that advocate, at the very onset of when you're first diagnosed, is a crucial part that would give the patient an opportunity to have somebody that's familiar with what people go through and also what to expect, how to work the complex system, and some emotions to understand that'll probably come over us. That's a very important part of this whole thing.

As far as the UHC team is concerned, the nurses in the hospital were grade A. The doctor, the surgeon, was a grade A. The only issues I had with the hospital were that maybe ... We got frustrated with the scheduling part of it. There were cancellations at the last minute or an appointment that wasn't booked with the doctor and we went and sat there and waited and found out that it wasn't really an appointment. That all requires a lot of work to sort out.

Table 5. Summary of the CarePoint section in the UHC patient guide

<p>CarePoint is your connection to personalized, supportive services before, during, and after your treatment.</p> <p>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.</p> <p>With just one call to CarePoint, you and your loved ones can speak with a nurse to access services that are right for you.</p> <p>UHC Cancer Center 555-555-5555—ask for the CarePoint team</p>		
Clinical Cancer Genetics Program	<i>Program description</i>	<i>Program referral checklist</i>
Integrative Medicine	<i>Program description</i>	<i>Program referral checklist</i>
Neuropsychology Clinic	<i>Program description</i>	<i>Program referral checklist</i>
Nutrition	<i>Program description</i>	<i>Program referral checklist</i>
Occupational Therapy	<i>Program description</i>	<i>Program referral checklist</i>
Pain Management	<i>Program description</i>	<i>Program referral checklist</i>
Palliative Medicine	<i>Program description</i>	<i>Program referral checklist</i>
.... 11 more pages of programs and descriptions ...		<i>Program referral checklist</i>

Figure 1. Picture of Patients' Work Constructing and Coordinating Networks of Service Providers

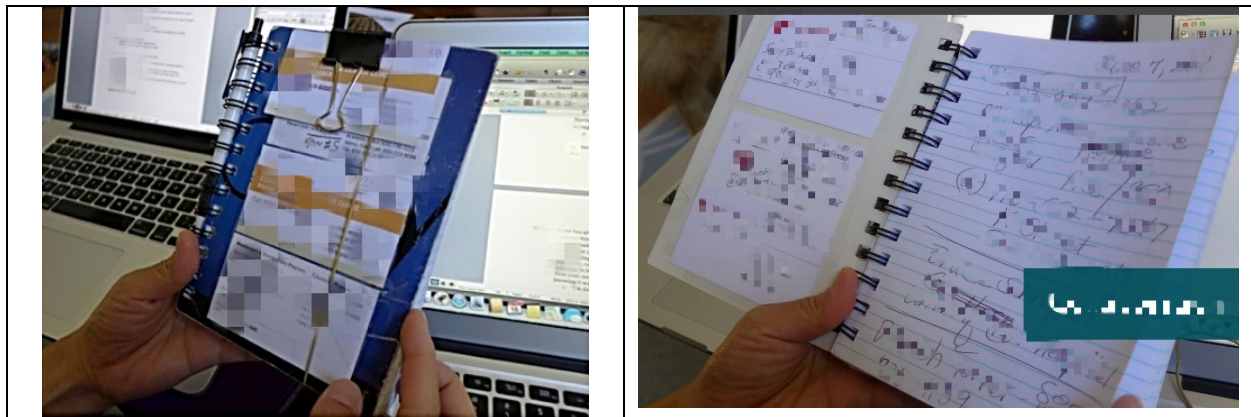


Figure 2. Picture of Patients' Work Managing and Coordinating Information

