Localizing Chronic Disease Management: Information Work and Health Translations

Elizabeth Kaziunas, Mark S. Ackerman and Tiffany C.E. Veinot
School of Information, University of Michigan
4370 North Quad, 105 S. State Street, Ann Arbor, MI USA 48109-1285
{eskaziu, ackerm, tveinot} @umich.edu

ABSTRACT
Based on interviews with people who had diabetes, high blood pressure, and kidney disease in Flint, Michigan, we found people actively doing information work to manage their health in the face of poverty, potentially violent conditions, high stress, and a distrust of institutionalized medicine. More specifically, we observed people translating information into the context of their everyday lives. We present various translations of health information in the form of local strategies for chronic illness management. Study findings highlight initial implications to support health information services on a community level.

Keywords
Information worlds, information behavior, context, knowledge translation, chronic illness, African Americans, diabetes, kidney disease, hypertension

INTRODUCTION AND BACKGROUND
African Americans, particularly those who are socio-economically disadvantaged, experience disproportionately high rates of chronic illness and mortality (Centers for Disease Control and Prevention, 2011). Racially and/or socioeconomically disadvantaged populations also experience more health risk factors, lower health care access, and poorer health-related quality of life than their more privileged counterparts (Agency for Healthcare Research and Quality, 2010; Centers for Disease Control and Prevention, 2011). Furthermore, because the United States is geographically segregated by race and socio-economic status (SES) (e.g., (Iceland & Nelson, 2008; Lee et al., 2008), the burden of illness also varies among geographic communities (e.g., (Acevedo-Garcia, Lochner, Osypuk, & Subramanian, 2003). For example, our research was conducted in Flint, Michigan, a city in which diabetes prevalence is greater than 14%, as compared to a prevalence of 8.5-10.1% in the state as a whole (National

Minority Quality Forum, 2012). Similarly, the prevalence of end-stage renal disease in Flint is 3,000-7,200 per 1 million people, as compared to 700-1,600 in the state as a whole (USRDS, 2011).

Living in an area where a large proportion of residents are socio-economically disadvantaged appears to exert an independent, negative effect on individual health status—even after accounting for individual characteristics. These "ecological" effects of place of residence on health have been consistently found across a number of health issues, including: mortality (Subramanian, Chen, Rehkopf, Waterman, & Krieger, 2005); diabetes (Auchincloss et al., 2009; Krishnan, Cozier, Rosenberg, & Palmer, 2010), and heart attacks (Rose et al., 2009). A number of environmental features of neighborhoods have been found to contribute to such negative health effects, such as: poor housing conditions (Schootman et al., 2007); distance from stores that sell healthy foods (Beaulac, Kristjansson, & Cummins, 2009); higher neighborhood concentration of alcohol retailers (Berke et al., 2010); and lower density of recreation facilities (Dahmann, Wolch, Joassart-Marcelli, Reynolds, & Jerrett, 2010; Smiley et al., 2010).

Living in disadvantaged neighborhoods may also confer informational challenges—which may in turn affect health. There is often a higher prevalence of ambient, negative health messages in marginalized communities (Yerger, Przewoznik, & Malone, 2007), and people in disadvantaged neighborhoods typically have reduced exposure to positive health promotion messages (Chivu & Reidpath, 2010). In resource-poor settings, weak institutional capacity can also act as a barrier to information acquisition (Veinot, 2013). Given the rise of chronic illnesses like diabetes, hypertension and kidney disease, there is a pressing need to better understand health information behavior in communities where these illnesses are widespread and where information access may be inconsistent.

In information behavior research, the concept of an information "environment" has been introduced by several researchers to emphasize the contribution of context to information access. Taylor's (1991) influential model of "information use environments" posits that workplace settings influence information behavior through factors

such as their organizational structure and culture, domain of practice, and perceived information accessibility. Lievrouw's (2001) model of information environments theorizes the informing process at a broader level of social aggregation, highlighting the informational role of resources such as institutions, social relations, and technologies. This concept has recently been extended in a health context in research that documents the variability of HIV/AIDS information environments in rural regions and the associated differential patterns of information access (Veinot, 2013).

Building on these insights, we examine the contextualized information behavior of residents of Flint, Michigan with chronic illnesses, including diabetes, hypertension, and/or kidney disease. Living in a city with a poverty rate of 38% and one of the highest rates of violent crime in the United States, residents of Flint cope with their health needs using limited resources and in tumultuous surroundings (U.S. Census Bureau, 2013). Consequently, we detail the ways in which health information is bound up with highly-situated everyday life activities and concerns, highlighting the strategies by which Flint residents localize information, or make it meaningful and actionable in their social and community context. While prior studies have pointed broadly to the sifting, integrating, and assimilating information work people perform in managing their health (Corbin & Strauss, 1985; Corbin & Strauss 1989; Hogan & Palmer, 2005), we contend that these activities might be more richly conceptualized as a type of translation work that is performed when information is made meaningful within a social world, and especially when it crosses the boundaries of social worlds.

Next we outline the theoretical framework that guided our analysis. After that, we describe our study design, detailing the field location, data collection, and methods. We then present our findings and discuss the themes regarding health information work that emerged in our analysis. Finally, in the last section we reflect on theoretical and practical implications of our findings, while suggesting directions for future research.

THEORETICAL FRAMEWORK
This study draws on two bodies of theoretical work: (1) Chatman's work on information "worlds" (Chatman, 1999); and (2) the concept of "information work," initially identified by Corbin and Strauss (1985, 1989), but subsequently elaborated by Hogan and Palmer (2005).

Information Worlds
Chatman's legacy of work represents an unfolding discussion on the localized information behavior found in close-knit social environments or "small worlds." Her fieldwork on marginalized populations of janitors, unemployed people, and retired women led her to propose a theoretical framework of considerable depth. While we are indebted to her earlier work on information poverty, we take as our starting point the theoretical stance she outlined

in "Life in the Round" (Chatman, 1999). Based on a study of female inmates in a prison, Chatman describes the characteristics of a social environment that is likely present in a number of bounded contexts. Chatman writes:

"A life in the round is one lived within an acceptable degree of approximation and imprecision. It is a life lived with a high tolerance for ambiguity. But it is also lived in a world in which most phenomena are taken for granted." (Chatman, 1999, p. 213).

Central to Chatman's theory is the concept of a "small world." Drawing on the sociological theory of Luckmann and Schutz (Luckmann, 1970; Schutz & Luckmann, 1973), Chatman describes members of a small world as having a "localized worldview, focused on everyday concerns" (Chatman 1999, p. 215). Furthermore, information in a small world is based primarily on personal experience (Luckmann and Schutz's life-world) and characterized by trust and believability. Following Chatman, we seek to understand Flint in order to more closely examine some of the local information behaviors that people use to manage chronic illness in a socio-economically disadvantaged community.

Chatman contends in her theory of life in the round that information rarely flows across the boundaries of a small world. In a critique of Chatman, however, Jaeger and Burnett (2010) argue that people live within multiple information worlds. Furthermore, while most small worlds are not as firmly bounded as a prison, Veinot and colleagues (2010) showed that boundaries need not be impermeable in the context of a relatively cohesive health information world. Similarly, Chatman (1999) noted that an exception to the immobility of information may emerge when members of the small world perceive they have a critical information need —a characteristic that is often true of information for chronic disease management. Therefore, we contend that Chatman's framework holds applicability for the study of health information behavior in a marginalized community.

Information Work
Strauss, in much of his writing, examined types of "work," the small-scale micro-interactional activities that enable other forms of activity and labor to occur (Strauss, 1993; Weiner et al., 1997). In this "work," for example, he and others included articulation work, the work that coordinates the efforts of people; machine work, the work that people do to make their equipment function; and, biographical work, the work that people do to maintain their identities. Others have extended and amplified these discussions: For example, Charmaz (1991) showed how biographical work is important for chronic disease patients as people come to identify themselves as having the illnesses and limitations.

Corbin and Strauss (1988) briefly discuss "information work." Information work involves "the quest for, the receiving of, and the passing of information" (Corbin & Strauss, 1988, p.10). As mentioned, Hogan and Palmer

(2005) drew from this concept of information work and extended it, and we do the same. Amplifying the concept of "information work" in Corbin and Strauss' (Corbin & Strauss, 1985; Corbin & Strauss, 1988) chronic illness trajectory model, Hogan and Palmer (2005) discuss the various types of "information work" performed by people living with HIV/AIDS. They argue that Corbin and Strauss's concept of information work "moves beyond the notion of information as a resource to account for the actual labor of locating, gathering, sorting, interpreting, assimilating, giving, and sharing information, and the fundamental nature of these activities in living with chronic illness" (Hogan & Palmer, 2005).

Analyzing qualitative data from a nationwide survey on people living with HIV/AIDS, Hogan and Palmer take critical first steps in explicating types of information work related to chronic illness. They discovered, for instance, that "sifting, integrating, and assimilating information" is a primary health management issue for people living with HIV/AIDS. We seek to build on Hogan and Palmer's efforts, through an examination of how the information work of chronic illness is localized within its larger social and community contexts.

STUDY METHODS

Data Collection and Analysis
Our data includes 24 semi-structured interviews with people diagnosed with diabetes, kidney disease and/or hypertension who live in metropolitan Flint, Michigan. We also conducted four focus groups that separately included healthcare professionals, community service providers, and representatives from local churches involved in community health work. Forty-three separate individuals participated in the focus groups. The interviews and data presented here were part of a larger study on community health information, and our analysis was supplemented by our understanding from additional interviews in Inkster and Detroit. An earlier study in Flint also provided additional background.

Participants were recruited partly through referrals from the National Kidney Foundation of Michigan (NKFM), a nonprofit organization that runs community health programs with local residents. Furthermore, flyers posted at health clinics and community centers and snowball sampling methods yielded a number of participants. Interview participants were pre-screened for one (or more) of the medical conditions, as well as primary residence in metropolitan Flint.

Individual interview participants included 11 females and 13 males; 22 participants were African-American and 2 Caucasian. The age range of participants was from 35 to 73 years-of-age, although most were in their 50's and early-to-mid 60's. Self-reported medical conditions included 13 participants with diabetes/pre-diabetes, 19 with hypertension, and 3 with kidney disease. (Participants could have multiple conditions.)

Interviews took place face-to-face and were conducted in participants' homes or public locations. Interviews were conducted by the first author; there were often two interviewers in the session. Interviewees were paid $20. The interviews lasted 1 to 2 hours, were audio-recorded, and were subsequently transcribed. The four focus groups were conducted by staff at the National Kidney Foundation of Michigan, and organized with the aid of a Community Advisory Committee. They lasted from 2-2.5 hours and had an average of 11 participants. Focus group sessions were also recorded and transcribed.

We coded interviews for participants' assumptions, meanings, feelings, and actions. Instead of grouping responses into static categories, we actively tried to discover how categories were related (Strauss & Corbin, 1998). We began with a base set of concerns, but as often happens in ethnographically-based research, new data led us to expand or modify our existing coding; this process is designed to explore and uncover the participants' experiences. Our focus group data were used to triangulate and corroborate the findings from the interview data. All identifiers have been made anonymous for publication.

FINDINGS

The Information World(s) of Flint
The city of Flint's history is closely tied to the U.S. automotive industry, and significant layoffs and plant closures over the last twenty years have left the city in deep economic and social turmoil. Flint's neighborhoods vary greatly: there are areas of large houses, well-kept lawns, and an air of prosperity. There are also areas of middle-class and working-class families. The downtown area has been the recipient of recent revitalization efforts, and Flint's Cultural Center boasts museums and a symphony orchestra.

The "northside" of Flint is a historically African-American community. Longtime residents remember it as a once flourishing neighborhood with many family homes, schools, and parks. The area, however, has changed drastically in the last 10-15 years as a population of less-stable residents moved in. A rise in violent crime and drug use spurred many remaining families who had the financial means to relocate to safer areas. As the population decreased, abandoned and boarded-up houses began sprouting up and local schools were closed. City services—already limited due to a budget crisis—were further reduced; for instance, our participants mentioned darkened street lights, limited garbage removal, and bus routes that have stopped running. Indeed, there are some sections of the city that participants described as forgotten, a kind of no-man's land where vacated houses are set on fire by bored teenagers.

In this study, we focus on describing the experiences of people from the northern neighborhoods of Flint. Out of our 24 participants, 16 currently live on the "northside" and 5 participants lived there for significant periods of their lives but have moved to other areas in Flint. Those participants

moved looking for more desirable apartments and neighbors, and except for one person, stayed in neighborhoods with a similar, or at most slightly higher, SES.

Poverty and Flint's Decline
In the interviews, our participants uniformly pointed to Flint's dire economic straits. Many of our participants in Flint have had irregular and marginal employment as cleaners, check-out clerks, medical aides, or fast food workers, jobs that require physical effort, offer little flexibility, and pay badly. Some, primarily those who worked in the auto industry or government, have pensions and some savings, while others "make do" day-to-day.

Concerns about money were commonplace. Many participants indicated worrying about the cost of medicine, food, electricity, and housing. *"Tight on money,"* lamented one retired female participant. *"Oh, Jesus. It's a headache ... Not too long ago I got behind on my rent and it's hard to catch up."* She explained that if she couldn't pay her back rent soon she was facing eviction from her apartment.

Many informal arrangements allowed our participants to get by on restricted incomes. For example, one important arrangement involved carpooling since Flint's public transportation was viewed as both tedious and dangerous to ride. For example, one female participant has an arrangement with a woman from church who helps her pay for gas and auto-repairs in exchange for transportation around Flint.

Participants' financial worries were intertwined with wider community concerns about their neighborhood's decline. These concerns have a direct impact on how residents logistically manage their health. Participants detailed, for instance, how the potential of violence where they live affects their daily activities, such as exercise, getting food, and traveling through the city for medical appointments. An older participant in a more impoverished area of the northside described how her daily activity had been greatly reduced by the threat of crime:

"The way they treat these senior citizens, they're robbing 'em, they're jumping on 'em, they're even killing 'em now, so it's kinda hard... I won't be even out at dark no more. Now you know I'm worried....But now, at daytime ain't even safe no more."

In short, the northside neighborhoods – and we emphasize that this is only part of Flint – reflects a climate of economic, social, and political turmoil. These conditions impact the type of resources participants utilize in managing their chronic illnesses; they also more subtly shape people's health experiences through heightened feelings of stress.

The Ubiquity of Stress
Given Flint's climate of economic poverty and social decline, it is perhaps unsurprising that our participants noted dealing with stress is a key issue in managing their chronic illnesses. As a participant who was without a permanent residence explained, *"Stress is very high with me some days. And I know this all attributes to your diabetic levels being within range or not."*

Participants described stress as coming from the city environment and personal/family situations, as well as their chronic illnesses. For example, Esther, a 57-year-old African American woman, shared her belief that stressful life experiences have built up in her body, tired it out, and manifested visibly as hypertension. Esther described herself as a hard worker and single mother who held down multiple jobs over the course of her life as she moved from state to state seeking a better life for her family:

"Come up from Mississippi. I worked hard there and I worked hard here. I used to have two to three jobs, so it paid a toll on me. I did housecleaning in Grand Blanc, a more ritzy area....Working like somebody crazy, all them jobs. No rest. No rest."

Five years ago Esther had a major heart attack. After she was released from the hospital, her doctor told her to cut back on housecleaning jobs, but she quickly returned to working 80-hour weeks because of financial need and a concern that it could take years to qualify for disability benefits.

For Esther, life stress—raising children, moving, and working for demanding employers—is directly linked to her chronic illnesses: *"You get all upset, stay bent out of shape, that's no good. That's hypertension and it's working on your kidneys."* Esther, who has now successfully obtained disability, still wrestles with economic instability. During the interview, she ignored the persistent ringing of her telephone landline, noting resignedly, *"That's a bill collector, I can tell by the way it's ringing."* She tries to deal with her stress in healthy ways, often turning to spiritual practices. *"So I have a load,"* explains Esther, *"but I just have to pray...and it helps me keep my blood pressure down."*

Esther's story is a powerful example of how stressful moments in life became deeply connected to the experience of illness; this was echoed in many other interviews. Our findings tie into a wider discussion in medical sociology on the impact of stress in marginalized populations. There is evidence that living under constant stress, arguably in part from just being Black in America, leads poor African-Americans to undergo premature aging and increases their risk of being diagnosed with chronic illnesses like heart disease and diabetes (Newman, 2003). These medical conditions, in turn, cause disruptions in work, increased isolation, and concerns about long-term care.

Institutional arrangements
We turn now to detailing the institutional arrangements for health information acquisition in Flint and discuss how our participants view key players such as the healthcare system, families, and religious organizations.

Healthcare in Flint

Flint residents faced a number of challenges when interacting with the local healthcare system. In terms of insurance, the majority of participants had Medicaid. Those over 65 and some with disability payments also had Medicare; a handful of our participants, those with guaranteed-benefit pensions, had private insurance. All others were covered by the Genesee (County) Health Plan, a safety-net provided by the county to provide basic health services to low-income adults without insurance. Many of our participants had been on the Genesee Health Plan at some point in their adult lives.

Participants, especially those with marginal health insurance, spoke of the limitations of the health care system in Flint. Doctors who accept patients with the Genesee Health Plan are difficult to find, and participants often relied on free healthcare clinics if they didn't have Medicaid insurance. The crowded conditions at these facilities resulted in difficulties getting appointments and long waits to see physicians. Participants reported extremely rushed consultations, as brief as 5 minutes in some cases. From the perspective of our participants, this did not leave time for them to find out why medications were being prescribed, let alone have a meaningful dialogue with healthcare providers about treatment plans and healthcare options.

For example, Clarence a 40- year- old African American man with hypertension, explained that one of the reasons he does not go to the doctor as often as he should is that it can take hours to be seen by a physician even with a scheduled appointment. *"You wait an hour to two hours to see the doctor,"* Clarence recounted, *"and then he [the physician] spends two minutes with you or less."* Another participant corroborated this view, noting:

"They have so many patients. They really don't have time to just, you know, to concentrate on just one person…They just don't take the time. They don't have time. Patient, patient, patient, and you are in there."

Unfortunately, the description of clinical care offered by many of our study participants could be likened to that of a patient mill churning out patient after patient with little more than a prescription in hand.

In addition, participants described many interactions with "bad doctors" who failed to adequately inform them or to inquire about their health and well-being. From our participants' perspectives, "bad doctors" spoke too quickly, appeared dismissive or even insulted when a patient asked questions, and didn't ask questions of the patient.

As one example, Melba, an African American woman in her 60s, grew up in Flint. At 17 Melba was diagnosed with diabetes, and she remembers that she was treated coldly and given almost no information about her medical treatment. *"They put me on some kind of pill,"* Melba recalled. *"He [her doctor] didn't even tell me what kind of pill it was."*

The prescribed medication led to a rapid weight loss that frightened Melba and made her wary of following that doctor's advice. Now as an adult, Melba continues to be frustrated with healthcare professionals. At a recent doctor's visit, for instance, she viewed the nurses as being terse and uninformative: *"They just gave me the papers and said, 'We'll see you in two days. Be here at such and such a time.' They didn't tell me the criteria for the test."* Melba's negative experiences, especially the feeling that she was being dismissed or that critical information was not being shared, was echoed by many other participants.

Simone, an African-American woman in her 50s, was also disappointed with her current physician, noting that he seemed uninterested in asking her questions and rarely offered information about her diabetes and hypertension conditions. *"I tried to get some information out of him,"* she described, *"but I'm the one who's constantly asking questions. And he's not asking me any."* She remembered that the last time she was at the doctor's office, her physician failed to tell her about the results of her previous blood test. After she pressed with an inquiry, the doctor told her brusquely that she needed some iron.

"Good doctors," on the other hand, were described with deep respect; in fact, some participants worried about losing their physician and expressed concern about disappointing him or her when they did not strictly follow their treatment plans. Sometimes a reluctance to be "fired" by a doctor led to the participants withholding information that would cast them in a negative light during their clinical visits. A good doctor to Simone is one who asks questions such as: "*Is it [the diabetes] messing with you this way? Or are you feeling this way*?" Likewise, Clarence explained that good doctors "*check you out from head to toe*." A good doctor to our participants is one who asks questions, listens, and teaches by giving concrete examples like providing interesting and healthy recipes to try.

Even when able to discuss their health conditions with medical professionals, participants were often skeptical about the information they received. Mistrust stemmed from the lack of time clinicians spent diagnosing patients during clinic visits, personal experiences of medical negligence or malpractice, and a long history of civil rights abuses against African Americans (Veinot et al., 2013).

Flint Churches

In comparison with healthcare services, participants generally spoke favorably of the churches in their community. As one participant enthusiastically explained, *"The churches are really good up here."* Many of our participants were active members of local churches or regularly utilized church services such as food give-aways, van rides, shelters, and health fairs. Another participant noted, *"there are churches that give you clothes and stuff, and they can help you with health issues. They help you pay the rent. If your house burned down, there are certain churches that really help you out."* Participants indicated

that they spent a lot of time during the week at their church socializing, as well as attending picnics, dinners, bible studies and prayer groups.

In focus groups, healthcare workers and church leaders indicated that many churches have organized walking programs to help community members get physical activity safely. Additionally, some churches have healthcare teams that work to engage their congregations around healthy lifestyle issues and to provide support for chronic health conditions like diabetes and hypertension.

Families
Participants relied heavily upon extended family and close friends living in Flint for financial and emotional support as well as providing a measure of safety. In the participant homes we visited, grandchildren, nieces and nephews, and grown children dropped by as we conducted our interviews to cook a meal, watch television, or borrow a vehicle.

Hetty is a retired homemaker and matriarch to a large family of five grown children (one of whom is disabled and lives at home) and 12 grandchildren, all of whom live in Flint. The entire family lives in close proximity to one another, popping in and out of each other's houses, and they make a point to go out together to run errands or exercise. "*They tell you don't go out by yourself,*" Hetty explained. "*Always go in a pair....And we just keep to ourselves and stay inside our house, and when we go out, we go in a bunch. Don't go out by yourself. Yeah. That's the way we roll, me and my kids.*"

Originally from the south, Hetty indicated that she's considered moving, but along with financial constraints, Flint is where her family has social ties. She explained, "*My kids went to school here, they graduated from here. And so, this is their home…And we going to be with each other. My daughter say, 'Mom, I'm just a phone call away if you need me.'*" Many of our participants echoed Hetty's reasons for remaining in Flint despite the difficulties.

Health Information Work in Flint
Next, we examine how our participants performed information work in Flint to manage their chronic illnesses. In this section, we focus on the work involved in interpreting and assimilating health information, drawing attention to context—the multiple information worlds—participants must reference in integrating health information into their everyday lives.

Managing Multiple Health Contexts
Many participants reported receiving and understanding information from healthcare providers, but struggled with putting that information into practice due to the particularities of living in their social context. We observed our participants *translating* information in ways that addressed such problems.

To conceptualize part of the information work in Flint more specifically as "translation work," we describe some local health translations. In the following section, we develop the concept of translation work, discussing what is involved in making the information fit into and be useful within participants' local, social contexts.

Impoverished Neighborhoods: Translations of Resourcing Action
As is common, our participants were instructed by their healthcare providers to regularly exercise, take prescribed medication, and test their blood sugar levels. Living on the northside with a scarcity of economic resources and neighborhood instability, however, made it difficult for participants to put such information into practice. Concern for personal safety, for instance, led some participants to create modified exercise regimens such as climbing the stairs inside their house rather than walking outside alone.

As well, residents who could not afford even the most minimal payments for medications often sought out trusted people in the neighborhood for assistance. One participant, currently unemployed and without insurance, went without medication until a friend "gave her a few bucks" to purchase the prescription. Darnell, an African American man with diabetes, noted that he has helped unemployed friends who have diabetes by sharing his diabetic supplies:

"I've gave a few people insulin, extra insulin I had, who didn't have any. And syringes…. Well, they just run out of medicine and couldn't get theirs and I had extra. So I let them use some of mine."

Local health information about how to access medication and supplies was often passed through close friends, neighbors, and family members so as to save money on health supplies, obtain help in the absence of insurance, and provide diet and eating tips. For example, participants commonly mentioned that when people didn't have insurance, the Red Cross might provide assistance, and friendly doctors could hand out free medical samples to tide them over until they could afford their prescriptions.

In sum, information provided by health professionals was translated by participants into the local context of the northside neighborhoods as they found ways to use the resources available to them—friends, staircases, and medical samples—to manage their chronic illnesses. Thus, "regularly testing blood sugar" had to be translated into "ways to manage diabetes without access to syringes or insulin." This work can be thought of as *translations of resourcing action*.

African-American History and Tradition: Translations of Culturalizing Self-Care
As described, participants typically had some contact with the health care system, and as a result, had usually been prescribed a treatment plan by a health care provider. Yet, participants' ideas of self-care or treatment were also grounded in a cultural context. Participants often turned to oral health traditions common to African American communities, casting a cultural past into an information world. Numerous participants, for example, recounted stories they heard growing up about "homemade" or

"Southern" remedies used to treat chronic conditions like diabetes and hypertension. These remedies were often associated with an older generation of African Americans who had migrated from the rural South; however, participants noted they were still in common use today.

One participant remembered hearing from "some old guys" that one could reduce the impact of carbohydrates in bread by toasting it. Another participant mentioned being told about ingesting baking powder to relieve heartburn, also a homemade remedy.

Notably, these remedies were accessible even with limited income or no health insurance. For example, a participant with hypertension explained that he was told by people in the neighborhood that vinegar could help regulate his hypertension:

"Before I really had any health insurance, and if I knew my blood pressure's gonna be up, I would drink some vinegar. About half a cup, but it is depending on what you think your blood pressure is up to. You don't have a monitor or some medication, that's what people were doing."

The prevalence of homemade remedies in Flint's northside speaks to the ways cultural history can bring an information legacy that may need to be reconciled with contemporary treatment approaches. Typically, this meant that participants added home remedies to their self-care regimens, but as the participant above noted, these approaches were also used when people did not have access to health care. We contend that use of home remedies helps participants to integrate cultural perspectives on self-care, thus making various forms of health information understandable and workable within the local context. This type of information work—integrating familiar forms of self-care with biomedical treatment—can be seen as *translations of culturalizing self-care.*

Family Life: Translations of Narrating Success

Family relationships played an important role in shaping the ways people both understand and manage their illness, perhaps especially given the low access to routine health care. All 24 participants in the study described how they learned about chronic illness through the experiences of family members (or close family friends) that had the same condition. These experiences ranged from the mundane to the traumatic as participants told us about preparing diabetic meals for siblings and watching relatives lose limbs or go blind from diabetic complications.

In the case of diet, participants learned from health professionals that nutrition was an important part of managing their chronic illness, describing a healthy diet as one high in fresh fruits and vegetables and low in fats, salt, and refined sugars. However, the practices around eating and preparing food to manage chronic illness were often learned through participating in family life. Donnie, for example, describes learning to "balance" his meals by watching his diabetic parents as he grew up:

"They learnt the 'give and take.'…In order to have this, you had to take away this…Like, mom loved [cooked] greens; she loved pork, but them was some of the things she couldn't have. In order to have it, she'd have to have some of this and take away some of that to balance it off. So it was a give and take thing."

Donnie, currently unemployed and living in a shelter, noted that while his food options are currently limited to the offerings of soup kitchens, in using his parents' balancing method he can control his hypertension without resorting to medication. Likewise, Joelle relied on family experiences to draw conclusions about how to best manage her diet:

"I saw my grandfather live to be 97 years old with diabetes. He was taking insulin, but my grandmother measured and done everything. But he would sneak off to his cousin's and eat some cake with his coffee. And then he wouldn't tell her, till … he'd be falling out. His sugar done went be too high."

Joelle's grandparents provided her with a model for how to take care of diabetes that was, for her, confirmed by her grandfather's long life. Replicating her grandmother's attention to maintaining a strict diet through measuring food has led Joelle to conclude that she too can manage her diabetes (and avoid injections). *"If you stay on something precise,"* Joelle explains further, *"you'll be all right."* Joelle recognized that while "falling out" is a state to avoid, giving in to temptation once in a while is also acceptable.

While our participants were given information about "eating right", they had to strategically manage their diet and illnesses in their Flint context. They drew on what they knew and adapted African American soul food recipes (e.g. greens and pork), or created eating practices such as "the give and take." Notably, these practices allowed participants to see how their condition might look in the future, with efforts to identify factors that allowed family members to survive and thrive. We see such information work as *translations of narrating success.*

Religion and Churches: Translations of Blending Knowledge Systems

Many participants indicated that religious or spiritual beliefs played an important role in how they understood and managed their health. Participants, for instance, mentioned praying for their own health, the health of friends and family members, and also for the physician's ability to treat them. Numerous participants also mentioned reading the Bible as a means of reducing stress and encouraging them in the management of their chronic illness. Although not typically discussed in biomedicine, these beliefs and actions were important to many of our participants.

Andrea, a woman with diabetes, hypertension, and bi-polar disorder, often exchanged inspirational text messages with family and friends. She explained that a cousin routinely sends her different text messages (such as "PFT" or prayer

for the day, "TFD" or thought for the day, and "SFD" or scripture for the day). Andrea explains that these texts are connected to the health information she shares with her cousin:

"Me and her talk a lot [about health]. I find a lot of information. I send her little inspirational texts on the telephone. She likes them. She calls me and thanks me. She has a lot of depression and stuff cause of her sickness."

These texts also encouraged Andrea, who had been out of work for a year and struggling to pay for necessities like food, rent, and medications. She saved the texts on her phone to look at when times are hard. Andrea also forwarded favorite texts from her cousin to her mother, daughter, and best friend who also have diabetes.

Notably, church participation could often accord a particular understanding of illness based in the tradition of faith-healing. We heard reoccurring stories of chronically ill people who would "not claim" their diabetes or hypertension. This practice of "not claiming" is associated with the belief that God can supernaturally heal the sick. Among certain congregations in the African American church community, "not claiming" an illness is a respected act of faith.

Participants who held such religious views could be seen as facing challenges in assimilating health information from clinicians. A more nuanced view would be that they had to translate multiple knowledge systems and make them as coherent as they could. This could lead some people to couple professional medical advice with prayers for healing or even to refuse to get a medical diagnosis of a suspected condition like diabetes. Health teams in these congregations indicated during focus groups that they continue to struggle with how best to provide health information to people who have such deeply held spiritual reservations.

The information work performed by those participants involved in religious information worlds required translations of biomedical health information into practices that acknowledge a spiritual worldview (and the reverse). We believe that practices around "spiritual text messages" and "not claiming" can be understood more broadly as *translations of blending knowledge systems*.

DISCUSSION

Health Translations
Examining the life experiences of our chronically-ill participants in Flint, we found that they often had access to a fair amount of health information, although it was not necessarily personalized by attentive health care providers. This problem was likely exacerbated by the aforementioned challenges in accessing healthcare. Overall, however, their problem was not scarcity of information; instead, they had to combine, transform, and recast the information before it could be turned into localized health practices.

Studies on health information acquisition often privilege communications exchanged between doctor and patient in an exam room or in the electronic health record (e.g., (Souden & Durrance, 2011)). Health information provided by professionals is often viewed as the *only* translation needed; and while professionally-provided information may be authoritative, alternative translations that are localized, connected to different information worlds, and often bound to personal biography persist and flourish.

A significant body of information behavior research has examined information needs and seeking and use (Case, 2012). Considerably less attention, however, has been accorded to the kind of information behavior, or "translation work" that is performed to make information meaningful and actionable in different social worlds. The concept of information "translation" developed here finds resonance with health services research that focuses on closing the gap between emerging research evidence and clinical practice (e.g., (Shea, 2011)). This research examines factors that facilitate behavior change among clinicians, particularly in the area of implementing clinical practice guidelines (e.g., (Straus, Tetroe, Graham, & Wiley online, 2009)). A core insight from this research is that guidelines may not "fit" with new clinical environments, whether due to resources such as staff skills and available equipment (Toman, Harrison, & Logan, 2001), or due to local acceptability of recommendations (Harrison, Graham, & Fervers, 2009), or due to local institutional arrangements (Fervers et al., 2006). These types of mismatches were also evident in Flint, where social factors such as poverty, religious faith, cultural history and tradition needed to be reconciled with biomedical information and advice.

As we saw in Flint, clinical settings must "adapt" biomedical information such as guidelines to make it actionable in a local context (Graham et al., 2006). Adaptation involves assessment of the value and usefulness of a guideline to one's setting (Harrison, et al., 2009), selecting relevant knowledge (Ward et al., 2012), tailoring or customizing information to one's local context (Graham, et al., 2006), reformatting or repackaging information (Fervers, et al., 2006), and/or linking guidelines to everyday language (Ward, et al., 2012). Parallels are also evident in our participants' acts of translation, as in efforts to tailor advice regarding diet and exercise to one's setting.

Information Work
If there is sifting, integrating, and assimilating information work in managing health (Corbin & Strauss, 1985, 1988; Hogan & Palmer, 2005), then what we have observed with our participants is within this information work. Here we have discussed how the translation work of chronic illness management draws on a multiplicity of local perspectives: the African American church, life in a low-income neighborhood, the extended family – and makes the information intelligible and useful for our participants *within their social context*. The information, in short, must become part of their everyday lifeworld (Chatman, 1999).

Here we extended the concept "information work" through the examination of the translations that allowed information to fit within our participants' everyday contexts. We identified, in our analysis, four types of information translations in Flint. This list is not intended to be exhaustive or mutually exclusive, but rather to suggest the rich and varied ways our participants engaged with information work. In short, our participants found themselves (1) resourcing action; (2) culturalizing self-care; (3) narrating success; and (4) blending knowledge systems in order to manage their everyday health concerns.

In this, viewing the process as one of translating information casts information transfer as a dynamic rather than passive activity in which people are actively engaged in (re)framing information from one form or version to another. Indeed, in managing their everyday health concerns, Flint residents routinely perform multiple information translations that can both align with and conflict with one another.

There is a serious level of risk involved in managing chronic illness that we do not want to trivialize or romanticize in our discussion of translation work. People can cause themselves harm or even die if they are given the wrong information or do not understand the biomedical facts about their illnesses. In low-income communities, however, following the "optimal" treatment plan as it is given in the physician's office or clinic is often not an option. In Flint even the most basic health information of "eat right, exercise often" variety needed to be contextualized at a very local level, e.g., safely traveling to the store, finding fresh produce, and being able to afford the food.

We must note that translations are not to be found only in poor or marginalized communities, but that the lack of resources and marginalization in places like Flint make translation work highly visible. In general, there may be a number of situations and contexts where not enough, not sufficient, or not understandable professional biomedical information is being provided. However, this is not the complete story. We also need to consider whether translation work is occurring, and if so, how translations should be supported.

Given that local information translations occur routinely in people's everyday lives, future work needs to consider how translations can be supported so as to maximize people's well-being. We also plan to consider how local people with expertise in both the community and in medical practice can serve as translators to provide contextualized health information and how digital information might be leveraged to facilitate this translation work on a community level.

CONCLUSION

In this paper we explore how different information worlds in Flint are tied to health information work, including varying translations that people make to manage their health in light of everyday concerns. Our study findings

highlight: (1) the importance of health information bound to local context(s); and (2) the translation work that takes place in "localizing" health information into relevant forms of practice given a community's values and resources. Our findings suggest that professional information practice may benefit from an increasing focus on supporting or facilitating local information translations.

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