

**Social Determinants of Health Screening Implementation: A Multi-Method Investigation to Bridge
Clinic and Community to Improve Healthcare Outcomes**

by

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Dedication

To my parents, who taught me benevolence, generosity, and the value of hard work.

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Abstract

Motivated by transitions to value-based payment programs, healthcare organizations are beginning to implement social risk screening and referral programs to address patients' social needs. This dissertation explores current efforts to conduct social risk screening in healthcare settings to identify social needs, as well as the policy and organizational factors associated with healthcare organizations' social care services to address those social needs.

In Aim 1, qualitative interviews are used to explore providers' experiences with social risk screening, including perspectives on the benefits and drawbacks of the use of social risk data, as well as how they data are used in practice. This study draws on professions theory as a framework to characterize the impact of the introduction of screening and referral work on clinicians, for whom this work may fall outside of their professional jurisdiction. This study describes the need to support clinicians as they perform screening and social care tasks via education, designated staffing, and informational tools. The adoption of social care work by clinicians represents a unique contribution for professions theory by demonstrating a case in which professionals expand their scope of practice involuntarily due to the managerialization of social needs.

In Aim 2, qualitative interviews are used to understand the patient perspective of social risk screening, including attitudes towards the disclosure and documentation of social risk data, as well as expectations for providers' response to disclosed social needs. Using medicalization theory as a framework, this study explores the impact of the healthcare efforts to exert social control on patients through screening and social care programs. This study identifies facilitators

of sharing information about social needs, including believing that data are relevant to accessing healthcare, having an expectation that providers can address social needs, and having trusting relationships with providers. Barriers to sharing information about social needs during screening are also identified, including feeling that social risk data are irrelevant to providers and perceiving risks of screening, including embarrassment, discrimination, or bias. This study highlights the potential harms of social control that may follow screening, suggesting the need for patient-centered design of screening and social care programs.

In Aim 3, national survey data from US hospitals is combined with Community Benefit spending data to characterize those hospital characteristics associated with providing social care services. This study demonstrates that increased Community Benefit spending is positively associated with the number of social care services offered by a hospital. However, hospitals in states with minimum Community Benefit spending requirements were negatively associated with the number of social care services offered, suggesting opportunities for new policy incentives to encourage the implementation of additional capacities to address patients' social needs.

Together, these Aims intend to guide the implementation of future social risk screening programs to ensure feasibility for providers and their workflows as well as acceptability for patients. The medicalization of social needs may create additional opportunities to address patients' social needs, though screening and referral programs may shift provider work practices and change patient-provider relationships, suggesting the need for consideration of these factors during the design and implementation of programs. As hospitals take responsibility for social needs, they must have sufficient capacity to promptly offer resources. The findings of this dissertation may help improve screening and social care programs implementation to create opportunities to address patients' needs and improve healthcare access.

Chapter 1 Introduction

Up to 80% of the variance in the health status of individuals is explained by social determinants of health (SDOH), those conditions in which individuals are born, live, and work [1,2]. The factors that are associated with negative health outcomes, such as food insecurity, are referred to as “social risk factors” [3]. “Social needs” are those social risk factors, that from a patient’s perspective, taking into account her specific preferences and priorities during shared decision making, are her most pressing social risk factors requiring intervention [3]. Currently, there are numerous efforts by healthcare organizations to capture social risk factor and social needs data to allow providers to address patients’ social needs [4–7]. Working together with patients, providers may offer social care, such as offering referrals to community social service agencies, such as food pantries or temporary housing [8]. When necessary, providers may also take patients’ social risk factors and needs into account when choosing a treatment plan, ultimately tailoring them to the constraints of individuals’ specific situations, such as when choosing an alternative medication option that is at an affordable price to the patient [9–11]. Much of the effort to screen for social risks and offer resources to address social needs come from insurers’ transitions to value-based payment mechanisms, which consider patients’ health outcomes rather than just service inputs when compensating providers [1,12,13]. By screening patients for social risks and needs during routine healthcare, and responding accordingly, the hope is that patient health outcomes can be improved — especially for socioeconomically disadvantaged patients [14,15]. Screening is thus an important means of identifying those social risk factors for providers to address more proactively than has been typical in the past.

Several knowledge gaps regarding the implementation of social risk screening and social care programs exist. Initially, healthcare organizations began to screen patients for social risks [16] with homegrown tools or one of many publicly available instruments [17]. More recently, many electronic health record (EHR) vendors have introduced built-in screening tools [18]. However, there has not been widespread adoption of a singular systematic method of capturing social risks for all patient populations. Aside from translations of some tools to non-English languages [19] and efforts to develop screening tools for pediatric populations [20–22], publicly available screening instruments and those found in EHRs are generally not tailored to the needs of particular patient populations or clinical specialties. Moreover, while some screening instruments feature validated questions [23,24], there is a need to validate individual screening questions for use in different clinical contexts. Implementation variation, including who performs screening, where and when screening is performed, and how screening is introduced and explained to patients, may cause the same questionnaire to perform differently.

Current evidence about the implementation of social care and screening practices in United States (US) healthcare organizations suggests that practices vary widely, even when identical screening instruments are widely deployed across multiple sites [25]. Accordingly, there is also a need to determine optimal methods for implementing screening in different populations and settings. Input from both providers and patients is necessary here, for social risk screening may change provider workflows [26]. While there is much recognition about the importance of social risk screening in healthcare, we do not yet know which SDOH data are most valuable to different types of healthcare providers. Similarly, because screening and social care work may fall outside of the current professional jurisdictions of many clinicians [27], there is a need for evidence regarding who should perform screening and how best to support

interprofessional social care work. Finally, screening implementation research is beginning to recognize the importance of nonclinical members of the healthcare team, including social workers, community health workers, and patient navigators, for screening and social care work [28]. This suggests a need for additional research that captures the experiences of a wide variety of staff and administrator roles, to better understand how screening and social care programs impact these professional groups and how these groups access and use social risk information.

There has also been comparatively little research regarding patients' preferences for when and how screening is performed, and how the data are subsequently used by providers and stored in the EHR [15,29,30]. Identifying best practices for the implementation of social risk factor screening and social care programs may help to avoid unintended consequences for patients, such as bias or stigmatization [31]. Screening may also set expectations for providers' to address social needs, regardless of their capacity to do so, suggesting the need for patient education regard hospitals' capacity to offer social care [32]. Finally, initial research highlights the role of interpersonal labor on patients' screening experiences, including staff interactions that may help patients feel cared for, as well as the need to help patients contact social services agencies to ensure access to resources [33]. Thus, there is the need for additional research to understand the facilitators and barriers of patients' participation in screening and social care to ensure that programs are designed to empower patients.

Despite recognition of the importance of widespread social risk screening and social care, there are several important concerns created by screening that must be considered throughout this investigation. First, social risks may be personal, sensitive details about people's lives, indicating the need for privacy and confidentiality in all stages of screening and social care. Patients may have a range of reasons for choosing to withhold information about social needs,

including limited trust in providers or fear of discrimination, stigmatization, or biased treatment [34–37]. Given this, providers may require training to learn how to ask patients about psychosocial experiences [26,38]. Additionally, providers may be ambivalent about surfacing patients’ social risks with greater vigor, as one recent report from primary care found that most providers feel that addressing patients’ social needs falls outside of their professional responsibility [39]. Accordingly, there is a need for research to clarify the impact of screening and social care work on providers of all specialties.

There are several knowledge gaps related to healthcare organizations’ efforts to implement social care programs. To realize the goal of achieving better health outcomes for patients who are disadvantaged by offering social care, social risk data must be collected from patients accurately and appropriately, conveyed to providers in actionable ways, and used to provide social care [40]. Hospitals are an important part of social care, as emergency departments make up an essential part of the American healthcare safety net by offering care to those without access to primary care [41]. Hospitals across the United States are beginning to implement social care services (SCS) programs to address patients’ social needs, motivated by calls to increase access and reduce low value or unnecessary care [55,56], as well as by the Community Benefit (CB) tax exemption program [57–59]. As a result, there is a need to understand how such SCS are distributed to determine hospitals’ capacity to meet social needs in communities, and the extent to which hospital characteristics, including CB spending, are associated with the presence of different types of SCS. Thus, it is important to understand how best to promote the availability of social care in hospitals once patients are identified as having social risks and needs through expanded programs. Hospitals may respond differently to policy and market pressures when implementing social care practices. Thus, healthcare organizations

may vary by social care capacity, including the number and types of services offered [42]. Variation in social care capacity may be driven by hospitals' resources; internal and external pressures, such as from peer or neighboring institutions; or hospitals' attempts to address the specific needs of their patient populations, as is evident from the different approaches to social care taken by healthcare organizations participating in the Accountable Health Communities Model [42,43]. Understanding the organizational drivers, including hospital characteristics and resource availability, of social care adoption may inform policy design and resource allocation to mitigate disparities in social care resources caused by coverage gaps.

Furthermore, scholarship from the perspective of social services agencies is necessary to understand the impact of hospital-provided referrals on these organizations. The implementation of screening programs at large medical centers may create a high referral volume, and thus, it is necessary to determine if local social services agencies have the capacity to accept and respond to referrals. While there has been initial studies of the capacity of community social services agencies [44,45], early work has been limited to specific types of referrals in a small number of geographic communities, suggesting the need for national research to characterize that prevalence and capacity of social care programs. Finally, as social care services are increasingly implemented, tracking this adoption over time will be valuable to policymakers, who may evaluate variation in social care resources by region or institution characteristics, advances or regressions of social care coverage over time, and coverage gaps that may perpetuate health disparities [46].

1.1 Overview of the Research

This dissertation attempts to contribute to current the knowledge gaps related to social risk screening and social care described above. In Aim 1 (Chapter 2), qualitative interviews with

36 providers are used to investigate the potential benefits and drawbacks of access to social risk factor data, as well as how providers use these data in practice. In Aim 2 (Chapter 3), qualitative interviews with 18 patients are used to understand patients' attitudes towards sharing information about their social needs, attitudes towards having these data documented in the EHR, and their expectations for support from providers following screening. In Aim 3 (Chapter 4), quantitative data from the 2018 American Hospital Association Annual Survey and 2017 IRS-Schedule H Community Benefit spending data are linked and used to understand the relationship between hospitals' spending on community health and the number and types of social care services they offer.

Dissertation Aim 1: Providers' Perspectives about Social Risk Factor Screening and Social Care in Healthcare Settings. There are currently significant efforts to implement social risk factor screening in healthcare settings, though only limited evidence about providers' experiences with adopting this work [47–51]. Using professions theory and its discussion of interprofessional jurisdiction as a framework, this aim explores providers' perspectives on the use of social risk factor data in practice. Social care has historically been the domain of social work, though screening efforts often require the involvement of other types of clinicians and staff members given the frequently limited availability of social workers and other social care experts in health care [27]. Interviews were conducted with 36 clinicians, staff, and administrators at a large Midwestern nonprofit healthcare organization. Interviews were used to extend prior research to include characterizing providers' perspectives on social risk factor screening and information use to help patients, including how providers use these data, what benefits and drawbacks they perceive, and their perception of the impact of screening on the patient-provider relationship. Professions theory, which is concerned with the professions'

claims of jurisdiction over certain domains [52], provides a useful lens for studying the introduction of new screening and social care workflows to be performed by a range of clinicians, staff, and administrators. Professions theory's intersections with information science research also explores professionals' unique uses of information, and social risk screening represents a unique opportunity to explore respondents' use of information potentially outside of their professional domain, including identifying opportunities to support clinicians in screening and referral work.

Dissertation Aim 2: Patients' Perspectives on Social Risk Factor Screening in Healthcare Settings. As social risk factor screening is implemented by hospitals, patients may find that they are being asked to share information about potentially sensitive and vulnerable social needs [53], which were previously the domain of social work and community social services agencies, rather than of healthcare [27]. Thus, as social needs are medicalized, or taken under the dominion of healthcare, it is necessary to understand patients' perspectives on screening and social care, which has previously been understudied [15]. Using medicalization theory as a framework, 18 patients who had participated in social risk factor screening and social care intervention at a large Midwestern nonprofit healthcare organization were interviewed to characterize patients' attitudes towards sharing information about their social risk factors, the documentation of these data in the EHR, and patients' expectations for clinicians to ask about and respond to their social risk factors. Medicalization theory is concerned with the process by which social problems become defined and treated medically, resulting in the medical establishment exerting social control over patients and potentially introducing unintended harms [54]. To determine best practices for implementing screening and social care in a safe and acceptable manner for patients, this aim explores patients' attitudes towards sharing information about their social needs with providers,

expectations for providers to provide social care, and the consequences of bringing social needs to the attention of a healthcare organization during screening. A goal of this work is to inform organization decisions about social risk screening, data access, and storage so that they align with patients' attitudes on these issues.

Dissertation Aim 3: Characteristics of U.S. Hospitals offering Social Care Services. In this paper, a novel dataset from a national sample of hospitals is used to characterize the prevalence of US hospitals that are providing social care, as well as the number and types of services available. By characterizing the prevalence of social care practices in the US, providers and healthcare administrators may be able to evaluate the services they provide relative to regional facilities or peer institutions.

Taken together, this body of work addresses issues related to the implementation of social risk factor screening and social care programs in healthcare settings from the perspectives of providers and patients, and the distribution of such services at the national level. Findings from these studies may inform organizational implementation decisions, the design of future health information technology to facilitate the delivery of social care in healthcare settings, and federal incentives for offering social care. Knowledge generated in this dissertation may thus create additional opportunities to help patients meet those needs necessary to live healthy lives.

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Chapter 2 Providers' Perspectives about Social Determinants of Health Screening in Healthcare Settings: A Qualitative Study

2.1 Introduction

Screening for patients' individual social needs, some of which stem from the social determinants of health (SDOH), is becoming increasingly common at American healthcare organizations [1]. As many as 80% of the health factors contributing to a patients' health status are SDOH [2,3], and as American healthcare transitions towards value-based payment models, providers may be financially motivated to identify and offer support for patients' social needs [1]. Screening for social needs, also called "social risk factors," creates opportunities for providers to identify patients' needs and to improve health outcomes by intervening via tailored care and social care, which includes interventions designed to address social needs, such as referrals to social service agencies [4,5]. While addressing social needs has long been the responsibility of governments or community social services agencies [6,7], screening and offering support for social needs in healthcare settings creates additional opportunities to reach patients. Currently, there is emerging discussion of avoiding "missed opportunities" for addressing social needs [8–10], similar to prior work addressing missed opportunities for HIV prevention [11–13] and Hepatitis B vaccination [14], by screening and offering support at healthcare encounters. Screening and referral programs in health care settings may create additional opportunities for social needs to be identified and addressed than relying on social services agencies alone, however, evidence of the effectiveness of such programs is mixed [15,16]. Screening and referral interventions have contributed to significant reductions in

patients' social needs and significant improvement in child health outcomes in trial settings [17]. Conversely, studies have demonstrated no significant impact on health outcomes, including mental and physical health-related quality of life [18] or healthcare utilization [19]. However, prior work has shown that screening and referral interventions improve patients' access to information about available resources, including higher confidence in finding resources [18], sharing information about resources with others [18]. Screening and referral interventions can also increase providers' access and use of resource information [19]. Lingering challenges, including lack of follow-up with patients following a referral to a community organization or limited information about the quality of community resources, may contribute to the mixed impact of screening and referral interventions [19,20].

This study is motivated by a need to understand how to support clinicians as they choose, or become required to, gather and use information on patient social needs, for which they may have limited training or education [21]. While social risk factor screening and social care represent one important case of the collection and use of new forms of data by providers, shifts towards value-based payment and precision health motivated by administrators, payers, and professional organizations may require clinicians to use many new types of data in practice [2,22–24].

One potential factor contributing to the limited impact of social risk screening and referral interventions is the relatively small amount of attention that has been paid to the academic study of screening implementation, including identifying best practices and the impact of screening work on clinicians, staff, and clinical workflows [25,26]. Successful implementation of programs and technologies, such as those to address patients' social needs, require attention to workflow integration [27–29]. Prior work has demonstrated that the impact of health information

technologies on professional identities and shifting roles between providers is a well-documented source of resistance to new technologies [30–32]. The current literature is beginning to document the implementation experiences of screening in individual healthcare organizations. Studies have demonstrated that offering workflow flexibility, having a social risk screening advocate, and having external motivators and incentives were important facilitators of EHR-based social risk screening [33], while potential workflow barriers included insufficient time to fully discuss patients' social needs and additional burden on staff at various stages throughout the visit workflow [34]. Additionally, there have been concerns of bias in which clinicians and staff may decide not to screen certain patients based on physical appearance, insurance status, or diagnosis [35]. Moreover, there have been concerns about which types of clinicians and staff should perform screening. For example, while some staff members feel that screening should be completed by nurses before discharge, others suggest that screening should occur at admission to maximize the usefulness of screening data [35]. In an evaluation of one screening program designed for non-clinicians, some primary care physicians wanted to discuss patient needs despite limited time during the visit, suggesting difficulty in dividing up screening and referral labor [34]. Finally, if social risk screening and response work are not considered to be reimbursable activities, providers may be unable to hire additional staff to conduct this work [36].

The implementation of social risk screening in healthcare settings creates the potential for unintended consequences that should be mitigated [37]. The act of screening for social needs may set expectations for response to those needs that may be outside of the capability for the healthcare organization to provide, and screening without sufficient capacity to appropriately alleviate needs has been described as unethical [37]. Furthermore, screening may result in

damage to the patient-provider relationship if patients perceive judgment from the provider [37]. As a result, clinicians may require training to develop the skills needed to adequately screen for and address social needs [37]. Unfortunately, while there is recognition of the importance of educating clinicians about SDOH [38–40], training to address social needs is not universally offered in health professions education [37]. Clinicians may have limited education about how to discuss sensitive social needs with patients, as well as which referral resources may be available to support these needs [41]. While institutions may offer courses and programs to train medical students and residents to act on SDOH [42,43], many opportunities are single lessons or service-learning activities rather than efforts sustained throughout the education experience [43–45]. Instead, current curricula may require transformation to train clinicians to learn not only about what SDOH are, but also what their origins are and how they impact patients [44]. While much evidence about the impact of SDOH training programs is limited to learner self-report [43], early research had demonstrated that medical residents who had undergone a SDOH training intervention felt more comfortable discussing social needs with patients, reported greater knowledge about SDOH, and were more likely to document social needs, though rates of referrals were not significantly different between residents who experienced training and those who did not [46]. Furthermore, clinicians may benefit from education about local social service agencies to which they may refer patients following the disclosure of a social need. Similarly, the co-location of health and social services may reduce barriers to access for patients [47].

In addition to training limitations, time constraints may limit clinicians' ability to address social needs. Increased demands on clinicians to perform numerous tasks during ever-shortening clinical encounters may leave insufficient time for clinicians to discuss patients' social needs and

relevant resources [48–51]. Similarly, clinicians may lack time to participate in education and training related to screening and social care work [48,50,51].

Informatics tools may create opportunities to alleviate the burden on providers when addressing social needs, and indeed, there have been calls for the integration of tools that help providers to assist with social needs into the EHR [34,47]. Presently, some EHRs can connect to community resource referral platforms, such as Aunt Bertha or Healthify, which facilitate referral linkages to social service agencies [52]. In one example, an EHR tool that generated utility protection letters allowed providers to increase the number of letters generated for patients by 350%, allowing a greater number of patients to benefit from utility shutoff protection [53]. Moreover, informatics tools may allow for tracking of patients throughout the referral process to allow providers and administrators to identify problems and measure the impact of referral efforts [34]. Finally, informatics tools must be capable of ensuring data access for both the treatment of individuals' social needs as well as healthcare organizations' population health efforts [54].

Given the complexities of screening for and addressing patients' social needs, including workflow barriers, the potentially limited training of clinicians related to social care, and the introduction of new EHR tools to facilitate referrals, there is a need to identify and understand the challenges and barriers of SDOH screening as programs continue to be implemented in healthcare organizations. Here, using professions theory as a theoretical foundation, we describe barriers and opportunities for providers related to data access, training, and support needed for expanded SDOH screening implementation and discuss opportunities for health information technology (HIT) to facilitate social referrals. The objectives of this chapter are as follows: 1)

assess providers' perceptions about social risk screening, including data access, tools, and practices, and 2) understand how social risk factor data is used by clinicians and staff.

2.1.1 Theoretical Framework: Professions Theory

Professions theory recognizes that professional occupations comprise demarcated jurisdictions over expertise and practice [55]. Scholarly study of professions has spanned three general movements across eight decades. In its critiqued first movement, early studies attempted to characterize professionals by creating a typology of their unique traits and functions, though survey tools to empirically measure professionalism [21,56–59] were quickly found to apply to a wide range of other occupational groups rather than to professionals alone [21,60,61]. In its second movement, research on professions turned its focus away from attempting to identify core attributes shared by professions and instead examined the power and privilege exerted by professionals over their environment, social conditions, other occupational groups, and clients [21,61–65]. This second wave included the pioneering notion of *social closure*, which explained how professions create barriers to, and claim of autonomy over areas of knowledge and practice through the implementation of licensing and professional organizations [61,66–70]. Such autonomy allowed professionals to gain a monopoly over economic gains (“rents”) related to their domains of knowledge, work, and status [71,72]. Finally, a contemporary third wave of scholarship on professions shifts attention towards the processes of professionalization, namely, the efforts made by an occupation to claim jurisdiction over knowledge and practice [61].

Other work in professions theory focuses on how professionals socially construct the authority of their professional domain [72]. In doing so, professionals continuously claim and negotiate jurisdiction over these areas, making them the exclusive domain of one's professional identity [73,74] and demonstrating the maturity of a profession based on having its own

knowledge system [75]. The ability to draw and maintain boundaries between and among professional groups contributes to the relative status afforded to each in society, and professionals use jurisdictional conflict to maintain and bolster professional status, both intraprofessionally and extraprofessionally amongst the general public [76].

Professions can also be distinguished by how and why information is used by practitioners, and indeed, information behavior is an important component of professionalization [77,78]. Professionals' unique use of information may be one manner by which professions differentiate each other, resulting in unique information needs and categories of information that are deemed to be relevant [78]. The information seeking literature has explored professional differences in information needs and uses, including highlighting the unique characteristics of clinicians [77]. For example, Gorman describes a taxonomy of four types of physicians' information needs: recognized is information articulated by physicians; pursued is information which physicians followed up on; satisfied is established sources of medical knowledge and patient data; and unrecognized is information which a physician did not initially recognize [79,80]. Similarly, Gorman provides a taxonomy of types of information available to physicians, including patient data, population statistics, medical knowledge, logistical information, and social influences related to how medicine is practiced locally [77,80]. Additionally, given the complex and specific nature of individual patient care, prior work has demonstrated that physicians also use narrative information about a patient's story, rather than a list of problems and treatments [77,80]. Finally, as professionals increasingly work within organizations, rather than independently, they may face constraints and demands on their information behaviors, including the imposition of tasks which require information outside of their professional jurisdiction [21].

The information science literature reflects the notion of information seeking, or those behaviors one completes when faced with an information gap in which internal beliefs and knowledge are insufficient to complete the goal at hand, and use as a critical component of professional work and identities [77]. Indeed, of the many theoretical models of information seeking, one, the Leckie Model, focuses specifically on information seeking by professionals and features. The Leckie Model considers professionals' roles and work tasks as influences of the characteristics of one's information needs and suggests that the outcomes of information seeking contribute to professions' awareness of information and sources of information [77,81]. Information behavior is an expression of one's professional identity, and thus, one's information needs and interests are a function of both individual preferences and professional competition [78]. Information seeking and use may subsequently help to gain social status as a profession, also referred to as a professional project [72,78,82]. For example, Johannisson and Sundin demonstrate that nurses use certain information seeking and usage behaviors as a means of expressing their professional discourse and identity, especially when distinguishing their knowledge work from that of other types of healthcare professionals [83,84]. Finally, professionals' use of information may be related to their independence in practice relative to other professions, such as that of nurses to physicians, resulting in a spectrum of behavior from subordination to resistance [82].

Healthcare delivery is an interprofessional activity containing a range of distinct professions, such as the medical, nursing, and social work professions, working together in hospitals and on healthcare teams. Given proximity, constraints, and instances of the routinization of certain workflows, the jurisdictional boundaries separating professions may come in contact or be crossed during the delivery of healthcare. Indeed, there has been a

significant effort made regarding the implementation of interprofessional education initiatives to train future healthcare professionals to work collaboratively as members of interdisciplinary healthcare teams. Additionally, there has been increased interest in the engagement of social care experts, including Social Workers and Navigators, to be fully engaged on healthcare teams [85–87]. This trend contrasts to historical hierarchies in healthcare in which physicians maintained much autonomy and power within healthcare organizations relative to clinicians and staff members in other roles [88–90]. Indeed, the adoption of standardization measures in healthcare, including clinical practice guidelines designed to ensure that Physicians practice evidence-based medicine [90–93], the introduction of new technology [94], and new payment policy designed to increase the value of healthcare [22,95–97], have begun to shift these hierarchies, making way for expanded influence of other members of the healthcare team, including social workers and other social care experts, on the delivery of care.

Considering the jurisdictional boundaries of professions is critical when examining social care practices. Social work, the healthcare profession that has historically had jurisdiction over patients’ social needs, emerged out of work at the boundaries of other roles in healthcare, education, and civil service, resulting in a highly interstitial field [98]. Social workers, and other social care experts, often perform tasks mediating work at the boundaries between other professions, and Abbott has described the emergence of the profession of social work as a process of change and conflict resulting in an enclosure of the boundaries of social work around this interstitial space. Social work, and specific tasks related to addressing patients’ social needs, require significant interpersonal work and specialized, constantly evolving knowledge of available resources. While much of the curation, recommendation, and referral tasks may have

the potential to be automated using information technology, the critical interpersonal labor of social care experts is a defining characteristic of the social work profession [85,98].

Additionally, clinicians are starting to experience external pressure from administrators and payers to address social needs during clinical encounters to improve health outcomes and reduce healthcare costs [5,95,99–102]. This “managerialization” of social needs is part of a shift towards value-based payment for healthcare, in which patients’ health outcomes are measured and factored into reimbursement for healthcare, thus incentivizing clinicians to address the social determinants of patients’ health outcomes [22,95,103–105]. As a result, clinicians may find themselves taking on responsibility for addressing patients’ social needs, which may not be a core component of their professional activities for which they may not have received formal training [39,43,45]. While the professions literature describes the negotiations and claims made by professionals about what types of knowledge fall under their jurisdiction, additional work is needed to understand the information behaviors that follow knowledge tasks demanded of professionals as a result of managerialization. This study may offer an extension of professions theory by demonstrating a case in which the expansion of clinicians’ scope of practice is imposed from outside entities, rather than the profession’s own effort to expand its jurisdiction.

Indeed, the implementation of social risk screening and social care programs may cause members of the healthcare team to begin to collect and use new types of information that fall outside of their professional domain, creating the potential for shifts in professional roles and workflows. As a result, professionals may require support to take on new information behaviors from outside of their jurisdiction that result from the implementation of screening and social care. Thus, this study has three research questions:

1. What benefits and drawbacks do clinicians and staff perceive with having access to social risk data?
2. How do different professional and occupational groups involved in health care delivery use information about patient social risk factors?

In each of my research questions, I attempt to build upon professions theory to characterize healthcare professionals' response to the introduction of social risk data in clinical practice. In my first research question, I attempt to build upon the professions literature to create an understanding of how healthcare professionals view having access to information that may be outside of their typical professional domain. Prior work describes the dynamic process of negotiating knowledge claims, and the implementation of social risk screening provides a case in which providers may choose to, or be asked to, collect and use social risk data in practice to address social needs. This question may shed light on such negotiations, especially when external agents, such as payers and professional organizations, begin to put pressure on particular professionals or other occupational groups to expand their knowledge work to include social risk factors. In my second research question, I attempt to build upon information science's contributions to the study of professions by showing how healthcare professionals use information about patients' social needs. This question attempts to characterize how clinicians adapt clinical workflows to take on the unique information behaviors involved with screening and social care work.

2.2 Methods

2.2.1 Settings and Participants

We recruited providers from Parkview Health (Parkview), a nonprofit hospital system in Fort Wayne, Indiana. The Parkview system serves over 900,000 patients in Northeast Indiana

and Northwest Ohio and includes 700 physicians, 100 clinics, and nine hospitals. To discover clinical areas at Parkview with formal or informal SDOH screening processes, as well as identify initial interview respondents, we held stakeholder meetings on the Parkview campus in November 2019. Two separate stakeholder meetings were held to facilitate scheduling, with a total of 31 provider and staff participants. In advance of each meeting, attendees were asked to bring a copy of any SDOH screening instruments used in that participant's clinical area. At each meeting, attendees were asked to participate in a show-and-tell activity in which each took a turn introducing themselves and the screening activities and tools of their clinical unit (Appendix A). Participants were provided a brief handout explaining the activity (Appendix B). Stakeholder meetings were audio-recorded and detailed notes were taken by both University of Michigan and Parkview staff.

After discovering which clinical areas currently have SDOH screening practices, we purposively sampled providers, staff, and administrators in those clinical areas as participants for semi-structured telephone interviews. Sampling aimed toward theory construction and attempted to capture a diverse sample in terms of both clinical settings and professional roles. Providers were recruited via email by a researcher within the health system (SW). A total of 65 clinicians, staff, and administrators were invited for an interview and 36 (53.7%) agreed to participate. Of the 29 (43%) who did not participate, 23 (79%) did not respond to the invitation, four (14%) declined to participate, and two were unable to participate (7%).

2.2.2 Data Collection

We conducted semi-structured interviews with 36 clinicians, staff, and administrators at Parkview Health from March-June 2020. Telephone interviews were conducted by three members of the research team. Each interview call included the completion of the informed

consent process and the administration of a brief verbal demographic survey. A researcher from Parkview Health remained on each interview call to answer any participant questions. An interview guide was developed and pilot-tested to ensure clarity. Interviews were collected until data saturation was achieved, as evidenced by later respondents confirming themes raised during earlier interviews [106]. Interviews lasted 45-60 minutes and were recorded and professionally transcribed. All interview transcripts were verified.

2.2.3 Data Analysis

Interview transcripts were qualitatively analyzed in NVivo 12. Coding was completed in two iterative rounds, with the first round featuring open; in vivo; and structural coding, and the second using focused coding to develop themes based on initial coding [107]. A second researcher coded 20% of the interviews to confirm the reliability of the codebook (Cohen's Kappa = 0.637, indicating "strong" agreement) [108].

2.3 Results

2.3.1 Participant Characteristics

Thirty-six clinicians, staff, and administrators were interviewed, with an average age of 43 years (range 32-61). Most respondents identified as female (84%) and non-Hispanic White (84%) (Table 1). Respondents occupied a range of roles in the health system, including social workers, nurses, administrators, pharmacists, and physicians across Community Health, Primary Care, and Specialty Care (Table 2). Respondents had an average of 15 years of practice experience (range 1-38) and an average of 10 years working at the health system. Table 3 shows the role and clinical categories of each participant.

Table 2.1 Demographic Characteristics of Study Participants (N=36)

Characteristics	Number	Percentage
Gender		
Male	6	17
Female	30	83
Age		
Mean/median	43/41	
Range	32-61	
Race		
White (non-Hispanic)	32	84
Black or African American	1	3
White, Arab descent	1	3
Multiracial (unspecified)	1	3
White and American Indian or Alaska Native	1	3

Table 2.2 Professional Characteristics of Study Participants (N=36)

Characteristics	Number	Percentage
Clinical area		
Population Health	6	17
Family & Internal Medicine	6	17
Cardiology	5	14
Community Health & Nursing	2	8
Women's and Children's	2	6
Home Health, Hospice, & Palliative Care	2	6
ER & ICU	2	6
Oncology	2	6
Outpatient Surgery	2	6
Pediatrics	2	6
Pharmacy Medication Assistance Program	1	3
Endocrinology	1	3
Orthopedics/Neurology	1	3
Peer Support Services	1	3
Family & Children's Services	1	3
Provider profession		
Administration	21	58
Social worker	5	14
RN Care Coordinator/Case Manager	4	11
Pharmacist	2	6
Physician	2	6
Community Nurse	1	3
Nurse practitioner	1	3
Practice Duration (Years)		
Mean/median	15/14	
Range	Jan-38	
Length of Employment at the Health System (Years)		
Mean/median	10/8.5	
Range	<1-38	

Table 2.3 Roles and Clinical Specialties of Study Participants

	Community Health ¹	Primary Care ²	Specialty Care ³	Total
Social Care Expert (Social Worker/RN Care Coordinator/Case Manager)	P1, P2, P3, P4 P5	P15, P18	P9, P12	9
Clinician (Physician/Nurse Practitioner/Nurse/Pharmacist)	P8, P33	P11	P34, P35, P27	6
Administrator	P6, P7, P14, P22, P23, P30	P20, P21, P24, P25, P28, P29, P13	P17, P19, P31, P32, P36, P10, P16, P26	21
Total	13	10	13	36

¹ Population Health; Community Health & Nursing; Home Health, Hospice & Palliative Care; Peer Support Services; Pharmacy MAP; Family & Children's Services

² Family & Internal Medicine, Pediatrics, Women's & Children's

³ Cardiology, ER & ICU, Oncology, Outpatient Surgery, Endocrinology, Orthopedics/Neurology

Interviews with Parkview clinicians, staff, and administrators surfaced themes related my research questions regarding the benefits and drawbacks perceived by providers when having access to social risk factor data, as well as the uses of these data by different professional and occupational groups. First, respondents described the benefits of having access to social risk factor data, including the use of these data to address patients' social needs. Respondents then described challenges faced when collecting and using social risk factor data, including the need for training and designated staff, as well as avoiding potential harms to patients. Finally, participants described the conditions which would best facilitate the collection and use of social risk factor data.

2.3.2 Uses of social risk factor data and their benefits

Participants described several benefits of having access to social risk factor data in practice both within and outside of clinicians' professional jurisdiction, including the ability to make referrals to social care experts and programs to address social needs; to provide information about community resources to patients; and to determine treatment eligibility and preferences. Respondents also described a range of opportunities for administrative uses for social risk factor data, such as to assess the social needs of the patient population and for reporting.

Referrals to social care experts and programs to address social needs

Respondents described making referrals to Parkview social care experts, to internal Parkview resources, and to external community resources to address patients' social needs. Such decisions often depended on the nature of the social need as well as the availability of resources to meet that need, as one Administrator explained,

“ It just depends on what it is. If it's an unmet social need around utilities or homelessness, then they would probably go to a community organization. If it's medication, if it's a need for a primary care doctor, then they would refer internally to a Parkview source” (P7, Vice President, Community Health).

In certain cases, decisions may be based on patient eligibility, such as based on one's insurance coverage.

Referrals to Social Care Experts

Social Care Experts in all clinical categories (7/9), Clinicians in Primary (1/1) and Specialty Care (3/3), and Administrators in all clinical categories (15/21) described making or receiving referrals to Parkview's internal social care experts, such as social workers, case

managers, community nurses, or dieticians, upon discovering a patient's social need. Referrals to social care experts were preferred in instances in which a provider felt that they had insufficient training or resources to assist a patient based on their own professional role, allowing them to leverage the expertise of social care professionals instead. One described making a referral to Care Management to find a long-term solution to medication cost challenges,

“so I say, “Well, yes you can have some samples today, but then let’s go ahead and put a referral into Care Management.” And then when we refer to Care Management, we have a [colleague] who looks at their financials, has connections, understands the programs with the companies and then will contact the patient, get more information and then will let them know if they can receive some financial assistance or even free medication”

(P35, Nurse Practitioner, Cardiology).

Subsequently, social care experts, such as social workers and staff members in the Population Health Department, reported offering resources such as food and fuel vouchers and making referrals to community resources, especially when patients' social needs were beyond the scope of social care services offered by the health system. Social care experts noted that often referrals to multiple resources were necessary to address patients' interrelated social needs, as one recalled providing resources for a range of financial needs when a patient described experiencing food insecurity,

“if the patient’s just in need of food, I’ll help provide the resource for food, but then I’m also going to maybe help provide resources to a church with clothing or give them information also for Bright Point, because if they can’t afford food, then they’re probably struggling to pay some bills and they just didn’t tell me that” (P5 Social Support

Specialist Population Health).

For clinicians and administrators, referrals to social workers were seen as particularly beneficial given the knowledge and access to resources which they provided, as one explained, *“Our social workers are very on top of what the resources are in the community... They might call the other organization themselves in terms of helping connect the patient.”* (P23, Administrator, Home Health). Additionally, when patients were referred to social care experts for a social need, they often conducted comprehensive social risk factor screening to identify the full extent of patients’ social needs, and in Population Health, such a workflow was routine.

Some clinical areas, including Family Medicine (P20, Administrator; P28, Administrator), featured an onsite social worker, which was preferred because of the immediacy of face-to-face assistance that can be provided when such a staff member is located directly in the clinic to ensure a smooth referral. For example, in Family Medicine, clinicians can place an electronic referral to the onsite Social Worker, who may be available to consult with the patient at the time of the visit or within 48 hours of the referral. Referrals to social workers were often placed when clinicians informally discovered that a patient had a social need, allowing the social worker to conduct a more thorough screening and response (P1, Social Support Specialist, Population Health). Similarly, pharmacists may identify financial resources, such as incentives from drug manufacturers, or make referrals to Parkview’s Medication Assistance Program. In the ER and ICU, social care experts routinely walk the floors, making these staff members highly visible and accessible to reach by other clinicians who may request assistance when attempting to address a patient’s social needs. As a result, educators occasionally are the first social care experts that clinicians can find, making them critical contributors in the social care infrastructure, explained one Clinical Education Supervisor,

“it’s who they can get to first... they do know to call the case manager and it depends on really, like number one, who do they see first? Who’s the easiest to get a hold of? Because as an educator, I’m on the unit. So I’m walking around. I’m talking and they may say like, ‘I’ve got this question, can you help me?’” (P16, ER & ICU).

Finally, local policy in Oncology required same-day face-to-face consults with social care experts when screening identified significant levels of social needs, as indicated by a score above a set threshold on the unit’s Distress Tool.

Referral to Centralized Internal Programs

Clinicians and administrators described making referrals to centralized internal resources and programs at Parkview, such as the Medication Assistance Program, the post-discharge free meal program, or a free vegetable program for those who are food insecure or low-income with uncontrolled chronic disease, to assist with patients’ social needs, and such referrals were viewed favorably due to the ease of transferring responsibility for a patient’s social need to a designated staff member or program. Referrals to internal resources were considered by some to be easier to utilize because due to direct electronic referral linkages already exist in the EHR, as one explained, *“We communicate with the Medication Assistance Program and we put their information in an inbox so then that team looks and sees what kind of medication [funding options exist]”* (P3, RN Care Coordinator, Population Health). The ease of referral to internal programs caused some participants to more readily offer resources to patients, as one described, *“Parkview has a free meal once a day for 30 days after discharge, so if they say anything about food insecurities... most times they say no, but a lot of times I’ll just offer it”* (P3, RN Care Coordinator, Population Health). Additionally, when referrals are made to internal resources, clinicians felt that the responsibility for managing a given social need was taken over by that

program, as one endocrinologist described making a referral to Parkview's Medication Assistance Program, *"we refer them to the Parkview Medication Assistance Program. We just put in a referral and it goes to them, and then they follow up with patients"* (P27, Endocrinologist). Respondents also describe instances in which patients in certain high-risk groups were automatically enrolled in programs, such as a heart disease prevention educational program for African American men (P7, Vice President, Community Health).

Providing Information about Community Resources

In some instances, in lieu of referrals made directly to community organizations, respondents in all professional categories instead offered information about resources to patients. This was similarly viewed as a benefit of access and use of social risk data. Providing patients with information about local resources was viewed as the only means of offering social care in clinics in which clinicians did not have the time to make referrals themselves, and participants stressed the large amount of time that gathering information and coordinating referrals to social care often takes. Respondents described creating their own binders filled with information about local resources to serve as references to share with patients when assistance was required. Others described sharing existing reference documents featuring a directory of local organizations and services, such as a local Senior Resource Guide, with patients. When possible, participants described sharing eligibility information about community resources to facilitate patients' access and use. Sharing informational documents about community resources was viewed as a low-effort workflow, and in one unique example, a community nurse in Family & Children's Services described mailing pamphlets to patients who declined social care intervention after screening, as she explained, *"I will send stuff in the mail... if it helps one person, that's one person less I have to worry about"* (P8).

However, respondents stressed that clinicians and staff should not simply hand out informational flyers to patients and instead described the importance of sitting down with patients to explain options amongst various resources so that information is tailored to patients' needs. Furthermore, in Pediatrics, one pediatrician described the distribution of pamphlets as ineffective compared to response efforts which involve a staff member working together with a patient to identify a solution to a social need, as he explained, *"handouts aren't super helpful, a lot of times they just end up in the trash can... I don't feel like that's really connecting with families as much as really closing the loop with somebody actually talking to them"* (P11, Pediatrician).

Use of social risk factor information to determine treatment eligibility and preferences

Another benefit of access and use of social risk data was ensuring effective treatment decisions and maximizing the change of positive outcomes. Administrators in all clinical categories (5/21) described using social risk factor data to determine eligibility for outpatient surgical treatment and for accessing social care programs, as well as to select the best course of cancer therapy in response to patients' social needs. In Outpatient Surgery, patients are assessed for their eligibility for outpatient surgical procedures, including having a ride home and access to necessary medications: *"we ask them about their meds and to make sure they have a ride home... we have to make sure that they bring someone with them to drive them home... or we can't do their surgery"* (P17, Administrator, Outpatient Surgery).

In Oncology, social care experts, including navigators, social workers, and nurses routinely attend weekly tumor board meetings, where they present patient cases to ensure that Oncology clinicians understand the social needs that may constrain patients' access to treatment, as one offered an example regarding reducing a patient's transportation burdens,

“[when] they’re recommending a treatment that they need to drive an hour and a half every single day... for six weeks, to look at alternative treatments that wouldn’t impact their clinical outcome but might impact the patient’s compliance to follow through with that treatment plan” (P26, Director of Oncology Services and Tumor Site teams).

Administrative uses of social risk factor data

Another benefit was to use social risk data for administrative purposes. Respondents in all professional categories described using social risk factor data for administrative uses, including to explore population-level trends, identify those patients at high readmission risk, and measure the impact of social care work. Accordingly, social risk factor data is evaluated in aggregate form to identify trends related to social needs in the patient population as well as referral patterns. By understanding the prevalence of different types of social needs in the patient population, respondents described adapting social care programs, as one explained, *we’re looking at the different barriers and it helps us with our programming in how we can better develop a program and curtail it to meet the needs of the patient so that that helps make them compliant, as well as helping them to be able to be an active part of their plan of care”* (P8, Community Nurse, Family & Children’s Services).

Additionally, RN care coordinators described running reports to identify patients who are at high risk of readmission and do not have a Primary Care Provider who may be in most need of a follow-up appointment regarding social needs (P2, Population Health). Participants described communicating across roles, especially from those with direct patient interaction, like social workers and community health workers, to administrators, to report on trends in patients’ needs and referrals. One Administrator underscored the importance of asking for feedback on social

needs in the population and the effectiveness of referral interventions from those working directly with patients,

“when I started doing this, I’ve been kind of building the plane as I’ve been flying it. I’m a nurse. I’m doing the best I can to learn and guide and build this... the smartest thing I did was actually listen to our community health workers, listen to people who are closest to the issues, and I believed what they told me (P13, Director of Community Outreach, Women’s & Children’s).

Finally, participants in Oncology (P26, Director of Oncology Services and Tumor Site teams) and Community Health (P7, Vice President) described generating reports containing demographic and outcome data to measure the impact of social care interventions, and when necessary, sharing these reports with national accreditation organizations, such as in Oncology, where reports are generated by the Nursing Coordinating Action Team from discrete social risk factor data and shared with the department’s accrediting body, the American College of Surgeons Commission on Cancer, twice a year.

Respondents in areas without access to such reports wanted access to aggregate data to understand the needs of their patient population and to measure the impact of social care interventions, as one Population Health Social Support Specialist explained,

“I also wonder like, what I’m helping impact and also like, if the patients are following through on those impacts or if there is more that I could be doing to meet their needs, rather than just what I assume is happening” (P1, Social Support Specialist, Population Health).

Additionally, aggregated data were desired by administrators for planning purposes. For example, one Family Medicine administrator described using aggregated data about a local

patient population to estimate the need for social care services in a community where a new clinic was to be built. This administrator suggested that data like the size of the Medicaid population and the walkability of the clinic served to keep the obstacles faced by patients “*always fresh in our mind*” (P20, Administrator, Family Medicine). Social risk data was also desired to aid in planning for provider training and education related to providing referrals to local resources, as one clinical education supervisor explained, “*if I had a dashboard that said, ‘we have this many people with this problem,’ us as educators could be like, ‘Whoa, okay. We need to focus on some education for our nurses so they can educate the patient’*” (P16, Clinical Education Supervisor, ER & ICU).

Using social risk data to build patient-provider relationships

Social Care Experts in Community Health (1/5) and Primary Care (1/2); a Healthcare Provider in Primary Care (1/1); and Administrators in Community Health (3/6), Primary Care (5/7), and Specialty Care (1/8) described the importance of building relationships with patients to facilitate the sharing of information about social needs. Screening for patients’ social needs was seen as a balance between capturing data that would aid clinicians and reducing potential violations of patients’ privacy, as one Family Medicine office manager described, “*Without violating a patient’s privacy in a way, you will get patients in here who are very prideful, and I can appreciate that... the more information we give our providers the better*” (P28).

Respondents suggested that by working on building trusting relationships, patients may feel more comfortable sharing information about their social needs and some participants described increased openness from patients following establishing rapport with providers. For example, one Population Health social support specialist explained that when patients have trusting relationships with providers, they may occasionally “spill” information about their social needs

(P1). In another example of the benefits of developing trust relationships with patients, one Peer Support Services team manager described how trust built with patients allowed for engagement with local police to provide transportation to a variety of local services, including to job interviews and the pharmacy,

“We have our police officers; when they’ve gone to a house and many people have surprised us and they say, “We’ll get in the back of your car if you can get us over to [the recovery center] ...” sometimes the police officers have taken them for a job interview... that just goes along to show the link of trust that we start building” (P6).

Respondents described facilitators of relationship building with patients, including conversing with patients, prioritizing relationship-building in the organizational culture, and having enough time to establish the relationship. In-person discussions were seen as favorable for relationship building due to offering the ability to gauge patients’ comfort level and build rapport. One Population Health social support specialist described the importance of face-to-face interactions to build patient-provider rapport and trust, *“a lot of times they will spill more if it is face-to-face, they’re not as trusting over the phone, but once you have that rapport built, then like the follow-up calls can be over the phone”* (P1).

Similarly, participants used face-to-face interactions to share small talk and to get to know patients before asking questions about potentially sensitive social risk factors, as one Home Health, Hospice & Palliative Care manager described how relationship-building was an important precursor to social risk screening,

“[Social Workers] first establish a relationship with the patient... more small talk at the beginning of their visit, getting to know their patient. And then throughout the visit then

we'll just start to ask questions about support. Do you have support in your family? How are you doing with transportation?" (P23, Clinic Manager).

Similarly, the way patients interact with different types of provider and staff roles in the physical clinical environment may contribute to patients' comfort when discussing social needs. One Family Medicine clinic manager described how patients may decide which type of provider or staff member to discuss social needs with to maximize comfort and privacy,

"I think at the front desk those are awkward conversations to have if there's anybody else around that could possibly hear them... I think the rooming person, again, sometimes, you know, there's more of a fear of, 'oh I'm going to see you at the grocery store...' and they're embarrassed to tell them things like that" (P24).

In rural settings, patients may have existing relationships with providers that are formed in the community outside of the clinic. Such relationships may be quite long-standing, as this administrator in a rural Family Medicine clinic explained, *"I have a couple of providers that have practiced for 30-some years... they're now delivering the babies of the grandparents... it's three generations that they've taken care of. So small town is definitely different than larger towns" (P25).* As a result, providers may gain information about patients' social needs from community encounters, such as at religious gatherings, *"or just by knowing them" (P25).*

Participants in Women's and Children's (P13, Director of Community Outreach), Pediatrics (P11, Pediatrician), and the Pharmacy Medication Assistance Program (P30, Supervisor) described using social risk factor data for relationship building, as well as to make conversations about screening and social care more comfortable for patients. In instances in which a social care expert is not able to immediately consult with patients, social risk factor data collected during the screening was used to initiate a conversation about social needs without requiring a patient to

regurgitate potentially sensitive information. In Women's and Children's, one respondent explains how previously completed screening tools are used to build rapport and make conversations feel "less like a cold call,"

"if the woman has marked that she is interested and needs things when the navigator walks in the room, it's 'Hey, I'm here in response to something that you already told me' versus 'I'm here to ask you a million questions.' So we've found that people seem to be more responsive that way, as we're here because you already indicated a need" (P13, Director of Community Outreach, Women's and Children's).

Similarly, some clinicians use virtual sticky notes in the EHR to keep pieces of social information from conversations with patients at hand for relationship-building, such as reminders about new jobs, housing, or vacations,

"it's all social stuff, like mom got a new job... having trouble finding daycare, we talked about this. They're just reminders for me that might not make it into their medical record. Whether it's pertinent or not might be up for debate, but there are questions that I, I feel like connect me to the patient more" (P11, Pediatrician).

Efforts to build relationships with patients were thought to be at the core of the health system's organizational culture and providers' practices by conveying to providers' focus on addressing patients' needs to help them thrive, as one explained,

"one of the things that we've all really worked on is service excellence and always going above and beyond what we do with every patient at every single visit... always having that, 'we're going to do whatever we need to do to make sure that you're taken care of and doing that at every single visit,' that just opens the patient up to being more warm and sharing with us when they're at the visit" (P20, Practice Manager, Family Medicine).

Conversely, in Outpatient Surgery, the short-term nature of patient engagement offered limited opportunity to build relationships with patients, and subsequently, because eligibility for surgical care in outpatient settings required select insurance coverage and arrangements for transportation and post-operative care, surgical staff did not collect or use social factor information in practice beyond verifying insurance status and patients' plans for transportation and in-home care.

2.3.3 Drawbacks to accessing and using social risk factor data: clinicians need support

Respondents described several challenges related to the access and use of social risk factor data, including the need for training regarding how to use these data to address social needs, the need for information about conducting referrals, barriers faced when using these data, the need for designated staff to perform social care work, and the potential for unintended harm to patients.

Desire for social risk factor education and training for clinicians and staff

Participants in all professional roles described the need for education and training for staff members related to the collection and use of social risk factors data, including education related to the relationship between social risk factors, health, and healthcare utilization; why screening is occurring, and about how to perform social risk factor screening and referrals.

Participants in the ER & ICU (P9, Social Support Specialist), Cardiology (P31, Ambulatory Nursing Supervisor; P35, Nurse Practitioner), Pharmacy Medication Assistance Program (P30, Administrator), and Family & Children Services (P8, RN Coordinator) specifically desired education about the relationship between social risk factors, health, and healthcare utilization. These individuals felt that explaining the impact of social risk factors on patients' health, including access to healthcare, was critical for clinicians, who may not have received such training during health professions education programs. Such education was

thought to be necessary to communicate the importance of social risk factor screening to provide care for the whole patient, and to improve compliance with treatment and to prevent disease. Furthermore, understanding how social care programs may ultimately reduce patients' use of healthcare resources was considered important, as one ER & ICU Social Support Specialist explained,

“widening your view of social determinants of health can address systematic problems to the healthcare delivery... if you've got somebody that doesn't have transportation... they're not getting follow-ups, so essentially they're just waiting until they get sick and have to call the EMS... So kind of changing that paradigm to a more, what do we need to do for this patient to reduce their use of healthcare resources?” (P9, Social Support Specialist, ER & ICU)

Finally, providing real-life anecdotes regarding how patients have been impacted by social needs was desired to communicate the importance of screening and social care work.

Additionally, respondents in Population Health (P3, RN Care Coordinator), Orthopedics/Neurology (P12, RN Case Manager), the ER & ICU (P16, Clinical Education Supervisor), Family Medicine (P28, Administrator), and Oncology (P26, Director of Oncology Services and Tumor Site Teams) desired education about the purpose of social risk factor screening at the health system. This would allow all members of the healthcare team to understand why screening is occurring and to foster team buy-in to screening. Some felt that it was important for clinicians to remember to care for *“the whole wellbeing of a person”* (P28, Administrator, Family Medicine). Furthermore, by understanding the purpose of screening, participants felt that providers and staff would also be able to answer patients' questions about why screening was occurring. Finally, respondents felt that understanding the purpose and

benefits of screening would be critical to motivate clinicians and staff to adopt screening and referrals into their workflows. One Oncology director underscored the importance of having an evidence-based tool, including having related scientific literature available, to build motivation among physicians, *“doing an evidence-based tool, again has definitely helped with - we’re a physician-led organization and having that buy-in when you can, show providers that there are evidence-based articles that support using it”* (P26, Director of Oncology Services and Tumor Site Teams).

Furthermore, clinicians and administrators desired education about *how to perform* social risk factor screening and referrals, including walking clinicians and staff through the steps related to the collection, access, and use of social risk factor data. One Cardiology nurse practitioner described the need for step-by-step training about how screening and referral workflows would operate to assuage concerns about the time burden of social care work and views that such tasks may not deliver value. Furthermore, participants advocated the need for scripts to guide the conversation during screening to help clinicians navigate uncomfortable discussions. Additionally, participants expressed the need for training to increase awareness about the availability of staff and departments with expertise related to addressing social needs. Finally, these respondents expressed the need for a multi-modal education about how to perform screening. In the Pharmacy Medication Assistance Program, one Administrator reflected on how to improve future training based on a prior experience with an education effort that took place over email, instead suggesting that training should take place in a dynamic, interactive manner, *“It was just an email that went out to everybody that said, hey this is changing and maybe some of the offices would have benefitted from one-on-one training or even a phone call or a*

teleconference that walked them through the changes and what was needed” (P30, Administrator, Pharmacy Medication Assistance Program).

Desire for information and tools to facilitate referrals to social care

In addition to education and training related to screening and social care workflows, professionals of all types suggested that clinicians may not know what to do in response to the identification of social needs during social risk factor screening, as one pediatrician explained, *“everybody gets a little apprehensive when talking about social needs and not being able to help when they flag positive” (P11, Pediatrician).* Participants suggested that clinicians’ ability to help with social needs may be constrained by the resources that they have access to and are aware of, and clinicians were thought to often not know of the full range of resources available both at the health system and in the community, as one Cardiology nurse practitioner explained, *“I just don’t even really know what resources are available. I don’t know that referring to Care Management would help... I guess I really don’t know what all they do, to be honest” (P35).* Thus, clinicians and staff may require information about local hospital and community resources which may be used to address these needs. Fast and easily accessible informational resources were highly desired, as one explained, *“there needs to be some resources available pretty quickly and pretty easy to access of what to do if I get somebody who has a major need” (P13, Administrator, Women’s & Children’s).* For example, information about the roles and departments associated with social care work within the health system, as well as lists of organizations or programs which offer transportation or access to food were desired, as one suggested, *some of the providers are aware... but I think a lot of times, our marketing here at Parkview is less than stellar, and so a lot of times they’re not even aware that [Population Health] exists” (P31, Ambulatory Nursing Supervisor, Cardiology).* Respondents stressed that

knowing how to respond to a social need requires a significant amount of information about community organizations and expressed concern about the limitations of their knowledge of local resources to offer to patients, as one Community Health administrator explained, *“it’s pretty cumbersome for people to know the landscape of all the different social service agencies that address all of the different things”* (P7, Administrator, Community Health). One explanation for this need was the realization that community social services agencies close and open at a relatively frequent pace, making it difficult to remain aware of all of the organizations in one’s community, as one social support specialist explained, *“I always wish I knew more about the community resources that are available to kind of address the social determinants of health, but they’re constantly changing and fluctuating”* (P9, Social Support Specialist, ER & ICU). A Cardiology nurse practitioner echoed this need, suggesting that informational materials would require frequent updating to keep track of currently available local resources, and as a result, it was often necessary to leverage subject matter experts who are very knowledgeable about community resources (P35).

One solution to this problem is the use of community resource referral platforms to automate certain parts of the referral workflow, including identifying relevant community social care resources. While such tools were not in use at Parkview during the study period, one Community Health administrator (P7) suggested that the use of these platforms would likely significantly reduce provider and staff burden related to providing referrals to social services agencies, especially in outpatient clinics with limited access to social workers. Similarly, recognizing the need to use informational resources about external social care resources, one Cardiology pharmacist described the need for information tools that are integrated into the EHR, as integrated tools were thought to be much easier and faster to access during patient encounters

relative to those tools which required leaving the EHR environment to enter into a separate software platform, as they explained, *“the fact that they’re not necessarily integrated into our system makes it harder to use them... it’s going to take a heck of a lot of time and it’s not going to then become something that I can use while the patient’s sitting there”* (P34, Pharmacist, Cardiology).

Barriers faced when using social risk factor data

Clinicians in Community Health (1/2) and Specialty Care (1/3), as well as Administrators in Primary (2/7) and Specialty Care (1/8), described facing barriers when attempting to use social risk factor data to assist with patients’ social needs related to local policy, following up with patients, and locating and interpreting screening data. First, participants noted that only patients with certain insurance policies, including Medicare, were eligible for referrals to Population Health, causing clinicians to have fewer referral options for those with other insurers.

Additionally, in Cardiology, one administrator described difficulty offering transportation resources to patients without nearby family members due to institutional policy requiring that a family member drive the patient home after a heart procedure. As a result, the transportation barriers faced by these patients were unable to be overcome with the existing community or insurance-provided transportation options, and subsequently, this participant struggled to solve these transportation challenges to provide patients with access to necessary procedures.

Respondents described similar challenges related to following up with patients. In Family & Children’s Services, one nurse described challenges related to contacting patients for follow-up after screening and referrals due to the transient nature of patients with the most needs, who may have limited access to a mobile phone or who may change addresses frequently and thus

require multiple attempts at follow up contact over different communication modalities, as she explained,

“a lot of our people, and this is a social determinant, is they’re transient. So, they don’t have the same phone number, they don’t live at the same address... we do make multiple attempts by calling, texting, and letter and email when available. That’s how you get a hold of most of the lower socioeconomic families, their minutes are run out but they have unlimited texting capability” (P8, Community Nurse, Family & Children Services).

Some respondents in Family & Internal Medicine (P21, Clinic Manager; P24, Clinic Manager) and Cardiology (P31, Ambulatory Nursing Supervisor; P35, Nurse Practitioner) described difficulty locating and interpreting social risk factor data in the EHR, and instead addressed social needs that are shared by patients during clinical encounters or those identified in narrative clinical notes. In Cardiology and Family & Internal Medicine, clinicians reported not collecting or accessing social risk factor data and instead relied on patients to voluntarily share any social needs that they may have. When social needs were disclosed, participants in these units described working to address them on a case-by-case basis. Furthermore, respondents in Cardiology and Family & Internal Medicine described having limited access to data about patients’ social needs in the EHR. For those in Family & Internal Medicine, access to social risk factor information required manual keyword search through prior clinical notes. In Cardiology, social risk factor data was found in the EHR on rare occasions by happenstance for some patients, rather than via routine screening on all patients.

Desire for specific staff to collect and use social risk factor data

To most effectively address patients’ social needs, Clinicians in Primary Care (1/1) and Specialty Care (1/3), as well as Administrators in Community Health (2/6) and Primary Care

(1/7), described the need for a specific staff member with expertise related to social needs to collect and use social risk factor data to leverage this individual's knowledge, to reduce the workload on clinicians, and to ensure that patients' needs are met as quickly as possible. Specifically, participants suggested that as screening and social care programs were implemented and providers saw the value of such work, there became a demand for a designated social care expert, such as a navigator or social worker, on the healthcare team, as one recalled hearing colleagues say, "*We want a navigator, we want a navigator' because they are seeing the value in the work that we're doing*" (P13, Director of Community Outreach, Women's & Children's). These respondents stressed the need for planning regarding which clinicians or staff would address any social needs that are identified by screening. In part, this was because clinicians often lack the time necessary to conduct screening and referrals, and as a result, these participants suggested that social care efforts would be more effective if someone a designated individual, especially other than the doctor or nurse, performs tasks related to the collection and use of social risk factor data. As one Community Nursing manager explained,

"if there was someone other than the provider [does] the screening, I think it will be done a little more effectively... it's a time factor there too.... I think more community health workers, working side-by-side with those providers would get that done and would get those referrals done much more effectively because they will have the time to spend with the patient to do it" (P14, Manager, Community Nursing).

Finally, one administrator stressed the importance of having a designated team member available in the clinic who could respond to needs as they are identified, rather than at a later date, to increase the likelihood that patients access and use referral resources, as this individual recalled working with an in-clinic social worker,

“she could come right in the room and talk to somebody if they had issues with getting their medicines ..., transportation, stuff like that... but they just didn’t have one at every office. So if you got somebody that has to wait three days to when she is in our office, they might not come back” (P24, Clinic Manager, Family Medicine).

Potential adverse experiences for patients during screening: concern about judgment, embarrassment, discomfort, & frustration

Social Care Experts in all clinical categories; Clinicians in Community Health (1/2) and Specialty Care (2/3), and an Administrator in Primary Care (1/5) expressed concerns about how patients may perceive social factor screening, including potentially feeling embarrassed or judged by providers. Participants expressed concern about how patients would respond to being screened for social factors, including perceiving judgment from providers based upon the disclosure of social needs, as one explained, *“I just don’t want to come across as being judgmental towards the person... the worst thing... is somehow passing judgment on someone and not realizing it”* (P3, RN Care Coordinator, Population Health). Similarly, the sharing of those social factors which patients consider sensitive was thought to be a source of embarrassment, especially if screening occurs within earshot of others in the clinical setting or if the patient believes that they may encounter the provider or staff member out in the community.

Social care experts offered strategies for reducing the potential for embarrassment and judgment during screening processes, including having discussions of social factors and considering communication styles when talking to patients. Respondents emphasized the importance of allowing time for discussion, including multiple conversations throughout building a relationship with a patient, to help make patients feel comfortable talking about social factors. Conversations were thought to help patients convey their social factors and needs with

less perception of judgment by providers, which was viewed as an advantage in clinical areas in which screening could be conducted as part of a conversation, rather than via a screening form, as one Cardiology pharmacist explained,

“A lot of people are embarrassed by their barriers and so, discussing things with them and being able to pick up on some of the things that they say and question them a little bit more about it in a non-judgmental and a little softer way” (P34, Pharmacist, Cardiology).

Finally, the participants described the role of communication styles in creating safe conditions for patients to share social factor information, including avoiding accusatory language when discussing social factors and communicating to patients that staff would work to help meet patients’ needs.

To avoid potential adverse experiences during screening, social care experts in Family & Children’s Services (P8, Community Nurse), the ER & ICU (P9, Social Support Specialist), and Population Health (P3, RN Care Coordinator) indicated that it was often necessary to explain the purpose and process of social factor screening to patients. Some of these participants described having a “shtick” (P8, Community Nurse, Family & Children’s Services) or “script... in my head” (P9, Social Support Specialist, ER & ICU) that is used to routinely explain screening to patients. Scripts included explanations of how data collected during screening would be used to help patients, including using examples of discharge planning or overcoming financial barriers to healthcare access. Another purpose of explanations was to assuage patients’ concerns about the collection of social risk data, which respondents suggested that patients may not be accustomed to discussing with clinicians relative to sharing medical information, as one explained,

“Sometimes people wonder, ‘why are you asking me about if I had a violent partner?’ They just want to know why, because... it’s not common for someone to ask you a lot of

these questions... So, I try to tell them it's for the purpose of collecting data and making sure the resources are available for the people who need them" (P3, RN Care Coordinator, Population Health).

Taking responsibility for screening and social care work

Participants described feeling different levels of responsibility for learning about and addressing patients' social needs. For respondents in Population Health (P4, RN Care Coordinator; P5, Social Support Specialist), Community Health (P7, Vice President), Outpatient Surgery (P19, Director), Family Medicine (P20, Practice Manager), and Oncology (P10, Navigation Team Manager) social need have always been the subject of their occupational role due to being social care experts or due to the division of labor in specialty clinics. The staff of the Population Health Department are primarily focused on addressing patients' social needs, as one explained, *"Pop Health is all about social determinants of health. I think that when you sign up to work for Pop Health, you are diving right into the social determinants pool"* (P4, RN Care Coordinator). In Oncology and Outpatient Surgery, social needs were thought to be the domain of Nurses and Navigators. In these units, nurses and navigators were relied upon to collect data about social risk factors and address needs, as well as communicate to Physicians about social needs if relevant to clinical care, as a Navigation Team manager shared, *"Doctors don't know that. Surgeons don't know that. We're the team at tumor board speaking up on the patient's behalf, being the voice for the patient, letting them know what those barriers may be"* (P10, Oncology).

Participants in Community Nursing (P14, Team Manager), Orthopedics/Neurology (P12, Nurse Case Manager), the ER & ICU (P16, Clinical Education Supervisor), Cardiology (P32, Inpatient Nursing Supervisor), Family & Children's Services (P8, Community Nurse) and

Pediatrics (P11, Pediatrician) accepted expanding the scope of their job practice to address patients' social needs. They described feeling that they were doing a more complete job within their role to improve patient health by addressing social needs, driven by a motivation to do more for patients following the identification of a need. For some, the scope of practice increased from solely focusing on medical needs to incorporating a more holistic picture of patient health, as one team manager explained changes following the implementation of screening, *"The day-to-day has changed because we're doing more overseeing a whole bigger picture than just the healthcare"* (P14, Team Manager, Community Nursing). Expanding one's scope of practice often occurred in response to the implementation of social needs screening and the subsequent identification of a wider range of patients' needs. As one explained, *"sometimes we're doing more of that social piece than we are nursing pieces... It has turned us into more case management social workers... as long as it's keeping people out of the Emergency Room, that's okay"* (P14, Team Manager, Community Nursing). Often, taking on the social care labor was described as difficult but worthwhile due to the potential to impact the health of patients, as one discussed, *"there are days where you don't want to be a social worker, but you are. That's all part of your job. Our job is ever evolving"* (P8, Community Nurse, Family & Children's Services).

Additionally, in Oncology (P10, Navigation Team Manager), Family Medicine & Internal Medicine (P21, Clinic Manager), Women's & Children's (P13, Director of Community Outreach), and the ICU (P9, Social Service Specialist) respondents described how dedicated workflows to engage social care experts to address patients' needs could reduce the burden on other clinicians. One Navigation Team manager explained the shift in workload from Oncology clinicians and onto the Navigation Team,

“[Navigation] work[s] alongside the offices so the offices reach out to us more so than handling it themselves, so they probably see a decreased workflow in the office because they know they can rely on our team to help them... they can handle more patients, they can have more job satisfaction, feel decreased burnout, because they have somebody on their team helping them” (P10, Navigation Team Manager, Oncology)

Similarly, having access to hospital-provided resources with a simple referral was thought to take much of the work off providers when trying to connect patients to programs and instead focus effort on identifying needs. Having a designated local infrastructure to handle connecting patients to resources was thought to be highly beneficial in instances when providers’ training related to the social determinants of health varied between roles and educational background, such as Nurses trained at the Associate and Bachelor’s levels, allowing for the transfer of responsibility (P21, Clinic Manager, Family Medicine & Internal Medicine).

Conversely, in Oncology (P10, Navigation Team Manager), Outpatient Surgery (P19, Director), Cardiology (P31, Ambulatory Nursing Supervisor), and Family & Internal Medicine (P25, Manager), responsibility for patients’ social needs was not considered to be the duty of Physicians and was instead be delegated to other staff or social care experts. For example, Cardiologists were thought to be willing to address heart health-related needs, including medication access and diet quality, but need beyond these were considered “*‘kind of above me’ or ‘below me’*” and instead the responsibility of a primary care provider or social care expert (P31, Ambulatory Nursing Supervisor). These respondents suggested that physicians often felt that social needs were outside of their control, and potentially issues that patients needed to take ownership of.

Timing of social risk factor screening: having enough time, at the right time

Social Care Experts in Community Health (2/5) and Administrators in Community Health (4/6), Primary Care (1/7), and Specialty Care (2/8) described the importance of having enough time to conduct social risk screening, and for screening to occur at the appropriate time in the clinical encounter. Clinicians in Home Health, Hospice & Palliative Care (P23, Clinic Manager) and Cardiology (P31, Ambulatory Nursing Supervisor) described the limited time available during short-duration clinical encounters and the timing of screening within the patient-provider relationship as potential obstacles to discussing social needs with patients. As a result, respondents worked around clinical time limits by learning about patients' social needs at longer encounters. In Home Health, Hospice & Palliative Care, staff leveraged 45–60-minute home visits, which were often longer than typical clinical encounters, to develop deeper relationships with patients and to learn about their social needs, as one explained,

“we’re establishing a much better rapport with that patient because we’re spending so much time with them and they’re more likely to let on to what their needs are. Our relationship is a lot more intimate than them going into a doctor’s office” (P23, Clinic Manager).

In Cardiology, respondents described the short duration of follow-up appointments (15 minutes vs. 30-minute initial visits) as a barrier to having detailed conversations about patients' social needs and their impact on heart health and ability to comply with treatment. One Ambulatory Nursing supervisor instead suggested that patients' best opportunity to discuss social needs may occur in the initial longer consult,

“usually [patients] would be more open, especially if they’re a new patient and just establishing care here. Once they have established... the physician doesn’t get quite as

much time with them. In the interview process, it's more of just a 'hey what's up,' checking in... the first intake interview would probably be the best time for [social needs to be discussed]" (P31).

Respondents in Population Health (P2, RN Care Coordinator; P3, RN Care Coordinator), Peer Support Services (P6, Manager), Women's & Children's (P13, Director), Home Health, Hospice & Palliative Care (P22, Clinic Manager; P23, Clinic Manager), and Oncology (P26, Director of Oncology Services and Tumor Site teams) grappled with identifying the appropriate time to conduct social factors screening. For some, screening during a patients' initial visit was not considered to be ideal due to a lack of time to build a relationship with the patient, and as a result, participants expressed concern that patients may be less willing to share their social needs during screening due to uncertainties about trust in providers, as one explained, *"they don't know you and they don't know if they trust you or not... once they actually know me a little bit, then they might actually answer the questions more... freely"* (P3, RN Care Coordinator). Thus, first encounters with patients were thought to be an important time for relationship building to occur, as one manager in Peer Support Services explained, *"[our] initial conversation is just trying to get them to engage with [us]"* (P6). Participants explained that without having relationships with patients, screening may not surface all the social needs that patients may be experiencing due to concerns about embarrassment or judgment, given the uncomfortable nature of sharing sensitive information with a new person, as one explained,

"There are some women who we find out later did have a lot of needs and didn't want to talk about it at that initial visit... that's why like the relationship-building is absolutely key... if I met somebody for the first time and I was struggling with homelessness, that's not what you want to lead with in a conversation right? It's uncomfortable... if we don't

have a relationship with somebody, we might not get... the full story” (P13, Director, Women’s & Children’s).

Furthermore, the Peer Support Services team described intentionally conducting social factor screening at the first interaction with a patient because this service often engages with patients in crisis scenarios, for whom the primary priority is to overcome obstacles to get treatment. As a result, patients may later experience regret from disclosing vulnerable social factor information in a crisis scenario. In these circumstances, staff may consider this information, provide the necessary resources, and let the patient bring it up later as needed.

Others described efforts to change the timing of screening to make the sharing of social factor information more comfortable and to support patients at different stages of care. For example, in Home Health, Hospice & Palliative Care, two clinic managers described starting home visits with small talk to build rapport with patients before asking questions throughout the remainder of the encounter. In the Population Health Welcome Clinic, a RN care coordinator described experimenting with calling patients before their appointments to carry out screening in order to avoid screening during a hospital stay, or shortly afterward, when patients are overwhelmed and less willing to discuss social factors. Finally, in Oncology, where cancer diagnoses and transitions between stages of cancer treatment often left patients feeling overwhelmed and uncertain, clinicians and staff screened patients for distress and social needs at each therapeutic transition to ensure that patients are supported.

2.4 Discussion

There has been significant interest in implementing social risk screening and social care in US hospitals given the potential to prevent disease, improve the health of the patient population, and lower healthcare costs [1,5,99,100,109]. Such efforts rely on the collection and

use of social risk factor data by professionals, though there has been limited investigation into providers' perspectives on the implementation of social risk screening and on how to best make use of such data in practice [25,26,33,34,110]. Thus, there is a need for scholarship focused on provider and staff perspectives on the collection, storage, and use of social risk factor data to support healthcare delivery goals and to address patients' social needs. Such research is necessary to inform the implementation of social risk screening and social care programs, as well as the design of EHR and clinical decision support tools to facilitate clinicians' use of these data. Screening and referrals by clinicians offer promise to address patients' needs, though if social care experts are not universally available at healthcare encounters, informatics tools may be required to facilitate this extraprofessional work for those not trained as social care experts when taking on tasks related to screening and referrals.

When discussing whether clinicians and staff would like to have access to social risk factor data, respondents described the benefits and drawbacks to this data access, as well as the format of these data that would best facilitate their use. Participants suggested that social risk factor data could be used by providers to help patients' social needs via referrals, to identify barriers to healthcare access, and to measure impact and plan future social care interventions. Respondents described facilitators to overcome the challenges of the use of social risk factor data, including the need for education and training for providers regarding how to respond to social needs shared by patients, the need for information and tools to facilitate referrals, and the need for designated social care experts to collect and use social risk factor data to avoid provider burn out.

This study demonstrates that providers view social risk factor information as useful to address social needs. Many clinicians desired access to social risk factor data, which would have

formerly been the domain of social work and community organizations [104]. Respondents described numerous benefits related to using social risk factor data to connect patients to social service agencies and programs to address social needs, including the ability to increase access to healthcare resources and feeling that they were doing more for patients than they had before.

However, this work was thought by some clinicians to be outside of the professional boundary of work practice based on their limited professional training and knowledge regarding why and how to address social needs, as well as having limited time and support in one's role to do this work. Furthermore, participants described challenges related to attempting to add screening and referral tasks to their existing workflows, including limited time in current workflows, suggesting the need for providers to have support when taking on additional work outside of their professional expertise and training. These clinicians suggested that others whose professional training provided expertise related to interventions targeting patients' social needs, should take on this work. Prior work in has shown that professionals may suffer role strain when working in organizations which reduce professional autonomy by making demands on the type of work that one performs [21] and clinicians may require support when taking on social care work. Here, the expansion of clinicians' scope of practice by the managerialization of social needs may extend existing professions theory by offering a case in which a profession's jurisdiction is broadened by outside entities rather than by the efforts of professionals. This suggests an opportunity for future scholarship to understand the impact of involuntary professional jurisdiction expansion on information behaviors and work tasks for professionals.

Subsequently, while the limited available evidence has shown that investments in social work interventions have been shown to improve health outcomes and reduce healthcare costs [111], unfortunately, many healthcare organizations do not employ enough social care experts to

be available for every clinical encounter [112,113]. This study shows that clinicians may require support when performing social care tasks when designated social care experts were not available, including education and training regarding how to conduct this work and easily accessible information about local referral resources. Participants in all role categories also described the need for education related to the SDOH, the impact of social risk factors on health, and the purpose for addressing patients' social needs in healthcare settings, suggesting a crossing of the professional boundary between the practice of healthcare and social work to help all members of the healthcare team shift their perspective from addressing only acute medical needs to meeting the entire range of one's social needs [55,98]. Indeed, interprofessional collaboration to leverage the expertise of all provider and staff roles may be necessary for social care to be effective, however, this study suggests that healthcare teams must also determine who will take responsibility for screening and referral tasks to ensure that designated social care providers have sufficient training, support, tools, time, and motivation to perform this work well.

Moreover, the unique organizational environments, healthcare team makeup, and individual providers' training, workflows, and preferences may result in different distributions of screening and social care work across roles at different healthcare organizations, mirroring prior experiences of new medical technology implementation in multiple hospitals [94]. Additionally, adding tasks to clinicians' workload, especially within the EHR, may contribute to burnout, which must be avoided to maintain provider efficiency and job satisfaction [114–117]. Thus, the integration of social care tasks into the scope of practice of clinicians suggests the need to support clinicians with education, informational resources, EHR tools, and collaboration with social care experts. This study suggests a range of directions for future research, including

investigating how should responsibility for addressing patients' social needs be determined and what obligations do healthcare organizations have to offer social care?

Additionally, this study demonstrates that collecting and using social risk factor data requires clinicians and staff to create certain conditions to ensure safety for patients, including investing in the human components of the sociotechnical social care system [52], including staffing social care experts and ensuring that there is enough time during screening workflows to build relationships with patients and address their concerns. Respondents echoed prior work expressing concern about the potential for unintended consequences of social risk factor screening in healthcare settings [37], and respondents expressed concern about causing patients about judgment, embarrassment, discomfort, and frustration. Building the patient-provider relationship is essential for creating trust in providers to facilitate information sharing in healthcare settings [118–121]. These interpersonal tasks demonstrate the value of professional social care work, which respondents suggested cannot be completely replaced by computer automation, suggesting the need for continued funding of designated positions for staff members with social care expertise, whose knowledge and presence may decrease the time between the identification of a social need and the access and use of a relevant resource.

One critical example is the importance of the professional knowledge of dedicated social care experts, who respondents felt could best keep track of the dynamically changing social services agencies in the community. While digital community resource referral platforms may keep databases of such organizations, there is concern that these databases may not be updated with sufficient frequency to track real-time social care capacity in the community [52]. Furthermore, social care experts play an important role in the referral feedback loop by receiving information about the accessibility, quality, and experience of using community-based resources,

which can be shared with prospective clients at the time of referral [52]. Indeed, respondents described the efficiency by which they could receive help identifying and addressing the full extent of a patient's needs when engaging social workers and educators in the clinic, relative to the use of HIT interventions, underscoring the importance of human capital in the social care system.

Finally, prior work has demonstrated that the sensitivity and specificity of social risk factor screening instruments vary across question and context [122,123], suggesting the need for clinicians and staff to use screening tools in conjunction with discussions with patients about their needs. The importance of such conversations was demonstrated by participants, who reported benefits related to rapport building and patient comfort when discussing needs with patients rather than solely relying on screening records in the EHR.

Informatics may offer potential solutions to reduce workload and burnout associated with social care work. Community resource referral platforms are a form of health information technology (HIT) which provide directories of social services agency, electronic referrals between healthcare and social services agencies, outcome tracking, and electronic health record integration [52]. The use of such tools may facilitate social care work by non-expert clinicians and staff. Furthermore, informatics tools may be developed to highlight urgent social needs or social risk factors relevant to care to reduce clinician information seeking burden [124]. Informatics has a long legacy of implementing clinical decision support systems to support users with work within their own professional areas [125,126], and this study suggests the need for similar tools which support clinicians as they perform social care tasks outside of their primary professional expertise. However, the effectiveness of community resource referral platforms and other HIT related to social care is dependent on the quality of data provided to these systems.

Respondents suggested that discrete data captured by screening tools allows for reporting and use by decision support algorithms, at the expense of losing the nuance and detail afforded by narrative data. However, even with computable forms of data, we must be mindful of which patients are represented in datasets. Lower trust in clinicians that result from historical discrimination and exclusion may cause certain groups of patients to withhold information from clinicians [121,127–129]. Similarly, attributes of social risk factor screening implementation, including who is chosen to be screened, where screening takes place, what languages and literacy levels are screening tools offered in, how the purpose of screening is communicated to patients, and patients' expectations of support after screening, may contribute to individual patients' decisions to participate in screening. When HIT tools use patient data to inform decision-making, those patients whose data are not included may not stand to receive the potential benefits of the tool [121]. Digital tools offer many benefits when used in collaboration with social care experts, including improved documentation, fast communication between healthcare and community organizations, and access to information about local resources, though the potential for bias due to data quality and participation in screening must be considered.

2.4.1 Limitations

Several limitations of this study must be considered. First, our sample consists of clinicians and administrative staff from a single healthcare system, limiting our sample to one Midwestern region in the United States. Other regions may have distinct screening needs based on local socioeconomic and cultural contexts. Additionally, our selection of specialties for the study was focused on identifying those units and individuals who have begun to engage in efforts related to social risk screening and referrals, and as a result, this sample may not reflect the specialties and roles participating in social care work in other medical centers. However, we

anticipate that the screening and response practices may have broader generalizability to other healthcare organizations such as comprehensive cancer centers and other institutions committed to providing social care. Moreover, due to the nature of qualitative interviews, we are unable to quantitatively measure patterns related to clinicians' and staff's actual access and use of social risk factor data and instead capture respondents' experiences and perspectives regarding performing this work. Finally, because this study is focused on the perspectives of clinicians, patients' preferences are absent, though the qualitative study of patients' perspectives and experiences with screening are included in Chapter 3.

2.5 Conclusion

Social risk screening and social care interventions create opportunities for clinicians to expand their professional jurisdiction to begin to intervene on patients' social needs, creating opportunities to improve health, prevent disease, and lower healthcare costs. However, this work requires clinicians to take on tasks that may require resources and knowledge outside of one's professional discipline, suggesting that practitioners may require support in the form of information about available referral resources and dedicated staffing to bear the responsibility of healthcare interventions on social needs. This study extends professions theory by offering a case in which the scope of practice of clinical professionals is broadened by outside entities via the managerialization of social needs, rather than by these professionals seeking to expand their own jurisdiction. Future implementation of social risk factor screening and response requires consideration regarding who can collect, access, and use these data, who has the responsibility to assist patients promptly, and how this work can be distributed to reduce burnout to ensure that such interventions make a meaningful impact on patients' lives.

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2.7 Appendix A. Stakeholder Meeting Agenda

Parkview Health SDOH Stakeholder Meeting Agenda

Meeting Goals:

- Learn the current status of SDOH screening underway, including relevant tools in use, at Parkview.
- Allow the UM research team to become acquainted with the network of providers who do this work.

Agenda:

- Share SDOH screening tools brought in by stakeholders
- Discuss SDOH screening roles and workflows at different sites
- Identify sites for observation
- Identify providers for initial interviews

Logistics

- Recording/notetaking
- Distribute sheets with these questions as prompts for attendees
- Time management – determine in advance how much each person can talk, saving time at the end for group discussion
- Slides (definition, agenda)
- Attendance sheet

Prompts:

- Introduction: SDOH definition, formal and informal processes, who's involved, project motivation
- What is your clinical area?
- What is your patient population like?
- Do you gather SDOH data?
- How do you gather SDOH data?
 - Do you use a particular instrument? Can you show it to us?
 - Who does the work of gathering SDOH data?
 - How often is SDOH data gathered?
 - Where do data go afterwards?
- Group discussion:
 - What have you learned about how best to gather SDOH data based on your experience so far?
 - So far we have been talking about SDOH as they pertain to individual patients. Do you currently gather and/or use data about communities in which patients live? If so, how do you gather these data?
 - How does your clinic find out about resources available in the community for patients?
 - If our research team were to observe SDOH gathering in your setting, what would we see in your facility that we would not see anywhere else in Parkview?
 - Our next steps: how findings will be used, deliverables

2.8 Appendix B. Stakeholder Meeting Participant Handout

Parkview Health – University of Michigan Collaboration Stakeholder Meeting
November 1, 2019

Social Determinants of Health (SDOH): The conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries and communities.¹

Show and Tell! (~3.5 minutes each)

- Introduce yourself
- What is your clinical area?
- What is your patient population like?
- Do you gather SDOH data?
- How do you gather SDOH data?
 - Do you use a particular instrument? Can you show it to us?
 - Who does the work of gathering SDOH data?
 - How often is SDOH data gathered?
 - Where do data go afterwards?

¹ WHO | About social determinants of health. http://www.who.int/social_determinants/sdh_definition/en/ (accessed 29 Jul 2018).

2.9 Appendix C. Provider Semi-Structured Interview Guide

Iott Dissertation Semi-Structured Interview Guide – Parkview Health

Objectives

- Document providers perceptions about existing SDOH screening tools
- Understand how SDOH data is used (or not used) in practice
- Identify variation in SDOH screening/use by provider type or specialty
- Inform the creation of a set of recommended SDOH screening questions, including how they should vary based on clinical setting

[Note: in keeping with the principles of qualitative research, these questions may evolve through the course of this research. However, this interview guide shows the possible range of questions to be asked.]

Introductory Statement: Before we start, I'd like to thank you for agreeing to participate in this study. Your participation will contribute to better understanding of how to improve SDOH screening and SDOH data use at Parkview. We will be recording this conversation so that our conversation may be transcribed and analyzed later.

For the purposes of this project, social determinants of health (SDOH) are “the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries.” Examples of social determinants of health include education, financial strain, social and community networks, and living and working conditions.

PART A: Screening for SDOH (XX min)

1) Walk me through your work at this clinic yesterday. What did you do in the morning? Afternoon? (if applicable) Evening?

Probes (ask only if not covered already):

- a) What were the characteristics of the patients you saw?
- b) What types of clinical issues did you address?
- c) Were you involved in gathering, recording, or using SDOH information about patients?
- d) How typical was your work yesterday?
 - a. If not typical, how did yesterday differ from a typical day in your clinic?

[N.B. Need to account for the fact that not all elicitation of SDOH may be formally called “screening.” We need to understand how screening fits into an ecosystem of addressing SDOH.]

2) Tell me about the last time you were involved with asking a patient about the social determinants of health that affect them.

Probes (ask only if not covered already):

- a) What triggered you asking about the patient’s experiences of the SDOH?
- b) What did you say to the patient?
- c) Did you use any tools to ask questions and record the answers?
 - i) *If yes, please describe the tool.*
- d) Did the patient screen reveal any specific social need in response to the questions?
If yes, what happened after they revealed this social need?
If no, how did this interaction with the patient end?
- e) *If yes, what did the patient say or do after revealing this social need to you?*
- f) Did you document a SDOH need anywhere in the EHR?
If yes, did you document the SDOH need as a narrative note or in a discrete data field?
Did you use a flowsheet to document this SDOH need?

3) (If not already covered) Tell me about a recent experience in which a patient screened positive for one or more social need.

Probes (ask only if not covered already):

- a) Who was involved in the screening?
- b) What was the need?
- c) How did you personally respond to the need that was revealed?
- d) What happened after they revealed this social need?
- e) What did the patient say or do after revealing this social need to you?

4) (If not already covered) You have mentioned XXX tools that you have used in your work.

(Or, if they did not mention any tools) Have you ever used a tool or instrument to collect or record SDOH among patients? If so, please tell me about all of the tools you have used.

(for each tool named, ask)

- a) When did you start using this tool? Who introduced it?
- b) To the best of your knowledge, who designed this tool?
- c) What do you think works well about using this tool to screen for SDOH?
- d) What about this tool does not work well for screening for SDOH?

- e) Are there any questions on this tool that you find particularly useful? Why?
- f) Are there any questions that you find to be not useful? Why?
- g) Is there anything you wish this tool asked about anything that is not currently included?
 - i) What makes you wish this was asked?
- h) If you could change the wording of one of the questions on this tool, how would you change it? What makes you want this change?
- i) How often do you think these SDOH data should be collected from your patients? Why?
- j) Do you ever get reports about SDOH in your patient population?
- k) Are you ever asked to provide reports about SDOH in your patient population?
 - i) If yes, how do you collect/capture these data?
 - ii) If yes, to whom do you provide reports?

5) Has SDOH screening affected the work in your clinic? If so, how?

Probes (ask only if not covered already):

- a) Did your work change at all as a result of the introduction of SDOH screening? If so, how?
- b) In your opinion, did the work of any of your colleagues at the clinic change at all as a result of the introduction of SDOH screening? If so, how?
- c) Has the workflow in your clinic changed? If so, how?

6) Parkview Health System is considering expanding SDOH screening across more of its healthcare sites. What could we do to make the process of introducing SDOH screening better for people who do this in the future?

PART B: Using SDOH data in practice (XX min)

7) Tell me about a time in which you used SDOH data to help a patient in your practice.

Probes (ask only if not covered already):

- a) How did you find out about the social need?
- b) How did you help them?
 - i) What information did you use to help them?
- c) How did SDOH screening tools or EHR systems help you, or not help you, in the process?
- d) What information or other resources do you wish you had had?

8) Right now, walk me through all of the types of information about patient social needs that you can access in your work.

Probes (ask only if not covered already):

- a) What information do you have access to?

- b) Where is it located?
- c) When and how do you find out about it?
- d) How is it presented to you?
- e) For what percent of your patients do you think you look at that information at least once/year?
 - i) Amongst these patients, on average, how many times per year do you look at that information?

9) Parkview is exploring ways to present SDOH data to clinicians so that they can use it to provide better patient care. Do you think that SDOH data can help you to provide better patient care? Why or why not?

- a) [If yes] What do you think could be done to make the data easier for clinicians to access and use?

10) Sometimes patients have difficulty in paying for prescribed medications. Are you aware of any time this has happened for one of your patients? If yes, tell me about it. [If no, imagine a time where that might be the case.]

Probes (ask only if not covered already):

- a) How did you find out that they couldn't pay for the medications? (e.g. did you ask them?)
 - i) Probe: For how many of your patients do you yourself ask about the cost of care? How do you ask about it?
 - ii) Probe: If you wanted to look up how much a medication would cost out-of-pocket for a patient, how would you get this information?
- b) In the case of that patient you mentioned, how did you respond to discovering that cost would be a problem for them? For instance, did you change the medication or refer for some kind of prescription assistance?
 - i) If you changed the medication, how did you decide to what else to prescribe?
- c) Do you think there was an impact on the patient's health? If so, what was the impact?
- d) What percentage of your patient panel do you think has difficulty affording prescription medications?

11) If you could wave a magic wand to give you information you wish you had on hand to tell you about cost of care, how would you want that information presented?

Probes:

- a) How would you interact with it?

- b) When would you interact with it?
- c) Would patients play a role in using it? If so, how?
- d) Would it help you in your work? If so, how?
- e) *If not discussed*, would technology be helpful to provide information about cost of care?

12) Is there anything else that we did not discuss that you would like to add?

Thank you for participating in our study. Your responses will be valuable in improving SDOH screening at Parkview!

Demographic Survey

1. What is your birth month? _____ What is your birth year? _____

2. What is your gender?

- Woman
- Man
- Non-binary
- Prefer not to disclose
- Prefer to self-describe

If you prefer to self-describe, please elaborate here: _____

3. What is your race? (Check all that apply)

- Black or African American
- White
- American Indian or Alaskan Native
- Asian
- Native Hawaiian or Pacific Islander
- Other _____

4. Are you Spanish or Hispanic or Latino?

- Yes
- No

5. Are you of Arab Descent?

- Yes
- No

6. What is your current employment activity?

- Nurse
- Medical Assistant
- Physician
- Advanced Practice Provider (e.g. Nurse Practitioner, Physician Assistant)
- Other: _____

7. In what clinic do you work? _____

8. For how many years have you been practicing in your clinical career? _____
9. For how many years have you been practicing at Parkview? _____

THANK YOU!

Chapter 3 Patients' Perspectives on Social Risk Screening in Healthcare Settings: A Qualitative Study

3.1 Introduction

While there is an emerging literature studying the implementation of social risk screening to learn about the social determinants of health (SDOH) that impact patients' lives in healthcare settings, it is primarily focused on providers and screening tools [1,2]. While social needs are increasingly medicalized, or brought under the dominion of the medical establishment [3], by screening and social care programs, there has been comparatively little investigation of patients' perspectives on social risk screening [4], including attitudes towards being asked about social needs and the long-term storage of social risk factor data in the medical record. Patients and providers may view social risk factor data as sensitive [5,6], suggesting the need to understand how social risk screening affects patient-provider relationships and communication. Disclosure of social needs through patient-provider dialogue may be limited, as physicians may not be able to recognize patients' needs [7], and patients may not wish to disclose social or financial issues [8,9]. Moreover, clinicians may skip sensitive screening questions [10] and patients may answer questions differently depending on how questions are asked and by whom [11]. How screening is conducted may impact patients' responses and willingness to participate. For example, in one study of patients who were given the opportunity to self-complete a screening form to reduce stigmatization, providers often instead asked the screening questions directly intending to save time, potentially affecting patient responses [12]. Similarly, different specialty and geographic areas may have unique screening needs and implementation processes. Thus, the tailoring of

social risk screening programs to the needs and preferences of patients may facilitate the disclosure of social needs to providers and staff.

Prior research has identified a range of concerns expressed by patients about disclosing social needs to healthcare providers and staff, including fear of stigma or discrimination from providers, uncertainty that social needs will be addressed by healthcare providers, worry about legal repercussions (e.g. immigration status, child protective services), and limited time during clinical appointments to fully explain social circumstances [13]. As social needs are medicalized, providers may become aware of sensitive aspects of patients' lives by accessing patients' social risk factor data, which may become the basis of stigmatization and bias by providers [14–16]. Screening programs must be designed to be inclusive, as certain vulnerable patient populations, including immigrants and those with limited English language proficiency, may be more likely to be lost to follow-up for support [17]. Additionally, prior work has shown that patients' concern about the security and privacy of health information is associated with the withholding of health information from providers [18]. The potential for data about social needs to be sensitive suggests that strong privacy protections are required for social risk screening and documentation to avoid breaches of these data, a possible unintended consequence of medicalization [19,20]. Determining how to safely store and access patients' social risk factor data in the electronic health record (EHR) represents an opportunity for future work, as current efforts to classify sensitive patient data do not include all of the different types of social risk factors that may be captured during screening [21].

Furthermore, patients may have concerns about who can access social risk factor data after it has been collected during screening. Patients' trust in their providers' practices of ensuring confidentiality have been found to be significantly associated with whether patients had

ever withheld information from their doctor [22]. Similarly, patients care about which providers and staff have access to the information in their medical records [23]. Furthermore, people with highly sensitive health or social issues in their records are less likely than those without such issues to be willing to share their records [23]. Given patients' concerns about the privacy and accessibility of sensitive information in EHRs, it is important to establish trust relationships with providers and staff who may use these data. Furthermore, patients may be concerned with the intended and unintended consequences of how social risk factor data will be used by healthcare providers after it is collected or whether they will experience stigmatization and bias from providers [14–16]. Social risk screening based in patient-provider relationships may avoid some of these negative consequences [24].

Similarly, as EHR data becomes increasingly useful for population health surveillance [25] and research purposes [26], patients may have concerns about the documentation and long-term storage of social risk factor data in the EHR. These uses of EHR systems creates a range of privacy risks, and nearly half of respondents in a patient survey reported feeling very concerned about the privacy of medical records, though the majority of these patients believe that the benefits of EHRs outweigh privacy risks [27]. Prior work has shown that patients may lack knowledge about what types of information are stored in EHRs and may not expect to have information about their social needs documented [28,29]. Patients reported interest in knowing what information is contained in their medical record, knowledge of who has access to it, and notifications when that information is accessed [26,28,30]. Patients also worry about unauthorized access to social risk factor information in the EHR [29].

Patient concerns may also extend beyond those about the sharing or recording of social risk factor information to how such information may be used. To facilitate the delivery of social

care for patients who have identified social needs, providers may refer patients to social services agencies in the community (e.g. via digital platforms such as Aunt Bertha, Healthify) [31]. Such external referrals may involve the transfer of social risk factor information, expanding the number of entities and users with these data. Additionally, the transfer of information about patients' social needs information involves relying on the security and privacy protections put in place by these organizations, which may vary [32].

Similarly, while the Health Insurance Portability and Accountability Act (HIPAA) Privacy and Security Rules provide privacy protections for individually identifiable protected health information (PHI) [33,34], there is concern that the 18 identifiers included in the current definition of PHI may not sufficiently cover the wide range of types of social risk factor data [35–37]. This is an important concern, as information about patients' social needs are documented in the EHR with increasing frequency [35–37], and the long-term storage of social risk factor data in the EHR creates opportunities for these data to be vulnerable to data breaches, which may compromise patient privacy [38,39].

The limited patient-focused literature about the capture and use of social risk factor data suggests the need for exploratory research to understand patients' perceptions of social need disclosure and data use. Using interviews with patients, I will characterize patients' experience of social risk screening, attitudes towards being asked to disclose information about their social needs, attitudes towards the documentation of social risk factor data, and expectations for clinicians to ask about and respond to their social needs. By understanding patients' experiences and perceptions about social risk screening, I will inform the implementation of patient-centered social risk screening and response programs in healthcare settings.

3.2 Theoretical Framework: Medicalization Theory

Medicalization is the sociocultural process by which social problems come under the influence and dominion of medicine [3,40]. Medicalization enables social control over social problems, groups and individuals via medical knowledge, practice, practitioners [3,41–43]. Social control via medicalization can come about in different ways [3,44]. For example, new technologies and medical interventions can be used to instigate social control of patients, such as the use of psychoactive medication to control “deviant” psychological behavior [44]. Also medical practitioners may surveil and lay claim to social behaviors, such as the surveillance of a wide range of pre and postnatal behaviors of women by obstetrics [3,45–47].

The social control of medicalization may occur at three levels: conceptual (in which medical vocabulary is used to define a social problem), institutional (in which an organization uses a medical treatment to address a social problem), and interactional (in which a medical provider may use medical treatment to address a social problem) [3,48]. The definitional component of medicalization has been described as particularly important in the context of medical social control due to labeling and surveillance of deviant behaviors, allowing them to fall under the purview of healthcare providers [3,48]. Similarly, at the institutional level, the medical establishment historically has claimed jurisdiction over the ability to label social behaviors as illness regardless of its ability to provide treatment [49,50]. The labeling of illness by the medical profession is thought to take place in four primary ways: 1) by expanding what is relevant to the practice of medicine to include a wider range of factors, such as physicians’ interventions on patients’ behaviors; 2) by maintaining control over certain skills and procedures, including prescribing medication; 3) by holding exclusive privilege to the treatment of bodies, such as by normalizing the medical supervision of childbirth; and 4) by the use of medical

evidence and rhetoric to advance any cause in society, such as justifying an antismoking policy due to health reasons [50]. The medical profession may use these techniques to exert social control both in the lives of individual patients as well as over areas of social life.

Despite medicalization expanding the domain and control of medicine over more aspects of individual and social life, the medical establishment may not have the expertise to properly address all the conditions which it claims jurisdiction over via medicalization. Indeed, prior work has described physicians' difficulty using a medical framework to engage with the social causes of patients' illnesses, resulting in efforts by providers to steer discussions back to medical problems or to offer individual interventions to social issues [51–53]. Additionally, through medicalization, societal issues may be individualized and decontextualized, shifting the responsibility for macro-level social issues onto individual patients [3]. Finally, because medicine may be assumed to have moral neutrality, medicalization can make the operation of power or particular interests less visible [3].

Numerous phenomena have been medicalized, including aging, alcoholism, childbirth, abortion, obesity, and gender [3]. For example, given the relevance of lifestyle factors to the onset of heart disease, physicians often make recommendations about healthy behaviors for patients to prevent heart disease, such as eating doctor-specified diets or meeting certain physical activity goals, potentially representing social control exerted by providers over their patients [50]. Another example of medicalization is “disease mongering,” in which pharmaceutical companies attempt to convince patients that they have an illness that requires a therapeutic product that may be sold to expand the potential market for such treatment, such as in the case of restless legs syndrome [54,55].

Healthcare organizations are starting to expand intervention efforts to address patients' social needs under population health management programs [56]. Social risk screening in clinical settings may be a step toward medicalizing social determinants of health through the routine surveillance of such needs. By conducting screening to identify social needs and offering social care referrals, healthcare organizations may begin to take responsibility for patient social needs, medicalizing them in the process, causing unintended harm [57].

3.3 Research Questions

Here I summarize the issues discussed above in the introduction and theory section to identify the research questions examined in this study. Screening programs may create expectations for patients to share information about their social risk factors to receive assistance with social needs during screening. This presents a concern because providers lack proper training, potentially leaving some clinicians to be ill-prepared to discuss sensitive social needs [58–63]. In addition to potentially exposing patients to distress or stigma during screening, the collection of these data may create legal consequences, such as reporting unstable housing to child welfare agencies [64]. Thus, patients may have numerous reasons to withhold important information from their providers, including lack of trust, fear of stigmatization or discrimination, or having had a prior negative experience seeking healthcare [22]. These concerns may also apply to the documentation of social needs in the EHR, which may be visible indefinitely to a wide range of providers, creating the potential for bias or stigmatization and suggesting the need for patient consent before collecting and sharing these data [64]. Somewhat differently, without universal social risk screening, patients may be screened based on appearance or apparent social status, which may reinforce prejudicial assumptions and stereotypes [57]. Screening programs may also create expectations for patients to get help with social needs from their provider or

healthcare organization, rather than from other community organizations, and pressure from providers to use referral resources may constrain patients' freedom to choose where to seek social assistance. Finally, the potential medicalization of social needs risks individualizing larger social determinants of health issues that would be better addressed through large scale social policy rather than interventions focused on individual patients via health care settings. In addition, medicalization of social needs may subject individual patients to increased surveillance and social control via health care providers and systems; control that may not be desired, and thus may be resisted, by patients.

Specific research questions addressed by this study:

1. As social needs are medicalized, what are patients' attitudes towards sharing information about their social needs?
2. Subsequently, what are patients' attitudes towards the documentation of information about their social risk factors in the EHR?
3. What are patients' expectations for clinicians to ask about and respond to their social risk factors?

3.4 Methods

3.4.1 Setting and Participants

We recruited patients from Parkview Health (Parkview), a nonprofit hospital system in Fort Wayne, Indiana. The Parkview system serves over 900,000 patients in Northeast Indiana and Northwest Ohio and includes 700 physicians, 100 clinics, and nine hospitals. The sampling strategy captured patients from settings in which social risk screening is occurring, including, primary care, specialty care, and home nursing. We identified potential interviewees from patient medical records to create a diverse sample of participants in terms of gender, race, and economic

status. We contacted each patient's provider to obtain permission to contact the patient by phone to invite them to participate. A Parkview researcher conducted recruitment by calling relevant patients, with follow-up as needed. Of 75 patients called, 26 agreed to be interviewed (34.7%) and 18 completed an interview (24%). Five patients (6.7%) of patients who agreed to complete an interview did not answer the phone when called for the interview and three patients (4%) who had initially agreed changed their mind when called for the interview. Of the 49 patients (65.3%) who were called and did not agree to an interview, three (4%) had a language barrier that was not identified in the chart, two (2.7%) had disconnected telephones, one (1.3%) was too ill to participate, 17 (22.7%) declined, and 26 (34.7%) had messages left for them to return the call. Participants were compensated \$25 for participating in this study.

3.4.2 Data Collection

An interview guide was collaboratively developed by the research team, including input from Parkview collaborators. The interview guide included open-ended questions and verbal preference ranking tasks. Respondents were asked to verbally complete a brief demographic survey at the beginning of the interview. The interview guide was pilot tested with a doctoral student participant and revised to ensure feasibility and clarity. Semi-structured telephone interviews were conducted in August-September 2020. Telephone interviews facilitated patient participation while minimizing safety risks during the COVID-19 pandemic. A Parkview researcher called interviewees and completed the informed process before connecting BI and another University of Michigan researcher to conduct the interviews. Patients were asked to verbally complete a brief demographic survey before the start of the interview. A Parkview researcher remained on each interview call to answer questions and offer resources in response to any social needs disclosed by the patient. Interviews typically lasted one hour. Interviews were

conducted until data saturation was reached, as indicated by the confirmation of themes raised in early interviews [65]. Interviews were audio-recorded and transcribed by a professional transcriptionist. BI verified all interview transcripts before analysis.

3.4.3 Data Analysis

A codebook was iteratively developed by all members of the research team. Qualitative coding was conducted in three cycles [66]. In the first cycle, structural, open, and in vivo codes were applied [66]. Intercoder agreement was calculated between BI and a Parkview researcher using Cohen's kappa ($Kappa=0.70$, indicating substantial agreement). In the second cycle of coding, focused coding was used to develop themes. Finally, a third cycle of coding used medicalization theory to deductively map codes to theory.

3.5 Results

3.5.1 Characteristics of Participants

Eighteen respondents were interviewed. The average age of participants was 52 years (range 24-81) (Table 1). Most respondents identified as female (61%), while 39% identified as male. The most frequently represented racial groups included non-Hispanic White (39%) and Black or African American (33%). Participants came from a variety of educational backgrounds, with four had received a Bachelor's degree or higher (39%), eight had a high-school education or less (44%), and six had either received an Associate's degree, attended trade school, or attended college without receiving a degree (33%).

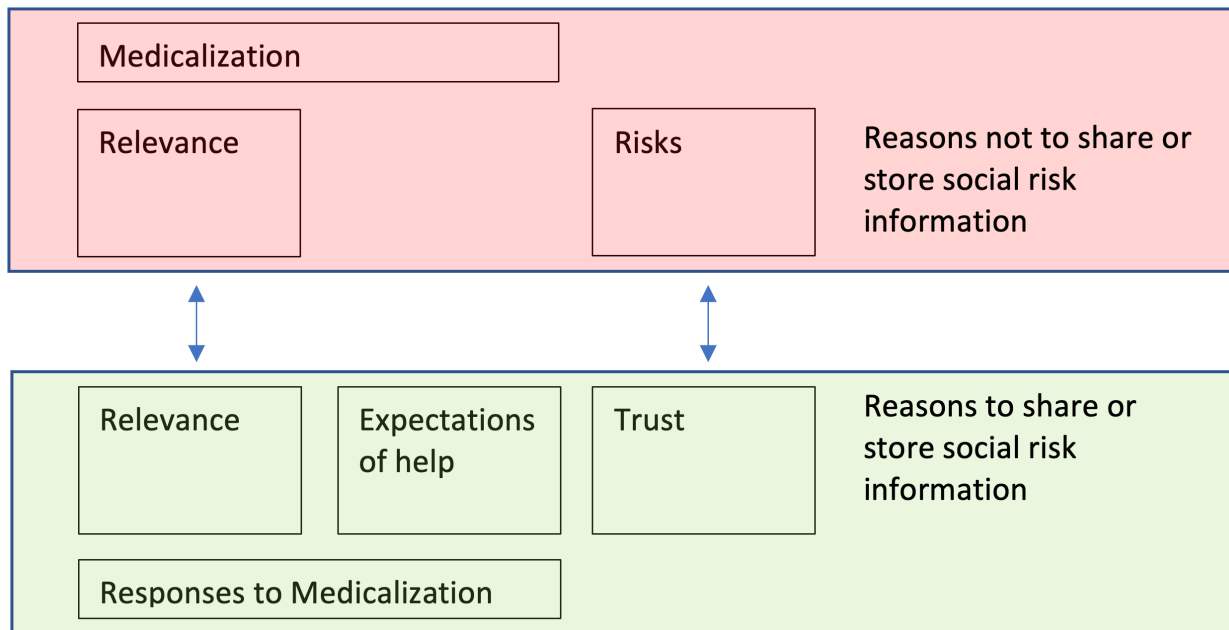
Table 3.1 Characteristics of study participants (n=18)

Characteristics	Number	Percentage
Gender		
Male	7	39
Female	11	61
Age		
Mean/median	52.4/49.5	-
Range	24-81	-
Race		
White (non-Hispanic)	7	38.9
Black or African American	6	33.4
White (Hispanic)	3	16.7
Multi-racial (unspecified)	1	5.5
Asian	1	5.5
Education		
High school or less (no diploma)	2	11
High school graduate or GED	6	33.4
Trade school	1	5.5
Some college	2	12.2
Associate's degree	3	16.7
Bachelor's degree	3	16.7
Doctoral degree	1	5.5

3.5.2 Patients' attitudes towards the sharing, storage, and use of information about their social risk factors

Respondents surfaced four themes related to their attitudes towards the sharing and storage of information about their social factors. First, participants made judgments about the relevance of information about their social factors to their health and healthcare. This was shaped by medicalization because patients had to make decisions about whether to share information about their social needs based on perceptions of responsibility and the relevancy of social needs to healthcare delivery. Second, respondents described expectations related to the experience of social risk screening and response. Third, participants discussed the role of the patient-provider relationship as a facilitator of sharing social risk information during screening. Finally, respondents described perceived risks of sharing social risk information with healthcare providers related to medicalization, including patients desire to protect themselves from potential harm or social control caused by the misuse of their sensitive social risk information

Figure 3.1 Barriers and facilitators of sharing social risk information during screening



3.5.3 Reasons not to disclose: Relevance. Is information about social factors relevant to the patient's health or healthcare?

When considering discussing social factors with providers, respondents considered the relevance of social risk information to their providers (Figure 1). While there have been many attempts to define relevance, especially in the field of information science [67–71], Harter's conception of "psychological relevance," or "bearing on the matter at hand" is used here [71]. Psychological relevance considers an individual's judgments about relevance (called "relevance judgments"), including considered the individual's context, or "assumptions about the world at any given time," which here may be a patient's view of their provider, the provider's use of social risk information, or the bearing of social risk information to the clinical visit [71].

Judgments of the relevance of social risk information

Assessments of relevance included considering whether social factors were related to the patient's own health, such as explaining the origins of a physical or mental health condition. Additionally, participants considered whether a given social risk was related to their healthcare, for example, whether a social need was relevant to the treatment of the physical or mental concern motivating a particular clinical encounter. For some respondents, certain social factors were not considered to be relevant to a provider or healthcare organization (e.g. believing that accessing food is the patient's responsibility, rather than the providers' responsibility).

Relevance to the delivery of healthcare

Certain social factors, including literacy and access to transportation, were considered relevant to the delivery of healthcare. Medical information was thought to be particularly difficult to understand without assistance, especially when patients were ill, and as a result,

literacy was thought to be an important part of understanding steps necessary for compliance with prescribed treatment, including understanding prescriptions and medical records. Information about patients' access to transportation was viewed by many participants as critically important to share with providers due to its relationship to the ability to access healthcare and medications. Respondents viewed transportation as especially relevant for patients who may rely on others to travel to healthcare appointments, including the elderly and those with mobility challenges. Some participants particularly felt comfortable sharing transportation needs because their doctor may have resources from insurers or the hospital to address these needs, especially related to gaining transportation to healthcare appointments.

Numerous participants described the importance of sharing information about transportation barriers in instances in which a lack of transportation prevented the patient from getting to a healthcare appointment (no-shows). The consequences of no-shows significantly affect patients without transportation. In addition to missing clinical appointments, no-shows may cause physicians to drop patients from their practice following numerous no-shows, further reducing access to healthcare. Furthermore, patients may experience financial penalties due to missing appointments, including fees or copays due to absenteeism. As a result, participants felt that it was important to communicate transportation barriers to receive support and avoid the consequences of no-shows.

Here, patients' decisions of the relevance of their social needs focused on those needs most relevant to their access to healthcare, highlighting the importance of attention to and awareness of those resources most relevant to ensuring access to healthcare. This represents a distinction from other important social needs which may be medicalized but less relevant to ensuring healthcare access.

Relevance to explain health

When making judgments about the relevance of certain social risk information, some respondents considered whether a social risk was related to a patient's health status and if that information may be used to explain one's health. Participants linked several social factors to one's health status, including housing, employment, social support, and intimate partner violence (IPV). One's ability to access safe and affordable housing was seen as important information to share with providers due to its relevance to an individual's health status or current life situation. Similarly, participants described the potential for one's occupation to have an impact on health, as well as the potential for one's health status to impact participation in gainful employment. For example, one respondent described the importance of telling her doctor about her occupation, as one's working conditions may potentially negatively contribute to health quality. Similarly, a respondent described the importance of discussing one's job with physicians if one's health, or medical treatments, may prevent a patient from participating fully in their job. Moreover, participants stressed the importance of social support for an individual's physical health, and as a result, all respondents were willing to share information about social support with their healthcare providers. Finally, participants stressed the importance of information about IPV experiences and whether patients felt safe at home for providers, especially given the potential danger for patients living in violent circumstances. For some, information about IPV experiences was necessary for providers to understand the context of injuries with which a patient presents, such as determining if bruising resulted from "falling down stairs" or from actually experiencing IPV. For others, information about experiences of IPV was important to share to facilitate referrals to the appropriate authorities, local shelters and organizations, or mental health providers.

Responsibility as a criterion for relevance

When discussing access to certain social factors information, including food access, social support, and literacy, participants discussed who they felt were responsible for addressing these social needs as a criterion for relevance. As social needs are brought under the dominion of medicine through the process of medicalization, healthcare providers and organizations may bear responsibility for addressing such needs, and indeed, respondents had varied views on who was responsible for social needs. For example, one respondent felt that it was patients' responsibility to find and consume healthy food and thus felt that it was not important for providers to know about food access and diet. This participant stressed that a physician could educate a patient about healthy diets, but that it was the patient's responsibility to follow such guidance. Similarly, one participant felt that it would be ideal for hospitals to provide referrals to local organizations to assist with food access needs, though he did not feel that this was necessarily the responsibility of the healthcare organization. Three participants suggested that the frequency of social risk screening should be driven by patients' desires to discuss social needs, rather than via screening at certain times or clinical encounters. These respondents felt that it was the patient's responsibility to choose to talk to a provider about their social needs, rather than being asked by providers during screening. Finally, one participant described experiencing difficulty when trying to receive clarification about paperwork in clinical settings due to providers having limited time to explain details, causing this individual to "*put the onus upon [himself]*" to figure it out later on his own (P4, 49, Male, White).

Social factors may be relevant if "bad enough"

Some respondents indicated that certain social needs would be relevant to providers if they felt that the need was sufficiently great. For example, one participant suggested that if she experienced a transient food access challenge, she may not talk about it with her doctor, instead only choosing to share such information if food access was a real problem. Another respondent described only being willing to share information about finances if she experienced “*a legit financial struggle,*” and would choose not to talk about finances if only experiencing temporary financial troubles lasting a matter of weeks (P12, 41, Female, White). Finally, three participants felt willing to talk about IPV with providers if their situation was “*bad enough*” (P15, 79, Male, White).

Irrelevant social factors

Certain social factors, including education, housing, and transportation, were seen as not relevant to healthcare providers by some participants. For example, for older respondents, information about educational attainment was viewed as not relevant due to age and lack of desire nor need for additional education. Additionally, participants also described reservations related to discussing housing needs with healthcare providers. Some respondents described feeling that, while housing was not a doctor’s business, they would be willing to share this information if absolutely necessary. Similarly, another participant described her willingness to talk about housing access only if it pertained to the nature of the clinical encounter. This respondent indicated that she would decide during screening whether to share information related to housing and would decline to answer if she felt it necessary to do so. Finally, some respondents suggested that transportation was beyond the scope of hospital-provided services and did not expect hospitals to offer transportation services themselves. Furthermore, one patient expressed concern about the time needed for providers to take additional steps to identify

transportation resources for patients beyond offering referrals, as he explained, *“I think they should be able to provide a solid referral. I think beyond that it currently just robs them of their time”* (P4, 49, Male, White). By deeming certain types of social risk data as irrelevant, patients may be resisting the medical framing of their needs, as well as the labeling of these needs as is characteristic of medicalization.

Relevance of social risk information over time: attitudes towards the storage of social risk information

Similar to discussions of the relevance of social risk information described above, respondents discussed the long-term relevance of the social factors as it pertains to the storage of such data in the EHR. Participants were asked about their attitudes towards the documentation of information about their social factors in the electronic health record (EHR). To discover respondents’ attitudes towards whether or not information about social factors should be stored in the EHR, participants were asked the following question, *“Should your data about your social factors be stored in your medical record? Yes or No.”*

Fourteen of 18 respondents felt that information about social factors should be documented in the EHR. Of these, multiple participants felt that any social risk information relevant to a patient’s health would be useful to providers and thus should be documented in the EHR for their access. Specifically, access to social risk information in the EHR was thought to give providers the ability to understand patients’ social contexts. Respondents offered two examples of how contextual data may be used: first, social risk data in the EHR could help identify patterns of social factors experienced over time that may contribute to a patient’s health; and second, such information may help providers to communicate with patients more effectively.

Additionally, participants were asked about their perspectives regarding how long medical and social risk information should be retained in the EHR. To facilitate comparison between medical and social risk information, respondents were asked about their preferred duration of storage of medical information via the following question, *“How long should clinical information, like blood pressure and medications be kept in your medical record? Why do you think that?”* To identify respondents’ preferences for the length of time for which information about social factors should be stored in the EHR, respondents were asked an open-ended question, *“How long should the social information, like your living situation and food, be kept in your medical record? Why do you think that?”* following discussing opinions about how long medical information should be kept in the EHR. This theme explores the potential harms of the medicalization of social needs related to the long-term storage of social risk data in the EHR, which may leave patients vulnerable to privacy violations or discriminatory uses of these data.

Indefinite storage of social risk information

In contrast to the nine who thought that clinical information should be stored indefinitely, five respondents preferred that information about social factors be stored in the EHR indefinitely (P2, P4, P12, P17, P18). Similar to justifications for indefinite storage of medical information, proponents of indefinite storage of social risk information cited the value of perpetual documentation of the patient’s “story,” giving doctors the ability to look back at prior data to gain context about a patient, especially in times of medical decision making. Another respondent echoed this and added that in instances in which patients transition to a new doctor, they may not tell the new provider their entire social risk factor history (P2, 55, Female, White). This suggests that indefinite documentation of these data may be a useful contextualization tool for such providers, similar to how one may relay information about their past when attending counseling.

Similarly, having longitudinal data may allow providers to “piggyback” on social risk data stored in the EHR to ask about changes to patients’ social factors in a non-judgmental tone and manner to avoid offending patients or making them uncomfortable (P18, 34, Female, African American). Finally, while participants indicated that social factors change relatively frequently over the life course compared to medical data, one respondent emphasized that older data in a record of permanently-stored longitudinal social factors may lose its relevance fairly quickly relative to the most recently-collected data (P4, 49, Male, White).

Four of the five participants who preferred the indefinite storage of social risk data highlighted the changing nature of social factors over the life course and subsequently desired the capacity to change or delete these data at the patients’ request to protect patients’ privacy given the sensitive nature of some social factors, to avoid the potential harms of medicalization. As one participant explains, *“I think it should be stored forever, but I also think that I should have the right to erase it whenever I want”* (P4, 49, Male, White). Respondents wanted their providers to ask about the social risk data stored in the EHR to discuss changes, update stored data, and provide patients with the opportunity to delete data that patients no longer wished to store. Three individuals in this group suggested that the presence of these data may prompt providers to ask patients about how they are doing, allowing for the updating of information about social factors over time. One participant likened the updating of social risk information to a medication list showing a patient’s current and past medications, as she explained,

“it should be updated... So, like when you take a medication off, it [shows] that you took the medication in the past, but it just doesn’t show that it’s a medication you’re taking at the time. So, once [a housing need is] situated, it will say that they had housing issues

prior to and this is the program that helped them, they were successful with it, and this is where they stand now” (P18, 34, Female, African American).

Situation-specific storage of medical information

Three respondents suggested that medical information should be stored in a situation-specific manner. These individuals indicated that medical information should be retained for as long as a patient is receiving care relevant to the stored information, at the healthcare organization at which the information is stored. Two participants (P10, 42, Female, Multiracial; P13, 72, Male, Black) suggested that medical information should be stored and kept up to date for as long as one is a patient at that healthcare organization, as one explained, *“as long as you’re a patient at that hospital, then it should just be in there. And just keep getting updated”* (P10, 42, Female, Multiracial). One respondent suggested that medical information was important to retain while a patient experiences a given medical condition or receives treatment, but that this information was not relevant after the end of the treatment, as he explained, *“if you don’t have the condition it’s not necessary. You ain’t getting any treatment for it”* (P6, 68, Male, African American).

Situation-specific storage of social risk information

Four respondents (P3, 78, Female, African American; P8, 81, Female, White; P11, 27, Male, Hispanic; P13, 72, Male, Black) suggested that the duration of storage of information about social factors should be determined based on situational changes, such as resolving social needs or changing healthcare providers. These respondents suggested that social risk data should be removed following the resolution of patients’ social needs, as one explained, *“when I get out of that situation, I think it should be... taken out of my record”* (P3, 78, Female, African

American). These participants felt that documentation of social factors should be retained until there was evidence that the patient received the necessary help, as one individual noted, *“if the doctors or hospitals could get you help, they should put that in the computer... whenever it is updated, they should know when your back on your feet... if you got help or what kind of help did you get”* (P11, 27, Male, Hispanic). For others, the positive resolution of a social need was the desired trigger to initiate the deletion of social risk data, as one individual described,

“If it’s got to be in the medical record, I’d say keep it until the situation is resolved. If it was up to them to follow through to make sure that it is resolved and then leave it there for a while and then remove it if everything seems good” (P8, 81, Female, White).

Finally, one participant felt that social data should be deleted when an individual is no longer the patient of a given provider or healthcare organization (P13, 72, Male, Black).

Temporary storage of medical information

Three respondents (P8, 81, Female, White; P15, 79, Male, White; and P16, 31, Female, African American) felt that the duration of the storage of medical information in the EHR should be determined by chronological time. Two participants preferred that medical information be retained in the EHR for five years, while the third individual suggested that medical records go back at least a couple of years. These respondents suggested that a fixed-term record of medical data was “long enough” for this information to be retained, though one indicated uncertainty about the current duration of medical data storage and referred to the physical thickness of former paper charts. Similar to the participants described above, these three respondents desired multiple years of records to allow providers to look back at a patient’s medical history as needed,

as one individual explained, “*so if something happens to you, they have a means of looking back and seeing what has taken place with you medical-wise*” (P15, 79, Male, White).

Temporary storage of social risk information

Eight participants (P1, 41, Female, Hispanic; P5, 52, Male, Hispanic; P6, 68, Male, African American; P9, 44, Female, Asian; P10, 42, Female, Multiracial; P14, 75, Female, White; P15, 79, Male, White; P16, 31, Female, African American) preferred that social risk information be stored in the EHR temporarily, with some suggesting that these data be removed after a set amount of time. Respondents viewed social risk information as distinct from medical data due to the dynamic nature in which social factors may change over time, and unlike medical data, social risk data should be kept only temporarily for as long as it represents an active social need or is still relevant to the patient’s health and healthcare. Beyond this, social risk data was thought to no longer be needed. In one example of this, one individual explained that ten years was long enough for clinicians to identify instances in which social factors contributed to patients’ health, as she explained, “*long enough for the doctor to like look back and say ‘during that period you were really having a rough time and that’s really why you ended up with all these ulcers’*” (P14, 75, Female, White). Similarly, another participant suggested that storing social risk data for ten years would suffice because a decade is likely as long as any patient sees the same doctor.

Five of the eight respondents who preferred the temporary storage of social risk information felt that information about social factors should be automatically removed from the EHR after a defined length of time. Participants offered a variety of lengths for which social risk data should be retained, including five years (P16, 31, Female, African American), seven years (P15, 79, Male, White), and ten years (P5, 52, Male, Hispanic; P9, 44, Female, Asian; P14, 75,

Female, White). Many used administrative processes from other aspects of life as reference points for suggested durations of data storage. Examples described by respondents included providing the last ten years of an applicant's employment history on a job application, the length of time financial documents should be retained for tax purposes (seven years), and the period of time information was thought to contribute to one's credit score (five years). Additionally, some respondents felt that while social risk data should only be stored temporarily, it should be updated frequently. One individual explained that a patient's social factors may change as frequently as on a daily basis, prompting the need to frequently update these data in the EHR, "*it changes every day. You never know what the next day is going to bring*" (P6, 68, Male, African American).

3.5.4 Reasons to disclose: Expectations of help. Does the patient believe that sharing social risk information will result in them receiving a helpful response from providers?

Should the healthcare organization address your social needs?

Participants were asked "*Should Parkview address your social needs?*" to identify their preferences for where assistance with social needs should be provided. Seventeen of 18 respondents answered positively about receiving assistance social from the healthcare organization. Some participants were in favor of receiving social care from the healthcare organization because it was the organization to which patients already turn to for help with health concerns, "*because the hospital, the doctor, that's who I go to*" (P5, 52, Male, Hispanic). These respondents noted that Parkview patients are already connected to the organization, avoiding the need to find and navigate a new institution to seek assistance. Additionally, some

participants simply preferred seeking support at Parkview, the healthcare facility where they receive all their medical care.

Similarly, respondents expressed the need for patients to have options related to talking about social factors with healthcare providers and electing to receive support. Multiple respondents suggested that patients have a choice regarding whether to seek help with social needs and share information about their social factors with providers. The decision to do so may be based on trust in providers and the healthcare organization, as one participant explains,

“...people have a choice [with] whom they decide that they want to have access to that type of information, so I don’t think everyone should have access to that stuff. There are people that just have trust issues and they feel like it could be a scam or something”

(P16, 31, Female, African American).

Additionally, respondents suggested that patients should have a choice regarding whether to receive information or referrals from providers and if necessary, allow patients to decline supportive efforts from their providers. Participants also desired the choice of where to seek help with social needs, including from either the healthcare organization, from a local social services agency, or both. One respondent described being open to receiving support from any organization that would provide it, including from both Parkview and other social services agencies,

“...if they are both willing to help, it’s just the simple fact of having whoever would help. To me, it wouldn’t bother me who the help came from... it’s nice to know that you would have these two places that are willing to help you, so I mean, out of those places, I would let either one help me. (P1, 41, Female, Hispanic).

To explain their opinions about whether Parkview should address their social needs, patients presented their evaluations of the proper role of a healthcare system. Social factors were thought to be intrinsically linked to a patient's health and thus worthy of consideration and intervention by the healthcare organization, as one participant explained, "*it all goes together with your health*" (P2, 55, Female, White). Respondents underscored the opportunity for health system intervention on social factors as a disease prevention step that may potentially reduce patients' healthcare needs, as one respondent explained, "*A lot of patients wouldn't be patients if they had their social needs addressed*" (P13, 72, Male, Black).

Despite wanting hospitals to offer resources to address social needs, some respondents offered critical responses to the discussion of whether the healthcare organization was responsible for aiding with social needs. These individuals felt that offering social care was outside of the range of normal services that the hospital must provide and, while not obligated to do so, offering social care services was viewed positively as going above and beyond the hospital's conventional scope of practice.

By offering social care services and referrals to community organizations, the hospital was thought to play an important role in filling in coverage gaps in the social safety net in the hospital's geographic community. Participants reflected on the need both to bolster the community's existing social services capacities as well as get patients connected to life-improving resources. However, this patient emphasized the magnitude of this undertaking and suggested the need for the healthcare organization to collaborate with the city of Fort Wayne to coordinate the provision of social care,

“It’s like another big responsibility... it’s a big undertaking. It’s not just something you can throw together with a couple of ideas... if Parkview were going to do it then I think the city of [city name] ought to somehow be involved with helping in the resources and whatever they need to do to help them have this work... Because it is a need and it’s not being met right now” (P14, 75, Female, White).

Finally, one participant indicated that the healthcare organization should not be the entity that addresses one’s social needs. Aside from participating in a healthcare payment assistance program, this respondent preferred to receive support for other types of social needs from her pastor and family members instead of from a healthcare organization.

Patients’ expectations for addressing needs and adjusting healthcare

Expecting that the healthcare staff and/or organization could offer support or assistance with social needs was viewed as a facilitator of disclosing social factors (Figure 1). Respondents desired providers to address social needs and adjust healthcare in response to social factors.

Addressing needs

Many respondents felt willing to discuss social factors, including financial hardship, employment, food access, and social support, because providers may be able to connect them with community resources, or another provider or a social services agency staff member who can. For example, respondents expected support for financial hardship via referrals to local organizations, including healthcare, religious, or governmental agencies, which may offer financial assistance, employment support services, and food vouchers. Similarly, other participants desired connections to community support groups when additional social support

was necessary, including Big Brothers Big Sisters of America, Adopt-A-Senior programs, and support groups for new parents. Furthermore, participants were interested in learning about other patients' experiences with using community social services agencies when receiving referrals to such resources.

Additionally, respondents desired referrals to other providers and authorities for needs related to social support and IPV. For example, numerous participants desired resources for social support, including directing patients to a psychiatrist, social worker, chaplain, or other healthcare team member in times of need or in the event of receiving a difficult diagnosis [31–35]. For others, offering social support could occur on an informal basis between patient and provider by taking the time to listen to patients' concerns on an ad hoc basis. Participants also suggested that providers be prepared to help patients overcome financial barriers related to accessing mental healthcare. Additionally, respondents desired check-in calls and home visits to be made to patients by the healthcare team in the days following medical treatment to ensure that sufficient support is present. Similarly, in instances of IPV, participants expected immediate reporting to police and referrals to shelters and other agencies which would be able to help get the patient out of the violent situation and into a safe place to stay.

While respondents who had received assistance with social needs from the healthcare organization described positive experiences, individuals expressed expectations for providers to treat patients in a supportive manner when addressing needs. Given the potential for social needs to be emotional experiences, how support is communicated and offered, such as with nonjudgmental and supportive communication styles, improved participants' experience of receiving assistance, as one recalled connecting to WIC resources, *“sometimes you need that extra support... they don't make you feel any kind of way because you need that help. I think*

that's good, especially too when you're in there and you've got all kinds of emotions and stuff like going through you" (P1). Finally, participants expressed the importance of giving patients options when discussing social factors, including choices about whether to be asked, whether to share information, and strategies and resources to overcome social needs.

Explaining screening, including the purpose of data collection and examples of types of assistance that could be provided, was viewed as a method of demonstrating the benefits of participating in screening. Believing that the provider can offer support was a facilitator of sharing social risk information, as one participant explained in the context of experiencing IPV, *"because I think they can get me out of that situation"* (P18, 34, Female, African American). Another participant emphasized the power that a doctor may have in addressing social needs by advocating on behalf of patients directly by explaining that his doctor wrote a letter encouraging that the patient be allowed to have a service dog in his apartment, a necessity for this patient to have access to safe housing. Conversely, a lack of clarity regarding how social risk information may be used to help patients may be a barrier to the sharing of these data, for example, respondents questioned what information about education and literacy would be used for.

Adjusting care

In addition to directly addressing social needs, respondents wanted providers to adjust healthcare treatment in response to social factors, including financial hardship, employment, access to healthy food, and transportation. Participants described feeling comfortable sharing information about financial hardship, including hardship resulting from limited or underemployment, because such barriers may impact patients' abilities to afford basic living expenses, like healthy food, and healthcare costs, including medications, tests, or specialist visits,

as well as adversely contribute to patients' health. As a result, respondents described being willing to discuss financial barriers with providers due to the potential for doctors to offer resources for healthcare-related costs, such as financial assistance programs or lower-cost medications and diagnostic tests. One respondent explained that doctors may be unaware of financial hardship faced by patients that prevent them from affording healthcare costs, including the cost of prescribed medications,

"I can't afford the stuff that they would prescribe me... They're not mind readers. They only can prescribe me things, but if I don't open up to them and let them know that I'm not working... is there some way you can give me some assistance where I can still get this medicine" (P7, 49, Male, African American).

Respondents described positive experiences of adjustment both directly related to healthcare costs, including providing access to necessary medication, and indirectly related to healthcare costs, including shifting appointments to a telemedicine platform to reduce transportation expenses. For example, one participant emphasized that providers should consider lower-cost, and even potentially less efficacious, therapies which would be more attainable for patients, as he explained,

"it's important to the extent that if your doctor has the flexibility to say, 'well I would like to give you this test, for instance, but since you aren't properly insured for this test or maybe there's something else I can do that's 80% as effective that won't bankrupt you.'" (P4, 49, Male, White).

Additionally, participants described the need for flexibility with healthcare billing payment deadlines in the event of missed work during periods of illness and subsequent delay of

paychecks or in instances in which employment challenges impact patients' insurance coverage. Moreover, respondents stressed the importance of financial assistance to consider all of the expenses a patient may have to attenuate the burden of healthcare costs and to identify resources to assist with other living expenses. Similarly, respondents were willing to talk to their providers about access to healthy food due to the relevance of food access to one's diet and subsequent health outcomes, as well as the importance of food access for survival and for maintaining a healthy diet. This was discussed frequently concerning diets and nutritional guidance offered by providers, which were thought to be difficult to comply with if access to healthy food was limited. As a result, many participants described the need to seek help from providers to source healthy food for prescribed diets. Similarly, one respondent stressed the importance of disclosing food access issues for patients who are prescribed medications that must be taken with food. Another participant suggested the need to communicate diet quality to identify malnourishment and vitamin deficiency concerns which may be addressable both through improving healthy food access and use of supplemental vitamins. Furthermore, overcoming food access, along with housing, was thought by one respondent to be more urgent than other needs because such needs are critical for survival and were thought to be more easily overcome with community resources than other social factors like employment.

Finally, respondents described significant barriers related to the scheduling of appointments to fit within the constraints of limited transportation access. Patients desired appointment schedule flexibility and modifications, including shifting appointment times, to support the use of alternative transportation services, which often followed schedules or demand. Furthermore, patients suggested that the frequency of follow-up appointments be determined with consideration to patients' transportation concerns, such as less frequent follow-up visits for

those with transportation barriers. Finally, patients desired the use of telemedicine visits to enable healthcare access when transportation was a concern.

Patients' expectations for organization and provider competence related to social factors

Respondents indicated that providing referrals to local social services agencies may require providers to have significant knowledge of local resources. Participants underscored the importance of such referrals due to the potential for patients to have limited awareness and knowledge of local community resources. For example, respondents highlighted the importance of healthcare providers and staff to be aware of local transportation resources, such as those offered by insurance plans, local public transit authorities, senior centers, religious organizations, ride-sharing corporations, or neighbors, to share this information with patients. In instances in which providers offer information about local resources to patients, participants expected that providers have knowledge about resources to answer questions, rather than simply offering pamphlets and referring to organizations' phone numbers, as one respondent explained, "*don't give me a pamphlet if you ain't read it yourself and you don't know nothing about these resources yourself. You need to know too, because I'm going to have questions*" (P17, 23, Female, African American). This respondent further explained that she desired providers to take the time to explain resources in order to increase patients' trust in those resources. Furthermore, respondents expected providers to have personal knowledge about such programs to answer patients' questions and describe the quality of the resources. Respondents recognized that such knowledge is not universally distributed across providers and staff, as one explained, "*you'd have to have a healthcare person that was versed in all facets of life basically... a lot of them don't know a lot about other stuff that a patient might need*" (P13, 72, Male, Black), and others indicated that it was difficult to gauge a provider's knowledge of social resources. Furthermore,

screening for and responding to social needs was thought to add a significant burden to providers, who balance numerous other responsibilities in their clinical roles.

Respondents offered several potential barriers to sharing social risk information in clinical settings. Participants often lacked expectations for support the healthcare organization can provide. Many respondents (P6, P11, P12, P13, & P15) believed that providing social care was outside of the scope of services to be offered by the hospital, and thus, opposed the medicalization of their social needs, as one explained, *“it’s just a doctor’s office. It’s not a social service office.”* These individuals believed that the healthcare organization’s functions were limited to serving medical needs, rather than offering social care, and instead suggested that the hospital make referrals to community social services agencies. However, for some (P11 & P12), the provision of social care by hospitals was viewed positively and thought to be an effort by the healthcare organization to go above and beyond the mission of offering medical care.

Expertise as a determinant of respondents’ preferred clinician for review and response to social risk screening

Eight of 18 participants preferred to work with social workers to identify and address social needs. For many respondents, social workers were preferred due to their expertise and knowledge about community resources, *“that’s their area of expertise”* (P12, 41, Female, White). Social workers were seen by participants as having access to supportive resources which doctors would not have access to due to limited knowledge and information resources. Additionally, social workers were seen as unburdened by physicians’ medical responsibilities, giving them more opportunity to work with patients on social needs relative to other types of providers and staff, *“the social workers I know have more latitude and possibly more flexibility*

of their time as to how they treat this or that case” (P4, 49, Male, White). Three participants noted the expertise of social workers related to offering assistance with social needs but also expressed willingness to receive support from other qualified healthcare staff, *“that has the resources”* (P17, 23, Female, African American), due to shortages of social workers in some clinics. For these participants, the providers and staff offering assistance needed to be qualified to respond to social needs, including having access to information about resources. The preference of some patients for social workers to address social needs may indicate a rejection of the medical view of social needs.

Conversely, some respondents generally felt that clinical providers lack training and the ability to address social needs, an important concern regarding the medicalization of social needs. Participants viewed social risk screening and social care as complex tasks requiring specialized training and skill. Due to the lack of such education in many health professions training programs, respondents felt that providers were not sufficiently prepared to offer assistance with social needs. Providers were thought to lack sufficient knowledge of local programs and resources, which limited respondents’ expectations for receiving assistance. Participants expressed concern that not all staff may have received sufficient training to review and respond to information about social factors and described instances in which an untrained staff member with access to social risk information and no way to offer assistance as being *“in your business because they don’t get to tell you to do anything”* (P17, 23, Female, African American). Additionally, providers’ difficulty with discussing sensitive and often vulnerable social needs with patients was viewed as a limitation of current training. As a result, individuals described feeling more open to sharing social risk information with those who they felt were sufficiently trained, including social workers or counselors. As a result, participants did not

expect providers and staff to be able to address social needs directly, and referrals to other community social services agencies or experts were desired. For example, some respondents lacked expectations for providers to offer assistance with employment due to feeling that healthcare providers and staff were primarily focused on patients' medical concerns and that employment was outside of the scope of practice, though many of these respondents suggested that providers could connect patients to existing community employment assistance resources to address such concerns.

Respondents expect help with social needs if screening is to occur, and screening without the capacity to offer support is inappropriate

Respondents felt that it was important for patients to feel that their needs could be helped by participating in screening and screening solely for the purpose of collecting data, without expectation of offering assistance for disclosed needs, was viewed as unacceptable, as one explained, *"I also want to be reassured that maybe you know something that could help me, not just you in my business"* (P17, 23, Female, African American). Participants suggested that the scope of screening of social factors should be limited to those which the hospital/health system can actually address or those factors which are relevant to the delivery of healthcare.

Respondents described being willing to discuss social needs to receive supportive resources. Subsequently, assistance was expected following the sharing of social risk information, and such data was not to be collected solely for record-keeping, as one explained,

"if you want to ask me that... you've got to be asking me for a reason. Like, do you have something that I can do to help myself, bring myself up or make some more money or

opportunity or a resource? Don't just ask me just to ask me for your chart.” (P17, 23, Female, African American).

When discussing screening for social support, another respondent shared the expectation that some form of social support resources be available if such screening is to occur to avoid asking “*empty questions*” which do not result in patients gaining additional social support (P12, 41, Female, White). Subsequently, participants suggested that only those needs for which resources exist or that aid in clinical decision-making are relevant to screening.

3.5.5 Reasons to disclose: Trust. Does the patient have a sufficient relationship with their provider and healthcare system to feel comfortable sharing social risk information?

Trust as a facilitator of sharing social risk information

Respondents shared several attributes of the patient-provider relationship which serve as facilitators of sharing social risk information, including the trust of the patient-provider relationship in general (Figure 1). First, positive relationships with providers and staff were particularly important to building the trust necessary to discuss social factors. Numerous participants described feeling that they could share anything with their doctor, including social needs like food insecurity, IPV, and social support, due to having a long-standing relationship with the physician, as one respondent described feeling comfortable sharing food access barriers due to her long relationship with her provider, “*part of it is I've known my doctor for a long time, so there's a relationship there, so I think it would be natural. It would be fine to tell her if it was a real problem*” (P12, 41, Female, White). Some respondents described being open to sharing information about social factors due to liking their current providers. For some, this included specifically selecting providers who were compassionate and caring. Participants

stressed that having providers act with sensitivity and caring attitudes was an important step towards building trusting relationships with patients. As a result, establishing strong relationships between patients and providers was thought to be necessary to facilitate open dialogues about social factors.

Trust as a determinant of respondents' preferred clinician for review and response to social risk screening

Seven participants preferred to work with their physician to review and respond to social needs. Respondents recognized physicians' expertise in clinical matters, but also suggested that they should be made aware of social factors, even if only to relay such information to social care experts, *"I think the doctors should pretty much get with the medical part and should be the line of communication for the referrals or different resources"* (P18, 34, Female, African American). Additionally, respondents described the role of the physicians in gathering and using information about patients' health statuses, including medical and social information, *"family doctor, they should have access to a lot of your information, so they know how you're doing"* (P10, 42, Female, Multiracial).

For some patients, doctors were preferred due to the trust relationships these patients had built with their physicians. Patients described relying on doctors for help, and that while the physician may connect the patient with a social worker for community resources, it is important to share such needs with the doctor, *"the majority of the time we depend on our doctors"* (P16, 31, Female, African American). Participants described the rapport they developed over time with their doctors as a source of trust which allows patients to rely on physicians for support, *"because they're there for you to begin with"* (P5, 52, Male, Hispanic). As a result, for some,

information about social factors was to be considered private and only to be shared with their doctor, *“there are personal things that a doctor should only be privy to”* (P15, 79, Male, White). Furthermore, one participant emphasized the professional training of his doctor to support his preference to discuss social needs with the physician, *“I would say a doctor because he’s the one that’s taking care of your medical things. I think talking to him would be helpful because you know, he’s a professional at what he does”* (P11, 27, Male, Hispanic).

Four participants preferred to have a nurse work to address social needs. Nurses were favored due to their place in the clinical workflow as well as the longer period of engagement with the patient relative to physicians. Two participants noted that nurses often access the patient’s chart and see relevant information, making them ideal to initiate referrals to social work, *“the nurse, she knows your information and then she can [reach out to the] social worker”* (P9, 44, Female, Asian) (Table XX). One patient described having more time to talk with nurses than with providers during most of her healthcare encounters, making it easier to discuss social factors, *“they’re with you”* (P8, 81, Female, White). Conversely, patients may be more have relationships with nurses in their community than other types of providers and staff, potentially limiting willingness to share social risk information, *“my main issue would be if I knew [a nurse] on a personal level outside of the doctor’s office”* (P18, 34, Female, African American).

Uncertainty about sharing information in the event of a social need amongst patients currently without such needs

Some respondents described feeling comfortable sharing information about social factors for which they did not have needs (such as having safe housing or access to transportation), in

part because these social factors were not an issue for them, and thus posed no embarrassment. However, in the case of certain social factors, some respondents who did not face such needs expressed uncertainty related to their willingness to share such information in the event of a hypothetical future social need. Specifically, in the case of education and literacy, housing, food access, and transportation, participants expressed concern about the difficulty of discussing social needs in these categories, citing that such needs would be emotionally difficult to discuss with a provider and potentially “*humbling*” to share (P12, 41, Female, White).

3.5.6 Reasons not to disclose: Risks. Are there any risks for patients when sharing information about social factors?

Disclosure risks

Respondents suggested that the disclosure of social risk information to healthcare providers and staff may create several risks for patients, including embarrassment and the potential for these data to be used against patients (Figure 1). For some, the presence of social needs may create the potential for judgment or stigmatization by providers, causing patients to feel embarrassed or vulnerable, as one explained, “*I always get embarrassed sometimes because I don’t want people to know that I’m having a hard time*” (P2, 55, Female, White). Three participants remarked that there was a possibility of judgment by providers following the sharing of information about educational attainment, or lack thereof. Respondents suggested that the level of education attained, or the perceived quality of the institution attended, may be used by the doctor as a measure of intelligence, as one explained, “*Just because I just finished high school doesn’t mean I don’t know anything outside of that... Because I don’t want them to determine, ‘She’s dumb because she didn’t go to college or she doesn’t have a degree...’*” (P17,

23, Female, African American). Similarly, some participants felt stress and embarrassment when discussing financial hardship with healthcare providers, as one explained, *“it can be embarrassing to say, ‘hey I don’t have any money’”* (P9, 44, Female, Asian). Finally, numerous respondents highlighted the sensitivity of discussions about IPV. For some, IPV was viewed as *“a very vulnerable thing”* to discuss with a provider (P12, 41, Female, White). Others described embarrassment related to experiencing and discussing IPV as well as situations in which fear may result in a patient feeling too intimidated to talk about IPV. In such situations, one participant suggested that the option to share such information on paper surveys may be preferable for some patients. Another respondent suggested that patients experiencing IPV may turn to providers for help if they feel uncomfortable talking to family members.

Participants also expressed concern about privacy breaches as a potential result of allowing Emergency Room providers, nurses, and staff members access to social risk information. Specifically, two respondents (P5 & P18) felt uncomfortable with nurse access to social risk information due to privacy concerns. Respondents expressed worry about the potential for gossip between Emergency Room providers and staff, as well as the potential for sensitive social risk information to be made known to staff members with whom a patient may know in the community, as one explained,

“when you live in a small town... a lot of the people you see... are people you know... although they can’t share that information, I don’t think I would want them with that knowledge of what’s going on in my household” (P18, 34, Female, African American).

Similarly, nurses were thought to be highly visible community members, especially in small towns, causing participants to be concerned about the potential for gossip and the potential for

social risk information to be made public to other staff, patients, and community members. Eight respondents (P2, P5, P7, P11, P13, P15, P16, & P17) did not wish for hospital staff to have access to social risk information due to the potential for embarrassment and gossip, as well as concerns that staff may not be the appropriate personnel to address social needs. Four participants (P2, P5, P7, & P16) warned against access and use of social risk information by hospital staff due to concerns about embarrassment and gossip. These individuals stressed the potential for social factors to be sensitive and embarrassing when made public to staff members. Additionally, two respondents (P5 & P16) expressed concern that staff members may gossip or discuss social risk information with other colleagues in public areas of the clinic, expanding the number of individuals who are made aware of details about one's social factors. Participants were also concerned that social risk information may be used against patients in the form of dropping patients from practice roster due to judgment by providers about one's worthiness based on social circumstances or by not receiving certain medication prescriptions due to providers' assumptions about patients' ability to pay.

Risks of storing social risk information

Privacy and confidentiality of social risk information

Social risk information was viewed as more private and confidential than clinical information by many respondents, and participants stressed the importance of preserving the privacy and confidentiality of social risk information when stored in the EHR. Of the 14 participants who desired the documentation of social factors in the EHR, three suggested that social risk information should be stored in the EHR in a manner in which only certain clinical providers and staff have access to it (P11, P16, P18). Information about social factors was

thought by some to be “*not for everybody to see*” (P11, 27, Male, Hispanic), and this respondent openly wondered which individuals had looked at data about his social factors.

Of the 14 participants who desired the documentation of social factors in the EHR, two wanted this so that social risk data could be stored in a single location to ensure the protection and privacy of these data. For one respondent, the medical record was seen as a safe and private central location for social risk data to be stored, which may mitigate concerns of the privacy breaches that documents stored at home may be susceptible to, as she explained, “*it’d be safer if the doctor had them. And nobody else can look at it [unlike] if you’d have them at your house*” (P2, 55, Female, White).

Respondents desired limits on the amount of social risk information stored and on access to social risk data. Two participants described limits for the storage and use of social risk information in the EHR: limiting the level of detail and ensuring that such data be used in an unbiased manner. First, one respondent preferred that any social needs stored in the EHR not be too detailed, as she explained,

“if he knows I’m poor then he knows that I’m eating Rally’s every day and that’s why I’m having heartburn... It don’t really have to be detailed, like ‘me and my boyfriend just broke up, that’s why I’m just so stressed out...’ Nothing like that... just kind of brief, little pointers” (P17, 23, Female, African American).

Secondly, another participant, who was an experienced nurse, cautioned against the potential for biases in medical decision-making when social risk information is highly visible in the EHR.

This individual worried that providers may avoid offering treatments to patients based on social risk information presented in the EHR, as she explained, “*if it’s all over your medical record*

that you're below the poverty line... I would hate for a provider to like maybe not offer you a medication that would benefit you – like make a decision based off of that” (P12, 41, Female, White).

Storing information in a patient-modifiable manner

If social risk information was stored in the EHR, three respondents (P4, 49, Male, White; P7, 49, Male, African American; P17, 23, Female, African American) desired the ability to edit or remove such data at their request. These participants emphasized the private nature of social risk information and suggested that the “*right to erase*” these data was an important consideration contributing to the desire to retain these data in the EHR (P4, 49, Male, White). One example of an instance in which respondents considered the need to delete data was upon a significant improvement to a social need, in which case such record of a past need was thought to be no longer necessary. Participants also grappled with the implications of having social risk information lingering in the EHR, including the possibility for these data to be forgotten about by the patient and the potential for these data to not be stored without benefiting the patient. One respondent indicated that patients may forget about or be unaware of what social risk data is documented in the EHR, which may cause these data to remain stored for years without the patient’s knowledge (P7, 49, Male, African American). Another participant weighed the value and utility of stored social risk information and considered removing it from the EHR when it was no longer being used to help the patient, as she explained,

“if I had the option to update it myself... it should just stay in there. And if I also had the option to delete it and get rid of it, that should be available for me to do too... It’s a matter of, if I got my information in there and I felt like it was just unnecessary because

I'm not being offered any help... then why do you need to know my business?" (P17, 23, Female, African American).

Not storing information

Four respondents (P3, P7, P8, P13) did not feel that that information about social factors should be documented in the EHR. Participants offered two reasons for not wanting social risk information to be stored in the EHR. First, three of these individuals preferred that such data not be retained due to privacy concerns, believing that social risk information should be known only to certain individuals and that the EHR should instead be focused on medical information. One respondent explains this perspective,

"No, I don't think that even should be in my medical record because that's personal about houses and financial assistance and stuff. That's kinda personal... that's confidential... Only thing that should be in my medical record is about my health... problems" (P3, 78, Female, African American).

Secondly, rather than storing social risk information in the EHR, one respondent (P8, 81, Female, White) preferred that her family be consulted to identify opportunities for the family to address social needs instead of having the healthcare system collect social risk data and offer an intervention.

3.6 Discussion

Much prior research on social risk screening is related to the study of providers' implementation experiences and the evaluation of screening tools [4,72–75]. For example, previous scholarship has investigated potential unintended consequences of social risk screening

[57], as well as implementation studies of specific screening tools [73–78], but there has been limited investigation into the patients’ perspectives on social risk factor screening and the medicalization of social needs. Physicians and nurses have long collected and used information about patients’ social risk factors in healthcare practice. However, national trends indicate that US healthcare is currently moving towards efforts to systematically screen patients for social risk factors and store comprehensive social risk factor data, which may represent the medicalization of social needs. Thus, there is a need to explore patients’ perspectives towards such efforts to identify concerns and to design screening programs to be acceptable to patients. Similarly, there is a need to understand patients’ attitudes towards being asked about social risk factors, their attitudes towards the documentation of social risk factor information in the EHR, and their expectations for support for social needs by healthcare providers. Such research is necessary to inform the design and implementation of future social risk factor screening programs.

This study demonstrates that patients’ attitudes towards participating in social risk screening were impacted by judgments of the relevance of social risk information to providers, expectations for support following screening, perceived risks associated with sharing and storing of social risk data, and trust in the patient-provider relationship. Respondents made assessments regarding the relevance of social factors to their health or to the healthcare they receive, whether social needs were “bad enough” to warrant sharing with providers, and who was responsible for identifying assistance for social needs. There has been much work on patient information sharing in clinical contexts [79], and recent work has shown that concern about security breaches related to electronic transfers of health data and feeling that one has little impact on how protected health information is used are significantly associated with higher odds of withholding medical information from a healthcare provider [18]. Screening for social needs in healthcare settings

may exert social control upon patients by placing pressure to share potentially vulnerable information about social risk factors with providers. As patients are increasingly asked about social factors, some of which may be sensitive for some patients, we may expect patients to have to make decisions regarding whether to withhold these data from healthcare providers. Assessing the relevance of these data may be one component of patients' decisions of whether to share information about social factors with providers.

Expecting that the healthcare organization could offer support for social needs following screening was an important facilitator of respondents' willingness to share social risk information. Respondents expected help with social needs if screening was to occur, and screening without the capacity to offer support was considered to be inappropriate. Thus, the scope of screening, and social care, should be limited to those which the healthcare organization has the capacity to readily address either locally or via partnerships with community organizations, or those factors relevant to clinical decision-making should be included in screening programs to avoid the collection of data which ultimately is not used in service of the patient. As a result, providers must have social care resources available so that data from social risk screening is actionable, for as social factors are medicalized, social risk data could be collected and stored without being used to assist patients, which may cause harm to patients as these data are accessible to providers and staff due to the risk of privacy breaches, stigmatization, and biased treatment. Additionally, some participants viewed healthcare-provided social care positively, especially given the potential for the hospital to fill in coverage gaps and strengthen the community social safety net, though not all individuals agreed that offering social care services was an obligation of the hospital, suggesting that social risk screening and intervention may be an expansion of the scope of practice of healthcare and thus a medicalization of social

factors. Furthermore, some respondents lacked expectations for healthcare organizations to provide support for social needs, suggesting the need for improved communication and advertising of social care services to increase awareness and utilization, or, indicating the lack of acceptance of a medicalized need. As social factors are medicalized, or come under the dominion of the healthcare enterprise [3], healthcare organizations must ensure that access to social care resources is equitable via patient education regarding the availability of such resources to ensure that such interventions do not worsen existing inequalities [80]. Participants also expressed concern about providers' lack of training related to discussing and supporting patients' social needs. A lack of training related to screening for social factors and offering necessary referral resources is a known limitation of healthcare professions education programs [57,62,81], and as a result, providers may benefit from leveraging members of interprofessional healthcare teams with specific expertise related to SDOH, including communication skills related to having conversations about sensitive or vulnerable social factors. Furthermore, the use of community resource referral platforms, or health IT designed to facilitate digital communication between healthcare organizations and community social services agencies to suggest local resources, facilitate referrals, and track outcomes [31,82], maybe be used to automate parts of the referral workflow to reduce provider burden. The use of health IT to facilitate screening and social care may aid healthcare organizations in offering such interventions at the same level of accessibility and quality as other healthcare services, which is necessary if hospitals hope to make a positive impact when addressing patients' social needs.

Respondents viewed having a trusting, long-term patient-provider relationship as a facilitator of sharing social risk information. An important component of patient-provider relationships is patients' trust in their providers, and trust is a multidimensional concept

consisting of patients' expectations of the competence of their provider, providers' concern about patients' welfare, providers' control over decision making, providers' confidentiality, and providers' openness to receiving and giving information [83]. Prior work has demonstrated the importance of patients' trust in the confidentiality of their provider on patients' decisions to withhold important medical information and feeling that it is important to find out who has looked at their medical records [22]. Similarly, patients' perception that it is very important that providers share their health information electronically has been significantly associated with trust in physician competence [22]. Thus, because social risk information may be sensitive for patients, leveraging patient-provider relationships may be one way to increase the safety of such information sharing, as respondents described having long-standing trust relationships with their primary doctors, which allowed them to feel comfortable and willing to discuss difficult or sensitive topics.

Respondents also made assessments of risks, including judgment, embarrassment, and bias, when considering whether to share social risk information with providers. Patients' concern of judgment by providers suggests that they fear negative or stigmatizing classification, and the creation of biomedical identities (such as "high risk") based on the measurement or assessment of patients is a feature of medicalization [84]. Prior work has suggested that safe environments, characterized by protecting patients' privacy, refraining from judgment, and being supportive, are vital for maintaining trusting relationships with patients to facilitate the sharing of social risk information [85]. Given the sensitive and private nature of social factors for some patients, participants desired the ability to modify or delete social risk information documented in the EHR so that these data are only stored as long as necessary. Furthermore, patients may wish to have social risk data removed after needs are resolved to avoid being labeled as having a

stigmatized social need [16], saving face [86], or to avoid the potential for bias by a provider who may view such data in a future encounter. There has been much work related to patient modification of information in the EHR, however, much of this scholarship is focused on the identification of errors by patients in the era of OpenNotes [87–92]. In my study, respondents did not express the need to error check social risk information in the EHR, but rather, they desired the ability to change the recorded narrative related to social factors which change over time, become less relevant, or were generally considered sensitive and in need of removal after social needs were resolved. This may represent a departure from patients' current level of control over data in the EHR and raises a host of issues related to current legal assumptions about the permanence, integrity, and provenance of data in EHR as they may be used for both medical and legal purposes [93–96]. In current systems, storing social risk information in a manner that allows for modification and deletion at patients' requests may require the creation of separate databases with distinct assumptions about data provenance relative to the rest of the EHR. Furthermore, given concerns about the additional time in providers' workflows required for screening, creating opportunities for patients to review and modify social risk records may require additional time. Additionally, communicating the ability and processes required to make changes to social risk records will require equitable education and training to avoid disparities amongst patients related to who has agency over the documentation of these data.

This study has several implications for the social control of individuals and society characteristic of the medicalization of social needs, including describing examples of four methods of social control in use (medical technology, collaboration, ideology, and surveillance) and two processes that medicine uses to claim to the ability to label illnesses (expanding what phenomena are deemed relevant to healthcare and maintaining control over medical procedures)

[3,44,50]. Social risk screening (technology) may be used to characterize patients as having social needs (ideology, surveillance), which may be used for referrals to other organizations (collaboration). First, screening patients for social needs may be considered an ideological form of social control in which patients are labeled as having undesired characteristics requiring medicalized intervention [44,50]. Some respondents stressed the dynamically changing nature of social needs over the life course and described resolved social needs from the past as irrelevant to present healthcare needs. This may be different than how medical diagnoses are treated, in which knowing one's entire medical history is desired for clinical decision-making, as well as an expansion of those factors relevant to health to include social needs. The ability to remove social risk factor data that is considered irrelevant may be critical to reducing potential discrimination, stigmatization, or bias that may result from the future access of these data in the EHR and may represent opposition to clinicians' control over what is documented in the record. Similarly, the permanent documentation of social needs, and their subsequent visibility to future providers in the EHR, may constrain patients' privacy and be used by clinicians adversely, such as to make judgments providers about patients' character or worthiness of treatment, as expressed by respondents. Furthermore, it is necessary to reflect on what is captured during screening, as there are numerous screening tools, few of which are widely validated to identify the social needs of diverse groups of patients [97]. Here, screening may represent ideological social control via assigning labels to patients based on socially constructed screening tools, necessitating critical study of what is meant by a positive response to screening as well as the sensitivity and specificity of screening questions as used in healthcare settings.

Screening interventions may exert individual-level social control on patients by decontextualizing societal problems and shifting responsibility onto individual patients [3,44].

Indeed, respondents described having expectations of support as a facilitator of participation in screening, and screening, a form of social control via surveillance, by providers holding much power in the patient-provider relationship [98], may create expectations of sharing sensitive social needs, causing participants to make decisions about the type and amount of personal information that they wish to share. Provider-offered referrals may be both an opportunity to address social needs and a source of constraint of patients' agency to choose if, how, and where they would like to receive help with needs. Indeed, it is critical to recall that social needs reflect a patient's own determination of those life circumstances which she identifies as a problem and for which she desires assistance [99]. Similarly, physicians may take on a gatekeeping role and exert control over which patients are screened and which have access to social services based on perceptions of need, worthiness, or internally-held biases [57], which may represent new examples of ideological social control as well as an effort to maintain control over newly-adopted medical procedures [44,50]. Additionally, while patients may have a responsibility to adhere to agreed-upon treatments and take steps to look after their own health when possible, [98,100], it is unclear what consequences will be faced by patients who choose not to use referral resources for social needs, which are currently not treated as prescriptions. Power imbalances and social control may be reduced if patients are educated about screening, including how their data may be stored, accessed, and used, allowing them to opt-out if desired or if they do not anticipate receiving commensurate support following screening.

Health information technology may contribute to the social control of individual patients, and indeed technology is one facilitator of medicalized social control. The capture of standardized social risk factor data may enable the measurement and reporting of social needs amongst individual patients and patient populations, a literal surveillance tool that may find

patients to be increasingly in the gaze of the medical establishment [3]. Similarly, clinical decision support tools may incorporate standardized social risk data to aid in medical decision-making, though included algorithms may require evaluation to avoid biased treatment based on perceived inability to afford care or other deviant characteristics and patients should be given choices regarding the use of social data in decision-making tools. Finally, participants cited perceived risks and relevance as barriers to sharing social risk data, and as these data are used in tools to adjust care and address needs, those patient groups who withhold information may stand to benefit less than those groups represented in datasets supporting algorithms given historic disparities in patient trust in providers for racial and ethnic minorities [22,101,102].

At the societal level, the social control of medicalized social needs may take the form of adopting a medical perspective as a dominant definition and framework for addressing social needs [44]. In doing so, healthcare organizations decontextualize complex social problems, including poverty, housing, food access, and discrimination, and attempt to create individual interventions. Thus, it is necessary to consider the limitations of such approaches. By medicalizing social needs, health system interventions focused on individuals fail to affect the community-level social determinants of health, including poverty, education, and discrimination, which require investments in institutions and policy at the national and local levels [44,103]. Furthermore, screening programs may represent social control through labeling and surveillance of social needs, and while some respondents in this study welcomed such programs and described them as efforts by hospitals to go above and beyond their mission, others felt that healthcare organizations did not have a responsibility or obligation to address social needs. Patients opposed to healthcare interventions on social needs may resist interventions in their lives by the medical establishment, potentially rejecting medical care in the process. Similarly,

patients underscored how large of an undertaking it would be for hospitals to address social needs, and healthcare organizations may attempt to take responsibility for social needs with limited investment in social work capabilities, training, or understanding of the capacity for local social services agencies to receive referrals from providers. Healthcare organizations may collaborate with governmental and social services agencies as they attempt to provide social care, and while referrals may provide benefit, reporting of unstable livelihoods to child welfare or immigration services may exert substantial negative control over patients [64]. Finally, as screening becomes widespread, what consequences clinicians will face for not acting upon social risk factor data remains an important question.

Additionally, one distinguishing characteristic of phenomena that have been overmedicalized is the observation that the medicalization process has caused harm to or social control of patients [104]. While the purpose of this study is not to determine the extent to which social factors have been medicalized or overmedicalized, recognizing the potential for harm to patients is necessary to avoid unintended consequences of social risk screening and social care, as well as to ensure that the surrender of patients' private information is worth the assistance that they receive in response. Here respondents expressed concern about experiencing embarrassment, judgment, and bias in treatment based on shared social risk information, suggesting that the design and implementation of social risk screening and social care must be carefully considered to avoid worsening inequalities and creating new challenges for patients as they seek healthcare [57,80]. There is a range of opportunities for organizational policy and health IT to attenuate the risk of unintended consequences of the medicalization of social factors. For example, while patients may share information about their social needs during normal healthcare delivery, screening and subsequent documentation processes create new ways for

these data to be viewed, shared, and used, potentially without patients' knowledge or consent. Thus, health systems may ensure that all providers and staff undergo training related to conducting conversations about social factors with sensitivity, as well as how to provide resources if patients have social needs. Additionally, to avoid biased medical treatment based on social factors, such as not prescribing an efficacious but high-cost medication due to a perceived inability to pay, internal audits may be implemented to identify and prevent such behavior to ensure that adjustment of clinical care is done only to aid, rather than harm, patients. Finally, given participants concern about the long-term storage of social risk information, databases may be designed in a manner that allows for role-based access, as well as allowing patient decision-making related to who may access their social risk information. Finally, this study suggests the need for further study of the privacy practices of social risk information currently stored in existing EHRs, including who accesses such data and when, as well as the extent to which patients are made aware of what social risk data is stored in their medical records.

Similarly, just as a positive medical screening may create motivation for treatment [105], a positive social risk screening may imply the need for social care despite patient interest or desire [99]. An open question in this literature concerns whether patients are obligated to use referral resources offered by providers after screening and what consequences may be faced if referral resources are not used as directed, potentially indicating a form of social control. Furthermore, while the healthcare organizations have financial and health incentives to promote community health [106], it remains uncertain the extent to which these organizations bear a responsibility or obligation to provide screening and social care to address the social needs of individual patients. For example, should hospitals only attempt to address those social needs with an impact on patients' health be addressed, or must they support a wide range of needs?

Healthcare organizations may be insufficiently equipped to conduct screening and provide social care, and prior work has demonstrated that hospitals may lack the expertise, infrastructure, and budgets to conduct interventions to improve individual and community social conditions [73,74]. Moreover, the potential medicalization of social needs risks individualizing larger social determinants of health issues that would be better addressed through large scale social policy rather than interventions focused on individual patients via health care settings. In addition, medicalization of social needs may subject individual patients to increased surveillance and social control via health care providers and systems; control that may not be desired, and thus may be resisted, by patients. Additionally, there is concern about the impact of healthcare-provided screening and referrals on community organizations that may receive these referrals to ensure that hospitals do not overextend or replace these local institutions which provide services for the entire geographic community, rather than only the hospital's catchment area. Thus, while the medicalization of social needs may create opportunities to offer resources to address specific patients' needs, the limitations of healthcare organizations' capacity to do this work and potential harms must be considered.

3.6.1 Limitations

Several limitations of this study must be considered. First, my sample consists of patients from a single healthcare system, limiting our sample to one Midwestern region in the United States. Patient populations in other regions may have distinct screening needs based on local socioeconomic, cultural, and geographic contexts. Similarly, given the limited nature of current social risk screening, patients of some clinical specialty areas are not represented in my sample. Additionally, while this study features rich qualitative telephone interview data, I lack observational data which may provide greater insight into the true nature of social risk screening

in clinical practice. Furthermore, with available data, I am unable to identify each distinct type of social risk screening which my respondents have experienced. This information may be important in future studies, as different screening programs may vary in terms of the questions asked, the context of screening, and the type of provider who conducts the screening. Finally, because this study is focused on the perspectives of patients, I do not capture providers' preferences here, though this is accomplished in Chapter 2. Future work will be needed to characterize patients' preferences for social needs screening across a wide range of patient populations and in different types of healthcare settings.

3.7 Conclusion

Social risk screening creates opportunities for healthcare providers to address and exert social control over patients' social needs. However, such screening relies on patients being willing to share information about social factors, and decisions to do so may be dependent on patients' views of the relevance of social risk data to their health and healthcare, patients' expectations for the healthcare organization to help with social needs, the quality of patients' relationships with providers, and patients' perceptions of risks associated with sharing information about their social factors. Local organizational policy and health IT intervention must consider patients' concerns to create safe environments for patients to participate in screening and social care referrals to reduce barriers to living healthy lives.

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3.9 Appendix D. Patient Semi-Structured Interview Guide

Iott Dissertation Patient Semi-Structured Interview Guide – Parkview Health

Objectives

- Describe patients' experiences and perceptions about SDOH screening

Research Questions

4. What are patients' experience of SDOH screening at Parkview Health?
5. What are patients' attitudes towards being asked to disclose SDOH information?
6. What are patients' attitudes towards the documentation of SDOH information?
7. What are patients' expectations for clinicians to ask about and respond to their social needs?
8. What are patients' perspectives regarding talking to providers about costs (and cost barriers) of medication?
9. What are patients' perspectives regarding talking to providers about costs (and cost barriers) of diagnostic tests (e.g. labs, imaging)?

[Note: in keeping with the principles of qualitative research, these questions may evolve through the course of this research. However, this interview guide shows the possible range of questions to be asked.]

Introductory Statement: How would you prefer to be addressed? Before we start, I'd like to thank you for agreeing to participate in this study. Your participation will contribute to better understanding of how to improve screening for patients' social needs at Parkview. We will be audio recording this conversation so that our conversation may be transcribed and analyzed later.

For the purposes of this interview, I am going to be talking about social factors that can help or hurt your health. These include your housing, access to healthy food, whether you can pay for things that you need, and having someone in your life to talk to or to help you. You can decide not to answer any question. You may stop and ask questions at any time. Please ask if you need any question repeated.

Because talking about social needs may bring up sensitive information, we have a registered nurse also on the call who is able to assist and direct you to any resources that you may need.

[N.B. Need to account for the fact that not all elicitation of SDOH may be formally called "screening." We need to understand how screening fits into an ecosystem of addressing SDOH.]

PART A: Asking patients about their SDOH (XX min)

12) Have you ever been surprised about the cost of a medication? What happened?

13) Have you ever talked about the cost of a medication with your doctor?

Probes (ask only if not covered already):

- a) If yes, what was this experience like for you?
- b) If yes, what type of doctor was this?
- c) If yes, did you pick a different medication because of cost?
 - i) Did you use any programs, such as the Medication Assistance Program (MAP) or the \$4 medication list at Walmart's Pharmacy, to get the medication?
- d) If you didn't talk about the cost of the medication, why was that?
- e) If not, have you ever talked about the cost of your medications with any other staff members at Parkview Health?
- f) If not, what do you think about talking to your doctor about the cost of medications before you are given a prescription?

14) Have you ever been surprised about the cost of a test? What happened?

15) Have you ever talked about the cost of a medical test with your doctor?

Probes (ask only if not covered already):

- a) What was this experience like for you?
- b) What type of doctor was this?
- c) What steps did you take to attempt to get the medical test?
- d) If you didn't talk about the cost of the medication, why was that?

16) Have you ever avoided getting a medication or a test due to cost or other barriers (such as transportation)? If so, what happened?

17) Imagine that your doctor begins using their computer to help decide between two different medication options based on cost and health benefits. How would you feel if your doctor wanted to use this computer tool at your next appointment?

Probes (ask only if not covered already):

- a) What would you want your doctor to do with this tool?
- b) What information would you like this electronic tool to use when making recommendations about medications or tests based on cost?
- c) What information could the computer provide that would help you and your doctor make a better decision?

For the next few questions we will be asking you about your experience with situations that impact your ability to live a healthy life, including access to safe housing, healthy food, adequate financial resources, and social support. This will help us determine what additional resources could be provided to help you live a healthy life.

18) Tell me about a time when your living situation, like your housing or not having a place to stay, affected your health. This could be in good or bad ways.

Probes (ask only if not covered already):

- a) [If respondent mentions a good experience:] Did you ever have a bad experience with housing that affected your health? If so, did you want help with this situation?
- b) Did you want help in this situation?
- c) Did you try to get help for this housing problem? If so, where did you go for help?
- d) Where would you like to get help with any housing problems in the future?
- e) Did you ever talk about this issue with your doctor or nurse? What was that like?
 - i) What kind of doctor/staff member was this?
- f) If you have not talked about this, do you think you would want to talk about this with your doctor or nurse, why or why not?
- g) *(If you did discuss any this with your provider)* What did staff do after you talked about your living situation?

19) Tell me about a time where your ability to get enough healthy food affected your health. This could be in good or bad ways.

Probes (ask only if not covered already):

- a) [If respondent mentions a good experience:] Did you ever have a bad experience with accessing healthy food that affected your health? If so, did you want help with this situation?
- b) Did you want help in this situation?
- c) Did you attempt to get help for this? If so, where did you go for help?
- d) Where would you like to get help with this in the future?
- e) Did you ever talk about this issue with your doctor or nurse? What was that like?
 - i) What kind of doctor/staff member was this?
- f) If you have not talked about this, do you think you would want to talk about this with your doctor or nurse, why or why not?
- g) *(If you did discuss any this with your provider)* What did staff do after you talked about getting enough healthy food?

20) Tell me about a time where your ability to pay your bills or household expenses affected your health. This could be in good or bad ways.

Probes (ask only if not covered already):

- a) [If respondent mentions a good experience:] Did you ever have a bad experience with bills or household expenses that affected your health? If so, did you want help with this situation?
- b) Did you want help in this situation?
- c) Did you attempt to get help for this? If so, where did you go for help?
- d) Where would you like to get help with this in the future?
- e) Did you ever talk about this issue with your doctor or nurse? What was that like?
 - i) What kind of doctor/staff member was this?
- f) If you have not talked about this, do you think you would want to talk about this with your doctor or nurse, why or why not?
- g) *(If you did discuss any this with your provider)* What did staff do after you talked about paying your bills or household expenses?

21) Tell me about a time where having social support, like having someone in your life to talk to or to help you, affected your health. This could be in good or bad ways.

Probes (ask only if not covered already):

- a) [If respondent mentions a good experience:] Did you ever have a bad experience with finding someone to talk to that affected your health? If so, did you want help with this situation?
- b) Did you want help in this situation?
- c) Did you attempt to get help for this? If so, where did you go for help?
- d) Where would you like to get help with this in the future?
- e) Did you ever talk about this issue with your doctor or nurse? What was that like?
 - i) What kind of doctor/staff member was this?
- f) If you have not talked about this, do you think you would want to talk about this with your doctor or nurse, why or why not?
- g) *(If you did discuss any this with your provider)* What did staff do after you talked about having someone to talk to or help you?

22) Tell me about the last time that you went to the doctor. Did anyone ask you any questions about the things we just talked about, like housing, healthy food, having enough money, and having someone to talk to?

Probes (ask only if not covered already):

- e) *[If not asked at last visit:] Has you ever been asked about housing, healthy food, having enough money, and having someone to talk to by someone at Parkview?*
- f) What happened?
- g) Were you asked to fill out any forms or surveys? If so, what did they ask for?
 - a. If it was a form, did you fill it out?
 - b. Where were you in the office when you did this?
- h) Did you answer questions on a piece of paper, or did you have a conversation with someone who worked there?
- i) How much does this usually happen when you go to the doctor? *(for example, every time you go to the doctor?)*
- j) When was your last clinical visit?
- k) Have you ever had any phone calls with the doctor's office/clinic/Population Health?

23) [Read out questions of the screening tool in use in this clinical area] Right now, I am going to read to you a list of topics that staff in [clinic area] ask to patients to answer. Now I am going to ask you about your opinion about what staff should do if you say yes to any of these questions. [Read SDOH domains one-by-one:] What do you think the healthcare staff *should* to do with this information?

Probes (ask only if not covered already):

- a) [list of domains: education/literacy, employment, financial hardship, housing, food, transportation, social support, and safety/intimate partner violence]
- b) [this screening tool asked about X,Y, Z types of social needs.] What other barriers to living a healthy life that you think would be important for your doctor to know about?

PART B: Documenting Patients' Social Needs

24) Information about your health, like your blood pressure or a list of medications that you are taking, is kept in your medical record on computers at the hospital. When healthcare staff ask about your housing or how much money you have, they may also keep this information in your medical record. For the next few questions I will list different types of people who may look at your health and social information and ask you questions about what information each person should be able to look at.

- My doctor
 - Do you want this individual to have access to your health data, like your blood pressure, height and weight, medications, and medical conditions?

- Do you want this individual to have access to your social data, like your housing, food, financial situation, or social support?
 - Why do you think that they are looking at this information?
 - When do you think that they are looking at this information?
- Other doctors that I may see in the future
 - Do you want these individual(s) to have access to your health data, like your blood pressure, height and weight, medications, and medical conditions?
 - Do you want these individual(s) to have access to your social data, like your housing, food, financial situation, or social support?
 - Why do you think that they are looking at this information?
 - When do you think that they are looking at this information?
- Nurses
 - Do you want these individual(s) to have access to your health data, like your blood pressure, height and weight, medications, and medical conditions?
 - Do you want these individual(s) to have access to your social data, like your housing, food, financial situation, or social support?
 - Why do you think that they are looking at this information?
 - When do you think that they are looking at this information?
- Hospital staff
 - Do you want these individual(s) to have access to your health data, like your blood pressure, height and weight, medications, and medical conditions?
 - Do you want these individual(s) to have access to your social data, like your housing, food, financial situation, or social support?
 - Why do you think that they are looking at this information?
 - When do you think that they are looking at this information?
- Emergency room staff
 - Do you want these individual(s) to have access to your health data, like your blood pressure, height and weight, medications, and medical conditions?
 - Do you want these individual(s) to have access to your social data, like your housing, food, financial situation, or social support?
 - Why do you think that they are looking at this information?
 - When do you think that they are looking at this information?
- The hospital billing office
 - Do you want these individual(s) to have access to your health data, like your blood pressure, height and weight, medications, and medical conditions?
 - Do you want these individual(s) to have access to your social data, like your housing, food, financial situation, or social support?
 - Why do you think that they are looking at this information?
 - When do you think that they are looking at this information?

- My insurance company
 - Do you want these individual(s) to have access to your health data, like your blood pressure, height and weight, medications, and medical conditions?
 - Do you want these individual(s) to have access to your social data, like your housing, food, financial situation, or social support?
 - Why do you think that they are looking at this information?
 - When do you think that they are looking at this information?
- My family members (including partner, spouse, children, other adult relatives, familial caregivers)
 - Do you want these individual(s) to have access to your health data, like your blood pressure, height and weight, medications, and medical conditions?
 - Do you want these individual(s) to have access to your social data, like your housing, food, financial situation, or social support?
 - Why do you think that they are looking at this information?
 - When do you think that they are looking at this information?

25) If you could make decisions about the storage of information about your social needs, what decisions would you make?

26) How long should the clinical information, like blood pressure and medications be kept in your medical record? Why do you think that?

27) How long should the social information, like your living situation and food, be kept in your medical record? Why do you think that?

PART C: Patients' Desires for Health System Action on Social Needs

28) Preference Ranking

We will read to you 7 hypothetical choices about talking about your social needs. Please pick either your preferred choice for each question.

- [After patient answers each question, ask why they have that preference.]
- How often should you be asked about your social needs?
 - Once a year
 - At each clinical appointment
 - Is there another frequency that you would prefer?
- When should screening be performed?
 - During your appointment
 - Before your visit, on your own time
 - Or is there another time that you prefer?
- Who should review and respond to data about your social needs?

- Doctor
- Nurse
- Social Worker
- A clinic staff member (such as a medical assistant, check-in desk staff, or home health staff member)
- Or is there someone else that you prefer?
- How should screening be done?
 - Someone should ask you questions
 - You would prefer to fill out a form (paper or online) on your own
- Should Parkview address your social needs?
 - Yes
 - No
 - Who would you like to help with your social needs?
- Should your data be stored in your medical record?
 - Yes
 - No
- For how long should your data be stored?
 - For no more than 1 year
 - Should be stored forever
 - Is there another duration that you prefer?

29) Given everything we have talked about, I am going to ask your preferences sharing information about different types of social needs. We want to know first if you think this is important for a doctor to know then if you're comfortable telling them that information and why or why not. For each:

- a) Do you think that your [social need category] is important for the doctor to know about? Why?**
- b) Do you feel comfortable sharing information about [social need category] with your doctor? Why?**

education/literacy, employment, financial hardship, housing, food, transportation, social support, and safety/intimate partner violence

Level of Analysis	Domains
Individual-level (patient-reported)	Race/ethnicity
	Education
	Financial resource strain
	Stress
	Depression
	Physical activity

	Tobacco use and exposure
	Alcohol use
	Social connections and social isolation
	Exposure to violence: intimate partner violence
Community-level (geocoded)	Neighborhood and community compositional characteristics (residential address; census tract-median income)

30) Is there anything else that we did not discuss that you would like to add?

Thank you for participating in our study!

Demographic Survey (ask questions verbally)

10. What is your birth month? _____ What is your birth year? _____

11. What is your gender?

- Woman
- Man
- Non-binary
- Prefer not to disclose
- Prefer to self-describe

If you prefer to self-describe, please elaborate here: _____

12. What is your Sexual Orientation?

- Straight/Heterosexual
- Gay or Lesbian
- Bisexual
- Prefer to self-describe: _____
- Prefer not to say

13. What is your race/ethnicity? (Check all that apply)

- American Indian or Alaskan Native
- African American
- Arab or Middle Eastern
- Asian
- Black
- Latino or Hispanic
- Native Hawaiian and Other Pacific Islander
- White
- Other (specify): _____

14. What kind of health insurance do you have? (check all that apply)

- None, I have no health insurance
- Medicare
- Medicaid
- Veteran's Health Administration ("the VA")
- Private health insurance (e.g., Blue Cross Blue Shield, Aetna, Cigna, UnitedHealth Group)
- Health care that you bought on a healthcare insurance marketplace (i.e., "Obamacare," or the "Affordable Care Act")
- Other (specify): _____

15. What is the highest degree or level of school that you have completed? (check one)

- Grade 8 or less
- Grades 9 to 12, no diploma
- High school graduate or equivalent (GED)
- Some college
- Associate degree (e.g., AA, AS)
- Bachelor's degree (e.g., BA, BS)
- Graduate degree (e.g., MA, MS)
- Professional degree (e.g., MD, JD)
- Doctoral degree (e.g., PhD, Dr.Ph)

16. What is your monthly income?

- \$0 - \$1,000
- \$1,001 - \$2,000
- \$2,001 - \$3,000
- \$3,001 - \$4,000
- \$4,001 - \$5,000
- More than \$5,001

17. Who do you live with? (check all that apply)

- I live alone
- I live with a spouse or partner
- I live with my child or children
- I live with my parent(s) or parent(s)-in-law
- Other (specify): _____

18. Are you:

- Married
- Divorced
- Widowed
- Separated
- Never married
- A member of an unmarried couple

THANK YOU!

Chapter 4 Characteristics of U.S. Hospitals offering Social Care Services

4.1 Introduction

Hospital investments in services to address patients' social determinants of health (SDOH), collectively referred to as social care services (SCSs), are expected to improve health for patients and potentially for communities as well [1–3]. By offering SCSs, hospitals seek to improve utilization of needed healthcare services (e.g., by providing transportation services to get to/from clinical appointments), reduce unnecessary or low-quality services like emergency department use or readmissions (e.g., by facilitating food delivery in the home post-discharge to help people maintain health outside of the hospital), and may even help people engage in healthy behaviors (e.g., via programs related to healthy foods such as cooking or nutrition classes) [4,5]. Healthcare providers may offer SCSs directly or make referrals to community resources and services [3]. SCSs have been identified in various clinical settings [6], but evidence describing the prevalence of SCSs in US hospitals is sparse [7].

Hospital, community, and economic factors may influence the provision of SCSs. At the hospital level, factors such as size (number of beds), teaching status, or church affiliation, may influence how many and which types of SCSs are offered [7]. At the community level, hospitals in low-income or rural communities may face greater community need for SCSs, but those providers may have fewer resources with which to provide them [8–12]. Economic factors, such as recent policy initiatives like value-based payment programs and Accountable Care Organizations incentivize improved population health outcome measures encourage, through reimbursement models, healthcare providers to address patients' social needs as well as

community-wide needs [8,9]. Hospital profit status is likely to be another important factor influencing the number and types of SCSs. Since the passage of Medicare and Medicaid, non-profit hospitals maintain their tax-exempt status conditional on producing “community benefit” (CB) [13–15]. Hospital CB spending includes free or subsidized charity care, medical research, continuing education for clinicians, as well as social care services and community improvement activities [13]. This tax exemption was valued at \$24.6 billion in 2011 [16]. Between 2009-2014, nonprofit hospitals spent on average between 7.5-8.5% of their total operating budgets on CB activities, though the majority of CB spending (>85%) is for unreimbursed care [13,17,18].

As of 2008, nonprofit hospitals must report details of CB spending as a part of their tax return (Schedule H, Form 990) [14,17]. In addition, the Affordable Care Act requires federally tax-exempt hospitals to conduct community health needs assessments and develop plans to address identified community needs [14,17]. Twenty-three states have passed legislation adding further requirements for hospital CB spending to maintain tax-exempt status, including five states that specify a minimum CB amount [17,19,20]. While prior work has shown that hospitals’ CB spending in community-directed categories (community health improvement services, cash and in-kind contributions for community benefit, and community-building activities) are associated with lower Medicare readmission rates [21], evidence suggests that hospital community-directed spending was not associated with the sociodemographic characteristics of communities [22]. There is growing demand for increased accountability for hospitals’ CB efforts, including calls for tax exemptions to be based on outcomes [17] and proposed changes to make CB program more responsive to community needs, SDOH and health disparities [13,23–25]. Despite criticisms of the CB program as a whole, there are examples of successful efforts to better connect medical centers with local community agencies to improve population health [26].

This study documents the number and type of social care services offered by U.S. hospitals and determines how hospital characteristics are associated with services offered. Specifically, we use data from the 2018 American Hospital Association (AHA) Annual Survey to identify whether hospital profit-status is associated with the likelihood of offering more and specific types of SCSs. Given the expectations for community benefits by tax-exempt hospitals, we expect such hospitals to offer more SCSs than for-profit hospitals. Next, we look at the subset of tax-exempt hospitals to determine how community benefit spending and requirements are associated with the likelihood of offering more SCSs, as well as the likelihood of offering specific types of services. We combine the AHA survey data with 2017 IRS-Schedule H data reporting on the amount and type of CB spending by tax-exempt hospitals. We also include consider the role of state requirements for CB spending. We expect that greater spending on CB activities (i.e., not charity or unreimbursed care) by tax-exempt hospitals, as well as being in a state with additional CB requirements, will be associated with offering a greater number of SCSs. Understanding the extent and nature of SCSs offered at US hospitals, as well as the hospital characteristics associated with which types of SCSs are offered, can help to identify the extent of resources available to meet residents' social needs. It can also contribute to understanding whether policies regarding CB need to be changed or strengthened to facilitate greater provision of SCSs.

4.2 Background

4.2.1 Social Care Services

Social care services are those resources that address patients' health-related social needs and social risk factors [3]. National healthcare systems approach the delivery of social care in a variety of ways, including improving care coordination between health and social care

organizations using financial incentives and developing data sharing and communication portals to connect health and social care providers [27,28]. In the United States, social care may be directed at the community level or individual level. To improve community health, hospitals may partner with local social services agencies to fill care gaps in the community, including offering health education and improving housing and transportation infrastructure [3]. To improve the health of individuals, hospitals may offer social care services which provide assistance for patients' social needs. Social care services may range from providing information or referrals to resources in the community and direct assistance (e.g. rides to appointments or food) to more intensive assessments, case management, and health behavioral activation interventions [3].

Evidence about the effect of social care services on patients' health outcomes have been mixed, suggesting the need for multi-faceted interventions to address social needs [6,29]. Social care services have been associated with a range of positive health and social outcomes, including increased likelihood of quitting smoking [30], improved mental health [31], reduced blood pressure and lipoprotein cholesterol [32], resolution of legal issues [33], and increased fruit and vegetable intake and medication adherence [34]. In one example, significant reduction in the social needs of families has been demonstrated by a study in which SDOH screening and in-person community resource navigation services were offered at pediatric primary care visits [35]. However, other studies have shown no significant improvement in health outcomes following social care use [36–39]. For example, two recent studies showed no significant improvement in HbA1c levels of patients assigned to receive connections to community resources [32] and participation in a supplemental nutrition assistance program [34].

Evidence describing the prevalence of social care services in US hospitals is sparse, with current evidence focused on particular clinical settings or disciplines [7]. Currently, social care

services have been identified in adult and pediatric primary care clinics; urgent care clinics; patient centered medical homes (PCMH); federally qualified health centers (FQHCs); community health centers; cancer centers; and urban, rural, and Level 1 trauma center hospitals [6]. One survey of American pediatricians showed large variation in rates of referrals of patients to community resources, ranging from 23% of surveyed pediatricians reporting having referred a patient to housing services in the past year to 68.4% of pediatricians having referred a patient to public health insurance enrollment assistance [40].

Additionally, hospital characteristics and environmental factors may influence the prevalence of social care programs offered by each facility for a variety of reasons. Hospitals in low-income or rural communities may have less resources for social care programs due to lower profitability than facilities in wealthier communities [8,9]. Alternatively, lower-resourced communities may stand to benefit the most from social care programs, and hospitals in such communities may choose to direct resources towards addressing patients' social needs. Finally, hospitals may have offer social care resources as a part of coordinated care delivery via the hospital system that the hospital is a part of. While hospital systems may be able to offer high quality healthcare in an efficient and coordinated manner [10–12], prior work suggests that promised improvements in healthcare delivery are not always delivered and there has been little investigation of systems' offerings of social care services [12,41–45]. However, hospital system administrators may play an important role in investing in social care programs for hospitals, suggesting the need to determine if the prevalence of social care resources is determined by internal or external forces. Thus, there may be diversity in the implementation of social care programs by hospital type, location, resources, CB spending, and system.

4.2.2 Community Benefit

Nonprofit hospitals in the United States have additional motivation to provide care for patients' social needs, as they may earn a tax-exempt status in part due to an understanding that the charity care, or discounted healthcare for those unable to pay and who meet criteria for financial assistance [46], provided by these institutions reduces significant burden on the government to provide such services [13,14]. This tax exemption was valued at \$24.6 billion in 2011 [16]. The increase in insurance coverage for patients following the formation of Medicare and Medicaid in 1966 greatly reduced the need for charity care, causing the Internal Revenue Service (IRS) to allow nonprofit hospitals to maintain tax-exempt status conditional upon producing community benefit [13–15]. Community benefit spending may take many forms, including free or low-cost charity care, research, health professions education, and community improvement activities [13]. As of 2008, nonprofit hospitals must report details of CB work as a part of their tax return (Schedule H, Form 990) [14,17]. In 2010, the Patient Protection and Affordable Care Act (ACA) mandated that nonprofit hospitals conduct community health needs assessments (CHNA) and subsequently create community health improvement plans (CHIP) every three years [14,17]. At the federal level, there are not minimum standards for the amount of CBs a hospital is to provide, rather, the IRS creates a benchmark for each hospital's unique circumstances [13,47]. Furthermore, while certain types of CB spending, including uncompensated care and medical research expenditures, are easily calculated and reportable for tax exemption purposes, CB spending specifically focused on supporting communities (including coordination with community agencies and serving as a healthcare safety net) have been described as more difficult to compute due to hidden costs, such as staff effort and relationship building [48]. While community supporting activities add value, some argue that the difficulty of determining costs suggest that such services are not appropriate for determining tax exempt

status and instead are more important for enhancing organizational legitimacy in the community [48]. Despite this, there is need for continued reform of the CB program to shift its focus towards addressing the upstream SDOH in order to make an impact on the health of communities, rather than paying for unreimbursed healthcare [49].

Between 2009-2014, nonprofit hospitals spent between 7.5-8.5% of their total operating budgets on CB, though the majority of CB spending (>85%) is used on unreimbursed care rather than improving community health (5%) [13,17,18]. Previous work has attempted to understand how CB spending is allocated using Schedule H data [17,18,50] and qualitative interviews of hospital CB directors [51], though there has been limited investigation of community health improvement spending on social care services and resources. Bakken and colleagues investigate New York hospital's CB "community building" spending, showing that Community Support, Workforce Development, and Community Health Improvement Advocacy make up the majority of these expenditures (32.3%, 25.9%, and 17.7% of total community building dollars, respectively) [50]. Additionally, for more than half of New York hospitals, CB spending was found to be concentrated in only one or two community building categories (33.8% and 25.3%, respectively) [50]. With such a large proportion of CB spending allocated to unreimbursed medical care rather than on spending directly on community building activities, there is concern about the impact of CB spending on community health and the value that this tax exemption policy provides [17,52]. While prior work has shown that hospitals' CB spending in community-directed categories (community health improvement services, cash and in-kind contributions for community benefit, and community-building activities) are associated with lower Medicare readmission rates [21], evidence suggests that community-directed spending was not associated with the sociodemographic characteristics of communities, indicating that CB dollars were

directed in manners largely unrelated to potential community needs [22]. Internal organizational factors may partially explain the limited CB spending directed towards addressing upstream determinants of health, as CB managers have been found to have limited control over community health improvement budgets and little guidance regarding the allocation of resources [51]. Additionally, hospitals have been thought to lack the competencies and infrastructure necessary to participate in community health initiatives [18]. Thus, there is growing demand for increased accountability for hospitals' CB efforts, including calls for tax exemptions to be based on outcomes [17] and proposed changes to make the CB program more responsive to health disparities and SDOH [13,23,24]. Amongst these proposals are calls for the reporting of population health outcomes to retain tax-exempt status [25]. Despite criticisms of the CB program, there are examples of successful efforts to better connect medical centers with local community agencies to improve population health [26]

4.3 Methods

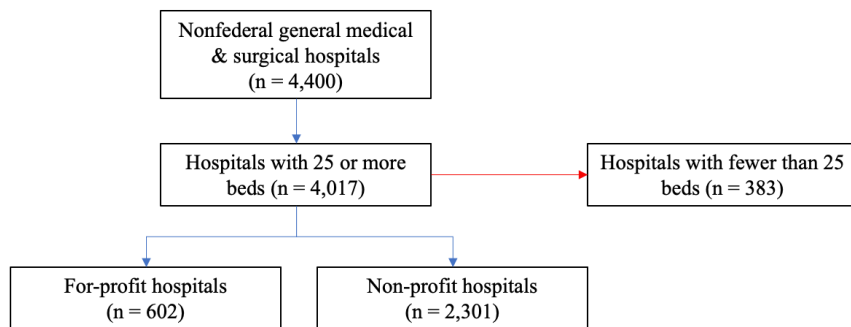
We performed a secondary analysis of data from the American Hospital Association (AHA) Annual Survey and data from Community Benefit Insight. The AHA Annual Survey collects data about facilities, services, payment, and staffing from 6,218 hospitals across the United States [53]. The 2018 version of the survey captures information about hospitals' participation in social care programs [53]. Community Benefit Insight provides information about the CB spending of tax-exempt hospitals [46].

4.3.1 Study Sample

We restricted our initial sample to nonfederal general medical and surgical hospitals (n = 4,400), with 25 or more beds (n = 4,017). Hospitals were categorized by the Control Code, or the

type of authority responsible for establishing policy concerning the hospital's operation of the hospital, variable in the AHA Survey as either For-profit (n = 602) or Non-profit (n = 2,301). Tax exempt hospitals include all nongovernment not-for-profit hospitals (Church operated or otherwise) as well as all nonfederal governmental hospitals, including those operated by a state, county, city, city-county, or hospital district/authority. For-profit hospitals include investor-owned facilities operated by an individual, partnership, or corporation. We excluded any observations with missing data in any of our measures of interest described below. For our sub-analysis of SCSs among Tax-exempt hospitals only, we exclude 1,226 hospitals affiliated with state or county governments exempt from Schedule H reporting requirements from the Non-profit group [54,55], as well as 1,233 hospitals that filed system-level CB spending as part of a larger health system with other hospitals on a single Schedule H Form 990 [18]. The final subsample of Schedule H Form 990 Tax-exempt only hospitals is 2,301.

Figure 4.1 Study Sample



4.3.2 Measures

Our dependent variables were count variables representing the total number of SCS offered by hospitals. While SCS are usually targeted at individuals, some SCS are focused at the community level [56]. As a result, we constructed two dependent variables: a measure of the total number of six individually-focused SCS [Enabling Services (programs to help patients

access health care services by offering transportation services and/or referrals to community social services agencies), Employment Support, Supportive Housing, Meal Delivery, Non-emergency Transportation, Insurance Enrollment Assistance Services] and a measure of the total number of five community-focused services (Community Violence Prevention, Community Outreach, Health Fairs, Community Health Education, and Mobile Health Services).

As our key independent variable of interest, we constructed a categorical measure of each hospital's total CB spending divided by total functional expenses. This variable featured 4 categories: below 5%, between 5%-7.49%, between 7.5%-10%, and greater than 10%, based on hospitals' average CB spending determined by Young et al. [18]. A continuous measure of each hospital's total CB spending divided by total functional expenses was also created.

We control for bed size (less than 100 beds, 100-499 beds, 500 or more beds), whether the hospital was affiliated with a system, whether the hospital had a teaching or religious affiliation, whether the hospital was its community's sole provider, whether the hospital was managed under contract by another organization, whether the hospital had any partnerships with local organizations community or population health improvement initiatives, the median household income of the county in which the hospital resides, and the type of area the hospital is situated in [metropolitan (50,000+ people), micropolitan (10,000-49,999 people), or rural (<10,000 people)].

4.3.3 Analysis

Data analysis was conducted using Stata 16.1. We calculated descriptive characteristics comparing For-profit and Tax-exempt hospitals on a range of hospital and community characteristics. We used negative binomial and Poisson regression models to first explore associations between Tax-exempt/For-profit status and number of SCS offered by hospitals in

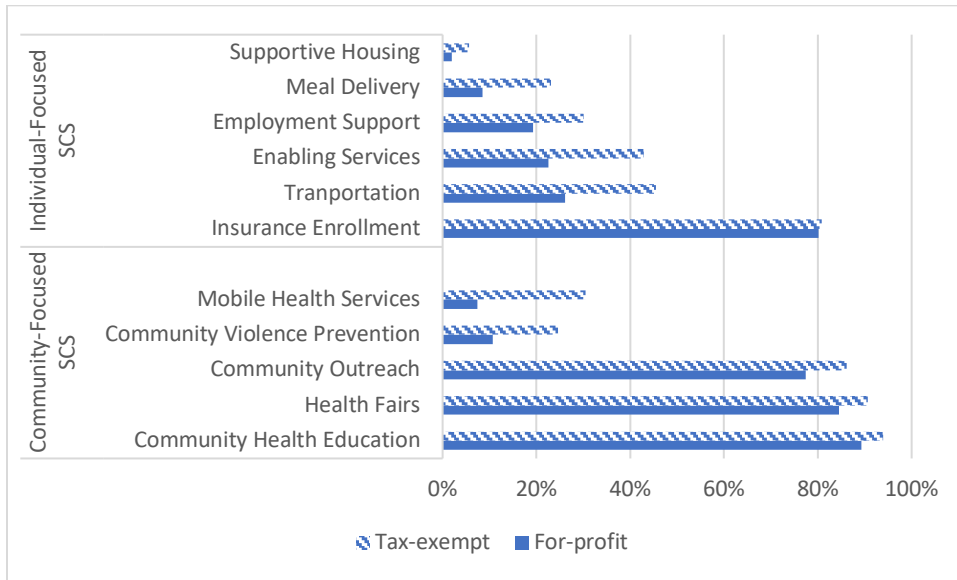
our full sample. Next, we use negative binomial and Poisson regression models to describe associations between CB spending and number of SCS offered within a subset of our sample, namely, those Tax-exempt hospitals which reported CB spending to the IRS via the Schedule H Form 990. In both Tax-exempt/For-profit status and CB spending models, we selected Poisson specifications due to tests of overdispersion of our dependent variables and the likelihood ratio test comparing fit of negative binomial and Poisson models. We did not find evidence of overdispersion of our SCS variables. Additionally, we used logistic regression models to explore associations between CB spending and each SCS independently.

4.4 Results

Table 1 compares the average number of SCS and characteristics of For-profit and Tax-exempt hospitals. Tax-exempt hospitals offered a significantly higher average number of SCS (5.54 total, 2.28 individual, and 3.26 community) compared to For-profit hospitals (4.28 total, 1.59 individual, 2.69 community).

Figure 2 shows the distribution of types of SCS offered by Tax-exempt and For-profit hospitals. Amongst individual patient-focused SCS, insurance enrollment was the most frequently offered SCS (For-profit: 80.17%, Tax-exempt: 80.86%), followed by transportation (For-profit: 26.17%, Tax-exempt: 45.45%) and enabling services (For-profit: 22.59%, Tax-exempt: 42.94%). Amongst community-focused SCS, community health education (For-profit: 89.26%, Tax-exempt: 93.96%), health fairs (For-profit: 84.57%, Tax-exempt: 90.64%), and community outreach (For-profit: 77.41%, Tax-exempt: 86.15%) were the SCS most frequently offered by hospitals.

Figure 4.2 Distribution of Types of SCS across all Hospitals, n=2,903



Source: AHA 2018 Annual Survey

Table 2 describes associations between the number of SCS (total number, number of individual SCS, and number of community SCS) offered by Tax-exempt and For-profit hospitals. Using Poisson regression, we do not observe any significant associations between Tax-exempt or For-profit status predictors and SCS (total number, number of individual SCS, and number of community SCS). We also observe significant positive associations between a number of hospital and community characteristics and number of SCS offered. Hospitals with 100-499 and 500+ beds were significantly associated with a greater number of total and individual SCS relative to those with 25-99 beds. Those hospitals with affiliations to healthcare systems were positively associated with having a larger number of total, individual, and community SCS relative to those hospitals with no system affiliations. Additionally, we observe a significant negative relationship between those hospitals who are managed under contract by another organization and SCS (total and individual), relative to those hospitals which are independently managed. Hospitals with partnerships with at least one external organization for population

health improvement were significantly associated with an increased number of both total and community SCS. Finally, while county median household income was significantly positively associated with the number of total and individual SCS, being located in a micropolitan (10,000-49,999 people) or rural (<10,000 people) area was significantly negatively associated with number of total (micropolitan and rural), individual (rural), and community (rural) SCS (Table 2).

Table 3 describes associations between the number of social care services and CB spending. We observe significant positive associations between CB spending at all levels ($\geq 5\%$ CB spending $< 7.5\%$, $\geq 7.5\%$ CB spending $\leq 10\%$, and CB spending $> 10\%$) and both total number of SCS (the sum of individual SCS and community SCS) and number of individual SCS offered by hospitals. We do not observe any significant associations between CB spending at any level with the number of community SCS offered by hospitals. Furthermore, while we do not observe any significant associations between the presence of a conditional or unconditional state CB requirement and number of SCS, we do find significant negative associations between the presence of a state minimum CB requirement and the total number of SCS and number of individual SCS offered by hospitals (Table 3). Additionally, in models with CB spending, we observe similar associations between bed size, system affiliation, contract management, partnerships for population health improvement, median household income, area, and the number of SCS offered by hospitals as shown in Table 2. In Poisson models featuring a continuous measure of CB spending/Total Expenses, we observe no significant association between CB spending and number of SCS offered by hospitals (Appendix).

Table 4 describes relationships between CB spending and the likelihood of offering each individual SCS by IRS Schedule H-reporting Tax-exempt hospitals. Here we report findings

regarding those SCS related to facilitating patients' access to healthcare. We observe significant positive associations between larger bed size, system affiliation, having partnerships for population health improvement, county median household income, and unreimbursed Medicaid and the likelihood of offering enabling services. Additionally, micropolitan and rural hospitals were significantly negatively associated with offering enabling services. (Table 4). We observed significant positive associations between the presence of a non-emergency transportation program and all levels of CB spending five percent and above, with hospitals with 100-499 beds, with system affiliation, and with median household income. Finally, the presence of insurance enrollment assistance services was significantly positively associated with unreimbursed Medicaid and hospitals with system affiliations, and was significantly less likely in rural hospitals, those managed under contract, and those operating in states with a minimum CB spending requirement.

Table 4 also describes relationships between CB spending and the likelihood of offering individual SCS unrelated to healthcare access by IRS Schedule H-reporting Tax-exempt hospitals. System affiliation and county median household income were significantly associated with an increased likelihood of offering employment support, while hospitals under contract management and in rural communities were significantly less likely to offer this service. County median household income was significantly positively associated with likelihood of offering supportive housing services, while having a state minimum CB requirement was significantly negatively associated with offering housing assistance. Finally, county median household income was significantly associated with increased likelihood of offering meal delivery, while the operating in a state with a CB requirement was significantly associated with a reduced likelihood of offering this service.

Table 5 describes relationships between CB spending and the likelihood of offering each community SCS by IRS Schedule H-reporting Tax-exempt hospitals. We observed significant positive associations between all levels of CB spending five percent and above and mobile health services, and between CB spending greater than ten percent of total expenses and offering community violence prevention programs. We find a significant positive association between state CB requirements and the likelihood of providing community violence prevention programs, as well as significant negative associations between offering mobile health services and having a minimum state CB spending requirement. Hospitals with system affiliations were significantly more likely to offer community violence prevention and mobile health services than non-system affiliates, while hospitals with teaching affiliations were significantly more likely to offer community violence prevention programs than nonteaching facilities. Hospitals serving as the sole community provider were significantly less likely to offer community health education programs, while those hospitals with partnerships for population health improvement were significantly more likely to offer community violence prevention, community outreach, and mobile health services than those without partnerships. County median household income was significantly positively associated with likelihood of offering community violence prevention and community outreach programs. The type of geographic area in which hospitals were located was significantly negatively associated with likelihood of offering community violence prevention (rural) and mobile health services (micropolitan and rural) relative to hospitals located in urban areas. Hospitals' amount of unreimbursed Medicaid expenditures were significantly positively associated with likelihood of community violence prevention programs. We observe no significant relationships between bed size, church affiliation, and contract management with any community SCS.

4.5 Discussion

There have been calls for healthcare organizations to address patients' social needs as a means of improving health outcomes and preventing disease [57,58]. As patients undergo SDOH screening to identify social needs, it is important to ensure that communities have sufficient capacity to offer resources to address those needs [59]. Hospitals, sometimes considered anchor institutions, are critical components in social services infrastructure [58], and here we explore the factors associated with the number of SCS offered by hospitals. Spending on CB, including on community health improvement, contributes to maintaining Tax-exempt status, and here we demonstrate that Tax-exempt hospitals offer significantly larger number of SCS than for-profit facilities. However, in regression analysis, we do not observe any significant associations between Tax-exempt/for-profit status and the number of SCS offered by hospitals. Furthermore, Tax-exempt hospitals spend on average 7.5% of their annual operating expenses on CB [18], and here we observe significant positive associations between CB spending (both below and above 7.5%) and number of total and individual SCS offered by hospitals. Finally, while CB spending was significantly positively associated with offering nonemergency transportation, CB spending was not significantly associated with the likelihood of offering any other SCS.

This study builds on earlier work describing the prevalence of SCS offered by hospitals [7,60,61]. Focusing specifically on nonfederal general medical and surgical hospitals, while we demonstrate the larger, resource-rich hospitals may provide more SCS than those lesser-resourced facilities, a recent study has shown that non-profit hospitals in the top quartile of financial performance spend less on charity care relative to overall net income than hospitals in the third quartile of financial performance [61]. While we show that CB spending is significantly positively associated with number of both total and individual SCS, we find no significant

relationship between CB spending and community-focused SCS. This finding is unsurprising, as much of hospitals' CB spending is focused on charity care and other direct patient medical care services, rather than on community health improvement efforts [18]. Moreover, we observe that hospitals in states with minimum CB spending requirements were significantly negatively associated with number of total and individual SCS, suggesting that hospitals in these states may be incentivized to not exceed CB spending beyond the minimum requirement. Hospitals are able to include numerous types of spending in CB reporting, including charity care, unreimbursed care, subsidized health services, research, health professions education, financial contributions to community groups, and community health improvement investments [18]. As a result, there may be opportunities to design policy specifically focused on incentivizing expenditures on SCS, including efforts by Medicaid and Medicare to expand coverage for SCS [7,62].

In order to address patients' social needs disclosed during screening, hospitals must have sufficient social care resources and programs in place. Decisions to disclose social needs to healthcare providers may carry emotional burden and require judgements by patients about where, when, and how to ask for help [63]. Collection of SDOH information in healthcare settings may create an expectation of action, and thus, screening without sufficient social care resources in place to address patients' disclosed social needs may result in a failure to meet expectations, causing compromise to the provider-patient relationship [63,64]. Thus, there is a need to ensure that hospitals have sufficient capacity to guarantee necessary referrals to community resources to meet patients' social needs prior to screening. Similarly, the distribution and capacity of existing social care programs have implications for the reduction or perpetuation of health disparities in the US. If a community's hospital(s) lack access to social care programs help address patients' social needs, then this absence of resources may cause patients' needs to

go unmet. Thus, it is important to identify those communities in which patients' social needs may not be sufficiently met by their hospitals' social care programs in order to inform policy related to the equitable allocation of social care resources.

This study has a number of implications for the provision of SCS in US hospitals. First, variation in the level of SCS observed here suggests that policy makers and administrators must consider the capacity of facilities to provide social care, especially as a sufficient amount of SCS should be provided by hospitals or community partners to support SDOH screening work. Additionally, while there is much support for hospitals to address patients' social needs, there is need for critical discussion of the potential of hospital-provided SCS to address those needs. While SCS may be necessary to improve the health of individual patients, these interventions are not sufficient to address the health of communities, also known as the upstream SDOH [56,65]. Furthermore, there is concern about who benefits from both individual and community level SCS. When offered by hospitals, the population that benefits from such resources are most often the facility's patient catchment area, rather than the entire geographic community in which the hospital operates, a phenomenon known as "denominator shrinkage" [56]. Instead, SCS are intended to address individuals' broader needs beyond physical health. Thus, SCS will not truly address "population health" and "the SDOH," which would require efforts to undo segregation, fund education, and address poverty, amongst many other necessary community interventions which may be outside of the capacity of what individual healthcare organizations can feasibly accomplish by providing SCS. Instead, SCS should be focused on addressing the social needs of individual patients. Furthermore, community-focused SCS may contribute to some population health improvement, such as by offering community antiviolence education programming or

farmers markets to improve access to healthy foods, though the limited potential impact of these interventions should be noted.

Additionally, this study has implications for the development of future health information technology (HIT). Expansion of SCS may require hospitals to leverage community partners by offering referrals for patients to seek social services at other organizations, which may offer SCS beyond what is available at a hospital. Electronic community resource referral platforms (CRRP) afford hospitals the ability to digitally refer patients to outside organizations, which may allow for faster and more efficient referrals [66]. However, the use of CRRPs may create cost barriers for community social services agencies and smaller hospitals, who lack the necessary technological infrastructure or be unable to afford the cost of implementation and service fees, further perpetuating existing inequalities amongst lesser-resourced organizations. Furthermore, social service agencies may enter and exit communities quickly, and in some instances faster than CRRP databases may be able to be updated, suggesting the need for local referral experts, including social workers and community health workers, to facilitate referrals [67]. Social workers and community health workers may also receive feedback from patients following referrals about the quality and experience of using a resource, further enriching knowledge of local resources [67]. Combining local expertise with HIT tools may lead to more successful referral practices which benefit from both the rich experiential knowledge of local experts as well as the broader databases of CRRPs to expand hospitals' abilities to offer a broad range of social care in collaboration with local organizations.

This study has several limitations that must be considered. First, because data about the SCS offered by hospitals is only available for one year, we use a cross sectional design. As a result, we are not able to explore any trends in the implementation of SCS by US hospitals. As

additional data about SCS implementation is made available, longitudinal designs may capture greater detail about how hospitals' capability to address individual social needs changes over time. Additionally, the AHA measures only a narrow set of SCS, suggesting that hospitals may be offering assistance for other social needs that we are unable to measure here. Finally, due to state variations in CB reporting requirements, our dataset does not have representation from all states, limiting our ability to measure SCS nationwide.

4.6 Conclusion

While CB spending is associated with larger numbers of individually-focused and total SCS offered by hospitals, the design of the CB incentive program may benefit from revisions to ensure that hospital spending is focused on programs which address patients' social needs to improve community health. Furthermore, as SDOH screening programs experience more widespread implementation, further research will be necessary to determine if hospitals have the capacity to address patients' social needs.

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Table 4.1 Characteristics of For-profit and Tax-exempt Hospitals (n=2,903)

	For-profit n = 602 (mean)	Tax-exempt n = 2,301 (mean)	Bivariate test
Total # SCS	4.28	5.54	t = -10.10, p = 0.0
# Individual SCS	1.59	2.28	t = -8.77, p = 0.0
# Community SCS	2.69	3.26	t = -9.02, p = 0.0
Characteristics	(%)	(%)	
Bed Size			
25-99	33.22	51.98	$\chi^2 = 92.73$ p = 0.0
100-499	63.79	41.89	
500+	2.99	6.13	
System Affiliated	86.88	53.28	$\chi^2 = 224.87$ p = 0.0
Not system affiliated	13.12	46.72	
Teaching Affiliation			
Teaching	0.83	6.00	$\chi^2 = 27.20$ p = 0.0
Nonteaching	99.17	94.00	
Church Affiliation			
Church	2.66	11.56	$\chi^2 = 43.12$ p = 0.0
Secular	97.34	88.44	
Sole Community Provider			
Yes	6.98	8.30	$\chi^2 = 1.13$ p = 0.29
No	93.02	91.70	
Contract Managed			
Yes	4.75	11.43	$\chi^2 = 14.43$ p = 0.0
No	95.25	88.57	
Hospital has a Partnership for Population Health Improvement			
Yes	13.57	15.52	$\chi^2 = 0.66$ p = 0.418
No	86.43	84.48	
Median Household Income in the Hospital's County	\$52,191.92	\$56,403.51	t = -1.40 p = 0.0809
Area			
Metropolis	75.58	52.89	$\chi^2 = 113.68$ p = 0.0
Micropolis	15.28	20.17	
Rural	9.14	26.94	
Unreimbursed Medicaid	\$4,242,205	\$9,159,595	t = -1.13 p = 0.1301

Table 4.2 Association Between Number of Social Care Services and Hospital Type, Incidence rate ratios

	Total # of Social Care Services	# of Individual Social Care Services	# of Community Social Care Services
Tax-exempt Hospitals (reference: For-profit Hospitals)	1.324	1.418	1.262
Bed Size			
100-499	1.093**	1.148**	1.055
500+	1.155*	1.249*	1.090
System Affiliated	1.143***	1.212***	1.096*
Teaching Affiliation	1.069	1.027	1.103
Church Affiliation	0.997	0.985	1.007
Sole Community Provider	1.000	0.996	1.003
Contract Managed	0.887*	0.805*	0.943
Hospital has a Partnership for Population Health Improvement	1.093**	1.087	1.098*
Median Household Income in the Hospital's County	1.000**	1.000***	1.000
Area			
Micropolis	0.915*	0.901	0.924
Rural	0.814***	0.756***	0.852**
Unreimbursed Medicaid	1.000	1.000	1.000

Table 4.3 Association Between Number of Social Care Services and Community Benefit Spending in IRS Schedule H-reporting Tax-exempt Hospitals, Incidence rate ratios

	Total # of Social Care Services		# of Individual Social Care Services		# of Community Social Care Services	
	1	2	1	2	1	2
CB spending/Total Expenses						
>= 5% & < 7.5%	1.088*	1.088*	1.134*	1.133*	1.058	1.057
>= 7.5% & <= 10%	1.107**	1.111**	1.136*	1.143*	1.089	1.090
> 10%	1.087*	1.087*	1.138*	1.138*	1.053	1.053
(ref: CB < 5%)						
State has a CB Requirement	0.998	1.022	0.943	0.981	1.041	1.053
State has a Minimum CB Requirement	-	0.909*	-	0.845**	-	0.956
Hospital has a Partnership for Population Health Improvement	1.090**	1.081*	1.086	1.071	1.093*	1.089
Median Household Income in the Hospital's County	1.000**	1.000***	1.000***	1.000**	1.000	1.000
Area						
Micropolis	0.912*	0.910*	0.898	0.896	0.921	0.921
Rural	0.820***	0.818***	0.763***	0.759***	0.858**	0.857**
Bed Size						
100-499	1.095**	1.092**	1.162**	1.157**	1.049	1.048
500+	1.149*	1.148*	1.263*	1.263*	1.070	1.070
System Affiliated	1.137***	1.137***	1.207***	1.208***	1.090*	1.090*
Teaching Affiliation	1.069	1.076	1.020	1.031	1.108	1.112
Church Affiliation	1.003	1.007	0.984	0.992	1.017	1.019
Sole Community Provider	0.991	0.998	0.983	0.995	0.996	1.000
Contract Managed	0.895*	0.895*	0.818*	0.817*	0.947	0.947
Unreimbursed Medicaid	1.000	1.000	1.000	1.000	1.000	1.000

Table 4.4 Odds Ratios for Hospital Characteristics, including Community Benefit (CB) Spending, on Individually-focused Social Care Services among Tax-Exempt Hospitals, N=2,301

	Insurance Enrollment Assistance Services		Non-emergency Transportation		Enabling Services		Employment Support		Meal Delivery		Supportive Housing	
	1	2	1	2	1	2	1	2	1	2	1	2
CB spending/ Total Expenses												
5% to < 7.5%	1.140	1.148	1.632**	1.635**	1.208	1.208	1.244	1.244	1.134	1.131	1.400	1.398
7.5% to 10%	1.436	1.425	1.598*	1.628*	1.283	1.287	1.165	1.182	1.013	1.022	1.322	1.412
> 10%	1.130	1.144	1.445*	1.450*	1.161	1.163	1.237	1.240	1.268	1.264	1.139	1.155
State CB Requirement	0.999	1.223	0.885	1.008	0.904	0.923	1.037	1.120	0.591***	0.647**	1.015	1.241
State Minimum CB	---	0.529*	---	0.597**	---	0.925	---	0.730	---	0.681	---	0.261*
Partnership for Population Health Improvement	1.646	1.572	0.907	0.868	2.033***	2.021***	1.220	1.188	1.124	1.095	1.321	1.218
Median Household Income in the Hospital's County in US Dollars	1.000	1.000	1.000*	1.000*	1.000**	1.000**	1.000*	1.000*	1.000**	1.000**	1.000**	1.000**
Region												
Micropolis	0.647	0.634	0.634*	0.627*	0.548**	0.547**	1.092	1.090	1.295	1.288	0.973	0.957
Rural	0.340***	0.331***	0.673	0.661*	0.416***	0.415***	0.608*	0.602*	1.317	1.304	0.727	0.692
Bed Size												
100-499	1.064	1.046	1.525**	1.509**	1.554**	1.553**	1.354	1.345	1.220	1.206	1.082	1.058
500+	0.971	0.906	1.913	1.916	2.966*	2.958*	1.601	1.601	1.269	1.266	1.897	1.897
System Affiliated	1.726**	1.685*	1.406*	1.405*	1.936***	1.934***	2.034***	2.034***	1.083	1.082	1.596	1.636
Teaching Affiliation	1.0	1.0	0.950	0.985	2.051	2.060	1.486	1.522	0.579	0.595	0.535	0.579
Church Affiliation	0.708	0.745	0.792	0.812	1.226	1.232	0.912	0.927	1.190	1.209	0.654	0.675
Sole Community Provider	0.835	0.903	0.963	1.004	1.382	1.391	0.669	0.681	1.258	1.293	1	1
Contract Managed	0.559*	0.555*	0.925	0.924	0.718	0.718	0.289***	0.289***	1.082	1.077	0.437	0.435
Unreimbursed Medicaid	1.000***	1.000**	1.000	1.000	1.000*	1.000*	1.000	1.000	1.000	1.000	1.000	1.000

Notes: * p<0.05, ** p<0.01; Source: AHA 2018 Annual Survey and Community Benefit Insight

Table 4.5 Odds Ratios for Hospital Characteristics, including Community Benefit (CB) Spending, on Type of Community-focused Social Care Services among Tax-Exempt Hospitals, N=2,301

	Community Health Education		Health Fairs		Community Outreach		Community Violence Prevention		Mobile Health Services	
	1	2	1	2	1	2	1	2	1	2
CB spending/Total Expenses										
5% to < 7.5%										
7.5% to 10%	1.510	1.516	1.083	1.083	1.179	1.184	1.273	1.271	1.813**	1.816**
> 10%	3.720	3.577	2.373	2.382	1.547	1.535	1.570	1.590	1.941**	1.992**
	0.876	0.881	0.826	0.814	0.763	0.772	1.635*	1.638*	1.694*	1.705*
State CB Requirement	0.877	1.226	1.619	1.372	1.442	1.669	1.487*	1.566**	1.179	1.316
State Minimum CB	---	0.402	---	2.233	---	0.626	---	0.806	---	0.633*
Partnership for Population Health Improvement	4.209	3.932	1.332	1.398	2.636*	2.548	2.341***	2.298***	1.612**	1.552*
Median Household Income in the Hospital's County in US Dollars	1.000	1.000	1.000	1.000	1.000*	1.000*	1.000***	1.000***	1.000	1.000
Region										
Micropolis	0.694	0.642	0.816	0.818	0.693	0.691	0.693	0.691	0.463***	0.459***
Rural	0.377	0.344	0.544	0.546	0.572	0.569	0.438**	0.434**	0.302***	0.296***
Bed Size										
100-499	0.621	0.576	1.643	1.660	1.700	1.690	1.245	1.239	1.342	1.330
500+	1	1	0.947	0.976	0.913	0.877	1.287	1.283	1.849	1.847
System Affiliated	1.177	1.115	1.307	1.327	1.537	1.513	2.043***	2.053***	2.060***	2.075***
Teaching Affiliation	1.0	1.0	1.0	1.0	1.0	1.0	2.646**	2.693**	1.692	1.755
Church Affiliation	0.848	0.912	1.086	1.055	0.856	0.881	1.041	1.051	1.278	1.306
Sole Community Provider	0.343*	0.387	1.687	1.567	1.360	1.438	0.827	0.839	0.987	1.018
Contract Managed	0.458	0.450	0.877	0.889	0.810	0.800	0.696	0.696	0.755	0.759
Unreimbursed Medicaid	1.000	1.000	1.000	1.000	1.000	1.000	1.000*	1.000*	1.000	1.000

Notes: * p<0.05, ** p<0.01; Source: AHA 2018 Annual Survey and Community Benefit Insight

Chapter 5 Conclusion

The call for achieving increased value in healthcare has caused healthcare organizations to begin screening to identify patients' social risk factors to address social needs, called social care. However, the implementation of many programs precedes the presence of ample scientific evidence regarding best practices for social risk factor screening and social care. Implementing screening and referral programs is not without potential consequences, as patient and provider respondents in this study expressed concern about the potential for patients to be embarrassed, stigmatized, or to receive biased treatment based on sensitive social risk factor data. Furthermore, without social care experts present at every healthcare encounter, much screening and related social care responses may shift to clinicians and staff who may have capacity and preparation for this work. There is a need to ensure that social care programs are available to patients who may screen "positive" for social risks that they subsequently identify as social needs.

This dissertation uses qualitative and quantitative data to characterize the implications of implementing social risk factor screening and social care programs for providers, patients, and healthcare systems. Together, these studies demonstrate the potential for social risk factor data to be collected to facilitate social care and medical decision-making, identify potential concerns about the capacity of healthcare organizations to do this work, and present opportunities for investment in both the social and technical subsystems of the sociotechnical social care system [1].

In Chapters 2 and 3, interviews with providers and patients affirm interest from both groups in healthcare-provided services to address patients' social needs. These data, when partnered with training, information, and tools to help clinicians make sense of and use these data, may allow providers to better understand those social contexts which may contribute to health outcomes and offer resources to address social needs. Providing social care in healthcare settings may require changes to the workflows and professional jurisdiction of provider and staff roles to take on new responsibilities related to social needs, including learning workflows related to screening and referrals, in addition to becoming aware of the range of available referral resources, programs, and the organizations which offer them. Furthermore, providers may require training in interpersonal communication skills related to the discussion of social needs and potential resources to address them. Respondents indicated that education and training may be important to create buy-in to adopting these new workflows, which may be perceived by some providers and staff as outside of their professional jurisdiction of responsibility.

In Chapter 2, in interviews with clinicians, social care experts, and administrators, respondents described numerous benefits of having access to social risk factor data, including providing referrals to social care experts and programs to address patients' social needs, sharing information with patients about local resources, using these data to determine treatment eligibility and preferences, and using aggregate data to assess social needs across the patient population and measure the impact of social care interventions. Respondents also described challenges faced when collecting and using social risk factor data, including a need for education about why and how to perform screening, the need for information and tools to facilitate referrals to social care, the desire for specific staff to collect and use these data, the potential for adverse experiences for patients during screening, including concern about judgment, embarrassment,

discomfort, and frustration, and the need for practitioners to take responsibility for screening and social care work. This study reiterates providers' interest in capturing and using social risk factor data to address patients' social needs while underscoring the importance of supporting providers in this complex work, which often extends beyond the typical professional jurisdiction of many clinicians, through training and informational tools. Additionally, considering the constraints under which many clinicians operate, healthcare administrators should consider investments in both training existing providers and staff to perform screening and social care, as well as expanding the workforce of social care experts, such as social workers, navigators, and community health workers, to expand hospitals' capacity to address patients' needs.

This study builds on professions theory by demonstrating a unique case in which demands are placed on healthcare professionals to collect and use social risk data, which may typically fall outside of the professional jurisdiction of many clinicians. Thus, the managerialization of social needs under value-based payment models [2–6] creates external pressure on healthcare professionals to adopt new information behaviors related to social care, and this study suggests that clinicians may require additional support to adopt these new tasks. Additionally, implementation of additional social care tasks may require delegation of tasks across professional boundaries to ensure that healthcare team members assigned with screening and referrals have sufficient time, training, tools, and support to complete this work without contributing to burnout. Future scholarship is needed to understand how professionals respond to shifts in their information behaviors caused by the pressures of managerialization.

In Chapter 3, participants described barriers and facilitators of sharing social risk factor information during screening. Barriers included the perceived risks and relevance of social risk factor data for providers, while facilitators included strong patient-provider relationships and

having an expectation of help following the disclosure of a need. Respondents made judgments of the relevance of social risk factor information on the delivery of healthcare, both in the short and long term, which in turn impacted views of whether these data should be documented in the EHR. Participants generally expected help from the healthcare system with social needs, though they also expected that providers and staff have competency related to performing this work, which subsequently contributed to which types of providers and staff respondents felt comfortable receiving assistance from. Similarly, having enough time to establish rapport and build relationships with providers was viewed as an important facilitator of discussing social needs. Finally, respondents expressed concern about potential risks of disclosure of social needs during screening, including embarrassment and bias, and such concerns caused some participants to prefer to have limited or modifiable documentation of social risk factors in the EHR. Thus, screening and social care programs in healthcare settings must consider these facilitators and barriers to create programs that are acceptable to patients.

Similarly, while patients expressed interest in participating in social risk factor screening to create new opportunities to address needs in healthcare settings, the implementation of screening and social care programs may require efforts to communicate the presence and purpose of these services for patients to understand how social risk factor data will be used and how these data will be stored. Such communication is critical given patients' decisions about the relevance of information about social risk factors to providers as a potential component of participating in screening and choosing to share experiences of social needs. Patients in this study described considering if information about social risk factors was relevant to the delivery of healthcare, including their access to healthcare or to explain their health status, as well as if one's social needs were "bad enough" to warrant discussion with a doctor.

Maintaining patient agency is critical as social control is exerted by screening, as patients may have preferences for whether and where to receive help with social needs. For example, a patient who is staying with friends on a long-term basis, but who does not have a home of their own, may screen positive for a housing need but may not want subsequent support. Similarly, patients may wish to seek assistance for social needs from community organizations or from within their social networks, rather than from the healthcare organization. A key component of such decisions was patients' perception of who held responsibility for social needs, with some believing that social risk factors were the responsibility of patients, including feeling that it is a patient's responsibility to share needs when they are relevant, feeling that it is up to patients to make healthy lifestyle choices and that it is not the responsibility of the healthcare organization to address social needs. Thus, patients' decisions to share information about social needs during screening may be based on their understanding of the range of services that they believe the healthcare organization can provide and their perception of the professional jurisdiction of providers and staff.

Interviews with patients present several implications for medicalization theory. First, screening may exert social control by labeling patients as having undesired characteristics. Screening itself may decontextualize complex social problems and shift responsibility onto patients. The data generated by screening may persist indefinitely in the EHR, potentially exposing patients to bias, discrimination, stigmatization, and privacy violations. Screening and social care may allow providers to become gatekeepers of access to referrals, as providers may make decisions about who to screen and which resources to offer based on biases and perceptions of morality or worthiness. At the societal level, healthcare screening and referral programs may disrupt community social safety nets, including placing a burden on social

services agencies to receive referrals. Open questions related to the medicalization of social needs remain, including what obligations do patients have to share information about social risk factors, what obligations do patients have to use referral resources, and what obligations do providers have to address social needs?

This body of work also suggests the need for healthcare organizations to create sufficient capacity to address social needs as a precursor to implementing social risk screening programs. Chapter 4, a quantitative study of US hospitals, explores associations between the current primary financial policy incentive for hospitals to implement various social care services, the Community Benefit tax exemption, and shows significant positive associations between hospitals' Community Benefit spending and the number of types of social care services offered, as well as a greater average number of social care services offered by tax-exempt hospitals relative to their for-profit counterparts, who have no Community Benefit spending requirements. However, it should be noted that hospitals spend relatively little of their annual operating budgets on social care (on average 7.5%) and much of this spending is used for financial assistance for direct patient care [7], despite calls for hospitals to begin initiatives targeting the “upstream” social determinants of health [8,9], suggesting an opportunity for new policy incentives targeted in this area.

Additionally, this analysis reveals two concerning findings. First, hospitals in states with minimum Community Benefit spending requirements offered fewer types of social care services on average, compared to states without such requirements. This suggests that current minimum spending policies may encourage hospitals to spend only up to the minimum threshold, potentially disincentivizing the implementation of additional social care services. Additionally, no significant relationship between Community Benefit spending and community-focused social

care services is observed, suggesting that hospitals currently do little to improve health conditions at the level of the patient population. Future iterations of Community Benefit policy must consider the impact of interventions targeted at patients' social needs to maximize benefit and value. The move towards documentation of social risk factors in the EHR, especially using standardized, discrete data formats, may allow for improved reporting and outcomes measurement, an understudied area of research [10]. Additionally, continued measurement of the implementation of social care programs is necessary to understand the capacity of hospitals to address patients' needs when identified during screening.

An important component of capacity to perform social care is providers' and staff's preparedness to address social needs, and Chapter 2 shows that clinicians require support to take on screening and social care work. Patients in this study emphasized the importance of sustained hospital investment in social care efforts if screening is to occur to ensure that the sharing of needs is met with an action-oriented response. Indeed, patients and providers agreed that screening without timely and efficacious response is problematic. For providers, as social needs are medicalized and social care work is incorporated into the range of tasks non-social care experts are expected to complete, support may be necessary to ensure that patients receive sensitive and high-quality social care similar to what would be expected from a social worker or navigator. Necessary support may include education about the purpose and importance of social care interventions and training regarding how to perform screening and referrals. For patients, it may be necessary to communicate which types of services a hospital can provide locally or via referrals to partnering organizations. Such communication may be important for patients to set expectations for providers' response following the disclosure of social needs, which in turn may help patients decide whether to share needs during screening. Ensuring capacity may also require

providers to create the right conditions for screening to take place, including creating time within the clinical encounter, facilitating the building of rapport and relationships between patients and providers, conducting the interpersonal work necessary to help patients understand and apply to programs, and offering patients choices regarding whether and how to participate in screening and referrals. Finally, interventions targeting social needs should not contribute to or perpetuate health disparities, and thus, programs should ensure that screening and social care are multilingual and available in a wide range of clinics to ensure that all patients have access.

5.1 Strength of Methodological Approach

This dissertation attempts to leverage the individual advantages of qualitative and quantitative research to provide a more comprehensive understanding of contemporary issues in healthcare-provided social risk factor screening and social care. Given the relatively emerging nature of the literature on healthcare interventions on patients' social needs, and the subsequent need to inform the implementation of screening and referral programs, qualitative interviews are used in an exploratory capacity to surface themes related to patients' and providers' experiences and perspectives. Given the relative youth of social care work at Parkview, two stakeholder meetings were held to identify a wide range of providers, staff, and administrators involved in screening and referrals, creating a range of perspectives across many clinical specialty areas in the sample.

In the quantitative analysis presented in Chapter 4, a combined dataset containing data from the American Hospital Association (AHA) Annual Survey with fiscal reporting and Community Benefit Insight is used to generate a novel dataset allowing me to explore associations between Community Benefit spending and the number and types of social care services offered by US hospitals. Additionally, given the focus on the number of social care

services offered by each hospital, Poisson regression models were used, which were selected after assessing potential overdispersion in the dependent variables and performing a likelihood ratio test comparing model fit with that of negative binomial models.

5.2 Implications for Policymakers

Analysis of current Community Benefits spending and social care service implementation data suggests a need for improved policy which more directly incentivizes interventions targeting both individual and community social needs. Presently, much Community Benefit spending is directed at charity care, with little remaining for programs addressing social needs, much of which is focused on the needs of individual patients rather than of the community at large. Furthermore, the observation that state Community Benefit spending minimum requirements are not associated with the implementation of additional social care services suggests the need for revised policy incentives for the creation of new social care capabilities. There has been much discussion about the limitations of social care programs to directly affect the community-level factors which influence health [8,9], suggesting the need for Community Benefit spending policy to require programs that address the needs of the hospitals' geographic communities, rather than only patient populations. Additionally, policy may be updated to suggest numerous types of social care which may be implemented to target a wide range of social needs, rather than allowing the majority of Community Benefit spending to be directed at charity care. The need for rigorous outcomes research to measure the impact of screening and social care interventions is known [10], and efforts to improve documentation of social risk factors using standardized, discrete data, completed by, rather than replacing narrative detail, may contribute to such research efforts.

5.3 Implications for Informatics

In addition to improving the documentation of social risk factors in the EHR, informatics may play an important role in improving social risk factor screening and social care from both the provider and patient perspectives. Providers may benefit from greater accessibility of social risk factor data in the EHR. Additionally, the utilization of a balance of standardized, discrete data fields and narrative text may provide the benefits of computable data, including searchability, interpretability, reporting, and analytics, with the need to capture additional detail outside of standardized data elements. From the patient perspective, there is a need to consider patients' desire for the ability to modify or delete social risk factor data in the EHR. This is an understudied challenge given the legally binding nature of medical records [11–14]. One solution to this challenge is to better inform patients of data documentation practices, including what types of data are collected, for how long data are retained, and who has access to them. By learning about data practices, patients may make more informed decisions about participating in social risk factor screening. The documentation of potentially sensitive social risk factors in the EHR is an important aspect of the medicalization of social needs which need to be considered to avoid potential embarrassment, judgment, or bias for patients. Finally, informatics may increase efficiencies during referrals with the use of community resource referral platforms to link healthcare providers to community social services agencies. The use of such platforms requires additional research to characterize their adoption, usage, and impact, as the implementation of these tools may represent significant financial barriers for local organizations. Finally, investment in informatics infrastructure should not signal the end of investments in human social care capital, including education, training, and dedicated social care experts. While informatics tools may create efficiencies in certain areas, this body of work provides evidence of the critical

role played by Social Workers, Navigators, and Community Health Workers, who have expertise and relationships which help them stay aware of the availability and quality of local resources.

5.4 Limitations and Opportunities for Future Work

This dissertation attempts to use both qualitative and quantitative to characterize issues in contemporary social risk factor screening and social care in US hospitals. However, while qualitative interviews capture rich detail that is invaluable in exploratory research, the sample is limited to one healthcare organization in the US Midwest, and thus, generalizability would be improved with a future multisite study. Similarly, we may expect screening and referral efforts to differ in healthcare organizations with different characteristics, patient populations, geographic locations, and state policy environments, reflecting the need for future multisite work to improve generalizability. Additionally, sampling for the patient and provider interviews described here included respondents who had conducted or participated in screening or social care and, thus, the perspectives of others without such experience may not be represented. Indeed, as screening and social care efforts become more widespread and better understood, there will be a need for evaluative work to measure the impact and value of such interventions [10]. Similarly, observational research may be necessary to better understand the interpersonal dynamics between patients and providers during screening and social care, as such visual detail, including nuance related to the physical environment is not captured by interviews.

In Aim 3, national survey data is used to observe the landscape of social care implementation in hospitals across the United States. Here, survey data provide complementary strengths and weaknesses relative to the qualitative interviews, namely, the AHA Annual Survey and reporting from Community Benefit Insight offers a national sampling frame at the cost of limited measures. Additionally, at the time of analysis, the AHA Annual Survey had only

captured one year of self-reported social care services implementation, precluding longitudinal analysis to observe trends over time. Longitudinal studies will be necessary to measure the potential expansion of screening and social care interventions. Furthermore, a novel survey design would allow for the capture of more detail regarding each hospital's social care service capacities through more comprehensive measures than what is currently included in publicly available data. Finally, complementary work is necessary to measure the capacity of community organizations to accept referrals from healthcare organizations following screening.

Implementing screening in a large number of clinical areas, or geographic areas with high need, may generate significant numbers of referrals, and care is needed to ensure that social services agencies can handle an influx of new clients. As a result, measuring community capacity may be necessary for hospitals to work together with partnering organizations to ensure sufficient capacity to provide social care in each community.

5.5 Conclusion

Social risk factor screening and social care in healthcare settings create opportunities for providers to assist patients and gain greater insight into patients' social circumstances. However, such interventions are new, and initial implementation research demonstrates concerns for both patients and providers that must be addressed to ensure that screening does not cause harm to patients, perpetuate existing health disparities, or create additional burden. Using qualitative and quantitative methods, this dissertation contributes new knowledge regarding barriers and facilitators of patients' and providers' involvement in social risk factor screening and social care. Additional areas for future scholarship to inform the implementation of future screening and referral programs are identified, as well as the policies that incentivize them. Addressing social needs in healthcare settings is a complex sociotechnical process, and continued investments in

both the social and technical components may help prevent disease, improve healthcare access, lower cost, and improve health outcomes.

5.6 References

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