Social Literacy: Nurses' Contribution Toward the Co-Production of Self-Management

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Abstract

We share findings from a larger ethnographic study of two urban complex care management programs in the Western United States. The data presented stem from in-depth interviews conducted with 17 complex care management RNs and participant observations of home visits. We advance the concept of social literacy as a nursing attribute that comprises an RN's recognition and responses to the varied types of hinderances to self-management with which patients must contend in their lived environment. It is through social literacy that complex care management RNs reconceptualize and understand health literacy to be a product born out of the social circumstances in which patients live and the stratified nature of the health care systems that provide them care. Social literacy provides a broader framework for health literacy—one that is situated within the patient's social context through which complex care management RNs must navigate for self-management goals to be achieved.

Introduction

At its most basic, to be literate means having the ability to read and write or to possess the requisite competencies and knowledge in a specific area (Oxford English Dictionary, 2013). The concept of *health literacy* has been around for decades. Simonds (1974) is credited with first promoting the term (Tones, 2002) in the context of school health education. Simonds (1974) conceived health literacy to be a "social service activity. . .intended for the well being of the population" (p. 3). As such, health literacy was a matter of social policy necessary to bridge the gaps between the services health institutions provide and the individuals who use them. He emphasized the importance of health education for its beneficial impact in the ways it could link biological sciences, medicine, and health care as well as organizations concerned with more efficient use of limited health care resources, harmful environmental factors, and personal habits and behaviors that were detriments to health. The goal of such linkages was to help consumers of health care become "producers of health" (Simonds, 1974, p. 3) through health education. Because individual behaviors have a great deal to do with health outcomes, Simonds (1974) opined that having

informed and "health-activated citizens" (p. 3) could lead the way toward a reduction in overall morbidity and mortality.

A large literature exists pointing to the importance of health literacy to maintain or improve health (Berkman et al., 2011; DeWalt et al., 2004; Heijmans et al., 2015). Those with limited health literacy are more likely to suffer poor health outcomes including higher mortality, worse health status, poor access to health care, overuse of emergency services, repeated hospitalizations, and higher health care costs (Institute of Medicine, 2004). Low health literacy has been found prevalent among those with overall low literacy, minorities, those with low socioeconomic status, and the elderly, and is recognized as a strong contributor to health inequalities (Berkman et al., 2011; Heijmans et al., 2015; Sudore et al., 2006).

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This confluence of low health literacy and low socioeconomic status in turn is associated with a heavy burden of unmanaged chronic illness and contributes to disproportionate health care spending, where the top 5% of patients account for 50% of total health care costs (Bodenheimer, 2013; Gawande, 2011; Mao et al., 2017). Patients with multiple morbidities have reported a range of barriers to self management of their illnesses, including depression, financial constraints, a sense of being overwhelmed by one dominant condition or the compound effects of multiple conditions, and low efficacy around self management tasks including health condition surveillance and tracking, and medication management (Bayliss et al., 2007).

The management of complex chronic conditions requires planned, timely, and coordinated care by an interdisciplinary team of health care staff managing the care of patients with multiple chronic diseases. Recently, complex care management (CCM) programs have constituted an innovative approach to improving health outcomes and lowering overall health care costs for this patient population (Bodenheimer, 2013). CCM is a "set of activities designed to assist patients and their support systems in managing medical conditions and related psychosocial problems more effectively, with the aim of improving patients' health status and reducing the need for medical services" (Bodenheimer & Berry-Millet, 2009, p. 4). In most models, the center of the team is the Registered Nurse (RN), supported as needed by a health coach, a physician, social services, and other ancillaries (Mao et al., 2017). The role of the RN is paramount given her/his unique skills in conducting in-depth assessments of a patient's physical and functional status, behavioral health needs (mental health and substance use), social support, and cognitive function. These findings are then coupled with the patient's health related goals and the health care team's medical goals to create a care plan from which the RN helps the patient to manage his/her social and medical needs through the promotion of chronic disease education, medication management and adherence, and the promotion of health behaviors.

The end goal of CCM programs—self management—consists of patients engaging in health protecting and enhancing behaviors and abandoning unhealthy ones; reciprocal interactions with health care providers and adhering to treatment regimens; self-surveillance of health conditions and making associated health related decisions; and managing the physical and psychological aspects of illness, all of which result in a lower use of health care services (Bayliss et al., 2007; Wagner et al., 1996). As a package of skills, self management comprises the elements of the concept of health literacy. In other words, to self manage chronic illness requires one to be health literate.

In this article, we provide a broader framework for health literacy—one that is situated within the patient's social context through which the CCM RN must navigate for self-management goals to be achieved. We offer the concept of social literacy as a nursing attribute—an attribute through which CCM

RNs reconceptualize and understand health literacy as a social product born out of the social circumstances in which patients live and the stratified nature of the health care systems that provide them care. As more and more health systems adopt CCM programs aimed at addressing the health burdens of specific populations, social literacy highlights the complex nature of the work CCM RNs do to advance population health.

Most of the CCM literature to date comes from the clinical realm and has focused on the associated cost and impact on health care utilization (Bodenheimer, 2013; Cosway et al., 2011); experiences of homeless geriatric patients; (Davis et al., 2012; Sandberg et al., 2014; Spoorenberg et al., 2015); and low income patients enrolled in CCM programs in safety net primary care settings (Mao et al., 2017). Our research team comprises scholars from nursing, sociology, social epidemiology, and anthropology. The analysis we present in this article is part of a larger ethnographic study of two urban CCM programs conducted in the Western United States, beginning in 2015. In over 1,000 hours of observations and hundreds of hours of interviews with patients, providers, nurses, social workers, and health coaches, we have explored a broad range of topics centered around the nature and work of CCM and the myriad ways that work is accomplished. For example, we have analyzed the ways in which health care providers assess patient engagement of those whom the health care system refers to as "super utilizers" of health care, many of whom face complex challenges related to socioeconomic and social marginalization (Fleming et al., 2017); the efficacy and effectiveness of the Patient Activation Measure (PAM) and the Patient Engagement Instrument (PEI) with high-need, high-cost patients receiving care in the urban safety net (Napoles et al., 2017); the contradictions of choice within complex care management programs (Van Natta et al., 2018); and the ways in which trauma is defined and understood by CCM providers in the an urban safety net (Thompson-Lastad et al., 2017). Yet, as central as the role of the RN is to the CCM team, there has been no research to date that explores the ways in which CCM nurses take up, engage with, and operationalize the concept of health literacy or how it guides their role on the CCM team. Given that the overt objective of CCM is self-management and recognizing the primacy of nursing to that end, the intersection of health literacy and nursing is our jumping-off point to analyze not only the content of the work nurses do to effect health literacy, but the fluid and contextual nature in which it is accomplished. In this paper, we examine the processes CCM nurses working in the safety net system engage in to cultivate particular types of health literacy and the extent to which they help patients become health literate.

Theoretical Underpinnings of Health Literacy and its Importance to Health

Previous research has demonstrated that health information and communication tailored to individual needs and capacities is likely to improve efficiencies in health care use, lead

to more productive interactions with providers, better compliance with recommended clinical care, and subsequently better clinical outcomes (Baker, 2006; Nutbeam, 2008; Paasche-Orlow & Wolf, 2007). However, *how* health literacy is defined matters—how the "problem" to be solved is defined makes a great deal of difference in defining the solutions believed to be effective. As Tones (2002) points out, early definitions of health literacy employed more narrow meanings of the concept, highlighting types of resources patients need to negotiate a complex health care system, and the American Medical Association's (1999) definition of health literacy focused on technical skills, such as an individual's ability to "read and comprehend prescription bottles, appointment slips, and other essential health related materials" (p. 553). In these contexts, health literacy is conceptualized as a package of individual competencies, the lack of which pose potential risks that need to be managed in the process of providing and receiving health care. These definitions presume that by narrowing the gap between specific types of health information one needs to know and specific actions or procedures one needs to follow, full patient compliance with the medical care plan can be achieved.

More expansive understandings of health literacy include that of the Institute of Medicine (2004) which considers health literacy as a "shared function" (p. 4) of both provider and patient, and social and individual factors mediated by cultural considerations, educational level, and language. Health literacy is defined as the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Institute of Medicine, 2004, p. 4). Necessary to achieve health literacy are specific skills including reading, writing, numeracy, speaking, and listening, that are context specific and partly knowledge based, and which can be developed through educational interventions and attention to the ways in which health services are organized and delivered (Nutbeam, 2008). However, despite these more capacious and systems-oriented definitions of health literacy, they still situate low health literacy as an individual health risk, one to be treated with the use of different types of printed, oral, or illustrative material that may be more effective in conveying medical information.

Nutbeam (2008) proposes a distinctly different approach to the IOM, by considering health literacy as an asset to be cultivated and built upon rather than a risk to be treated. Health literacy is an outcome of health education developing different forms of competencies that allow individuals greater control over personal, social, and environmental determinants of health, and greater empowerment in making health related decisions. He suggests a typology of literacy skills that go beyond the mere ability to read prescription bottles, follow procedural instructions, and sign informed consents, but rather are characterized by their practical application in "empowering" people to "participate more fully in society and to exert a higher degree of control over everyday events" (p. 2,075).

The first set of skills in Nutbeam's (2000, 2008) typology is *functional literacy*, which he defines as possessing basic skills in reading and writing to allow an individual to capably function with everyday tasks, comporting with the more technical definitions of health literacy described earlier. Second, he describes *communicative/interactive literacy* as a somewhat higher-ordered set of cognitive and social skills required to "extract information and derive meaning from different forms of communication and apply new information to changing circumstances." (Nutbeam, 2000, p. 264). Lastly, he defines *critical literacy* as an altogether more advanced set of skills needed to critically analyze information and use it to exert greater control over one's life situations. According to Nutbeam, these assets can be built through patient education resulting in more comprehensive self-management of disease, confident and reciprocal interactions with health care providers, and better ability to navigate and negotiate one's way through a complex health care system. However, these forms of health literacy may be variably important depending on context: for example, Heijmans et al. (2015) investigated the level of functional, communicative/interactive, and critical health literacy and found functional literacy to be less associated with chronic disease self-management than more complex communicative and critical skills. Health literacy skills were found to be important for some aspects of self-management but not for others, signaling the importance of context.

In sum, common definitions of health literacy as a one-size-fits-all package of individual level skills that can be taught and measured neglect not only the contextual nature of the skills themselves but also the nature of the context in which they must be deployed and the characteristics and social circumstances of the patients expected to acquire it. As described above, in many prevalent understandings of health literacy, it is the patient's burden to acquire and utilize a variety of skills and resources in ways that improve his/her health outcomes that subsequently decrease the economic and capacity burdens of the health care system. There is little understanding, however, of what health literacy might mean for a patient whose social circumstances vary from the often idealized context described in the literature. As a result, health literacy is often seen as a decidedly one-sided proposition.

As well, there are silent partners to the health literacy calculus who are not accounted for in prevailing definitions of health literacy. For example, current conceptualizations of health literacy do not account for the hierarchical nature of health care relationships or the disproportionate power that providers wield during the health care encounter where particular patient skills are valued over others, may be recognized and rewarded in some patients but not seen in others, or the pressures and burdens exacted by the health care system to control costs and increase efficiency (Abel et al., 2014; Abel & Frohlich, 2012; Chang et al., 2016; Dubbin et al., 2013; Papen, 2009; Shim, 2010). We argue that the

"work" and the role of the CCM nurse is contextual. That is, the role of the CCM nurse inherently takes account of both the patient's social circumstance and the hierarchical and power laden nature of the health care system, by offering patients access to a provider who can lower the barriers to entry into a complicated healthcare system, help the patient navigate it, and advocate on behalf of the patient to physicians and specialists. Additionally the work of the CCM nurse focuses on forging a bridge between the patient's social environment and the institutional one by providing additional social and support services in addition to meeting his/her health care needs. The CCM program and the ways in which nurses are situated within it, then, becomes a vehicle through which we can explore how health literacy and its constitutive elements are viewed, valued, and operationalized by CCM nurses. By analyzing what types of skills are leveraged by low-income, "high-utilizing" patients and which are cultivated by CCM nurses, we can better understand the influences various types of health literacy have on the ultimate goal of self-management, and the ways in which providers can best support patients to develop them.

As the CCM nurse navigates his/her way through the patient's lived environment, s/he is introduced to a broad range of the patient's cultural skills, competencies, and knowledges that are unaccounted for in the health literacy literature, but that may be leveraged in service of the end goal of self-management. In addition, the nurse confronts firsthand the dynamics of the patient's social circumstances and the extent to which those dynamics hinder or can be harnessed to build the patient's capacity for self-management. In this paper we ask the question, how and to what extent do CCM nurses cultivate particular types of health literacy and to what end? Through an ethnographic exploration of the work RNs do as part of a CCM team, our goal in this article is three-fold. First, we provide a more nuanced understanding of the health literacy skills patients acquire in CCM. Second, we illuminate the socio-environmental conditions in which patients live that affect their ability to acquire health literacy as it is typically defined. And third, we describe a *nurse-specific* form of literacy we term "social literacy" that CCM RNs acquire and mobilize during their interactions with patients. That is, we find that before CCM nurses can attend to traditional aspects of health literacy, they must first negotiate a path through the patient's social terrain, developing and deploying social literacy. Going beyond the framework of structural competency that encourages providers to recognize how social, economic, and political conditions produce health inequalities (Metzl & Hansen, 2014) social literacy is the vehicle through which the CCM RN actively navigates the precarities of the patient's social, economic, and environmental circumstances and translates these understandings into actions that further the goal of self-management—hence social literacy becomes the primary "work" of the CCM nurse.

Methods

This analysis stems from a larger ethnographic study of two complex care management programs situated in two different public safety net health care institutions in a densely populated urban area of California. The two primary goals of this ethnographic projects were (1) provide a detailed, in-depth ethnographic description of the interactions, processes, and organizational arrangements for CCM programs that contribute to patients' retention in the clinical care system and fulfillment of their social and medical needs, and (2) identify and analyze individual (patient and provider), program, and organizational characteristics that enhance or inhibit patient engagement with health literacy systems. Program 1 began in early 2012 and included an adult medicine clinic and a family health clinic embedded in a public hospital. A nurse and health coach dyad worked in close collaboration with other providers outside of the program, including primary care providers and social workers. Program 2 launched in 2013 at another public hospital in a different but nearby city. In both programs, patients whom the health institutions categorized as "super utilizers" of health care resources—identified as patients requiring over three or more hospitalizations over the previous 12 months period and/or multiple visits to the emergency department or urgent care centers were referred to CCM through a primary care provider, inpatient attending physician, or the local health plan. Most patients enrolled in these programs were extremely low-income and were diagnosed with at least 3 or more chronic health conditions that required active treatment, including type 2 diabetes, hypertension, congestive heart failure, chronic obstructive pulmonary disease (COPD), coronary artery disease, and end-stage renal disease. Most CCM patients also had concurrent mental health disorders and problems with active substance use, and unstable housing including homelessness. Both programs aimed to reduce hospitalizations, improve self-management among participating patients, and then "graduate" them from the program once these goals were met.

Over a 16 months period during 2015 to 2017, four ethnographers (two at each site) conducted observations of patients and providers in the clinic, patients' homes, and other settings. The ethnographers shadowed staff participants during patient visits to the clinic in order to understand clinic work flows and processes, and during home visits conducted by the RN and health coach to explore how interactions between the CCM team and patient unfolded in a non-institutionalized setting. Observation of patients focused on the ways in which team-based care sought to develop effective trust and reciprocal communication, self-management, and engagement strategies. Observations of providers (which include physicians, RNs, and social workers) involved tracing interactions with patients, workflow and communication systems, and problem solving within the

CCM context. These observations were recorded in detailed field notes.

Eligible patient participants were at least 21 years of age, proficient in spoken English or Spanish, and currently enrolled in a CCM program. A study information sheet as well as a verbal description of the study was presented by the ethnographer during clinic observations. After informed consent was obtained from interested participants, in-person semi-structured interviews were scheduled at a mutually convenient place and time to the participant and researcher. The interviews focused on patients' experiences with the CCM program and their thoughts about their past, present, and future health. Clinic staff had no knowledge of which patients agreed or not to the interviews. Descriptive data were gathered through a brief questionnaire that included items on race/ethnicity, highest educational level attained, transportation, and cognitive function via the Mini-cog test (Borson et al., 2003). The average patient was 54 years old, earned $1,000 or less per month, and had less than a high school education. The sample was evenly distributed between male and female participants and those who were covered with insurance and those who were not. The race/ethnic distribution of patient participants was: Black/African American (41%); Hispanic/Latino (28%); White/Caucasian (16%); Asian/Pacific Islander (7%); and other (8%). Participants were invited to three interviews a 6 to 12 months intervals and received a $25 gift card for each interview. Ethnographers conducted a total of 72 interviews with patient participants.

Most of the data that comprise this analysis are the result of two in-depth semi-structured interviews conducted at least 1 year apart with 17 CCM RNs working at either program. The race/ethnic distribution of RN participants was: African American (23%); Hispanic/Latino (10%); Asian/Pacific Islander (15%); White/Caucasian (41%); and other (11%). While females accounted for 76% of the RN participant pool, we found no variability in our findings that we could attribute to sex or gender. Individual RNs were asked if they wished to participate in the interviews by the ethnographer during the course of their daily observations. Clinic leadership had no knowledge of which nurses elected to participate or not. Our interview guide was structured to elicit perspectives about the goals and impact of the CCM programs, processes and progress of the programs, as well as experiences regarding provider staff interactions with patients, various hospital departments, and each other. Each interview lasted approximately 1 hour. All interviews were digitally recorded, transcribed verbatim, and uploaded to a secure and encrypted server. Atlas.ti was used as our data organization software. All study procedures were approved by the study university's Institutional Review Board (IRB) as well as the IRBs associated with each CCM program.

The concept of social literacy was developed through an iterative process with research team members as well as in-depth memo writing following the conventions of constructivist grounded theory (Charmaz, 2007). Given the unique and central role of the RN to the CCM team, and the preeminence of health literacy as a foundational pillar to CCM programs, our goal was to understand the ways in which RNs take up, use, and transmit the principles of health literacy and self-management to their patients. For this particular analysis, we focused on the data from the RN participants separately from other members of the care team. Our analytical approach to the data is anchored by the theoretical underpinnings of critical interactionism, a fusion of critical and symbolic interactionist approaches which has been described at length elsewhere (Dubbin et al., 2017). A critical interactionist approach facilitates an in-depth exploration of a broad range of social factors, power relations, and social structures that influence not only the health care experiences of those who receive it but also those who render it. In this case, we explore how RNs render care within their patients' wider physical and social environments and describe the processes they engage to effect the end goal of self-management. A critical interactionist approach requires the researcher to examine participant experiences and circumstances within a wider socio-structural context to understand the myriad ways in which health and illness are experienced (Dubbin et al., 2017). Our research team collaborated to identify emerging themes and analytic codes that enabled detailed analysis of the data. We found the concept of social literacy to be not only the overarching theme of the nurses' experience and thoroughly saturated by the data, but the primary vehicle through which CCM nurses engaged *with* patients and maintained the engagement *of* patients. In our rendering of findings, all participant information and research sites have been anonymized.

Findings

In what follows, we present an ethnographic portrait of the ways in which CCM RNs working in safety net settings enact the concept of social literacy, the overarching goals for the work they do to cultivate particular types of health literacy and the extent to which their patients become self-managing. While we share data from multiple RN participants, we center our findings around an extended case exemplar of a nurse's visit to a patient's home to demonstrate the concept of social literacy and its fluid nature. We demonstrate that while nurses struggled with the concept of health literacy, there was acknowledgment that a patient's social precarities were intimately linked to their ability to become self-managing, even conceding that some patients simply would never be. As a result, the CCM RNs recognized that successful complex care management required more of the nurse than providing health information, appointment reminder calls, or filling medication administration sets. To "co-produce" a health literate, self-managing patient required the nurse to navigate the often turbulent waters of the patient's social and environmental circumstances.

Grappling with the Concept of Health Literacy

While CCM nurses we interviewed had an abstract understanding of health literacy, many struggled to provide a workable definition to guide their role as a CCM nurse. Nurses of both programs agreed that the primary goal of CCM was an institutional one, decreasing emergency room visits, and inpatient hospitalizations. To accomplish this goal, in the words of one nurse, nurses "work with patients to self-manage. Everything from how to and understand their chronic illnesses and understanding how to take their medications; how to navigate the health care system and how to contact us [CCM team] when there is a need."

Yet, most nurses we interviewed, like Pam, recognized that a patient's ability to self-manage could not be disconnected from a patient's social circumstances. Pam acknowledged that, "Our patients, for so long, have had so many bad things happen in their life. . . for lots of many reasons [many] are very socially isolated." Frank expanded on this theme: "People's health is so contingent on all other areas of their life. Even though my goal is to improve their health, it's to try to improve their whole life and then that allows them to improve their health." While there are clinical aspects to Frank's role on the CCM team, most of his time is directed in finding stable housing for his patients recognizing that in order to "increase people's functionality," stable housing was a key element to the equation.

Whatever thoughts nurses had about the concept of health literacy, all agreed that those patients who needed CCM the most—patients suffering from substance use dependence and/or severe mental illness—were those most likely not to get it. What comes through in the following narratives is the tacit recognition that there are a multitude of reasons that keep patients from successful self-managing beyond lacking particular skills and competencies as framed in the health literacy literature. Pam noted that for many of her patients, "There's a lot of lack of trust in their fellow human beings," including those in the health care system—hence, repairing that trust becomes a provider obligation. Sometimes repairing trust comes in the form of providing a specific resource a patient needs, and at other times it consists of continual outreach:

> I think we're all sort of humbled by the fact that trust building can take months. Some of it is after you feel like you've kind of hooked them a little bit, you have this very meaningful communication with them and then you follow up with getting them a walker, which maybe they've had a prescription for a walker, but they messed up [and didn't get it]. . .we fill in the cracks in terms of logistics of getting things, so it's another little notch of the trust building—Like, 'Wow, they not only talked about the walker, they actually GOT me the walker!' Those are very concrete things that we do to make things happen for them, so that builds on that already meaningful relationship. It's not just communication. We're not just talking the talk. We're going to walk the walk. And they get that. So then you do get them hooked.

Here, Pam moves beyond an abstract acknowledgment that some patients have trust issues. Trust building requires action—in this case providing a concrete and much needed resource. By prioritizing and fulfilling an immediate need immediately, Pam recognizes the importance of the walker not just for its intended use, but also as a means to further social interaction, communication, and relationship building with her patients, key elements of social literacy.

For Frank, trust building is not a one-off attempt to get patient's engaged in healthful behaviors. Rather, it's a commitment to being consistent and therefore trustworthy:

> I do what I say I was going to do. People talk about that. Clients say they notice that. This woman [for example] who just got sober, she just said to me in the last two weeks, 'You guys just kept showing up. You kept coming, even though I wasn't ready.' She really noticed that. I think it's showing up up over and over.

What Pam and Frank are pointing to is the work of social literacy—recognizing social barriers to self-management and actively forging paths around them by reading and responding to a patient's needs in the context of his/her social circumstances. Social literacy involves creating conditions of possibility for building trusting relationships and paths of communication through which elements of standard health literacy may then be exchanged.

Social Literacy: Navigating the Patient's Social Terrain

We also found that CCM nurses work hard to impart conventional aspects of health literacy as described by Nutbeam (2008). For example, CCM nurses do actively assist patients with functional type tasks like helping patients to organize their medications and take them properly, adhere to treatment regimens and keep their appointments. Educating patients to recognize and convey concerns to the health care team about changes in their clinical condition is reflective of a communicative type of literacy advanced through nurses' skills at health promotion. Reflecting a desire that patients develop some critical health literacy, Maddie stated that the ultimate goal for her respective CCM program was "to produce patients who really feel like they are in control of their chronic disease and feel like they can go through their lives making decisions that will support their health" that is, for patients to develop, "self-advocacy skills that they will internalize" so they can handle the day to day activities required for self-management.

However, this production of health literacy skills necessitated the development of a provider-specific form of health literacy—social literacy—the ability to understand, situate, and respond to patients' needs given the social contexts in which they live and in spite of them, co-produce an environment through which effective patient-provider relationships and communication are achieved. It is only through first

building these trusting and often times long-lasting relationships that it even becomes possible to cultivate a range of health literacy skills and realize some level of self-management. Most nurses found that more often than not, a patient's social circumstances were a significant hinderance to successful self-management even if the patient had the requisite complement of health literacy skills as defined by Nutbeam (2008). We explore this below in an extended case exemplar representative of the experiences we observed many times over in the course of our fieldwork.

JC is 68 years old and was referred to CCM by his primary care provider. JC has a 4 years college degree, is a voracious reader, uses the internet (what he considers his "window to the world") for information gathering, and takes care of paying his own bills. Surely, JC encompasses the functional skills of reading, writing, and numeracy often cited in the health literacy literature as prerequisites for successful self-management. Yet, over the last year and beyond, JC has been hospitalized several times for chronic obstructive pulmonary disease (COPD) exacerbation and has had difficulty keeping his primary care appointments. As part of our ethnographic work, we followed Pam and Ina (health worker) to a home visit to see JC. Home visits—a key component of the CCM programs we observed—provided the nurse a first-hand view of the patient's lived environment. More pointedly, it gives the CCM staff a sense of the stores of resources (or lack thereof) the patient could leverage in service to the end goal of self-management, by more informally "getting to know the patients and identify their strengths, weaknesses, and barriers," as Pam put it.

JC lives in a small studio in the center of the city. The front door is buzzed open, and a long steep staircase leads to a studio apartment. We find JC in a wheelchair, tethered by plastic tubing to an oxygen concentrator. After introductions and Pam explaining what she hopes to accomplish in today's visit, JC begins by insisting we understand some background about him, thereby demonstrating an ability to apply a communicative type of literacy, that is, highlighting important information contextualized to a specific situation (Nutbeam, 2008). JC was born with cerebral palsy and as a result has a speech impediment which at first, makes him difficult to understand. JC explains that his cerebral palsy also makes it difficult to walk, "stumbling from place to place, looking for something to hold onto. Even with a walker, my balance is so bad, I can't depend on that. So, out of an abundance of caution, I decided to stick with the wheelchair." Pam sums what she has just learned and what she thinks the most important points JC wants to convey: "What you're saying is that you use your wheelchair to get around." Pam then asks about his mobility in the home, how he tends to his bathroom needs, cooking, cleaning, etc. While JC has a home care assistant for several hours a day to help him, JC can tend to his basic bodily necessities on his own.

During the home visit, Pam actively assesses JC's functional health and illness related skills and knowledge. For example, JC explains that just after he wakes up, he is the most uncomfortable because of mucus buildup overnight. He tells us that he eats a lot of hot salsas to get things moving as it helps him cough. Pam is very approving of this, explaining that this is a natural intervention and comes with a bonus of getting JC to eat. Pam explains that it is very common for people with COPD to become malnourished because they use up so much energy just to breathe. JC attests to this and adds that the constant use of oxygen keeps him from being able to smell things, which in turn also affects his appetite. Here, Pam intersects health education with home remedies— hot salsa as a decongestant and the importance of caloric intake so JC will have the requisite stores of energy needed for proper pulmonary hygiene, while JC offers his self-learned experiential knowledge linking oxygen use to a decrease in his sense of smell and its impact on his appetite. This active knowledge exchange goes far beyond formal health education. Social literacy provides Pam a more complete and contextualized picture of why JC may be malnourished—JC's experience of the side effects of oxygen use complements her biological knowledge of COPD.

When asked whether or not he understood why his primary care provider, Dr. Tanner, referred him to the program, JC says, "No, not really. . .The last time I saw her was in mid January," which was some 3 months ago. JC explains why he does not come regularly to his appointments: it is not for a lack of knowledge that seeing his provider consistently is important for his condition. He explains instead that in order to get to a doctor's appointment, he has to be carried down the steep staircase we encountered on our arrival, and transported by ambulance with oxygen, then transported back home and carried back up the stairs. Says JC, "It's a very inefficient way of using health care" and posits that one reason he was referred to CCM was to "keep an eye on my COPD. . .so that I don't have to use up all these resources." Here, JC demonstrates his ability to critically assess his own health status situated in the larger realm of health care utilization. For JC, his main problem is finding a way to negotiate his environmental barriers that make it so difficult for him to actively engage with his primary care physician and his medical treatment plan. Pam explains that Dr. Tanner is also concerned about his lack of transportation and says, "We can serve as a little bit of a backup. . .Dr. Tanner wants us to help try to keep on top of whatever's going on with your COPD." JC nods and says, "I understand the framework of trying to do what you can do and farm out what you can't do. . .COPD is not something you can turn around—that all you can do is manage it." Pam is visibly impressed by this description. "Exactly," she says. "Our team is all about helping people manage chronic conditions." JC describes his main health related goal, "I know I can't turn the COPD around completely, but would like to try to keep my respiratory system clear, if possible, under the circumstances." Pam then describes the nature of the coaching JC can expect while in the program that will eliminate most of the need for JC to

come to the clinic while alerting them to any signs of impending exacerbation of his COPD that can be managed earlier, hopefully interrupting the need for multiple hospital admissions. Pam tells JC that her main goal is to create a plan that will minimize his COPD flares by making sure he can recognize the signs and symptoms of a flare up early so that they can help him before it gets too bad and he has to go to the hospital.

Pam and JC also discuss his virtual immobility. JC describes how he can maneuver himself from his wheelchair to the sofa so he can elevate his feet that tend to swell after sitting for long periods. He mentions that he did work with physical therapy for a while and it was helpful, but that he "was lazy about it when I should not have been. I should have been better when I had the opportunity." In a very non-judgmental way, Pam tells him she will arrange another opportunity, telling him that immobility is not a good thing. "Our bodies are meant to move." While she acknowledges that COPD makes things more complicated because of the fatigue, she states physical therapy could be helpful to maximize his activity throughout the day, giving him more strength and making him more mobile. She warns, however, that the limits of physical therapy will be determined by the fatigue of his COPD. "People with COPD, when they are tired, they need to rest. You know what it's like—getting shortness of breath—things get scary." They discuss finding the balance between getting the benefit of the therapy and not pushing so far to make him short of breath. "You're the only person who's going to find that sweet spot, JC," Pam says, "but we'd like to help you find it." She then notes on the care plan to arrange home physical therapy for JC.

As care managers, CCM nurses do not come to patients with the intent to impart a pre-packaged, one-size-fits-all set of interventions or skills that will suddenly make them health literate or self managing. As in the example above, Pam acknowledges to JC that he is the expert of his COPD because he lives with it everyday. She actively assesses his own stores of health-related knowledge and validates the home remedies that have helped him live with COPD, augmenting them with an added layer of medical surveillance: the weekly or more frequent phone check-ins JC can expect going forward, the ability to call Pam and/or health worker Ina, anytime for any reason, and the home physical therapy. In this example, bridging gaps in access to health care through material means was certainly an important intervention the nurse provided. However, social literacy accounts for Pam's recognition of how JC's social circumstances, strengths, and challenges influence his health-related decisions and acceptance of JC's experiential knowledge through a reciprocal exchange of expertise and information, the foundation through which a burgeoning and productive health partnership is being created. First, Pam conveyed to JC that she appreciated the fact that he was creatively using resources at his disposal to find health-related solutions that worked for him. Second, JC was able to communicate, and Pam was able to understand, the

synergistic effect of JC's physical immobility due to his cerebral palsy with the physical barriers inherent to his living space (the steep staircase) that kept him not only socially isolated but unable to attend his physical therapy appointments or maintain regular contact with his primary care provider.

As a socially literate nurse, Pam understood that JC's "super-utilizer" status was not related to a lack of skill or competency, rather it was the confluence of his clinical condition and his lived environment that prevented him from acting manifestly as a successful self-manager. It was only through this mutual recognition, understanding and acknowledgment that Pam could then cultivate in JC a *communicative* type of literacy—a knowledge of when to call the team and encouragement (i.e., permission) to do so—that was key to ongoing engagement and foundational to self-management.

Social Literacy and Negotiating Health Related Behaviors

As JC's example indicates, many so-called lifestyle practices in which people engage have implications for health and health outcomes. Through the lens of health literacy, health is viewed somewhat as an achievement as well as an expectation and responsibility (Whitmarsh, 2013) that individuals are supposed to work to improve their health and to minimize risk of illness, chronic disease, and premature death (Clarke et al., 2003; Cockerham, 2005; Giddens, 1991). Even though many of the nurses in our study understood the structural tethers to ill health, many advanced the view that individuals had the capacity to choose health enhancing or harming behaviors regardless of their social circumstances. Hence, social literacy explicitly required the nurses to negotiate and renegotiate health-related behaviors with their patients. For example, Pam explained how her CCM program had not been terribly successful for active substance users who were "pre-contemplative" about their drug use:

> Pre-contemplative means they lack readiness in terms of dealing with their substance use which is adversely affecting their medical problems. . .[We will work] with people who are either willing to work on their substance use or they have a mental health problem that is being treated. Those without active substance use or mental health problems. . .are the folks that are easiest to engage, for sure. Or they have a recent history of substance use and they've stopped using whatever they were using—we have a lot more success getting them to engage.

Viewing some patients as "willing to work" as opposed to those who "lack readiness" is reflective of the standard view in most biomedical and public health approaches that health behaviors are matters of individual choice, hence interventions are deployed through individual-targeted education (Cockerham, 2005; Van Natta et al., 2018). Yet, as we learn from Berna, the nurse's role as patient advocate provides a more nuanced view of a patient's *choice* being a patient's

right and that complicates the extent to which the nurse was willing to reach out to the patient:

> The whole thing is that we respect our patients' rights. If a patient is coherent and if they tell you, "No, I don't want it", then there is nothing you can do. That's where my frustration sets in because you really want this person to be in a better place. You can't do anything when they tell you "No". . .It's very, very, very frustrating because you worry about the patient so much.

As we continue with our extended exemplar, we demonstrate how CCM nurses navigate the boundaries between patient agency and the goal of self-management. With JC's permission, health worker Ina looks around the apartment, taking notes as she goes. She collects all the medication bottles she finds scattered around the house and lays them in a pile on the floor between JC and Pam; Pam then goes through them one by one. She picks up a bottle of Tylenol with codeine and asks why JC is taking this medication, given that "codeine is a narcotic and it suppresses your central nervous system, which is your breathing center." JC states he takes it for dental pain. We can see why: many of his teeth are cracked and broken, and they look painful. Again, he talks about the logistical problems of getting to the dentist, but understands he will need dentures eventually. Pam explains that CCM can help with that, saying, "We can fix your mouth . . . [and] we can get you off this," pointing to the Tylenol with codeine.

Pam asks JC about any use of alcohol or illicit drugs. He answers in a matter of fact tone, "I drink beer—four 24oz PBRs [Pabst Blue Ribbon, a brand of beer] a day." Pam warns, "Alcohol also suppresses your central nervous system. Alcohol is not good for you." JC, in a frank but calm tone replies, "I'm getting defensive here, but PBR is the lightest beer you can drink. The oxygen dries my mouth all the time, and this is something I can sip on. It's adult 7-Up. I can drink a case of it and not get drunk. That's just the reality." In a very warm, almost playful tone, Pam responds, "It's not just because your mouth is dry. You can sip on some mineral water all day for dry mouth—you like the alcohol." JC smiles and says, "this is true. A 24oz beer is the Hell's Angel breakfast," explaining that he has many friends who are Hell's Angels. Pam then relents a bit, "You're right. It's not like you're getting wasted, passed out on the floor." Pam acknowledges the difficulty required to change these types of behaviors, that they cannot be undone overnight, and tells JC she respects that. "This is a low priority issue," she admits. He says, "Thank you," and then Pam pauses, looks at him and coyly says, "But you did manage to give up smoking," in a "just saying" kind of way that playfully warns him eventually she's going to want to work on his alcohol consumption. She then lets the topic drop and moves on to the next.

Looking at the entire landscape of JC's chronic conditions, Pam picks the most health concerning battles to wage in order to maintain a nurse-patient relationship in which JC exercises meaningful agency and feels he is the ultimate decision maker. Within the context of CCM, an essential element of social literacy is the recognition that adoption of health enhancing behaviors is a negotiation and that importuning specific behaviors, though they may be "healthy," may actually harm the relationship-building through which the possibility of eventual self-management can actually be achieved. In this example, negotiation is comprised of Ina checking in with JC to frequently to monitor his respiratory status and JC will proactively call at the slightest hint of an exacerbation rather than wait until an emergency exists. JC will continue the home remedies he finds helpful, paying particular attention to his nutrition and Pam will arrange for home physical therapy to help JC optimize his strength. Pam will provide a mechanism so JC can get the dental care he needs, and JC will give up the codeine. Pam will not push him on his beer drinking recognizing that JC has demonstrated the capacity to change his health-harming behaviors as evidenced by him quitting smoking on his own. For the CCM nurse, cultivating health enhancing behaviors is not necessarily "do this, don't do that." Rather it is a process of interaction and a product of relationship-building where give and take is designed to minimize risk of acute illness.

What we learn through this extended exemplar of JC is that having the foundational skills of reading, writing, and numeracy may not be enough for successful self-management of chronic health conditions. In this example of how social literacy works, JC and his nurse have co-produced a plan of care that attends to the end goal of health literacy— self management. This co-production required more from the nurse than health education about chronic conditions or training in particular types of skills like medication management or additional physiologic surveillance. The nurse's ability to respond and adapt to the patient's needs given the social contexts in which those needs are made manifest are the building blocks of an effective patient-provider relationship. It is through these trusting and often times long-lasting relationships that a range of health literacy skills are effected and self-management is achieved.

Open and consistent lines of communication and frequent interaction with the CCM team (through a variety of means) has helped JC remain connected to the primary care team and engaged in controlling his chronic COPD. While he considers his health status as "not great," over the course of the next year, his clinical condition did stabilize. As he put it, "As long as I'm moving along without too much of a problem. As long as I have communication with Pam and Dr. T and can declare what the situation is without having to go through this whole thing of dragging my puny butt [down the stairs]. . .I'm generally happy with the way things have worked out."

The concept of social literacy takes account that self-management is a downstream product of a nurse-patient relationship that first must be negotiated and shaped through interaction, and emphasizes that the nurse must see the

patient in their full social context, and take stock of their readiness and willingness to commit to the CCM program *within* that context and its opportunities and constraints. Beyond the socio-environmental circumstances as we have described above, there were also deeper and more personal obstacles with which the CCM nurse had to contend. For example, Maddie cares for a generally younger population of patients suffering from heart failure. She underscores the importance of understanding how illness may fundamentally alter a patient's sense of self, the impact it may have on a patient's health outcomes, and the emotional work required of the patient:

> [I]n general it's about supporting the patients as they are— understanding that because we're dealing with a younger population that has had this identity of being well, of being strong, of being invincible, that then they have to change their identity because they might look like the same person, but now they can't go up the stairs. . .Outwardly, they look like they should be a perfectly healthy person. So, we really work to try to help people go through that journey—and it really is a journey. A lot of patients hit us at first with denial, real loss of identity—"I don't want to do these things you are telling me to do because that's not who I am. I am this young man who is able to make my way through the world and be healthy, so F-U!" Patients generally figure out that's not a winning strategy. [There's] a lot of guilt; a lot of bargaining, a lot of "Let me try this, then we'll try that." Then they stick with us and keep on going with us, and maybe they do have a readmission. Maybe they're able to avoid a readmission. Then they kind of get to the other side where the medications have the time to do their work, so they're feeling better. They're feeling in control. They're stable again and they are able to interact with the world in a way that they feel more in control. Some patients are able to get there really quick, and for others it's kind of a tortuous road. . .But, it's everyone's journey. . .We don't care how you show up, we just want you to show up and we are going to care for you.

In this example, acknowledging the patient's biography and having an understanding of the nature of the illness and how illness may reshape a patient's vision of him/herself is a central element of social literacy and part of the fabric of the nurse-patient relationship. Supporting a patient through this adjustment requires steadfastness, perseverance, and time.

Evaluating Success

For many of the nurses we interviewed, whether their patients were progressing down the road to self-management or had reached that destination, their main goal had very little to do with health literacy per se as the concept is described in the literature. In fact, we were hard pressed to find any nurses who used or discussed the term unless we specifically asked about it, even though most of the patients for whom they were caring had demonstrably very low health literacy and for whom low health literacy proved to be a significant barrier to self-management. While part of their practice was to

administer a simple test to determine the presence of cognitive impairment, no surveys like the Rapid Estimate of Adult Literacy in Medicine (REALM) or the Test of Functional Health Literacy in Adults (TOFA) were administered to patients in either of the programs we observed. Most nurses described a patient having "graduated" the program as one who had "met all of the care goals" set by the patient and the CCM team. Yet still, most nurses were vague when asked to describe exactly how and under what circumstances a patient was considered to be self-managing. Most described clinical variables such as blood pressure control, keeping clinic appointments, returning clinic phone calls, medication adherence, and obtaining prescription refills. While some mentioned decreasing visits to the emergency department or in-patient hospitalizations, most of the nurses we interviewed used that metric for program performance overall. Most, like Maddie, preferred to give qualitative narrative examples of "success stories" to demonstrate how the program worked and to what extent a patient became self-managing:

> We have had so many [success stories]. We had a patient who was cussing us out, telling us that he was just ready for God to take him. He was done. This was a patient who was a veteran, probably dishonorably discharged, spent some time incarcerated, a 40-year history of heroin use. . .[We] started doing home visits on him at his SRO [single room occupancy] and just slowly but surely really established trust with him and he got with the program. He stopped being readmitted to the hospital, and as soon as he was eligible for Medi-Cal, he got on it and got into a methadone program and today whenever he sees you he is a completely different person. . .He's a happy, happy man. Happy to be alive. He was able to reconnect with his family and all of these things. I think he really was expecting to die on the streets until he came into our clinic.

While Pam credits the nurse-patient partnership through which trust is built as as a main driver of successful self-management, she acknowledges the primacy of the work the *patient* ultimately accomplishes:

> Really, it's [the patient's] inner strength that we are trying to tap and say, "Okay, you can do this." Start with very small goals and have them be successful at that, and we build on those successes. I think it's mostly the patient that's doing it. That's where the success comes from because we can't do it for them. . .but we can be super encouraging and supportive. It just goes so far in these patients' lives because they've had their spirits broken many, many times so, the fact that somebody's there for them and it happens to be the right timing. Sort of a magical combination and it works.

These success stories evolved not only through elements of standard health literacy imparted to patients by the CCM nurses, but also, and perhaps more importantly, through the creation of conditions of possibility through which trusting relationships are built and reciprocal communication is achieved. As our exemplars have demonstrated, social

literacy comprises *nurses*' recognition and response to the varied types of hinderances to self-management with which patients must contend in their lived environment; valuing their patients' stores of experiential knowledge, skills, and competencies leveraged in service of self-management; respecting their patients' rights of agency through the negotiation and renegotiation of patient health behaviors; and the express commitment *by nurses* to nurturing at times very fragile partnerships over the long-term. In this article we have used social literacy as a vehicle to understand how CCM programs work and the distinct contributions that RNs make to CCM. Through their unique and transportable assessment, diagnostic, and evaluative skills, CCM RNs occupy a prime vantage point that allows them to bridge the gap between how health literacy is described and is supposed to operate, and the ways in which self-management is achieved.

Discussion

Over the last several years, CCM teams have developed as a mechanism to provide specialized care of patients with multiple chronic diseases. The central aim of these teams is twofold: improve patients' health status and reduce the need for medical services through self-management (Bodenheimer, 2013; Bodenheimer & Berry-Millet, 2009; Mao et al., 2017). Given that the skills required for self-management comprise the many of the elements of health literacy, the central purpose of this article was to critically interrogate the concept of health literacy and the ways in which CCM nurses working in safety net settings take up and operationalize its various elements in furtherance of producing self-managing patients. We demonstrated that the concept of health literacy was vaguely understood by CCM nurses but did not in any real sense guide their role in providing complex care to their patients. Rather, self-management required the building of a nurse-patient partnership, the scaffolding of which was predicated on the nurse developing and deploying what we term social literacy.

Social literacy, as we have conceptualized it, is a nursing attribute that develops over time and through numerous interactions with patients in their physical and social environments. While some may argue, and we would agree, that a basic principle of comprehensive nursing care requires the consideration of culture and the unique circumstances of each individual patient in providing individual care, such consideration is not a given. It takes substantial work. The concept of social literacy begins to define and describe the work that is often necessary for such care to be accomplished. Given that the concept of social literacy was developed through analyzing data from CCM RNs specifically, we acknowledge that other members of the health care team (i.e., community health workers and social workers) likely develop and deploy social literacy in the work they do as well. Further research is needed to understand the ways in which social literacy may develop and unfold throughout the interdisciplinary team.

We also note that the language of CCM ("super-utilizers," "producing" certain types of patients, etc.) may not seem to well represent the intended goal of building collaborative patient-nurse relationships. Such phraseology has an implicit neoliberal ideological tone where a premium is placed on achieving a return on investment reflected in cost savings from decreased hospitalizations and emergency room visits. However, the CCM nurses we talked to understood the social impacts of their work to be far more valuable than the program's financial impacts. Social literacy, conceived as a provider attribute, offers a critical rethinking of the unequal relations of power and coercion in health care and functions as a means to capture the work being done to address them.

There is, however, one social dynamic not illuminated by our data—the numerous ways in which gender and gender relations may influence the uptake of health literacy or the development and deployment of social literacy. Given the growing literature on the intersections of gender and health behaviors, health seeking, and health care interactions (See for example: Chakraverty et al., 2020; Heise et al., 2019; Peerson & Saunders, 2009), there remains a large terrain yet to explore.

As a broader framework for health literacy, social literacy actively accounts for the weight that a patient's social and personal circumstances may have in the furtherance or hinderance of a patient's ability to self-manage. To be socially literate, the nurse must recognize and understand how the social environment is likely to impact a patient's health, but also how s/he must navigate paths through the patient's social and environmental circumstances to negotiate interventions likely to be successful given the patient's social context. The concept of social literacy helps to fill a gaping hole in the prevailing discourse around health literacy—that there are a multitude of reasons that keep patients from being able to self-manage beyond lacking particular skills and/or competencies. The ability to understand and respond to a patient's needs while accounting for the unique social contexts in which those needs are situated allows the nurse and the patient to co-produce a patient-provider relationship through which a range of health enhancing skills can be effected and self-management ultimately achieved.

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