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Abstract

Background: Health literacy (HL) is the ability to make informed decisions using health information. As health data and information availability increase due to online clinic notes and patient portals, it is important to understand how HL relates to social determinants of health (SDoH) and the place of informatics in mitigating disparities.

Objective: This systematic literature review aims to examine the role of HL in interactions with SDoH and to identify feasible HL-based interventions that address low patient understanding of health information to improve clinic note-sharing efficacy.

Methods: The review examined 2 databases, Scopus and PubMed, for English-language articles relating to HL and SDoH. We conducted a quantitative analysis of study characteristics and qualitative synthesis to determine the roles of HL and interventions.

Results: The results (n=43) were analyzed quantitatively and qualitatively for study characteristics, the role of HL, and interventions. Most articles (n=23) noted that HL was a result of SDoH, but other articles noted that it could also be a mediator for SdoH (n=14) itself.

Conclusions: The multivariable nature of HL indicates that it could form the basis for many interventions to combat low patient understandability, including 4 interventions using informatics-based solutions. HL is a crucial, multidimensional skill in supporting patient understanding of health materials. Designing interventions aimed at improving HL or addressing poor HL in patients can help increase comprehension of health information, including the information contained in clinic notes shared with patients.

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KEYWORDS

health literacy; social determinants of health; SDoH; social determinants; systematic review; patient education; health education; health information; information needs; information comprehension; patient counseling; barriers to care; language proficiency
Introduction

Overview

In recent decades, medical providers, health systems, and legislators have prioritized increasing patient access to health information. For example, the 21st Century Cures Act mandates that patients must have access to their electronic health records, including clinic notes, in a rapid and convenient manner [1]. However, clinic notes and other health information can contain jargon that is difficult for patients to comprehend, reducing the utility of health information sharing. The Healthy People 2030 initiative, sponsored by the US Department of Health and Human Services, aims to address this issue by increasing patient comprehension of health information received from providers and web-based sources, such as their electronic health records [2].

A key part of health information comprehension is health literacy (HL), the ability to understand, contextualize, and make well-informed decisions based on health information [3]. Reducing HL gaps is crucial to meeting the goals set forth by Healthy People 2030 and maximizing the benefits of the 21st Century Cures Act.

Health Literacy

Having high HL correlates with greater shared decision-making between patients and physicians and promotes positive health outcomes because patients can better comprehend and act on the health information they receive [4]. Healthy People 2030 distinguishes between two dimensions of HL: personal, as previously described, and organizational [2]. Organizational HL holds health care systems and providers accountable for providing their patients with comprehensible health information to make informed decisions. This newer understanding of HL raises questions about how HL fits into the public health framework addressing disparities in health comprehension.

Social Determinants of Health and Health Literacy

Social determinants of health (SDoH) are nonmedical social and economic factors that fall into the following 5 domains: economic stability, education, health care and access quality, neighborhood and built environment, as well as social and community context [5,6]. SDoH affects health status and outcomes, and it can generate health disparities between population groups by influencing patient behavior and organizational responses. These determinants are also distinct from social factors or needs that exist at the individual level and instead exist as community- or population-level barriers [7-9].

HL has been categorized in different sources as an SDoH itself and as a midstream consequence of SDoH that can impede or improve patient interactions with health care institutions and health outcomes (ie, vaccination status and screening utilization) [10-12]. For example, a study by Schillinger et al [13] proposes that a higher education level improves HL, which was associated with better glycemic control among patients with diabetes. This is a unidirectional characterization of the relationship between SDoH, HL, and health outcomes, depicted in Figure 1.

Figure 1. Relationships characterized by the influence of social determinants of health on health literacy (personal and organizational), subsequently impacting health outcomes.
literature analyses that macroscopically evaluate how SDoH and HL are related across different SDoH domains [15]. Understanding the nature and role of HL in interactions with SDoH can also indicate the most effective approach to designing HL-targeting interventions for patients who struggle to understand health information.

Objectives
Due to the literature gap in examining the complex relationship between HL and SDoH, we aimed to conduct a systematic literature review to (1) understand this relationship and (2) recommend informatics-based interventions to address low HL among patients.

Methods

Search Strategy
We systematically reviewed literature in PubMed and Scopus, two major biomedical and social science literature repositories. The initial database searches were conducted on June 22, 2020. The review followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2009 guidelines to understand the relationship between HL and SDoH [16,17].

The search terms used were “health literacy” AND “social determinants of health.” After filtering for non-English articles and articles without abstracts, the remaining 281 articles were compiled in a Microsoft Excel sheet with their title, author, publication year, DOI or PMID, and abstract.

Screening Process
Two researchers (SB and CX) independently screened 281 papers by title and abstract and used the following exclusion criteria: (1) HL is a minor factor in the article; (2) the article is not an empirical study; (3) the article focuses on HL measurement tool development or evaluation; (4) the paper does not examine HL in relation to SDoH; (5) no abstract is available; and (6) the paper is not written in English.

Each researcher independently gave the article a score of “1” for inclusion or “0” for exclusion. The scores were summed; articles scoring “2” were automatically included, and those scoring “0” were excluded from the full article eligibility review. Disagreements (any papers with a total score of “1”) were resolved by the authors after the initial screening. The process was repeated for the full-article eligibility review and subsequent reference screening from the included full articles. Reference screening was a precautionary step to ensure the inclusion of articles that may not have been included in the initial database search. Original exclusion criteria were consistently used.

Quality Assessment
Before the information extraction, all included articles were assessed by 2 researchers (SB and TG) for study quality. Using the Agency for Healthcare Research and Quality (AHRQ) guidelines, separate quality assessments were developed for each type of study included in the review—observational studies and randomized clinical trials (RCTs) [18]. Domains included in both study types were study questions, population, interventions, outcome measurement, statistical methods, results, discussion, and disclosure of funding or sponsorship. Domains evaluated in the RCT assessment also included blinding and randomization.

The reviewers created a 3-point scoring system for the quality assessment. Articles were rated by 2 team members (SB and TG) with scores of “good,” “fair,” and “poor” for each domain and assigned numerical values of 2, 1, and 0, respectively, as per the AHRQ guidelines [18]. Values were averaged and translated back to a rating of “good” (1.50 or higher), “fair” (1-1.49), and “poor” (0-0.99).

Information Extraction
Based on quality assessment results, 43 papers were included for information extraction. Four researchers (CB, CX, AN, and TV) extracted data for the following PRISMA-based criteria: title, author, article ID, year published, location, study design, sample demographics, results, and limitations [16]. To answer the research questions, information specific to SDoH focus, HL measurement, and health outcomes was collected. The information extraction sheet is attached as Multimedia Appendix 1.

Quantitative and Qualitative Data Analysis
Extracted data were analyzed both quantitatively and qualitatively. Location, year of publication, and study design were statistically summarized. AHRQ guidelines were used to categorize studies as RCT, cross-sectional, and qualitative designs, with the last two being types of observational studies [19].

Qualitative analysis was conducted in 2 steps. First, a narrative synthesis of the chosen articles summarized the relationships between SDoH and HL. Narrative synthesis involves analyzing the data from systematic reviews to create textual explanations of observed patterns or trends rather than relying solely on statistical data. This involves developing textual descriptions of the data by extracting key information pertinent to the research question (ie, methods used or results) and exploring commonalities and differences between and within studies (ie, through visually mapping relationships) [20]. These methods were also used in a systematic review previously published by the authors [21]. The included articles were classified by SDoH domains they addressed, per the 5 domains defined by Healthy People 2030: economic stability, education, health care access and quality, neighborhood and built environment, as well as social and community context. Then, information extraction data from article results and discussion sections were used to define roles for HL. Finally, a theme visualization was conducted that plotted HL roles against publication year to understand how HL perception has evolved.

In the second step, lessons learned were summarized regarding HL roles, again using the results and discussion sections. From these same sections, the authors then extrapolated possible interventions that use HL to improve patient comprehension of health information.
Results

Literature Search Results

The PubMed and Scopus searches yielded 389 articles, resulting in 281 unique articles (Figure 2). After screening titles and abstracts, 43 articles remained for full-text eligibility assessment. Not discussing HL and SDoH together (n=95) was the largest cause for exclusion. Other papers were excluded because HL was not a substantial focus of the paper (n=62). A total of 19 articles were excluded from the full-text eligibility, once again for a minor focus on HL. References of the remaining 24 articles were screened for inclusion, yielding 20 additional articles. After the quality assessment, 1 low-quality article was excluded. Information extraction and narrative synthesis were conducted on a final sample of 43 articles.

Figure 2. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram of articles from the PubMed and Scopus search. A total of 24 articles (underlined) were included from the first database search.
Quantitative Analysis

The final 43 articles were analyzed for study location, year of publication, role of HL, and study design (Table 1). A total of 14 (32.6%) studies took place in North America (12 in the United States and 18 in Europe). All articles from South America originated in Brazil (n=4). Publication year trends revealed an increased focus and discussion of the topic in recent years, with 90.7% (n=39) of the articles being published after 2010. Most articles (n=40, 93%) had a cross-sectional design and used surveys, while 4.7% (n=2) used a qualitative design with semistructured interviews and focus questions to assess SDoH and HL.

Table 1. Summary of articles included in the literature review (N=43).

<table>
<thead>
<tr>
<th>Category</th>
<th>Values, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study location</td>
<td></td>
</tr>
<tr>
<td>Europe</td>
<td>18 (41.9)</td>
</tr>
<tr>
<td>North America</td>
<td>14 (32.6)</td>
</tr>
<tr>
<td>Asia</td>
<td>6 (14)</td>
</tr>
<tr>
<td>South America</td>
<td>4 (9.3)</td>
</tr>
<tr>
<td>Australia</td>
<td>1 (2.3)</td>
</tr>
<tr>
<td>Year published</td>
<td></td>
</tr>
<tr>
<td>2006-2009</td>
<td>4 (9.3)</td>
</tr>
<tr>
<td>2010-2013</td>
<td>9 (20.9)</td>
</tr>
<tr>
<td>2014-2017</td>
<td>15 (34.9)</td>
</tr>
<tr>
<td>2018-2021</td>
<td>15 (34.9)</td>
</tr>
<tr>
<td>Study design</td>
<td></td>
</tr>
<tr>
<td>Cross-sectional</td>
<td>40 (93)</td>
</tr>
<tr>
<td>Qualitative</td>
<td>2 (4.7)</td>
</tr>
<tr>
<td>Randomized controlled trial</td>
<td>1 (2.3)</td>
</tr>
</tbody>
</table>

The search was not limited to 2006 for publication year; this was the earliest date among the 43 articles.

Qualitative Analysis

Narrative Synthesis

The narrative synthesis generated 4 roles for HL in relation to SDoH (Table 2). Most of the articles discussed multiple SDoH domains, but all 43 articles discussed education access and quality [5].

The most common categorization of the HL role was as a “result of SDoH” (n=23), followed by “modifiable SDoH” (n=14), and finally, as a “mediator of SDoH” (n=6). HL can be a “result of SDoH” (n=23), which suggests that SDoH domains contribute to HL levels and that it is a downstream variable [22-44]. As mentioned, 14 studies identified HL as a “modifiable SDoH,” where they identified HL as an SDoH, often citing the World Health Organization’s categorization of it; these studies suggested that HL can be improved through interventions and is actionable at multiple levels [14,45-57]. Finally, the articles that categorized HL as a “mediator of SDoH” (n=6) discussed how HL is an intermediary between other SDoH domains, such as educational attainment or economic stability, and that high HL levels can compensate for lower domain levels that compromise positive health outcomes [58-63]. Occasionally, the same paper would suggest multiple roles for HL (eg, an article’s Results and Discussion sections would inform both modifiable and mediatory roles for HL), but the most prominent relationship that appeared was used to categorize each article.

These 3 roles were plotted against the years of publication in Figure 3. In the few HL-focused articles published before 2010, HL was recognized as having a variety of roles, but only 1 article identified it as a modifiable SDoH. In the next 5-year period, being a result of SDoH was the most common role assigned to HL. In 2013, a total of 5 out of 7 articles identified HL as being a result of SDoH. As the number of published HL-focused articles increased in subsequent years, being a result of SDoH remained the most consistent and most prominent role assigned to HL to appear across all articles. Nevertheless, there has been increasing recognition of HL as a modifiable SDoH in the years 2015, 2018, and 2020, further cementing HL’s multidimensional nature.
Table 2. Summary of narrative synthesis themes.

<table>
<thead>
<tr>
<th>Category</th>
<th>Values, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SDoH</strong> domain&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>Education access and quality</td>
<td>43 (100)</td>
</tr>
<tr>
<td>Economic stability</td>
<td>38 (88)</td>
</tr>
<tr>
<td>Health care and access quality</td>
<td>11 (26)</td>
</tr>
<tr>
<td>Social and community context</td>
<td>11 (26)</td>
</tr>
<tr>
<td>Neighborhood and built environment</td>
<td>9 (21)</td>
</tr>
<tr>
<td><strong>HL</strong> role</td>
<td></td>
</tr>
<tr>
<td>Result of SDoH</td>
<td>23 (53)</td>
</tr>
<tr>
<td>Modifiable SDoH</td>
<td>14 (33)</td>
</tr>
<tr>
<td>Mediator of SDoH</td>
<td>6 (14)</td>
</tr>
</tbody>
</table>

<sup>a</sup>SDoH: social determinant of health.
<sup>b</sup>Most of the articles included more than 1 SDoH domain they studied.
<sup>c</sup>HL: health literacy.

**Figure 3.** Theme visualization of the evolution of health literacy roles over time. SDoH: social determinants of health.

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**Lessons Learned**

In addition to analyzing articles for the HL role, each article was further examined to determine details about the nature of the relationship between HL and SDoH. These were titled “lessons learned.” Figure 4 [14,22-63] shows an idea map that organizes articles by the role of HL and lessons learned. Although most of the articles are cross-sectional and do not always draw a causal relationship between HL and SDoH, the authors of the articles nevertheless offer hypotheses on factors influencing HL or how it interacts with SDoH and health outcomes.
HL as a Result of SDoH (n=23)

Being a result of SDoH was the most frequent role identified for HL. These articles characterized HL as being associated with, influenced by, or resulting from other SDoH. All articles addressed that a higher level of education, such as high school graduation, had implications on HL levels [22-44]. Bazaz et al [22], Berens et al [24], and Rocha et al [39] have suggested that HL is developed through interactions with health care due to age and disease condition, and more interaction with health care over time leads to an improvement in HL. Hou et al [31], Jovic-Vranes et al [32], Kamberi et al [34], and Todorovic et al [41] also note that lived environments have an important role in HL development. Kamberi et al [34] argue that rural versus urban environments influence SDoH, such as health care access and quality, thereby, impacting HL development [34]. Beauchamp et al [23], Berens et al [24], Cudjoe et al [26], and Sentell et al [40] observed that HL is also influenced by the patient’s primary language, especially if the patient’s primary language is different from the language of the health system. Bo et al [25] and Pop et al [37] elaborated on the relationship between education and HL; they found that lower levels of language proficiency and self-perceived health can indicate lower HL. Heizomi et al [30] and Dashli et al [27] notice gender disparities in HL among students in Iran, with the latter observing that cultural differences encouraged technology access for men at a younger age, leading to higher HL levels among men compared to women [27,30].

HL as a Mediator of SDoH (n=6)

A total of 6 articles established that, as a mediatory variable, HL can both compensate for and contribute to disparities in SDoH. Some articles define HL as an SDoH itself but further classify it as a mediator for other determinants. All 6 articles included education and income as SDoH for which HL could serve as compensation [58-63]. Bennett et al [59] also suggest that having high HL can compensate for racial or ethnic disparities in health outcomes. Zanchetta et al [63] describe that HL mediates between disparities in health care access and quality as well as social cohesion and context. To address poor HL among patients, van der Heide et al [62] recommend simplifying medical jargon. When designing these interventions, Bennett et al [59] emphasize considering complex patient perspectives and unique demographic needs, such as those of research or by defining determinants as factors that impact or predict health outcomes. Aaby et al [45] classify HL as an SDoH because it is a combination of “personal competencies and situational resources” that affects individuals’ interaction with health care institutions. Some authors, despite describing HL as an SDoH, still note that it is related to other SDoH as well. Cheuhuen et al [47] identify that HL is associated with economic stability and education, and Lee et al [55] and Sentell et al [46] both associate it with the social context. Articles also identified various health outcomes that HL may impact. Cabellos-Garcia et al [48] and Zhou et al [57] identified that poor HL could lead to reduced understanding of disease conditions and engagement with providers. Nevertheless, all 14 articles emphasize that HL is a modifiable SDoH that can change over time through interventions [14,45-57].
the geriatric population, which differ from those of younger patients.

Informatics Interventions

The secondary objective of the study was to identify informatics-based interventions to improve HL. Articles rarely provided specific intervention recommendations but instead listed several potential problems, such as complicated medical jargon or low health awareness, that complicate patient understanding of health information. Therefore, 4 informatics-based solutions were proposed based on the research team’s knowledge and experience for the identified problems, as follows: (1) language or text simplification, (2) population-focused (or policy-based) interventions, (3) health education efforts, and (4) patient identification. Since the included articles were largely not interventional in nature, the following sections extrapolate on the recommendations with references to ongoing studies that have implemented these strategies.

Discussion

Principal Findings

This systematic review included 43 papers and reported the results following the PRISMA guidelines. Most studies were conducted in Europe in the past 5 to 10 years. The studies examined HL in relation to the two themes of SDoH—health-focused and demographic—and generated 3 roles for HL, as follows: a mediator of SDoH, a result of SDoH, and modifiable SDoH. More than half of the studies had a cross-sectional design. However, HL is a complex, actionable variable that may be targeted by various strategies.

Proposed Interventions

As clinical note sharing becomes more popular, generating interventions that address low HL becomes even more crucial. In this vein, we generated 4 recommendations for focused HL interventions based on the key findings of this systematic review.

Interventions with an informatics focus could play a particularly vital role in improving patient comprehension of health information as the healthcare field becomes increasingly mobile and technology dependent. It is important to consider experimental methods to measure the efficacy of implementing these strategies. Including control groups and validated HL measuring tools can help monitor how different interventions influence patient HL levels. Validated measuring tools include the Rapid Estimate of Adult Literacy in Medicine (REALM), REALM-Short Form, Short Assessment of Health Literacy-Spanish and English (SAHL-S&E), Brief Health Literacy Screen (BHLS), and Test of Functional Health Literacy in Adults (TOFHLA) [64-66]. The REALM, REALM-SF, and SAHL-S&E have all been validated and recommended by the AHRQ. The REALM and SAHL-S&E are recommended for research purposes to assess participant HL, while the REALM-SF, BHLS, and TOFHLA have been validated for use in screenings in clinical settings [66,67]. The REALM-SF is particularly designed to identify limited literacy levels [67]. Therefore, the clinically usable metrics may be more relevant for interventions that take place in healthcare settings, such as patient identification.

Language and Text Simplification

Text simplification addresses the tendency of clinic notes and health information in general to include medical jargon that exceeds the comprehension levels of most patients [42,44,62]. Even patients with highly educated backgrounds have shown low scores on HL surveys. Therefore, text simplification can benefit patients across all HL competencies by reducing jargon and making health information more easily understandable and usable [62]. Text simplification does not replace the existing clinic note shared between providers; it provides a simplified version for patients in addition to the original note. Current research indicates that the most effective manner of text simplification relies on manual editing techniques using human oversight of a text simplification process, combined with information visualization [68]. Although simplification improves patient comprehension, manual editing could strain healthcare professionals’ workload. Therefore, developing informatics interventions that automate text simplification while retaining the grammatical and logical integrity of the clinical text is important. Current automated simplification methods scored poorly due to grammatical errors, repetition, and inconsistencies in the autogenerated documents [68]. Artificial intelligence–derived text simplification methods may overcome these barriers by matching a document’s reading level to the readers’ needs, as shown in a study where ChatGPT was able to modify answers to men’s health condition questions to accommodate lower reading levels [69,70]. However, popularly used AI tools, such as ChatGPT, need considerable evaluation to minimize inaccurate information delivery and improve comprehensibility. Current studies indicate that these tools lack citations for the information they provide and cannot differentiate between low-quality and high-quality information [70,71].

Population-Based Visualization and Cross-Cultural Communications

HL needs are different across populations and cultural contexts, and interventions should account for these differences. For example, non–English-speaking individuals are overlooked in many HL studies, and interventions targeting English speakers will not always suit those with a limited or nonnative grasp of English [23,72]. Realizing this limitation, the OPHELIA (OPtimising HEalth LIterAcy) [73] project is a multisite study that assesses HL strengths and weaknesses in their patient population at each study site and uses these responses to determine appropriate intervention methods. Equally important is including representatives from the community in intervention design. A systematic review looking at interventions that address HL among Aboriginal and Torres Strait Islander community members noted that many failed to include these patients in the design process and consequently had limited participant retention [74]. Another facet is implementing policy-level changes that increase access to HL support. This is particularly relevant for patients who face health inequity. However, implementing these changes has been slow. In the European Union, challenges such as funding constraints and obstacles to
initiatives have prevented effective execution beyond a few countries [75]. The population-based and policy-level interventions should consider visual analytics to explore meaningful patterns in a large data set and use recent advances in natural language understanding and translation to promote cross-cultural communication [76].

Patient Identification
Although population-focused and policy-level interventions address low HL at the macro level, such methods may overlook the individual HL needs of a patient. Therefore, screening HL levels as a part of standard practices in health care settings can help identify patients who need additional support at the clinic visit and can expedite provider response [36]. For example, Vanderbilt University Medical Center and the University of Arkansas Medical Sciences incorporate HL screening as part of their educational health assessment and have done so since 2010 and 2016, respectively [77]. Screening may also involve various informatics tools. For example, patients can be actively screened using electronic data capture tools (eg, REDCap) [78]. These informatics tools should be integrated into clinical workflow to ensure the quality of data. On the other hand, patient cohorts can be identified by reports or dashboards of electronic health records or medical text search engines (eg, Electronic Medical Record Search Engine [EMERSE]) [79]. Once the patient group is targeted, inclusive HL interventions can be designed and executed. However, implementing screening practices should be done with caution to avoid perpetuating stigma or embarrassment. Integrating screening questions within the clinical workflow and training health professionals on screening administration can help address these concerns [77].

Health Education and Online Community Building
Given the relevance of socialization and environment on HL development, it is important to consider interventions that cultivate HL through health education. Health care providers, such as nurses and community health workers, have important roles in providing education and reinforcing patient understanding of their health conditions [63,80]. However, the burden on health education cannot be placed on providers alone. Health education programs implemented by health care organizations and community health centers can actively and effectively improve HL [81]. It is important to adapt these programs for cultural and demographic sensitivity and patient-provider communications. For example, a recent study targeting older adult needs emphasized the need to include the patient’s caregivers and to accommodate barriers in comprehension, especially cognitive ones [82]. Health education intervention should consider developing an online community, such as ImproveCareNow, to promote collaborative care and build repositories of patient education materials with well-designed education programs to help patients improve their HL [83]. Including the input of individuals who are well-integrated into and familiar with the needs of a patient population, such as community health workers, can also be helpful in this process [80].

Limitations
There are a few limitations in the methodology and generalizability of our research. First, we conducted a database search of only PubMed and Scopus, limiting the scope of the article search. However, PubMed and Scopus are two of the most popular and largest databases in biomedical and social science research. During the analysis, it was clear that the results were concise and supported one another. For example, several articles noted multiple roles for HL but tended to focus on one. Second, very few articles included noncorrelated results because of their cross-sectional designs. This prevented researchers from drawing a causative relationship between HL and SDoH, but they nevertheless had hypotheses for relationships that informed our classification. Third, the PRISMA guidelines were updated in 2020 with new standards and recommendations for systematic reviews. As we had already made considerable progress in this project before the revision was published in 2021, we completed the data analysis using the 2015 reporting standards that originally informed our methods. However, in cross-referencing our methods with the 2020 revisions, our research largely adheres to the new guidelines [84].

Conclusions
The articles included in this literature review indicate that HL can adopt various roles in conjunction with SDoH. This flexibility makes HL an appropriate topic for intervention to accommodate poor health outcomes and improve patient autonomy. However, the complex nature of HL means that it warrants further research to understand how HL-targeted interventions impact this process.

Acknowledgments
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Conflicts of Interest
None declared.
Multimedia Appendix 1

Literature search and information extraction.

[XLSX File (Microsoft Excel File), 61 KB - ojphi_v16i1e50898_app1.xlsx]

Multimedia Appendix 2

PRISMA Checklist.

[PDF File (Adobe PDF File), 109 KB - ojphi_v16i1e50898_app2.pdf]

References


Abbreviations

AHRQ: Agency for Healthcare Research and Quality  
BHLS: Brief Health Literacy Screen  
EMERSE: Electronic Medical Record Search Engine  
HL: health literacy  
OPHELIA: Optimising HEalth LIteracy  
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses  
RCT: randomized clinical trial  
REALM: Rapid Estimate of Adult Literacy in Medicine  
SAHL-S&E: Short Assessment of Health Literacy-Spanish and English  
SDoH: social determinants of health  
TOFHLA: Test of Functional Health Literacy in Adults

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Discussions With End Users to Inform the Vision for a Shared Care Record in Ontario: Qualitative Interview Study

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Abstract

Background: Improving the health outcomes of populations of individuals through population health management requires the use of electronic health records that can exchange real-time digital information using an accurate and complete shared care record that is accessible to health care providers, services, and patients.

Objective: The aims of this study were to understand end users’ (health care providers) experiences, attitudes, and insights using current electronic health records; their expectations of what is required to establish a shared care record; and how they anticipate adapting to the use of a shared care record in daily practice. This work is the result of a quality improvement initiative deemed not to require ethics approval according to the Western research ethics board checklist.

Methods: Clinicians were contacted using voluntary response sampling and interviewed via Zoom (Zoom Video Communications) between June 2022 and July 2022. The participants were from various health care sectors and at various stages of career development.

Results: Overall, adaptation to the use of a shared care record was viewed positively by health care providers, highlighting the benefits of a centralized, shared, and accessible location for real-time data, promoting patient continuity of care. The main concerns included the privacy, confidentiality, and security of the record along with patients’ ability to interpret their own medical information found in a patient portal. The resources requested by end users included multifaceted ongoing training on the use of a shared care record.

Conclusions: This study provides practical findings that will help emphasize factors that facilitate clinicians’ practical use and process of adaptation to the use of a shared care record.

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Keywords
population health management; shared care record; health information exchange
Introduction

Population Health Management

Defining population health management (PHM) requires taking a step back and thinking of the bigger picture. The Population Health Alliance PHM framework explains that “a population health management program strives to address health needs at all points along the continuum of health and wellbeing through the participation of, engagement with and targeted interventions for the population” [1]. Their definition specifies that the goal of PHM is to uphold or improve the “physical and psychosocial wellbeing of individuals through cost-effective and tailored health solutions.” Breaking it down, PHM involves the use of data to proactively manage the health and well-being of an identified population of individuals while considering the diversities within that population along with their social determinants of health [2]. PHM is a constantly progressing concept that is increasing in popularity worldwide. For example, in Ontario, PHM has been characterized as a fundamental element in Ontario’s health system transformation. In the Netherlands, several PHM initiatives are working to tackle the health-related social needs of residents by building partnerships among medical care, public health, social services, and community-based organizations [3]. Managing populations of patients based on their diagnosis while maintaining their health and keeping them out of dangerous circumstances has recently become popular as it affords the ability to deliver high-quality and efficient care that is satisfying to everyone involved [4]. Examples of leaders in PHM and integrated health care delivery include those in Denmark, Spain, and the United States, such as Geisinger, Memorial Hermann, the Department of Veterans Affairs, and Kaiser Permanente. Another important mention is Epic, a widely used software company among hospitals that allows for the exchange of medical records across organizations in the United States and beyond. They are all highly regarded for high-quality and efficient health care through integrated care delivery processes [5].

PHM can be viewed as improving the health outcomes of a population using appropriately coordinated care and proper patient engagement, which is sustained through adequate economic and care models [6]. The question then becomes how to best support the entire population clinically and financially. According to the Health IT Playbook [7], examples of PHM services involve efforts to proactively help people improve their health, guarantee they obtain preventive screenings, and help them effectively manage their chronic conditions. A vital feature of this approach to care delivery is that the population whose health is being managed is a complete group of people, not only those who are pursuing health care. This population can be defined in ways such as all the employees of an employer, members of a health insurance plan, or residents of a community, but the key feature in PHM is that the health of all members of this population is considered [7].

Another crucial aspect of PHM is coordinating a diverse and progressive group of stakeholders who work together to provide programs, services, and tools for interoperable care for patients in various health care settings [8]. This is also where the integration of services occurs, such as financing and delivery of health care working together [4]. According to Jones and Smith [4], an entirely integrated care system is defined as both horizontally and vertically integrated. Vertical integration combines provider and care delivery, financing, and support services such as IT. Horizontal integration combines provider services, home health services, hospitalization (tertiary and secondary), and ambulatory care, entailing continuous and seamless care [4].

Health Data

The growing burden of chronic diseases challenges health care system sustainability in countries worldwide. Working toward coordinating care to prevent unnecessary hospitalizations is a crucial solution to limiting increasing health care costs. According to Burnel [9], to reach this goal, clinicians and professionals must be able to exchange information using electronic health records (EHRs). An EHR is a real-time digital form of a patient’s health care record, allowing information to be available to providers authorized to access it across different health care organizations instantly and safely [10]. Beyond providing a patient’s collected medical data, an EHR offers a comprehensive view of a patient’s care. An EHR contains information from all providers involved in a patient’s care concerning admission documents, diagnostics, ongoing assessments, and health care plans and can be shared with other health care providers; caregivers; patients; and organizations, including laboratories, medical imaging facilities, specialists, pharmacies, and clinics [10]. EHRs make it possible to reduce medical errors, increase health care provider communication, and improve care coordination [11]. The broad implementation of EHR systems in primary care has permitted the compilation of enormous amounts of clinical data that have the potential for secondary use, such as improving clinical programs, system management, and population health research [12].

Shared Care Record

With EHRs in mind, the concept of the shared care record is introduced. A shared care record is an enabler that helps allow PHM to be possible. According to the Patient, Family, and Caregiver Declaration of Values for Ontario [13], to enable integrated care, each resident in Ontario ought to have access to their health-related information record, which is “accurate, complete, available and accessible across the provincial health system at [their] request.” The record should be accessible to health care team members and patients as required and in a manner that encourages appropriate care and positive experiences. A complete and accurate shared care record includes up-to-date information about the person and their demographic information, the administrative services they use, their medical or clinical information, and additional health-related information involving the social determinants of health.

Shared care records permit all primary and secondary care providers to view and use a single dependable source of documentation that is up to date and provides accurate clinical information in real time about a patient [14]. It is about giving everyone access to the information they need but does not require everyone to be on one common information system.
Patient records from a variety of care providers and sources can be linked through a health information exchange (HIE) system. The vision of the shared care record would give providers, in the home database system they work in daily, access to information captured about their patients from other care providers and other systems. For example, a provider (or patient) can view medications prescribed by provider A alongside those prescribed by provider B in the same place even if providers A and B use different EHR technologies. This information could come from their primary care records, home and community care records, community mental health and addiction records, or hospital systems. Systems worldwide are using this approach to link information on allergies, laboratory test results, procedures, appointments, and much more. The HIE simply enables information exchange between systems, for example, between hospitals and primary care [15]. Moving this information between the systems aims to help the care team locate and use the correct information to provide safe, efficient, and equitable patient-centered care. This means that a patient only needs to describe their health care history once instead of sharing it multiple times at each health care encounter. If done properly, information from this system can also provide information to public health teams to understand the health and health needs of the population [15].

The Need to Reform Service Integration in Ontario

The current health care system in Ontario is experiencing increasing strain from the aging demographic, overloaded hospitals and emergency departments, and a significant increase in chronic diseases, putting our care delivery model at risk [16,17]. Completely changing the Ontario model of health care delivery is not feasible; therefore, we must work with the existing structures. One example is health IT systems that can be better connected to improve workflows; centralize health data; and deliver information to health care providers, patients, and families where and when they need it. Ontario is not alone; fragmented care exists among health care systems worldwide involving a lack of communication between primary care physicians, other health care providers, specialists, patients, and families, leading to negative impacts on patients and gaps in continuity of care. Many systems have realized the benefits of interoperability, “defined as the ability of different health information systems to cooperatively access, integrate and exchange data to advance effective delivery of health care” [16]. Several obstacles must be kept in mind when it comes to the electronic exchange of health information, such as technical, financial, legal, and privacy barriers that can impede the implementation of interoperability. Nonetheless, as health care providers request continuous integration of information and patients stress the need for access to health data, health care organizations will be forced to share information appropriately. This may require funding for information management technology such as EHRs and IT to enable care across the continuum [4,17].

The concepts of integrated care, digital health, interoperability software, and centralized health data, exemplified by the shared care record, are crucial to exposing the benefits of a restructured and better coordinated health care system. Collectively working toward a shared care record can help reduce medical errors, health care costs, and redundant and unproductive work while improving communication among health care providers, quality of patient care, and seamless transitions of patients across health care providers and settings to create a resourceful system [17,18].

Aim of the Study

This qualitative study used semistructured interviews to improve the understanding of end users’ (health care providers) perspectives and insights regarding how they anticipate adapting to the use of a shared care record. Information gathered from the interviews will support the development of use case storyboards to inform various stakeholders across Ontario of considerations for developing a shared care record across the province. Talking with end users will help understand what a range of clinicians from different specialties believe is required to establish a shared care record and how they will adapt to its use over time.

Methods

Setting

Middlesex County is in Ontario’s Southwestern region, covering a geographical area of 2800 km² and home to >450,000 people. This region consists of a mix of urban and rural residents. London is the largest metropolitan area within Middlesex County and is home to >450,000 residents. The region also surrounds 3 sovereign First Nations: the Chippewas of the Thames, Oneida Nation of the Thames, and Munsee-Delaware Nation. For several years, legislators in Canada’s most populated province, Ontario, have endeavored to change the local health care system to create a more coordinated and financially united system [19]. This initiative resulted in the Government of Ontario Ministry of Health formation of 54 approved Ontario Health Teams (OHTs) within specific geographic areas across the province. OHTs modify how health care is financed and delivered and concentrate on collaborative partnerships in which providers and organizations such as primary care, mental health services, hospitals, and home and community care work as one synchronized team [20,21]. The Middlesex London OHT is specifically responsible for supporting the health of the population residing in the Southwestern Ontario region [22]. Using OHTs, the provincial government is assembling sustainable systems that will respond to local populations’ short- and long-term needs, support local services, and enable straightforward system navigation and transition among providers [19,23]. Another critical player providing guidance and regulation is Ontario Health, a government-formed agency working to coordinate and connect the province’s health care system [24]. This new visualization of Ontario’s health care system is aligned with the Quadruple Aim, a framework internationally understood to design and provide a system that improves patient and caregiver experiences, patient and population health outcomes, and provider experiences while reducing total costs [23].

Participants and Recruitment

Using voluntary response sampling, clinicians were contacted via email based on preexisting professional relationships. A
A total of 14 health care providers were interviewed, comprising those who volunteered or agreed to participate upon request. These health care providers hold positions in various care sectors, including nursing, community care, primary care, emergency medicine, dietetics, practice specialties, occupational therapy, and physiotherapy. The list of health care provider interviewees who agreed to participate in the data collection, organized by occupation, is shown in Table 1. The providers also ranged widely across stages of career development and duration, from new graduates to experienced employees.

### Table 1. Interviewees.

<table>
<thead>
<tr>
<th>Professional title</th>
<th>Care setting</th>
<th>Professionals (N=14), n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered nurse</td>
<td>Inpatient acute care</td>
<td>3 (21)</td>
</tr>
<tr>
<td>Registered nurse</td>
<td>Cardiac outpatient clinic</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Registered nurse</td>
<td>NSWOC&lt;sup&gt;a&lt;/sup&gt;</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Clinical nurse specialist</td>
<td>Chronic diseases and clinical informatics</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Clinical dieticist</td>
<td>Bariatric outpatient clinic</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Physician</td>
<td>Emergency medicine</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Physician</td>
<td>Primary care practitioner</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Registered physiotherapist</td>
<td>Outpatient clinic and inpatient acute care</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Registered practical nurse</td>
<td>Home and community care</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Clinical practice specialist</td>
<td>Occupational therapy</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Clinical practice specialist</td>
<td>Palliative care and oncology</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>Home and community care</td>
<td>1 (7)</td>
</tr>
</tbody>
</table>

<sup>a</sup>NSWOC: Nurse Specialized in Wound, Ostomy and Continence.

### Data Collection

Participants in the study were first introduced to the concept of a shared care record verbally and through a video demonstrating its functionality. All participant questions about a shared care record were answered before the interviews. A semistructured question guide ensured that each interview covered essential topics and allowed participants to disclose issues and stories as they saw relevant. The use of a prepared guide also worked to decrease interviewer bias by decreasing interviewer involvement. Confidentiality and anonymity were established at the beginning of the interviews. Verbal consent was obtained from each participant to potentially use quotes from the discussions in future publications or presentation materials that result from the initiative. The semistructured interviews averaged 15 (SD 2.56) minutes and were web-based via Zoom (Zoom Video Communications) between June 2022 and July 2022.

The interview format was chosen, as opposed to focus groups, as it allowed for direct, individual engagement with each end user. Stokes and Bergin [25] discussed the opportunity for the interviewee to truly analyze their motivations for a particular action while being given a feeling of empowerment because of the anonymity in the individual interview setting without the pressures of a group setting that may lead to a consensus view. The interviews were designed to elicit the health care providers’ understanding of and experiences with the EHRs they currently use along with their attitudes, beliefs, and expectations regarding the future use of a shared care record in their daily practice. The sequence of interview questions used and additional instructions to guide the interview are shown in Table 2. The interviews were audio recorded with permission from the participants, transcribed using web-based software, checked for accuracy, and then analyzed to develop a report. The results present the participants’ initial reactions to the concept of a shared care record and then transition to their interpretation and reflections on the use of and adaptation to a shared care record.
Table 2. Interview guide.

<table>
<thead>
<tr>
<th>Interview portion</th>
<th>To do</th>
<th>Additional notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Warm-up</td>
<td>• Introduce and explain the purpose of the interview. Obtain consent to use quotes from the interview and to record the interview.</td>
<td>• Introduce the idea of the shared care record and how it works.</td>
</tr>
</tbody>
</table>
|                   | • Consider your electronic health record today (name the record), what additional health or social information regarding your patient would you like to have access to in this new shared care record or would make a difference for you, when providing care for that patient?  
  • Prompt: tell interviewee more about what a shared care record could offer them. | • Build each question off the previous one and rearrange the order as needed according to the flow of the conversation. Use the prompts to further stimulate conversation. |
|                   | • So, for you, tell us how this information would impact or change the care you provide (or can) to your patients?  
  • Prompt: what difference would it make if you had access to all of your patient’s information (the type of information you just listed) on the shared care record?  
  • Prompt: would you look at it more or make use of that information? | |
|                   | • This would be a change and change is never easy, but what do you think you and your colleagues would need to do to adapt to using a shared care record in your day-to-day practice?  
  • Prompt: what would help your colleagues benefit from this change?  
  • Prompt: what support or resources would help you with the introduction to and adaptation to this system? | |
|                   | • Do you have any concerns with the concept of a shared care record?  
  • Prompt: Overall, what factors or conditions challenge or serve as barriers to your personal use of a shared care record? How might this change that? | |
|                   | • In closing, do you have any concluding thoughts or comments related to the shared care record that you would like to convey? | |
| Closing           | • Thank the interviewee for their time. Let them know not to hesitate to reach out if they have anything else they would like to discuss. | • Ask interviewee whether they give permission to be contacted in the future. |

Data Analysis

The interviewer first read and interpreted the individual transcripts to become well acquainted with the data collected. After developing the initial semantic codes based on the data, the interviewer grouped the codes into categories and themes and then reviewed, named, and discovered various connections between the themes to write the analysis. The themes were modified using an iterative process, adjusted, and grouped, with categories and subcategories added as they arose from the data analysis. The interviewer used a qualitative interpretative approach, the framework method, to analyze the data by joining thematic analysis with comparison so that the data were surveyed for known literature themes and emerging themes. The interview findings are presented in the Results section of this paper; quotes are included from the interview transcripts to illustrate the generated themes. End users are identified by their health professions in each quote.

Ethical Considerations

This publication is the result of a quality improvement initiative deemed not to require ethics approval according to the Western research ethics board checklist.

Results

Participants’ Reflections on the Shared Care Record

Theme 1: Opportunities for Using a Shared Care Record

Lack of Communication Affecting Care Delivery

A lack of adequate communication among health care providers, services, and health care facilities across the care system was a common response among participants. Discussions with end users highlighted frustrations across the care continuum, such as entering care encounters with inadequate or lacking information, more difficult care management and planning, and delays in access to information causing delays in care. Registered nurse 4 stated the following:

Why are we doing the same assessments over and over again? Patients are forced to repeat tests because the results are not passed between the health care providers, which in the end only delays their [the patients’] treatment.

The introduction of a shared care record could drastically improve communication among health care providers, potentially decreasing the current workload, increasing confidence in decisions, and affecting patient safety and continuity of care:
...with a client that I’m seeing, he’s a cancer patient, so he’ll go to London, and then he’ll go to Stratford for example. The two hospitals they don’t communicate very well...the communication between the two kind of gets lost in between...it’s all of these extra steps between myself and this patient’s daughter. We are trying to figure out when was his last treatment? And was the medication provided? What was that medication? And how long was he supposed to take that? So, you have Stratford asking this and trying to get through to London to get those questions answered, the whole process becomes very difficult.

[Registered practical nurse]

End-user discussions touched on the impact of poor communication on patient satisfaction, trust, and their subsequent health care journeys. Occupational therapist 1 described how enhanced communication between providers could affect the patient care experience:

From a patient perspective, it might be one less time they have to answer the same questions. Not being asked the same questions all over again seems trivial, but if you’re the patient who’s had to answer the same question twenty times you think people aren’t listening to you...we could just kind of summarize what we know, which I think also makes the patients feel like we’re all a team speaking with each other. So, we’re communicating what we know about the patient, as opposed to having to ask them the same information over and over and over again.

The retrieval of information to provide proper care was deemed exceptionally crucial among end users working in community settings, where some may not have any connections to EHRs:

I mean our nurses are walking in really with very minimal information. Again, relying on the family a lot of the time to tell us, even as far as medications that they’re on, you know, we’re going through all of their bottles and discharge lists, and lists they pull out of their wallet, and trying to reconcile it. So, it’s really pieces of information. [Clinical practice specialist]

Real-Time Information

End users collectively admired that one of the most critical advantages of the record would be the access to real-time information as it changes and becomes updated. A clinical nurse specialist described information access as “very much a game changer for clinicians,” with other participants agreeing, describing it as “taking the legwork” out of obtaining essential patient information. The shared care record real-time information feature “would not only help the patients but also the healthcare team be up to date, and they wouldn’t have to take so long to find the information they need” (registered nurse 3). Considering their daily practice allowed the end users to visualize clinical patient data being stored in one central location where the information could be accessed, analyzed, uploaded, and used, with one process going to everybody involved in the patient’s care:

I’m really intrigued by receiving information in real time, I find that especially in the community if there has been a medication that’s been added, I don’t always receive that information, unless I’m at the client’s home and I see the new bottle because they don’t typically tell me if they are on a new medication, and the doctors just prescribe it, they definitely don’t inform us. That would be information would be very helpful for me when trying to figure out why they’re having a change in their health status, or maybe a cognitive change or something along those lines. [Registered practical nurse]

Theme 2: Perceived Benefits of Using a Shared Care Record

Effective Use of Time

Access to clinical information through the shared care record was described as promoting the effective use of time and resources. End users felt that the record would provide “an accurate picture of what’s going on,” and it would be “a lot less doubling and tripling of assessments.” Registered nurse 1 recalled a common scenario occurring in their inpatient hospital unit:

...on my floor patients come up with a bag of medications or just a list of medication names and dosages that they have scribbled onto a piece of paper...the time we are spending on doing something very basic like manually inputting medication information that should be available through the pharmacy or from a physicians list would save so much time and then you would be able to spend more time doing a proper assessment on the patient, providing care or starting a treatment.

Within the complex and fast-paced acute care setting in which several of the interviewed end users worked, the ability to save time was the most significant determinant of efficiency. Effective care must be provided with often limited resources and high workloads. Occupational therapist 1 discussed the vision of the shared care record as a benefit to their work:

...we’re always looking in acute care for efficiencies. The length of stay is already very short, and the more information that we have access to when we are doing our initial triage or chart review, the earlier we can start to at least reflect on what the likely plan is.

Informed Circle of Care That Promotes Continuity of Care

The vision of the shared care record would allow the patients’ circle of care, everyone involved in the patients’ care, to be well informed, leading to better care, time savings, and less frustration. According to registered nurse 1, “it would promote continuity of care and keep everybody in the loop and informed, which is so important in healthcare in general.” End users discussed the benefit of being able to collaborate with other clinicians and share more information in general:

...even when our clients go into hospital, they [the hospital occupational therapists] have no idea what we have been working on at home. And then if they...
go to discharge the client, sometimes they’ll put in new OT and PT services without realizing there’s already different things in place. There’s just poor communication, so I think this idea would make a huge difference. [Occupational therapist 2]

The consensus among the participants was that this vision becoming reality would change the way they practice, offering the ability to connect with everyone that the patients are in contact with:

...everything is just in silos right now, and I think anyone that’s had any contact with the healthcare system knows that. I think it’s very prominent in community...it is not practical how it is right now, so I think any move in that direction [access to a shared care record], would help immensely. [Registered nurse 4]

With regard to the patient-provider relationship, providers indicated that patients in the hospital setting can feel vulnerable and left out of conversations and might not know what is going on:

If we could retrieve those records...it would help the patients feel comfortable, they would be able to ask more questions during their stay and obtain answers from us as providers.

No one wants to be in the hospital as it is, so when they [the patient] come in, and they notice that their cardiologist has no idea that so and so [other healthcare providers] prescribed a certain medication, patients tend to become annoyed, and rightfully so...having that information prior to their visit would make their visit a lot easier, faster, and more efficient for them and for everyone involved. [Registered nurse 5]

Overview of Patient Health Status

The increased amount of health and health-related information accessible to health care providers would help them understand their patients’ medical requirements. A physiotherapist discussed how treatment of his patients would be enhanced “by helping me know and understand their timeline for recovery.” The record would “help understand other areas they [the patient] need help with because patients forget things and don’t always understand what other healthcare providers tell them when it comes to their injury.” Participants noted a lack of patient awareness regarding what providers are involved in their care, medication management, or even their diagnoses. Physicians discussed situations in which, unless their patients informed them, they were unaware of new allergies or changes to medication dosing made by other physicians. Registered nurse 2 discussed that, when noticing a new irregular sign or symptom, the shared care record would allow for “a quick reference, if that’s something they [the patient] have at baseline or if you need to look into it further, and just kind of base your actions on that information”:

...especially going into people’s homes, it would just make me more aware of things. People won’t always tell you the truth about things or they’ll leave out things they don’t feel are important but are impacting how they are managing at home...If you knew the information, walking into it, you kind of have a more holistic picture before moving forwards with them. [Occupational therapist 2]

Adaptation

Theme 3: Factors That Promote Use of the Record

Positive Outlook on Adaptation

Overall, the participants revealed an incredibly positive outlook when considering their own and their colleagues’ adjustment to the record. Participants made comments such as “it wouldn’t be a challenge for me and my colleague’s personally” (registered nurse 3) and “I don’t think there would be a large change-related level of concern or anxiety” (occupational therapist 1). End users acknowledged that technology is on the rise, with many individuals of all ages using digital solutions in their daily lives:

...even just logging in and seeing their bloodwork online, people are more comfortable doing that...even if they’re older or they haven’t done that they’re comfortable reaching out to their neighbor or their child to help them with that...I think it would be easier than you know even 5 years ago. [Registered nurse 4]

Health Care Provider Requests for Health Information Access

When end users were asked what other patient health or social information they would like access to when providing patient care, most made remarks regarding the difficulty of obtaining access to clinical data documented beyond the organization they worked within. The most common request among end users was access to a verified list of medications. Often, providers must rely on medication bottles, discharge lists, and family members to reconcile patient prescriptions:

...patients might know the name of the drug, or what the pill looks like, but they have no idea what it does, or why one of their physicians ordered it. For example, when they come into the clinic telling us that their nephrologist ordered something to bring their blood pressure down because their kidneys are failing, their cardiologist might just be finding out about the medication and realizing the medication could be affecting their heart. So being able to see what was ordered and when it was ordered would be such a big help. [Registered nurse 5]

The lack of integrated health IT was found to cause duplication of efforts and lack of comparison across documentation from the hospital versus the community or across organizations or different regions:

I cannot see pictures of x-rays that they [patients] get in the community. So, people get sent in with a break and I need a picture to see if I need to push on it, to put a cast on it and get it in the right place. We often repeat x-rays that probably wouldn’t need repeating if we could just see the original picture. [Physician 1]
Interoperability between organizations can reduce redundant tests, save time and costs, and result in better continuity of care. Participants regarded patient diagnostic imaging as the information they would like to access, including the actual pictures and not just the reports of x-rays, ultrasounds, computed tomography scans, echocardiograms, and other imaging modalities. Furthermore, patient exposure to radiation or contrast dye would decrease without the need to repeat tests and scans:

...it would help me if I had access to imaging without having to rely on what the patient tells me or what they can even remember. Sometimes patients don’t even know what type of imaging they had done or even what that imaging was for. [Physiotherapist]

Participants listed patient medical-related appointments as the information they wanted to see on the record. Many patients have complicated cases and multiple teams following them in the community, which can be overwhelming to manage independently. Family physician records or membership in a family health team was another common request, along with up-to-date access to all referrals sent out and specialist information:

Knowing what doctor the patient was referred to...a lot of time people will come in and will say “well my doctor sent me to a cardiologist, but I haven’t heard anything in three months” So then I’m like “well I’ll send you to a cardiologist as well.” Am I sending them to a different cardiologist? I have no idea. [Physician 1]

Access to patient social history information was highly requested, including living arrangements, home care reports, and community support or professional services that patients were using as this information significantly affects patient care planning and discharge planning. According to physician 2, “it would be nice if the patient could update things like occupation, substances, family members, consent to family members”:

In many cases, we don’t have a true understanding, at least initially on chart review, without speaking with our team about the exact specifics of what type of services or equipment or programs they are [the patient] currently involved in, in the community. A true understanding of that social and community history allows us to initially strike off maybe some options that we may not have at our disposal, or start to plan out some of the gaps that we anticipate based on what we know that they already have. [Occupational therapist 1]

End users discussed situations requiring access to patients’ medical histories and complete health records. Requests for clinical data access included a complete list of diagnoses and when the patient was assessed for them; laboratory test results; previous rehabilitation journeys; surgeries; and conversations that had taken place, which could indicate the patient’s understanding of their illness or where they are at:

Almost every single clinician that I have spoken to would say, we wish we had more, or the information is just a very brief summary...especially with acute care, the length of stay is so short, we’re trying to piece together as much as we can...so the more the more understanding of the patient’s history and journey through the healthcare system, the more efficient we can be as occupational therapists. [Occupational therapist 1]

Ongoing Training

The most common suggestion among end users was the provision of proper education and training on the new system. As one of the primary objectives of an EHR is to improve collaboration among health care providers, it only makes sense that they are offered the chance to provide feedback on the system they use daily:

From a training perspective, it’s nice to first of all be part of the process of building the system, or having some input on that system, which helps with the engagement and integration when we’re actually putting the rubber to the road...it definitely would help with the connection to the implementation. [Clinical nurse specialist]

Most participants suggested that they would benefit from getting to know the new system through proper training on the layout of the information and how to find the information that they could use. End users visualized the benefits they could obtain from an introduction to and familiarization with the system before it becomes implemented in practice:

...obviously, there needs to be training, and along with that comes the resources. Not only do the training but pay for them [the end users] to attend, which is always an issue. And then I think even support along the way, for example IT support, do we need to build that internally in our IT department...up front, it’s just really the education and making sure it is ongoing...in healthcare in general, there is a lot of turnover, so how do we sustain the education moving forward. [Clinical practice specialist]

Many participants discussed “multi-pronged approaches” as the most effective method for introducing and adapting to the record. Resources mentioned by the participants included a chat or live support option for immediate questions, videos on how to use the system, a toolkit or tip sheet developed by the system creators, and in-person and web-based computer sessions. Occupational therapist 2 described the introduction to their current EHR system as they recalled:

Clinicians felt more comfortable using the system if they had some test patients to go through trial cases of what a daily patient intervention might look like prior to the go live.

Several participants mentioned the idea of “super users”:

...our nurse colleagues on the floor, who had additional training and were more familiar with the record so that we could reach out to them if we needed help or if we had questions. [Registered nurse 1]
These super users would function to support their colleagues in the transition while helping others learn to use the record to the fullest extent.

Another resource identified was the use of clinical educators who already work to support staff with clinical updates to rules, procedures, policies, and methods of accessing information.

Record Accessibility
Several questions from end users concerned how to physically access the clinical data on record and the timeliness of finding information. Questions included the following: “where do we need to click?” “Under what icon?” “How do I add things to the shared care record?” “Do I have to do it manually?” “Does it just happen automatically?”:

The biggest adaptation would be how to access the information, like opening the charting system will look different, so getting used to the new layout and the new system and knowing where to find things. [Physiotherapist]

A key finding among participants included statements regarding the user interface or usability of the shared care record. Participants used terms such as “seamless,” “simple,” “accessed quickly,” “user friendly,” and “easy to follow” to describe how they envisioned the software to function:

But we need to really limit where they’re [frontline staff] finding their information, if they need to upload, that they are not having to do it to all of the people we need to report to. There are so many layers and rules, and we just need to make it as simple as possible. [Clinical practice specialist]

Participants considered the least amount of clicking and integration with their current systems to obtain data or add to their assessments as crucial features of the record. Information being uploaded automatically was considered foundational, with physician 1 commenting the following:

If we have to do an additional step at the end to get it uploaded, you’re going to get way less uptake...as long as in the back end of things, my EHR links it all up.

Regarding user-friendliness, the physicians explained that they would not appreciate retying a password to access the charting or repeated verification of the designation upon entering the system:

I don’t want to have to log into something else, I’m already logging into so many things every day...and so there’s that information that sits somewhere but that it gets pushed to all the different places and then shared between the different places. [Physician 2]

Theme 4: System-Dependent Considerations and Concerns
Clinical Data Consistency, Accuracy, and Organization
Although participants recognized numerous potential benefits, they also discussed fundamental considerations of functional practicality, such as the consistency and accuracy of data across the record. To present clinical data across different EHR systems uniformly, health care providers must be consistent with the documentation methods and upload the documentation to the record:

I would be concerned about it being unorganized or messy, um if everyone has different styles and systems of taking notes or recording, maybe it would be difficult to find one particular piece of information that you are looking for. [Physiotherapist]

Understanding patient rostering or enrollment was discussed as a critical element of the record, understanding who is involved in a patient’s care, and participating providers can change or adjust that if needed:

I changed my practice maybe three years ago, but I am still on some people’s charts at the hospital. I have requested to have my name taken off, but unless the patient calls and changes that, nothing can happen. And so that becomes a privacy issue, I keep getting files for people who I am not actually taking care of. [Physician 2]

Beyond consistency, participants identified the importance of double-checking the information obtained from the record with the patients themselves. Updates may not be revised, data could be deleted, and mistakes can still occur:

If you have a medication record from two years ago, you would still have to do your due diligence to make sure the information you are using is accurate. [Registered nurse 1]

An auditing system of the record was suggested that could review charting to help ensure that health care providers input the required information to maximize the utility and reliability of the clinical data. According to registered nurse 5, “that way people have to take responsibility for what they’re changing or what they’re contributing towards this shared documentation.”

Change in Workflows
Uncertainty regarding daily practice workflows came up as a barrier to overcome when participants discussed adaptation to the use of the record. Visualizing the details of the change to their current EHR system interface was difficult for certain participants:

It’s hard to know what the change management strategy would be. [Clinical practice specialist]

My hope is that there would be very little that we would actually have to change...everything else I would expect to be kind of behind the scenes where I do my normal process, that it would just sort of happen in the background. [Physician 2]

Discussions held with professionals in the community setting revealed that there would be an adjustment to their current workflow, with the additional time spent reviewing history, reports, and other data accessible in the record before going in to see the patients:

Right now...I really only check [name of EHR] to look at when appointments are confirmed, phone numbers, names, and then I find out a lot more information from the patient once I get there [to their place of
residence...for home care, that’s just kind of how it’s been. If I am seeing four or five people every day and driving between these destinations, it would take time maybe at the beginning before getting used to it as part of the routine. [Occupational therapist 2]

Upon introducing the idea for the record, a statement from the Ontario Patient, Family, and Caregiver Declaration of Values [10] was presented to participants explaining the vision for transparency in patient access to their health records. Wondering how patients would interpret seeing physicians no longer in the patient’s circle of care re-entering their medical information and whether this would be concerning, physician 1 stated the following:

...Most of us [physicians] require understanding of, did the treatment I gave actually have a good effect? And what did the follow up doctor think? So, we will access records a few weeks later to see what happened so that we can learn...that’s how I learn and how I can change how I practice, which is super important...we are expected to do continuing professional development and take courses, but then it’s always read and learn around your cases. How am I supposed to learn around my cases when I can’t find out what the specialists thought of this unique situation that I can’t just open a textbook and read about.

Privacy, Confidentiality, and Security of the Record

The most common concern among participants regarded privacy and confidentiality. The extensive personal health information or personal information accessible in a central location, this being the record, increases the risk of a privacy breach:

I think about it, not only as a clinician, but as a user of healthcare as well. [Occupational therapist 1]

Regardless, health care providers considered the inclusion of these types of documentation to be vital to the patient’s record:

...there might be certain things...in the record that maybe patients themselves would not want to see...if the patient was confused after a surgery and there was an episode of violence that was documented. It may almost be triggering or upsetting to them [the patients]. [Registered nurse 2]

When considering patient access to records, participants emphasized the importance of patients being able to interpret the information correctly and objectively, especially regarding medical jargon. Participants suggested that clinicians may be inclined to use different terminology or a different writing style or reformulate the information in a meaningful way for patients:

...kind of helping socialize the clinicians to the new reality of the patients being able to read their notes more readily or easily. I think there would be value in having a discussion as a team about those types of changes. [Occupational therapist 1]

Discussion

Overview

Concepts such as PHM, data security, and privacy can be complex to explain to individuals; however, they will become progressively essential to the design and delivery of health care. PHM is founded on interoperability, data sharing, and integration with diverse health sectors and services. Although people tend to understand the role and significance of EHRs, they may neglect the value of inputting accurate and high-quality data into them. PHM and primary health care strive for many of the same features, including person-centeredness; continuity; accessibility; and consideration of physical, mental, cultural, and social aspects of health, among others [2]. Health care providers commonly have a good understanding of the population that they serve, often living within the community themselves, and appreciate the needs and some of the determinants of health of these populations. A PHM approach rooted in quality data quantifies this understanding and enables an even deeper level of understanding [2,17]. As the vision for a shared care record using HIE technology starts coming to life,
obtaining end users’ opinions and ideas will be imperative. End-user involvement in the record’s design; development; and, ultimately, operation will help simplify the adoption of changes and attain the goals of proactive and coordinated care that actively engages patients.

**Principal Findings**

This study provides practical findings that will help emphasize factors that facilitate clinicians’ process of adaptation to the use of a shared care record. Considering the fast pace of health care, clinicians highly commended and admired a central location for real-time information availability that could promote efficiency through the effective use of time. The benefits of accessible retrieval of information were especially highlighted among end users practicing in the community setting. Discussions with end users brought forth the importance of an informed circle of care, promoting patient continuity of care, and more effective provision of care. Health care providers requested access to additional information that would help them in their practice, from medication lists and diagnostic imaging to social community and home care support, laboratory test results, and referrals. Discussions also brought forth questions regarding the interoperability of the record, its functional usability, and changes in workflows.

Adaptation to a shared care record was viewed positively by health care providers. Several end users spoke about the benefits of getting to know the new system through proper ongoing training using multifaceted approaches. Some of the approaches considered included videos, in-person and web-based computer sessions, and live user support options. The idea termed “super users” was brought forth, whereby colleagues who would be more acquainted with the software would function as support for their coworkers in the transition and adaptation to use of the record. End users wanted to understand the functionality of the record, the impact of changes on their daily workflows, and the consistency and accuracy of data across the record to maximize the utility and reliability of the clinical data. The main concerns of participants were the privacy, confidentiality, and security of the record and patient information interpretation through the patient portal.

A growing body of literature on the topic of patient access to health care provider electronic visit notes suggests that the active involvement of patients at the point of care can foster stronger patient-provider therapeutic partnerships. A study by Wolff et al. [26] suggested that most patients reported benefits of reading provider notes, such as more agreement concerning treatment care plans, increased ability to formulate questions to ask their care providers, and more productive care discussions. Walker et al. [27] brought forth challenges such as patients not being registered on portals to allow for access to notes or patients being unaware of provider notes being available to access. Nevertheless, the benefits of expanded patient access to clinical notes have been established, holding the potential to better support and involve patients in care, increase communication, and provide feelings of control and preparation for health care visits [26-28].

**Limitations**

This study was limited in certain ways. The range of clinicians could have included various other providers within diverse health care settings to broaden the perspectives included. Furthermore, the application of voluntary response sampling in the recruitment of health care providers for this study is a limitation because of the possible sampling bias of respondents who volunteered, meaning that the study could have involved EHR advocates. Future research should involve a subsequent round of health care provider interviews once the record has a fully developed user interface design functioning across several systems involved with the HIE initial demonstration project. At this stage, health care provider interviews may offer further understanding of the functional usability of the shared care record once the providers can visualize and use it within the home database system they work in daily. These interviews could be geared toward comprehending how information design principles align with clinician workflows, patient information examinations, or decision-making in the medical environment. Building on this effort can help populations receive high-quality care while ensuring that it meets community needs.

**Conclusions**

This study provided insights into health care providers’ perceptions of a shared care record and presented their reflections on the practical use and adaptation to the use of a shared care record. It is essential to bring end-user perspectives into the shared care record’s development, introduction, and maintenance, along with the training necessary to permit the use of the system. There is an urgent demand for high-quality, integrated, and timely health data allowing individuals, health care providers, and communities to be involved and informed partners in the provision and attainment of health care [17].

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**Conflicts of Interest**

None declared.

**References**


Patient Characteristics Associated With Phone and Video Visits at a Tele-Urgent Care Center During the Initial COVID-19 Response: Cross-Sectional Study

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Abstract

Background: Health systems rapidly adopted telemedicine as an alternative health care delivery modality in response to the COVID-19 pandemic. Demographic factors, such as age and gender, may play a role in patients’ choice of a phone or video visit. However, it is unknown whether there are differences in utilization between phone and video visits.

Objective: This study aimed to investigate patients’ characteristics, patient utilization, and service characteristics of a tele-urgent care clinic during the initial response to the pandemic.

Methods: We conducted a cross-sectional study of urgent care patients using a statewide, on-demand telemedicine clinic with board-certified physicians during the initial phases of the pandemic. The study data were collected from March 3, 2020, through May 3, 2020.

Results: Of 1803 telemedicine visits, 1278 (70.9%) patients were women, 730 (40.5%) were aged 18 to 34 years, and 1423 (78.9%) were uninsured. There were significant differences between telemedicine modalities and gender ($P<.001$), age ($P<.001$), insurance status ($P<.001$), prescriptions given ($P<.001$), and wait times ($P<.001$). Phone visits provided significantly more access to rural areas than video visits ($P<.001$).

Conclusions: Our findings suggest that offering patients a combination of phone and video options provided additional flexibility for various patient subgroups, particularly patients living in rural regions with limited internet bandwidth. Differences in utilization were significant based on patient gender, age, and insurance status. We also found differences in prescription administration between phone and video visits that require additional investigation.

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KEYWORDS
telehealth; telemedicine; tele-urgent care; virtual urgent care; nonemergency care; televisit; phone visit; video visit; urgent care; health services research; COVID-19; health disparities; insurance status; cross-sectional study
Health systems rapidly adopted telemedicine as an alternative health care delivery modality in response to the COVID-19 pandemic. Demographic factors, such as age and gender, may play a role in patients’ choice of a phone or video visit [1-3]. However, it is unknown whether there are utilization differences between phone and video visits.

The pandemic led to a rise in phone and video consultations, providing an opportunity to study their usage across demographics and outcomes, such as medication prescriptions. Telemedicine can help improve health access and reduce disparities for vulnerable populations [4-7]. Although we know that medication prescription differs between in-person and video visits [8], there is a gap in the knowledge regarding differences in prescription administration, whether medication was prescribed or not, between telephone and video visits. Driven by prior differences in prescription administration among providers based on gender and specialty [7], we hypothesized that prescription administration, a service outcome of telemedicine, may differ between phone and video visits.

Phone-based treatment has been found feasible, acceptable, and effective compared to face-to-face visits. It is a promising alternative in telemedicine, offering tailored interventions [9]. Phone visits have taken less time and have been used more frequently, but there have not been significant differences in patient perceptions or other clinical outcomes [10].

Telemedicine’s growth during the pandemic has led to a need for understanding the limitations of telephone-based versus video-based consultations for clinical care [11,12]. Patients reported that video consultations were more favorable compared to phone consultations, claiming that video visits led to improved outcomes, better diagnostic accuracy, and patient satisfaction [13-18].

Previous studies have looked at the impact of phone or video visits on vulnerable patients [19-23], but there is a lack of research on the differences in patient characteristics between the 2 modes of telemedicine-based care. Understanding these differences can help health organizations and policy makers tailor telehealth options to better suit patients.

Telemedicine use during the pandemic has been examined in various clinical environments, such as primary care, geriatrics, and subspecialties [5,22,23]. It is unclear how phone and video health care delivery in urgent care clinics was affected during the initial phases of the COVID-19 pandemic, especially regarding wait times and visit duration. The demand for urgent care clinics increased due to emergency department overcrowding, cost increase, and long wait times [24,25]. Therefore, it is important to understand the changes in urgent care practices considering telemedicine deployment postpandemic.

In this exploratory study, we examined patient and service characteristics of on-demand telehealth utilization and whether they differed by modality during the initial phase of the pandemic when the health care system suspended all in-clinic visits. We used the Donabedian framework of structure-process-outcome to inform this study design [26].

Methods

Study Overview

We conducted a descriptive analysis on a cross-sectional study of patients using a statewide, on-demand tele-urgent care clinic in the southeastern United States region. The Virtual Urgent Clinic (VUC) is an on-demand clinic open for nonemergency concerns 24 hours a day and 7 days a week. Regardless of whether they are new or existing patients, any individuals can log on to the virtual clinic through the web-based portal. To use the telemedicine service, individuals must create an account, input their medical history, and request a virtual care visit. Individuals can choose their telemedicine modality—telephone or video—through a computer, tablet, or phone.

The cost of the visit was the same for phone and video visits. The clinic provides on-demand service such that individuals can log on to the web-based portal and choose to have a visit immediately or schedule a visit for a later date. Board-certified physicians are available 24 hours every day of the week to provide care for patients. If an individual is an existing patient, documentation of the virtual visit is integrated into the electronic medical record after the visit is completed.

Data Collection

VUC monthly data were collected from March 3, 2020, through May 3, 2020, using the institutional data warehouse. The data set included patient information, such as age, gender, insurance status, and residential address, and service characteristics, such as telemedicine modality, wait time, visit duration, and medication prescription outcomes. To avoid double counting of patients or visits, each patient and each visit received a unique identifier. Incomplete encounters were recorded in the data set as incomplete if the call was not completed for any reason. The rate of incomplete encounters was only 7.9% (142/1803) of the total visit volume in this study and was included to better understand the characteristics of patients who sought care via telehealth.

Outcomes

Our primary endpoints were the characterization of telemedicine modalities (phone vs video) on patient characteristics measured by demographics and insurance status, utilization measured by the volume of visits; and service characteristics measured by medication prescriptions and visit wait times. The secondary endpoint was utilization, which was measured by the number of visits from rural and urban neighborhoods.

Statistical Analysis

The study data included patient age, gender, health insurance status, address, number of medication prescriptions, number of visits, and choice of telemedicine modality. For each of these variables, we calculated descriptive statistics for each demographic category stratified by modality (phone or video) and the total of both groups. A $\chi^2$ test was calculated to check for significant differences between telemedicine visits and these
variables. Additionally, we calculated the average wait time and visit duration for phone and video visits. A 2-sample t test assuming unequal variances (Welch t test) was also conducted to determine if there was a statistically significant difference in the average wait times and visit duration lengths between phone and video telemedicine visits.

To examine the predictors of prescription administration, we constructed a logistic regression model with a dichotomous dependent variable of prescription administration (0=no prescription=0 and 1=at least 1 prescription given) as a dependent outcome variable and patient age, gender, insurance status, location, and telemedicine modality as independent variables in the model predictors. We used a P value level of .05 to indicate statistical significance.

**Geospatial Analysis**

Geographical locations for patients with VUC visits over the phone or video were examined to assess the urban-rural spread of the patients in this data set. Using the US Census definition, cities with populations of 50,000 people or more were designated as urban, and those with less than 50,000 people were designated as rural. In the telemedicine data set, 198 places in North Carolina were found, of which 179 were classified as rural and 19 were classified as urban, which was used to develop the health access map. A $\chi^2$ analysis was used to determine the significance between an encounter from an individual in an urban or rural area and the encounter modality.

To understand the association between telehealth modality and location, we used ArcGIS (Esri) to map zip code–level populations, as reported in the 2010 US Census Bureau data, with VUC visits based on Zip Code Tabulation Areas (ZCTAs). We used the 2016 American Community Service (ACS) to calculate the percentage of households with internet access by ZCTA. We then mapped the ACS data and visit counts from the VUC by modality on the North Carolina (NC) map to better understand the preference of patients for modalities based on internet availability.

We used natural breakdowns to quantify the percentage of households with internet in each NC zip code to determine the threshold for low, medium, and high categories based on the 2016 ACS data set. The colors along the bottom row (gray to light blue to teal) represent ZCTAs with a low percentage (0%-71%) of households with internet access and an increasing number of phone (or video) visits. The colors in the middle row (light pink to light purple to blue) represent ZCTAs with a medium percentage (72%-82%) of households with internet access and an increasing number of phone (or video) visits. The colors along the top row (pink to purple to dark purple) represent ZCTAs with a high percentage (83%-100%) of households with internet access and an increasing number of phone (or video) visits. The colors along the diagonal (gray to light purple to dark purple) represent ZCTAs with low internet access and low telemedicine visits, medium internet access and medium telemedicine visits, and high internet access and high telemedicine visits. For phone visits, the breaks were 1-2 (low), 3-6 (medium), and 7-37 (high). For video visits, the breaks were 1 (low), 2-3 (medium), and 4-15 (high). We used quantiles to determine the threshold for low, medium, and high categories based on the ACS 5-year estimates from 2015-2019.

**Ethical Considerations**

University of North Carolina at Chapel Hill institutional review board approval was obtained prior to conducting this study (18-1628).

**Results**

**Telemedicine Visit Overview**

Table 1 shows a series of visit counts of the patients who used the telemedicine service during the observed period categorized by the patient characteristics captured in this study. It also indicates the $\chi^2$ and $P$ values for significance tests for the differences between these observed characteristics.
Table 1. Percentage statistics and $\chi^2$ values for phone and video telemedicine visits.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Phone visits (n=1414)</th>
<th>Video visits (n=389)</th>
<th>Total visits (N=1803)</th>
<th>Chi-square (df)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visits per day, mean (SD)</td>
<td>22.8 (9)</td>
<td>6.3 (3.1)</td>
<td>29.1 (10.7)</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>16.79 (2)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Women</td>
<td>1033 (73)</td>
<td>245 (63)</td>
<td>1278 (70.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>377 (26.7)</td>
<td>144 (37)</td>
<td>521 (28.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nonbinary</td>
<td>4 (0.3)</td>
<td>0 (0)</td>
<td>4 (0.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years), n (%)</td>
<td></td>
<td></td>
<td></td>
<td>24.99 (4)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>&lt;18</td>
<td>96 (6.8)</td>
<td>57 (14.7)</td>
<td>153 (8.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-34</td>
<td>579 (40.9)</td>
<td>151 (38.8)</td>
<td>730 (40.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35-50</td>
<td>486 (34.4)</td>
<td>123 (31.6)</td>
<td>609 (33.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>51-64</td>
<td>185 (13.1)</td>
<td>44 (11.3)</td>
<td>229 (12.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥65</td>
<td>68 (4.8)</td>
<td>14 (3.6)</td>
<td>82 (4.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health insurance status, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>18.91 (1)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Insured</td>
<td>329 (23.3)</td>
<td>51 (13.1)</td>
<td>380 (21.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uninsured</td>
<td>1085 (76.7)</td>
<td>338 (86.9)</td>
<td>1423 (78.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residence, n/N (%)</td>
<td></td>
<td></td>
<td></td>
<td>6.74 (1)</td>
<td>.009</td>
</tr>
<tr>
<td>Rural</td>
<td>782/1370 (57.1)</td>
<td>189/381 (49.6)</td>
<td>971/1751 (55.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>588/1370 (42.9)</td>
<td>192/381 (50.4)</td>
<td>780/1751 (44.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescriptions per visit, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>24.07 (1)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Received</td>
<td>980 (69.3)</td>
<td>218 (56)</td>
<td>1198 (66.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not receive</td>
<td>434 (30.7)</td>
<td>171 (44)</td>
<td>605 (33.6)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

aN/A: not applicable.

Patient Characteristics

Phone visits constituted most of the 1803 total visits (n=1414, 78.4%), with an average of 22.8 (SD 9) daily visits, while video visits accounted for the remaining visits (n=389), with a daily average of 6.3 (SD 3.1) visits. Most of the patients were women across both phone and video modalities (phone visits: n=1033, 73%; video visits: n=245, 63%). Among age groups, patients aged 18 to 34 years had the most visits (phone visits: n=579, 40.9%; video visits: n=151, 38.8%), with patients aged 35 to 50 years being the next most represented age group (phone visits: n=486, 34.4%; video visits: n=123, 31.6%). Across both modalities, the least present age group included patients older than 65 years being the next most represented age group (phone visits: n=486, 34.4%; video visits: n=123, 31.6%). Most patients across both modalities were uninsured (phone visits: n=1085, 76.7%; video visits: n=338, 86.9%).

Significant differences between telemedicine modalities and gender ($P<.001$), age ($P<.001$), insurance status ($P<.001$), health access ($P=.009$), and prescriptions given ($P<.001$). This suggests that men, patients younger than 18 years, uninsured patients, and patients residing in urban areas preferred the video modality for telemedicine visits, and video visits were more associated with not getting prescriptions.

Telemedicine Service Characteristics

Prescription Administration

More patients received at least 1 prescription (phone visits: n=980, 69.3%; video visits: n=218, 56%) from a telemedicine visit rather than no prescription. Video visits were more associated with no prescriptions than phone visits ($P<.001$). Significant differences were found in medication prescription administration between phone and video visits ($P<.001$; Table 1).

For phone visits, of a total of 1414 phone visits, 980 (69.3%) resulted in at least 1 prescription given, while the other 434 did not receive any prescriptions. On average (SD), patients received 1 (1.02) prescription per encounter. Of all phone visits, 434 (30.7%) patients did not receive a prescription, 944 (66.8%) patients received 1-3 prescriptions in an encounter, and 36 (2.5%) patients received 4-7 prescriptions in an encounter.

For video visits, from a total of 389 video visits, 218 (56%) resulted in at least 1 prescription given, while the other 171 did not receive any. The average (SD) number of prescriptions per encounter was 0.84 (1.00). Of all video visits, 171 (43.9%) patients did not receive a prescription, 210 (54%) patients received 1-3 prescriptions in an encounter, and 8 (2.1%) patients received 4-7 prescriptions in an encounter.

We found that 5 patient characteristics were strong predictors of telemedicine prescription administration (Table 2). Predictors
that were positively associated with prescription administration were patients aged 18 to 34 years ($\beta=0.62, P<0.001$), 35 to 50 years ($\beta=0.81, P<0.001$), and older than 65 years ($\beta=0.94, P=0.002$). Predictors that were negatively associated with prescription administrations were video visits ($\beta=-0.47, P<0.001$) and male patients ($\beta=-0.38, P<0.001$). There was no significant relationship between patients’ insurance status and prescription rates.

Table 2. Logistic regression model showing patient demographic associations with telemedicine prescription administration. The independent variables were modality, age, gender, and insurance status. The depended variable was prescriptions given.

|                     | Estimate | SE    | z score | Pr(>|z|)$^a$ | $R^2$  |
|---------------------|----------|-------|---------|--------------|--------|
| Model intercept     | 0.2711   | 0.1853| 1.463   | .14          | 0.027269|
| **Modality**        |----------|-------|---------|--------------|--------|
| Video               | -0.4724  | 0.1204| -3.922  | <0.001       | N/A$^b$|
| **Gender**          |----------|-------|---------|--------------|--------|
| Men                 | -0.3878  | 0.1108| -3.5    | <0.001       | N/A    |
| Nonbinary           | 0.4606   | 1.1715| 0.393   | .69          | N/A    |
| **Health insurance status** | | | | | |
| Insured             | 0.1629   | 0.1308| 1.245   | .21          | N/A    |
| **Age (years)**     |----------|-------|---------|--------------|--------|
| 18-34               | 0.6227   | 0.1858| 3.351   | <0.001       | N/A    |
| 35-50               | 0.8057   | 0.19  | 4.241   | <0.001       | N/A    |
| 51-64               | 0.3573   | 0.2173| 1.644   | 0.10         | N/A    |
| $\geq$65            | 0.9421   | 0.3045| 3.094   | 0.002        | N/A    |

$^a$Pr(>|z|): $P$ value associated with the value in the z score column.

$^b$N/A: not applicable.

**Wait Times and Visit Duration**

The average wait time for patients to start their phone visits was 64.1 (SD 129.9) minutes, while the average wait time for patients with video visits was 24.6 (SD 45.6) minutes. The average visit duration for phone visits was 7.3 (SD 4.4) minutes, while the average visit duration for patients in video visits was 9.0 (SD 5.9) minutes. Significant differences existed between the average wait times and durations for phone and video visits (Welch $t$ test $P<0.001$ for both wait times and duration). For phone and video visits in this data set, the daily wait times for patients to see a physician across each modality are indicated in Figures 1A and 1B, respectively. The number of physicians working daily shown in these figures peaked at a maximum of 33 physicians on March 21 and 22. The number of phone sessions facilitated was also at its peak on these days at 47 phone visits. Phone users experienced the longest wait times in the second half of March, but both phone and video users experienced extended wait times in this same period compared to April.
Telemedicine Utilization in Rural and Urban Areas

Of the 1080 NC zip codes, 262 (24.3%) had a low percentage of households with internet access, 277 (25.6%) had a medium percentage of households with internet access, and 269 (24.9%) had a high percentage of households with internet access. There were 272 (25.3%) zip codes with no internet access. The overall utilization of video visits was higher in areas with high percentages of households having internet access (Figure 2). Among the individuals from zip codes with low internet access there were 127 (83.5%) phone visits and 25 (16.5%) video visits. Zip codes with medium internet access had 367 (80.8%) phone visits and 87 (19.2%) video visits, and those with high internet access were 879 (76.2%) phone visits and 274 (23.8%) video visits.

Figure 1. Comparison of (A) phone visit and (B) video visit wait times with a count of daily visits and physicians working.

A) Phone visits

B) Video visits
Visits to the telemedicine-based clinic came from 431 (40%) unique NC zip codes. Of these, 251 (58.2%) were rural zip codes and 180 (41.8%) were urban zip codes (Figure 2). The density of the visits, shown in larger icons in Figure 2, originated mostly from major metropolitan areas like the state capital or the Research Triangle Park. Phone visits provided further reach into areas with low internet access, while video visits mainly occurred in urban settings with high access to internet services.

Phone visits provided significantly more access to rural areas than video visits (P<.001). There were 1363 phone visits from patients in NC, with 780 (56.8%) being from rural areas and 583 (42.5%) from urban settings. There were 383 video visits from patients in NC, with 190 (49.2%) being from rural areas and 193 (50%) from urban settings.

Phone visits originated from 290 (26.9%) unique NC zip codes, of which 170 (58.6%) were from rural areas, 80 (27.6%) were from urban areas, and 40 (13.8%) were from out of state. Video visits occurred in 141 (32.4%) unique NC zip codes, of which 80 (56.7%) were from rural areas, 56 (39.7%) were from urban areas, and 5 (3.6%) were from out of state. Phone visits provided better reach into rural areas; however, video visits had widespread coverage, demonstrating the potential to complement phone visits in rural areas. Both phone and video visits within urban areas provided comparable coverage as expected.

Discussion

Principal Findings

We conducted a cross-sectional study of telemedicine urgent care visits completed through phone or video using a statewide,
on-demand urgent care telemedicine clinic, focusing on demographics, utilization, and service characteristics. We observed significant differences in service characteristics between phone and video visits. The rate of medication prescription was much higher among phone visits compared to video visits. Patients had a higher probability of receiving a prescription during a phone visit, while the probability of receiving a prescription was lower during a video visit. Differences in gender, age, and telemedicine modality were associated with significant variations in prescription administration.

Similarly, significant differences in wait time and visit duration were observed between phone and video visits, where phone visits had higher wait times and longer visit durations. The high volume of requests for phone visits can justify the long wait. It was unclear if providers compensated for the long wait times by providing more visit time or if patients who waited longer had more questions based on the differences in visit durations.

Utilization of phone and video visits differed significantly. Women, insured patients, and those residing in rural areas preferred phone visits, while men, uninsured patients, and those residing in urban areas preferred video visits. Patients older than 65 years were equally split. The increase in video visits was due to pandemic-related cancellations of in-person appointments. Video visits were more common for children due to the need for clinical examination. Phone visits were more common in rural areas with no internet access for video visits. Rural patients preferred phone visits while urban patients preferred video visits. The reason for this preference is unclear. We suspect that a combination of privacy concerns, lack of confidence in their internet connection, and a lack of awareness may drive patients’ decisions; however, more investigation is needed [27,28].

Tying our findings to similar studies in the literature was a challenge because of a gap in studying the differences between telephone and video visits on the same outcomes [29]. Comparative studies have indicated that there has not been a meaningful difference between these modalities, having similar consultation session lengths, content, and perceived quality [30-32]. One study reported that older, rural, and ethnic minority patients were associated with lower utilization rates of video visits compared to phone visits [23]. A previous study reported that patients who had telephone visits had longer visit durations than those who had video visits [32], which contradicts our finding where video visits were longer in duration. A few studies have indicated increased utilization of telemedicine to trend toward women, with women being more likely to attend telephone-based interventions and to benefit from such interventions in the context of addiction treatment [33,34]. Moreover, another study showed that no major differences in utilization were found between video and telephone visits [31], which contradicts our findings demonstrating higher utilization of telephone visits compared to video visits.

Other studies explored telemedicine modalities separately demonstrating limitations due to selection bias in patient populations, such as including patients from a single hospital or clinic setting [13,14,16]. There is also concern that these studies often cater to specialized medical concerns or treatment options, which limits the demographic diversity of the patients recruited regarding factors such as age or gender, making the findings less generalizable [17,30]. Little was known regarding the patient characteristics of telephone or video telemedicine modalities across the rural-urban divide, patient insurance statuses, and prescriptions provided to the patients.

The COVID-19 policy waivers by the Center of Medicaid and Medicare and private insurers to include phone and video visits appear to be an effective decision that increased access and reduced disparities [35,36]. Additionally, this study shows that internet access is still limited in rural areas, which may limit the ability to conduct patient video visits, resulting in more phone visits. We recommend policymakers to continue to support video and phone visits equally, and we highlight the importance of building internet capacity within rural and vulnerable communities to expand the effective use of telemedicine.

Limitations
This study had several limitations. We conducted a cross-sectional study as we could not randomize patients to a telemedicine modality due to the complexity of the process and given the sensitivity of COVID-19. In addition, the study was conducted over 2 months (March 3, 2020, to May 3, 2020) at the height of the pandemic with a limited amount of data; however, this reflected the initial response to the pandemic when telemedicine was the primary option for care. A large proportion of patients in this study were uninsured. Uninsured patients preferred telehealth during the initial phase of the pandemic due to the suspension of in-person visits and the shutdown of health care systems and primary care clinics, which are more expensive for uninsured patients compared to emergency departments [37]. This study did not include a comparison to in-person consultations because the health care system suspended all nonessential visits during the observed study period, starting on March 20, 2020. There were no data collected on race, ethnicity, or type of insurance used or covered, which could have added value to the findings of this study. The diagnosis type may confound the difference in prescription administration of phone and video visits. We could not merge the telemedicine data with the electronic health record data to assess the difference in documentation quality between phone and video visits. No information was available to determine if the visit wait times in the data set included those seeking a telemedicine visit immediately as opposed to at a later date. Wait times could be separated for those seeking immediate appointments to improve our findings. Physician-level data was not accessible, limiting our assessment of factors such as clinician preparedness. Finally, the study findings were limited to 1 site, and so the generalizability to other settings is limited.

Conclusion
Our study analyzed the use of phone and video visits at a telemedicine clinic during the COVID-19 pandemic. We discovered that providing patients with a variety of phone and video options was beneficial for many patient groups, especially those in rural or low-bandwidth areas. Gender, age, and insurance status were also factors affecting usage. Moreover,
we observed differences in prescription administration between the 2 modalities that require further investigation. Our findings indicate that phone visits were more prevalent in rural regions compared to urban areas. To promote telemedicine adoption and quality, we must work toward improving internet infrastructure in rural areas, educating patients on selecting the appropriate modality, and establishing equitable service policies for phone and video visits.

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Authors’ Contributions
SK contributed to the data collection, study design, analysis, and manuscript writing. RJ contributed to the data analysis and manuscript writing. MP contributed to data analysis and manuscript writing. PM contributed to map creation and manuscript revision. BE contributed to the study design and data collection. All authors have reviewed and agreed to submitting the manuscript.

Conflicts of Interest
None declared.

References


Abbreviations

ACS: American Community Service  
NC: North Carolina  
VUC: Virtual Urgent Clinic  
ZCTA: Zip Code Tabulation Area
Trends in the Ophthalmic Workforce and Eye Care Infrastructure in South India: Cross-Sectional Questionnaire Study

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Abstract

Background: This study is part of broad-based research to determine the impact of blindness control activities in general and with special reference to the Andhra Pradesh Right to Sight Society (APRTSS) activities in the southern Indian states of Andhra Pradesh and Telangana. As part of the global “VISION 2020: The Right to Sight” initiative, the APRTSS was established in the undivided state of Andhra Pradesh in 2002. Since then, the APRTSS has been actively implementing the strategies of VISION 2020 to reduce visual impairment and blindness in the state.

Objective: The availability and distribution of the eye care workforce are essential to reach the goals of VISION 2020: The Right to Sight, the global initiative to eliminate avoidable blindness. This study assessed the trends in the availability and distribution of eye health professionals and eye care infrastructure in 2 southern Indian states: Andhra Pradesh and Telangana.

Methods: This cross-sectional study used a pretested questionnaire to gather data for the year from 2012 to 2013. Data for 2002 to 2003 were collected from available historical records. The questionnaires were pretested in a pilot study conducted before the main survey. Pretested questionnaires were administered to all eye care professionals—ophthalmologists (n=1712) and midlevel ophthalmic personnel (MLOP; n=1250)—eye care facilities with ≥10 inpatient beds or performing ≥100 cataract surgeries per annum (n=640), local nongovernmental eye care organizations (n=182), and international eye care organizations (n=10). Data were collected for 2 different time periods: the baseline year of 2002 to 2003 and the target year of 2012 to 2013. Data analysis was conducted using SPSS version 19.0.

Results: The response rates were 81.1% (519/640) for eye care facilities, 96.1% (1645/1712) for ophthalmologists, and 67.6% (845/1250) for MLOP. From 2002-2003 to 2012-2013, there has been an increase in eye care facilities, from 234 to 519 (121.8%); ophthalmologists, from 935 to 1712 (83.1%); and MLOP, from 767 to 1250 (63%). The ophthalmologist:population ratio improved from 1:88,260 in 2002-2003 to 1:51,468 in 2012-2013. The MLOP:population ratio improved from 1:168,283 in 2002-2003 to 1:138,117 in 2012-2013 but still falls short of the ideal number.

Conclusions: Both southern Indian states are able to meet the requirements for ophthalmologists and eyecare infrastructure as per the goals of VISION 2020. However, the number of MLOP falls short of the ideal ratio for the population. This study has some limitations. For example, most of the data collected through questionnaires were based on self-report, which might introduce bias due to memory recall or over or under-reporting of certain information. However, this was addressed by cross-checking the collected data with information from supplementary sources.

Key Words: trends; human resources; infrastructure; eye care; South India

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Introduction

Blindness and visual impairment represent a major public health problem in India [1-4]. The major causes of blindness and visual impairment in Andhra Pradesh and Telangana include cataract, refractive errors, retinal diseases, glaucoma, and corneal opacities, as reported in the Andhra Pradesh Eye Diseases study [5]. To tackle the problem of blindness and visual impairment, we need adequate human resources and sufficient infrastructure in eye care. Since the global “VISION 2020: the Right to Sight” initiative was launched in 1999, there has been a lot of progress in not only lessening the burden of blindness and visual impairment but also increasing the number of skilled eye care professionals and eye care infrastructure [6,7].

In line with the global Vision 2020 initiative, the undivided Andhra Pradesh state (the state was divided into Andhra Pradesh and Telangana states in 2014) established the Andhra Pradesh Right to Sight Society (APRTSS) in 2002 to work toward the VISION 2020 goals. Since its formation, the APRTSS has coordinated closely with major stakeholders in eye care such as those in the government, nongovernmental organization (NGO), and private sectors. Its activities include human resource development, infrastructural strengthening, disease control, and advocacy. To determine the impact of APRTSS VISION 2020 activities, we carried out a research project collecting information about the APRTSS activities from the baseline year of 2002 to 2003—the year in which the APRTSS was established—and the target year of 2012 to 2013—after a period of 10 years.

As part of the aforementioned research project, we carried out a survey about the ophthalmic workforce and infrastructure to identify the trends over a period of 10 years. An evidence base is essential to understand trends in human resources for health [8]. However, no regular mechanism exists in India to collect data on human resource trends in the provision of eye care services [9]. This study fills that gap by identifying trends in eye care. The results of the survey will be helpful to identify gaps, strengthen the eye care facilities, and overcome the maldistribution of human resources and infrastructure, in order to achieve the goals of VISION 2020. This study assessed trends in the availability and distribution of eye health professionals and eye care infrastructure in 2 southern Indian states: Andhra Pradesh and Telangana.

Methods

Study Design

This cross-sectional study used a pretested questionnaire for the year 2012 to 2013. The data for the 2002-2003 period were collected from available historical records.

We used questionnaires in both electronic and hard copy formats to collect the data. The questionnaires were developed based on the 6 building blocks of the universal health care system [10].

Ethical Considerations

This study was conducted as part of the research project on the “Impact of implementation of blindness control activities in the state of Andhra Pradesh,” which was approved by the ethics committee of the LV Prasad Eye Institute (reference number: LEC 09-13-097) and conducted in accordance with the tenets of the Declaration of Helsinki.

Definitions

For the purpose of this study, an eye care facility was defined as any health care facility where ophthalmologist services are available. The eye care facilities were identified as secondary or tertiary eye care facilities. For the purpose of this study, secondary eye care was defined as any eye care facility having an ophthalmologist conducting cataract and basic minor surgical procedures. Tertiary eye care was defined as any eye care facility with secondary eye care services as well as at least one subspecialty such as cornea, glaucoma, retina, or oculoplasty. Eye care facilities were categorized as government eye care facilities if they were established and funded by the government or other public sources such as universities and public sector organizations. NGO eye care facilities functioned on a no-profit, no-loss basis. Eye care facilities with a profit motive, irrespective of whether owned by an individual or a group of people or agencies, were categorized as private eye care facilities.

Inclusion Criteria

All eye care facilities with ≥10 inpatient beds or performing ≥100 cataract surgeries per annum were eligible.

Questionnaire

The questionnaire had 4 sections. Each section was distributed to concerned eye care professionals both in electronic form and hard copy to obtain the data.

Section 1: Questionnaire for Eye Care Facilities

The questionnaire for eye care facilities (Multimedia Appendix 1) was distributed to the director, superintendent, administrator, or manager in charge of the care facility. It was completed to obtain information for both the baseline and target years. It contained questions ranging from the services available, human resources, infrastructure, training facilities for eye care professionals, and any other relevant data.

Section 2: Questionnaire for Ophthalmologists

The questionnaire for ophthalmologists (Multimedia Appendix 2) was sent to all ophthalmologists working in government, NGO, and private eye care facilities. It was intended to be completed both by email and in hard copies by surface mail. It contained questions about demographic details; whether the ophthalmologist performs surgeries; whether the ophthalmologist practices in any subspecialties such as anterior segment surgeries, glaucoma, or retina; the average number of cataract surgeries per month; the principal method followed during cataract surgeries; professional experience; academic activity; and any training undergone.
Section 3: Questionnaire for MLOP

The questionnaire for MLOP (Multimedia Appendix 3) was distributed to all optometrists, ophthalmic assistants, and nurses working in all government, NGO, and private eye care facilities. It contained questions to elicit information on knowledge, skills, experience, and special training undergone such as in contact lens practice, refresher training in retinoscopy methods, and biomedical training for equipment maintenance. We also collected information on how many refractions were conducted per month, how many pairs of spectacles were prescribed per month, any administrative work, and any research activities.

Section 4: Questionnaire for District Blindness Control Societies and NGOs in Eye Care

The questionnaire for district blindness control societies (DBCSs) and NGOs in eye care (Multimedia Appendix 4) was distributed to program managers to obtain information on the impact of the implementation of blindness control activities in the district. It contained 3 subsections: section A for program managers of DBCS, section B for NGOs in eye care, and section C for international NGOs in eye care who were active in the state.

Follow-Up

Follow-up mechanisms were instituted every 2 weeks after mailing the questionnaire to the various stakeholders, and reminders were sent at the 3rd month and again at the 6th month.

Additional Data Sources

In addition to the data collected through questionnaires, we gathered information from the following sources: (1) member directory for the All India Ophthalmological Society and its website, (2) directory of the Andhra Pradesh Ophthalmological Society and its website, (3) directory of the Telangana Ophthalmological Society and its website, (4) directory of the Andhra Pradesh Paramedical Board, and (5) websites of leading eye care institutions.

The information obtained from these sources helped us cross-check the data received through the questionnaires from eye care facilities, ophthalmologists, MLOP, and DBCSs. The data collected were entered in Excel sheets by 2 different data operators and cross-checked for any typographical errors. The data were analyzed using SPSS version 19.0 (IBM Corp) for Windows.

Results

Participants

As per the inclusion criteria, a total of 640 eye care facilities were identified, and a questionnaire was sent to the directors or those in charge of the facilities. Of the 640 facilities, responses were received from 519. Table 1 shows the number of questionnaires distributed to the various participants and the response rates. All the DBCSs responded to the questionnaire, whereas the lowest response rate was from MLOP.

Table 1. Response rates for eye care facilities, eye care professionals, and eye care organizations.

<table>
<thead>
<tr>
<th>Questionnaire recipient</th>
<th>Questionnaires distributed, n</th>
<th>Response rate, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eye care facilities</td>
<td>640</td>
<td>519 (81.1)</td>
</tr>
<tr>
<td>Ophthalmologists</td>
<td>1712</td>
<td>1645 (96.1)</td>
</tr>
<tr>
<td>Midlevel ophthalmic personnel</td>
<td>1250</td>
<td>845 (67.6)</td>
</tr>
<tr>
<td>Local NGOs</td>
<td>182</td>
<td>165 (90.7)</td>
</tr>
<tr>
<td>International NGOs</td>
<td>10</td>
<td>9 (90)</td>
</tr>
<tr>
<td>DBCSs</td>
<td>23</td>
<td>23 (100)</td>
</tr>
</tbody>
</table>

*NGOs: nongovernmental organizations.

The number of eye care facilities delivering secondary eye care in the undivided state increased from 234 in 2002-2003 to 519 in 2012-2013 (121.8% increase). From 2002-2003 to 2012-2013, there was a marginal increase in the number of eye care facilities in the government sector (44 to 58, 31.8%), there was a substantial increase in the NGO sector (105 to 165, 57.1%), and the highest increase was seen in the private sector (85 to 296, 248.2%; Table 2).

Table 2. Number of eye care facilities in the combined state of Andhra Pradesh in 2002-2003 and 2012-2013.

<table>
<thead>
<tr>
<th>Type of facility</th>
<th>Facilities in 2002-2003, n</th>
<th>Facilities in 2012-2013, n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government</td>
<td>44</td>
<td>58</td>
</tr>
<tr>
<td>NGO</td>
<td>105</td>
<td>165</td>
</tr>
<tr>
<td>Private</td>
<td>85</td>
<td>296</td>
</tr>
</tbody>
</table>

*NGO: nongovernmental organization.

The number of eye care facilities delivering secondary eye care in the undivided state increased from 198 in 2002-2003 to 440 in 2012-2013 (122.2% increase), and the number of eye care facilities delivering tertiary care increased from 36 in 2002-2003 to 236 in 2012-2013 (631.8% increase).
to 79 in 2012-2013 (119.4% increase). The secondary and tertiary eye care facilities experienced a large jump in number from 2002-2003 to 2012-2013, whereas there was no increase in the number of tertiary eye care facilities in the government sector for the same period (Table 3).

Of 519 eye care facilities, 455 facilities (87.7%) were offering patient care services exclusively. Only 17% (88/519) of eye care facilities offered training facilities for eye care professionals and eye bank services in addition to patient care.

Regarding the eye care workforce, there was a substantial increase in the number of ophthalmologists in both southern Indian states. There was an insufficient increase in MLOP to meet the need. There was a large jump in the number of eye care managers, mostly in NGO and private eye care facilities (Table 4).

### Table 3. Increase in secondary and tertiary eye care facilities from 2002 to 2012 by sector.

<table>
<thead>
<tr>
<th>Eye care facility sector</th>
<th>Facilities in 2002-2003, n</th>
<th>Facilities in 2012-2013, n</th>
<th>Increase, %</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Secondary</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government</td>
<td>34</td>
<td>48</td>
<td>41</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>NGO&lt;sup&gt;a&lt;/sup&gt;</td>
<td>88</td>
<td>139</td>
<td>58</td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>76</td>
<td>253</td>
<td>233</td>
<td></td>
</tr>
<tr>
<td>All secondary</td>
<td>198</td>
<td>440</td>
<td>122</td>
<td></td>
</tr>
<tr>
<td><strong>Tertiary</strong></td>
<td></td>
<td></td>
<td></td>
<td>.009</td>
</tr>
<tr>
<td>Government</td>
<td>10</td>
<td>10</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>NGO</td>
<td>17</td>
<td>26</td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>9</td>
<td>43</td>
<td>378</td>
<td></td>
</tr>
<tr>
<td>All tertiary</td>
<td>36</td>
<td>79</td>
<td>119</td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup> NGO: nongovernmental organization.

### Table 4. Eye care workforce in the 2002-2012 period.

<table>
<thead>
<tr>
<th>Job role</th>
<th>Andhra Pradesh, n</th>
<th>Telangana, n</th>
<th>Both states, n</th>
<th>Increase, %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ophthalmologists</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professor or senior consultant&lt;sup&gt;a&lt;/sup&gt;</td>
<td>132</td>
<td>288</td>
<td>146</td>
<td>338</td>
</tr>
<tr>
<td>Assistant professor or junior consultant&lt;sup&gt;b&lt;/sup&gt;</td>
<td>257</td>
<td>364</td>
<td>248</td>
<td>467</td>
</tr>
<tr>
<td>Ophthalmologists acting as superintendents or directors</td>
<td>69</td>
<td>148</td>
<td>83</td>
<td>107</td>
</tr>
<tr>
<td>All ophthalmologists</td>
<td>458</td>
<td>800</td>
<td>477</td>
<td>912</td>
</tr>
<tr>
<td><strong>Midlevel ophthalmic personnel (MLOP)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optometrists, refractionists, ophthalmic assistants, vision technicians</td>
<td>272</td>
<td>410</td>
<td>238</td>
<td>472</td>
</tr>
<tr>
<td>Ophthalmic nurses and general nurses working in eye care facilities</td>
<td>58</td>
<td>111</td>
<td>72</td>
<td>130</td>
</tr>
<tr>
<td>All MLOP</td>
<td>330</td>
<td>521</td>
<td>310</td>
<td>602</td>
</tr>
<tr>
<td>Eye care managers</td>
<td>69</td>
<td>163</td>
<td>83</td>
<td>244</td>
</tr>
</tbody>
</table>

<sup>a</sup> Ophthalmologists with ≥10 years of experience.

<sup>b</sup> Ophthalmologists with ≤10 years of experience.

The ophthalmologist:population ratio ranged from 1:6309 in Hyderabad district, which is the capital area, to 1:193,822 in Nalgonda district (Table 5). This shows there was a maldistribution of ophthalmologists among the districts in the state. The ratio of optometrists and allied personnel to the population ranged from 1:66,209 in Ranga Reddy district to 1:221,173 in Guntur district. Overall, the ophthalmologist:population ratio in the state was 1:49,404, which appears to be optimal as per the VISION 2020 guidelines. We looked at the number of eye care beds available for the population, and this improved from an average of 1:17,457 in 2002-2003 to an average of 1:13,877 in 2012-2013 (Table 6). There was also a lot of variation in the availability of eye care beds among the districts; for example, in Hyderabad district, 1 eye care bed was available for 3805 persons, compared with 1 eye care bed for 30,014 persons in Karimnagar. The total number of eye care beds increased from 4339 in 2002-2003 to 6103 in 2012-2013 (40.6% increase). On average, 1
ophthalmologist was available per 100,000 people/6 eye care beds in 2002-2003, which increased to an average of 2 ophthalmologists per 100,000 people/7 eye care beds in 2012-2013. A greater number of ophthalmologists per 100,000 population will improve the accessibility and availability of ophthalmologists to the public.

Table 5. Human resources in eye care in the districts of undivided Andhra Pradesh.

<table>
<thead>
<tr>
<th>District name</th>
<th>Population, n</th>
<th>Ophthalmologists, n</th>
<th>Ophthalmologist:population ratio</th>
<th>MLOP, n</th>
<th>MLOP:population ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adilabad</td>
<td>2,479,347</td>
<td>2,741,239</td>
<td>N/A</td>
<td>22</td>
<td>N/A</td>
</tr>
<tr>
<td>Hyderabad</td>
<td>3,686,460</td>
<td>3,943,323</td>
<td>N/A</td>
<td>625</td>
<td>N/A</td>
</tr>
<tr>
<td>Karim Nagar</td>
<td>3,477,079</td>
<td>3,776,269</td>
<td>N/A</td>
<td>42</td>
<td>N/A</td>
</tr>
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<td>Khammam</td>
<td>2,565,412</td>
<td>2,797,370</td>
<td>N/A</td>
<td>30</td>
<td>N/A</td>
</tr>
<tr>
<td>Mahbub Nagar</td>
<td>3,506,876</td>
<td>4,053,028</td>
<td>N/A</td>
<td>18</td>
<td>N/A</td>
</tr>
<tr>
<td>Medak</td>
<td>2,662,296</td>
<td>3,033,288</td>
<td>N/A</td>
<td>14</td>
<td>N/A</td>
</tr>
<tr>
<td>Nalgonda</td>
<td>3,238,449</td>
<td>3,488,809</td>
<td>N/A</td>
<td>18</td>
<td>N/A</td>
</tr>
<tr>
<td>Nizamabad</td>
<td>2,342,803</td>
<td>2,551,335</td>
<td>N/A</td>
<td>29</td>
<td>N/A</td>
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<td>Ranga Reddy</td>
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<td>5,296,741</td>
<td>N/A</td>
<td>99</td>
<td>N/A</td>
</tr>
<tr>
<td>Warangal</td>
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<td>3,512,576</td>
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<td>55</td>
<td>N/A</td>
</tr>
<tr>
<td>Anantapur</td>
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<td>4,081,148</td>
<td>N/A</td>
<td>45</td>
<td>N/A</td>
</tr>
<tr>
<td>Chittoor</td>
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<td>4,174,064</td>
<td>N/A</td>
<td>44</td>
<td>N/A</td>
</tr>
<tr>
<td>East Godavari</td>
<td>4,872,622</td>
<td>5,154,296</td>
<td>N/A</td>
<td>93</td>
<td>N/A</td>
</tr>
<tr>
<td>Guntur</td>
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<td>4,887,813</td>
<td>N/A</td>
<td>41</td>
<td>N/A</td>
</tr>
<tr>
<td>Kadapa</td>
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<td>2,882,469</td>
<td>N/A</td>
<td>23</td>
<td>N/A</td>
</tr>
<tr>
<td>Krishna</td>
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<td>4,517,398</td>
<td>N/A</td>
<td>108</td>
<td>N/A</td>
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<tr>
<td>Kurnool</td>
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<td>N/A</td>
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<td>Nellore</td>
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<td>58</td>
<td>N/A</td>
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<td>N/A</td>
<td>47</td>
<td>N/A</td>
</tr>
<tr>
<td>Srikkulam</td>
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<td>2,703,114</td>
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<td>11</td>
<td>N/A</td>
</tr>
<tr>
<td>Visakhapatnam</td>
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<td>4,290,589</td>
<td>N/A</td>
<td>171</td>
<td>N/A</td>
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<tr>
<td>Vizianagaram</td>
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<td>N/A</td>
</tr>
<tr>
<td>West Godavari</td>
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<td>3,936,966</td>
<td>N/A</td>
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<td>N/A</td>
</tr>
<tr>
<td>All districts</td>
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<td>8,458,077</td>
<td>858e</td>
<td>1712</td>
<td>1:88,260</td>
</tr>
</tbody>
</table>

aMLOP: midlevel ophthalmic personnel.
cCensus 2011 [12].
dN/A: not available.
eApproximate number from supplementary records.
Table 6. Population and number of eye care beds by district.

<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
<th></th>
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<td>2,737,738</td>
<td>265</td>
<td>1:11,978</td>
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<td>Hyderabad</td>
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<td>1:3805</td>
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<td>3,811,738</td>
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<td>1:30,014</td>
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<td>Khammam</td>
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<td>2,798,214</td>
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<td>1:26,448</td>
<td>1:14,964</td>
</tr>
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<td>Mahbub Nagar</td>
<td>3,506,876</td>
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<td>4,002,191</td>
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<td>1:24,353</td>
<td>1:21,968</td>
</tr>
<tr>
<td>Medak</td>
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<td>87</td>
<td>1:30,601</td>
<td>1:34,849</td>
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<td>Nalgonda</td>
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<td>3,483,648</td>
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<td>1:15,279</td>
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<td>1:16,499</td>
<td>1:12,955</td>
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<td>Ranga Reddy</td>
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<td>5,296,396</td>
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<td>1:27,612</td>
<td>1:21,886</td>
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<td>Warangal</td>
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<td>1:13,352</td>
<td>1:10,722</td>
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<td>1:28,962</td>
</tr>
<tr>
<td>East Godavari</td>
<td>4,872,622</td>
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<td>5,151,549</td>
<td>372</td>
<td>1:25,378</td>
<td>1:13,848</td>
</tr>
<tr>
<td>Guntur</td>
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<td>4,889,320</td>
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<td>1:17,651</td>
</tr>
<tr>
<td>Kadapa</td>
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<td>152</td>
<td>2,884,524</td>
<td>297</td>
<td>1:16,931</td>
<td>1:9712</td>
</tr>
<tr>
<td>Krishna</td>
<td>4,218,416</td>
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<td>4,529,009</td>
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<td>1:26,641</td>
</tr>
<tr>
<td>Kurnool</td>
<td>3,512,266</td>
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<td>4,046,601</td>
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<td>1:32,825</td>
<td>1:24,979</td>
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<td>Nellore</td>
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<td>2,966,082</td>
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<td>1:28,599</td>
<td>1:26,483</td>
</tr>
<tr>
<td>Prakasam</td>
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<td>3,392,764</td>
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<td>1:13,886</td>
<td>1:15,214</td>
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<td>Srikakulam</td>
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<td>1:17,201</td>
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<td>Vizianagaram</td>
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<td>2,342,868</td>
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<td>1:10,797</td>
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<td>1:11,888</td>
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<td>84,665,533</td>
<td>6103</td>
<td>1:17,457</td>
<td>1:13,877</td>
</tr>
</tbody>
</table>

Discussion

Principal Findings

Estimates indicate there are 4.95 million people who are blind (0.36% of the total population), 35 million people who are visually impaired (2.55%), and 0.24 million children who are blind in India [13]. Cataract and refractive errors remain the major causes of blindness and visual impairment, respectively, in India [13-16]. Cataract is responsible for nearly two-thirds of the blindness load in the older population in India [1-4], and one-fifth of blindness is due to uncorrected refractive errors [1-3]. There have been significant improvements in the field of blindness prevention, management, and control since the “VISION 2020: The Right to Sight” initiative [17]. In view of this background, India needs a pool of well-qualified, skilled, and optimal eye care professionals and sufficient infrastructure to eliminate avoidable and needless blindness and visual impairment.

The global advisory committee for VISION 2020 recommended a set of criteria for human resources and infrastructure based on expert consensus of the number of cataract procedures that could be performed by a surgeon per year under optimal conditions and the number of beds required for the same per 1 million population [9]. It was assumed that at least 50 procedures per bed per year could be optimally performed. Based on these assumptions, the following norms were recommended: 1 ophthalmologist per 50,000 population, 1 MLOP per 50,000 population, and 1 eye care bed per 20,000 population.

In this study, the ophthalmologist:population ratio in 2002-2003 was 1:88,822, and in 2012-2013, it reached 1:51,416. The state had almost reached the optimal ophthalmologist:population ratio. Previous data show that the national average ophthalmologist:population ratio is 1:107,000, ranging from 1:9000 in some regions to 1:608,000 in some areas [9]. There was a decrease in the percentage of ophthalmologists in the government sector and virtually no change in the percentage of ophthalmologists in the NGO sector. In addition, there was a substantial increase in the number of ophthalmologists in the private sector from 2002-2003 to 2012-2013. Some of the ophthalmologists, who were mainly working in the private sector, offered their services for a few hours a day or 1 to 2 days a week to NGO eye care facilities, either free or for a fee. As
per our study definition, these ophthalmologists who were providing their services part-time for the NGO eye care facilities were treated as working in the private sector only. Hence, the number of ophthalmologists working in the NGO sector appears to be under-reported when compared with that of other sectors.

As per VISION 2020, there should be 20 ophthalmologists and 50 beds per 1 million population [18]. The importance of the ophthalmologist:population ratio is that it can serve as a guide to forecast ophthalmic manpower requirements [19]. As per the norm, the number of available eye care beds is sufficient, and there is no need to increase the number of eye care beds; in addition, there is a shift toward day surgeries for cataract [8].

The distribution of ophthalmologists was skewed toward urban areas. Due to the lack of educational facilities for their children and other lifestyle-related infrastructure in underdeveloped areas, ophthalmologists and private eye care facilities tend to be established in developed urban areas. In the Telangana region, the majority of the ophthalmologists were practicing in Hyderabad City, whereas in coastal Andhra, many of the ophthalmologists were practicing in the urban areas of Visakhapatnam and Vijayawada. Compared with the coastal Andhra region, this phenomenon of ophthalmologists working in urban areas was more pronounced in the Telangana region. As urban areas became more crowded with ophthalmologists, there was a trend that some ophthalmologists started their practices in smaller towns in 2012-2013. In 2002-2003, ophthalmologists were mainly present in the district headquarters and major population areas. This trend changed in 2012-2013 when more eye care facilities were opened in less populated areas.

Murthy et al [20] reported that 69% of ophthalmologists worked in the private and NGO sectors, while 31% were working in the government sector. In this study, 88% of ophthalmologists were working in the private and NGO sectors, and the remaining 12% were working in the government sector. In this study, the majority of the ophthalmologists in the government sector were working in teaching institutions rather than in district and subdistrict hospitals similar to that reported by Murthy et al [20]. In this study, we found the average number of surgeries performed by surgeons in the NGO sector was significantly higher than that in other sectors in both the baseline and target years. After the ophthalmologists in the NGO sector, ophthalmologists in the government sector were performing more surgeries than those in the private sector.

Ophthalmologists with less than 10 years of experience were performing more cataract surgeries than those with more than 10 years of experience (P=.001). This may be because some of the senior ophthalmologists were involved in teaching and research. This finding corroborates the fact that nonteaching ophthalmologists were performing more cataract surgeries than their teaching counterparts.

The state should ideally have 1693 MLOP for its population of 84.6 million. The state needs 1080 more MLOP to reach this number. The majority of the MLOP either were not trained in streak retinoscopy or did not have access to streak retinoscopes. There is a need for a strategy to ensure that all MLOP can perform streak retinoscopy.

There were many reasons for the increase in the number of both secondary and tertiary eye care facilities in all 3 sectors—government, NGO, and private—from 2002-2003 to 2012-2013. The number of eye care facilities as well as the number of eye care professionals increased during this period. The highest increase in eye care facilities (248%) was seen in the private sector due to the establishment of many institutions for eye care professionals in both government and NGO sectors. People trained at these institutes either were absorbed into the private sector or started their own practice, because there was no recruitment in the government sector or minimal opportunities in the NGO sector. This is the reason why the number of secondary eye care facilities increased more than tertiary eye care facilities. Another reason was, compared with other fields in medical practice, it is easier to start a solo practice in eye care, as it does not depend on cooperation from other medical streams. For example, to start a general surgery or orthopedics practice, one requires the services of an anesthetist. To start a pediatric practice, good laboratory services are required. Of the 519 eye care facilities functioning in 2012-2013, 253 (48.7%) were from the private sector. This was similar to the findings reported by Murthy et al [11], in which more than one-half of the eye care facilities belonged to the private sector.

Limitations

This study has some limitations. Most of the data collected through questionnaires were based on self-report, which might introduce bias due to memory recall or over or under-reporting of certain information. However, this was addressed by cross-checking the collected data with information from the supplementary sources mentioned in the Methods section.

Conclusion

Regarding human resources, there was a substantial increase in the number of ophthalmologists, particularly in the private sector. In fact, the percentage of ophthalmologists in the government sector decreased from the baseline year to the target year, whereas in the NGO sector, it remained the same.

Though all 3 sectors—government, NGO, and private—showed an increase in the number of eye care facilities from the baseline year to the target year, substantial increases were seen in the private sector and, to some extent, in the NGO sector. Most of the eye care facilities offered patient care services only. The outpatient services and inpatient services were also higher in 2012-2013 in all 3 sectors, but the NGO sector contributed a major share, followed by the private sector. Regarding outreach activities, the NGO sector dominated the services, to the extent of 80%-97%. One NGO facility collected the majority of eyes for corneal transplantation, and the remaining eye care facilities in the government, NGO, or private sector showed very little improvement in their collection of eyes.

Regarding eye care infrastructure, there was a 41% increase in the number of beds available for eye care, and this increase was mainly due to the NGO sector, followed by the private sector. The average number of surgeries per surgeon per annum was highest in the NGO sector, followed by the government sector. There was a major shortage of MLOP in the state to attain the ideal ratio of 1 MLOP per 50,000 population. To attain the ideal
number of MLOP, there is an urgent need to increase the number of training facilities for MLOP. Overall, the functioning of the DBCSs for planning and supervising district eye care programs was satisfactory.

Acknowledgments

The authors would like to show appreciation to all the eye care professionals and eye care administrators who readily provided the information required for this mammoth study. We would also like to acknowledge the support received from the Government of Andhra Pradesh Health Department in giving access to the records necessary for our study.

This research study received financial support from the Government of Andhra Pradesh, India.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Questionnaire for eye care facilities.
[XLSX File (Microsoft Excel File), 658 KB - ojphi_v16i1e50921_app1.xlsx]

Multimedia Appendix 2
Questionnaire for ophthalmologists.
[XLSX File (Microsoft Excel File), 485 KB - ojphi_v16i1e50921_app2.xlsx]

Multimedia Appendix 3
Questionnaire for midlevel ophthalmic personnel.
[XLSX File (Microsoft Excel File), 494 KB - ojphi_v16i1e50921_app3.xlsx]

Multimedia Appendix 4
Questionnaire for district blindness control societies (DBCSs) and nongovernmental organizations (NGOs) in eye care.
[XLSX File (Microsoft Excel File), 463 KB - ojphi_v16i1e50921_app4.xlsx]

References


National Programme for Control of Blindness and Visual Impairment. 2020. URL: https://npcbvi.gov.in/writeReadData/mainlinkFile/File341.pdf [accessed 2023-12-13]


**Abbreviations**

- **APRTSS**: Andhra Pradesh Right to Sight Society
- **DBCS**: district blindness control society
- **MLOP**: midlevel ophthalmic personnel
- **NGO**: nongovernmental organization

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Electronic Health Records for Population Health Management: Comparison of Electronic Health Record–Derived Hypertension Prevalence Measures Against Established Survey Data

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Abstract

Background: Hypertension is the most prevalent risk factor for mortality globally. Uncontrolled hypertension is associated with excess morbidity and mortality, and nearly one-half of individuals with hypertension do not have the condition under control. Data from electronic health record (EHR) systems may be useful for community hypertension surveillance, filling a gap in local public health departments’ community health assessments and supporting the public health data modernization initiatives currently underway. To identify patients with hypertension, computable phenotypes are required. These phenotypes leverage available data elements—such as vitals measurements and medications—to identify patients diagnosed with hypertension. However, there are multiple methodologies for creating a phenotype, and the identification of which method most accurately reflects real-world prevalence rates is needed to support data modernization initiatives.

Objective: This study sought to assess the comparability of 6 different EHR-based hypertension prevalence estimates with estimates from a national survey. Each of the prevalence estimates was created using a different computable phenotype. The overarching goal is to identify which phenotypes most closely align with nationally accepted estimations.

Methods: Using the 6 different EHR-based computable phenotypes, we calculated hypertension prevalence estimates for Marion County, Indiana, for the period from 2014 to 2015. We extracted hypertension rates from the Behavioral Risk Factor Surveillance System (BRFSS) for the same period. We used the two 1-sided t test (TOST) to test equivalence between BRFSS- and EHR-based prevalence estimates. The TOST was performed at the overall level as well as stratified by age, gender, and race.

Results: Using both 80% and 90% CIs, the TOST analysis resulted in 2 computable phenotypes demonstrating rough equivalence to BRFSS estimates. Variation in performance was noted across phenotypes as well as demographics. TOST with 80% CIs demonstrated that the phenotypes had less variance compared to BRFSS estimates within subpopulations, particularly those related to racial categories. Overall, less variance occurred on phenotypes that included vitals measurements.

Conclusions: This study demonstrates that certain EHR-derived prevalence estimates may serve as rough substitutes for population-based survey estimates. These outcomes demonstrate the importance of critically assessing which data elements to include in EHR-based computer phenotypes. Using comprehensive data sources, containing complete clinical data as well as data representative of the population, are crucial to producing robust estimates of chronic disease. As public health departments look toward data modernization activities, the EHR may serve to assist in more timely, locally representative estimates for chronic disease prevalence.

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Keywords: public health informatics; surveillance; chronic conditions; electronic health record; health management; hypertension; surveillance; public health; prevalence; population-based survey
Introduction

Hypertension is the most prevalent risk factor for mortality throughout the world [1]. The condition is characterized by elevated systolic blood pressure (>140 mm Hg) or diastolic blood pressure (>90 mm Hg) [2]. An estimated 1 out of 3 adults in the United States has been diagnosed with hypertension, which translates to almost 75 million Americans [2]. This result is in substantial use of health care services and medications, as well as lost wages [3,4]. The estimated direct and indirect costs of hypertension exceed US $48 billion each year in the United States [5]. In concurrence with economic loss, uncontrolled hypertension is associated with excess morbidity and mortality, and nearly one-half of individuals with hypertension do not have the condition under control [2].

Uncontrolled hypertension is associated with an increased risk of coronary heart disease, stroke, and kidney disease, which are the 3 leading causes of death in the United States [5]. Hypertension is a comorbid condition for nearly 70% of individuals who have their first myocardial infarction and almost 80% of those who have their first stroke [6]. Additionally, hypertension is associated with an excess risk of severe COVID-19 illness with a risk of hospitalization more than double that of nonhypertensive individuals [7]. The association with increased morbidity and mortality is a critical public health concern given the high prevalence of the condition. To address this increasing public health concern, public health programs and policies aimed at reducing morbidity, mortality, and costs associated with hypertension are required. To create these policies, public health departments are reliant on timely, accurate, stable estimates of disease prevalence. This is required both for timely detection and effective evaluation.

Identifying the prevalence of hypertension as well as measuring hypertension control at the community level remains a challenge for local health departments. While clinical guidelines from the National Quality Forum and others (eg, Centers for Disease Control and Prevention and Healthcare Effectiveness Data and Information Set) exist [8], measurement happens at the level of a provider or health system as opposed to the community. Public health departments typically rely on surveys for measuring community-level estimates of hypertension. However, surveys have known limitations including cost and timeliness due to long gaps between data collection and when results are available. Additionally, the local samples are insufficiently small for precise estimates within communities and subpopulations (ie, wide CIs). Therefore, local health departments seek alternative methods for obtaining timely, complete, accurate, and precise information about the prevalence of chronic conditions such as hypertension and measures of control for individuals with chronic illness.

Since the passing of the Health Information Technology for Economic and Clinical Health Act of 2009, electronic health record (EHR) systems have become more common, representing a potential data source for chronic disease surveillance. As of 2016, over 70% of ambulatory providers use EHR systems [9]. As health care organizations increasingly capture data from routine health care visits in EHR systems, national initiatives, including the digital Learning Health System of the National Academy of Medicine [10] and the Robert Wood Johnson Foundation’s data for health [11], aim to leverage such data to improve the delivery of health care and community health outcomes. The hope is that by leveraging existing digital data sources, public health agencies may access more timely and precise information to assess and improve health in their communities.

While there exists much optimism about EHR systems’ ability to provide timely, complete, and accurate estimates for hypertension and other chronic diseases, evidence to date has been mixed. In a systematic review of the quality of data used for quality-of-care measurement, the completeness of data varied “substantially across studies,” ranging from 0.1% to 51% for blood pressure and from 10% to 38% for smoking status [12]. Missing data ranged between 24% and 38% for cholesterol; 3% and 31% for blood pressure; and 5% and 23% for blood glucose (hemoglobin A1c) [12].

Despite these challenges, EHR data may be useful for community health surveillance. More recent work by the New York City (NYC) Department of Mental Health and Hygiene shows promising results in using EHR data for measuring the prevalence and control of chronic diseases [13,14]. By querying EHR systems in primary care practices representing 15% of the city’s population, the health department found prevalence rates were in line with community-based surveys for diabetes, obesity, hypertension, and smoking even when the survey respondents were limited to those who had received primary care in the prior year (NYC Health and Nutrition Examination Survey and the NYC Community Health Survey [15]). More recent studies give hope that EHR data could be used by health departments to improve the timeliness and precision of their community health assessments [16-18].

Given limited prior evidence, we sought to validate computable phenotypes for hypertension using EHR data available through a community-based health information exchange (HIE) network. The use of HIE data was selected to examine data representing a geographic community rather than the population of a single health system. Our goal is to identify methods that can be leveraged by health departments for the surveillance of chronic illnesses and the calculation of control measures.

Accordingly, the objective of this analysis was to analyze the equivalence of EHR-based methods for deriving the prevalence of hypertension compared to an established community survey. To facilitate this analysis, 6 distinct EHR-based phenotypes for hypertension were used to establish prevalence rates in 1 county. These rates were then tested for equivalency with the prevalence calculated by a national survey. We hypothesized that at least 1 of the selected phenotypes would produce equivalent estimates.
Methods

Data Sources

Indiana Network for Patient Care

The primary data source was the Indiana Network for Patient Care (INPC), a regional HIE with data covering emergency department visits, hospital admissions, and large outpatient health care clinics from across the state. Data were supplemented with direct extracts from 1 health system to provide additional vital measurements and medication data that were not currently shared with the INPC. For this study, the focus was Marion County, Indiana, which is the county containing the largest city, Indianapolis, and we leveraged 3 of the 5 major health systems. Using the 3 health systems ensures that approximately 780,000 (80%) of the population of Marion County was captured for this study. According to the 2010 census, Marion County had a resident population of 977,203 with a racial composition of 30% Black or African American, 11.6% Hispanic, and 61.9% White.

Data were extracted for all adults (at least aged 18 years as of January 1, 2014) living in Marion County who sought care (outpatient, inpatient, or emergency department encounters) at 1 of the 3 large integrated delivery networks that connect to the INPC between January 1, 2014, and December 31, 2015. We used 2 years of data to capture a representative number of clinical encounters since individual health care use may not occur annually. This period was used due to the availability of comprehensive data from 3 of the 5 major health systems in the area. Given the period covered in this data set, the data do not establish current prevalence rates for Marion County but rather serve as an example for the surveillance methodology deployed. The algorithms to detect hypertension in the community were implemented on the data set, which contained diagnosis codes, vital measurements, and medications.

Behavioral Risk Factor Surveillance System

For the gold standard comparison, we used the Behavioral Risk Factor Surveillance System (BRFSS)—the US national survey related to health-related behaviors, chronic health conditions, and the use of preventive services. The prevalence estimates produced by the BRFSS are carefully developed, validated, and weighted to minimize biases in response or coverage [19]. The BRFSS collects data in all 50 states, the District of Columbia, and territories. However, for small geographics (eg, county) or population subgroups, the BRFSS is imprecise with large CIs. For this study, the data related to the 2015 prevalence of hypertension in Marion County, Indiana, was used.

Measures

To facilitate analysis, BRFSS prevalence measures were compared to EHR-based measures extracted from the HIE. The 2015 BRFSS results include an overall hypertension prevalence rate as well as rates by age, race, and gender for Marion County. These measures were extracted from the US Centers for Disease Control and Prevention website [20].

The computable phenotypes used for this study were previously developed and reported separately [21]. Briefly, 6 phenotypes for hypertension were developed using algorithms (or rules) executed using 1 or more types of structured EHR data. These rules were validated using chart review to calculate sensitivity, specificity, and positive predictive value [21]. Defining multiple permutations allowed for evaluating the best-performing phenotype. The phenotypes are as follows:

- P1: clinical diagnostic codes only (in which an individual has either 1 inpatient or 1 outpatient encounter documenting a hypertension diagnosis)
- P2: vital statistics only (in which an individual has at least 1 blood pressure reading above the hypertension threshold)
- P3: vital statistics only (in which an individual has at least 2 blood pressure readings above the hypertension threshold)
- P4: clinical diagnosis and vital statistics (P1 and P2)
- P5: clinical diagnosis and vital statistics (P1 and P3)
- P6: Inclusive of P1-P5 and medications (P1, P2, or the use of hypertension medication)

Using the 6 different EHR-based computable phenotypes, we calculated hypertension prevalence estimates from data for residents of Marion County, Indiana, from the years 2014 and 2015. Prevalence was calculated as the number of persons with data satisfying the given phenotype divided by the number of persons with any HIE record for a health care encounter.

Ethical Considerations

Exempt approval for this study was received by the Indiana University Institutional Review Board (1701925087).

Statistical Analysis

Demographics for the INPC-derived cohort were calculated using P6, which is the broadest and most sensitive phenotype [21]. Using the estimates for Marion County outlined above, equivalency testing was performed. Equivalence testing examines whether 2 independent statistics are similar enough to be treated as though they are equivalent. The null hypothesis is that the statistics differ by at least a specified amount. If the test results in a P value <.05, then the null hypothesis is rejected with a conclusion that the 2 statistics differ by less than the specified amount. We used the two 1-sided t test (TOST) to test equivalence between BRFSS- and INPC-based prevalence estimates. The TOST was performed at the overall level as well as stratified by age, gender, and race. The TOST was performed with 80% and 90% CI. As with other large national surveys, BRFSS estimates have wide CIs. Accordingly, widening the TOST analysis threshold was considered to account for the wide CIs within the BRFSS data set compared to the small CIs associated with the larger INPC data set. The 95% CI of the BRFSS overall hypertension estimates for Marion County is 7-7.5 percentage points wide. The stratified BRFSS hypertension rates are slightly wider. Accordingly, our specified amounts align with the CIs for the BRFSS. This study used SAS (version 9.4; SAS Institute Inc) and Excel 365 (Microsoft) for analyses.

Results

The demographics for the BRFSS and INPC cohorts are presented in Table 1. The EHR-based phenotypes were calculated from INPC data for 548,232 patients, which was the number of adult patients with at least 1 clinical encounter during
the period. Overall, the cohort was 61.2% (n=335,548) women and 27% (n=148,117) Black or African American. Of the total INPC-derived cohort, 210,764 (38.4%) patients were identified as hypertensive by phenotype P6, which is the broadest—and most sensitive—definition of hypertension according to Valvi et al [21]. The INPC-derived hypertension cohort was 57.6% (121,307/210,764) women and 33.2% (70,060/210,764) Black or African American. The BRFSS-derived hypertensive cohort was 55.2% (197/357) women and 17.6% (63/357) Black or African American. The INPC cohort was more racially diverse than the BRFSS cohort overall. The BRFSS cohort had less representation of the younger population and overrepresentation of those aged 65 years and older.

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Overall population</th>
<th>Hypertensive population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>BRFSS ( n=934 ), n (%)</td>
<td>INPC ( n=548,232 ), n (%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>524 (56.1)</td>
<td>335,548 (61.2)</td>
</tr>
<tr>
<td>Men</td>
<td>410 (43.9)</td>
<td>212,684 (38.8)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>152 (16.7)</td>
<td>148,117 (27)</td>
</tr>
<tr>
<td>White</td>
<td>702 (75.2)</td>
<td>308,213 (56.2)</td>
</tr>
<tr>
<td>Other</td>
<td>80 (8.6)</td>
<td>91,902 (16.8)</td>
</tr>
<tr>
<td>Age group (y)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>197 (21.1)</td>
<td>214,655 (39.2)</td>
</tr>
<tr>
<td>40-64</td>
<td>406 (43.5)</td>
<td>240,064 (43.8)</td>
</tr>
<tr>
<td>65+</td>
<td>331 (35.4)</td>
<td>93,513 (17)</td>
</tr>
</tbody>
</table>

\( ^{a} \)Table 1 contains gender, race, and age counts and percentages for each of the cohorts. The cohorts include the overall population for both BRFSS and INPC as well as the hypertensive population.

\( ^{b} \)BRFSS: Behavioral Risk Factor Surveillance System.

\( ^{c} \)INPC: Indiana Network for Patient Care.

Table 1. Cohort demographics

The TOST analysis was undertaken at both the 90% and 80% CIs. The TOST analysis at the 90% CI resulted in 2 phenotypes (P2 and P5) having statistically significant results, indicating their equivalency to BRFSS estimates, or, more specifically, given the assumptions of this analysis, it is at least 90% likely that hypertension prevalence estimates from the BRFSS and phenotypes P2 and P5 will differ by no more than 5 percentage points. However, performance in the stratified groups was much poorer with statistical significance for women only in phenotypes P1 and P4. By the nature of TOST, the wider an estimate’s CI, the less chance that the null hypothesis will be rejected; some stratified groups have CIs so wide that their TOSTs had zero power. The analysis at the 80% CI yielded statistically significant results across multiple phenotypes. At the 80% CI, phenotypes P2, P3, and P5 showed equivalency overall, with P2 and P5 also showing equivalence in 9 of the demographic subsets and P3 showing equivalence in 7 of those subsets. Tables 2-4 depict the full 80% CI analysis for P2, P3, and P5. All remaining analyses are included in the Multimedia Appendices 1 and 2.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>BRFSS&lt;sup&gt;a,b&lt;/sup&gt;, n/N (%)</th>
<th>INPC&lt;sup&gt;c,d&lt;/sup&gt;, n/N (%)</th>
<th>%Δ&lt;sup&gt;e&lt;/sup&gt; (Δ80% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>235/934 (28.4)</td>
<td>159,330/548,298 (29.1)</td>
<td>0.7 (–1.8 to 3.1)&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>127/410 (31)</td>
<td>66,758/212,684 (31.4)</td>
<td>0.4 (–10.6 to 11.4)</td>
</tr>
<tr>
<td>Women</td>
<td>137/524 (26.1)</td>
<td>92,570/335,548 (27.6)</td>
<td>1.5 (–6.6 to 9.6)&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>54/152 (35.7)</td>
<td>57,026/148,120 (38.5)</td>
<td>2.8 (–3.3 to 8.9)&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>White</td>
<td>187/702 (26.6)</td>
<td>89,205/308,224 (28.9)</td>
<td>2.3 (–0.3 to 5)&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>Other</td>
<td>18/80 (22.6)</td>
<td>13,099/91,954 (14.2)</td>
<td>–8.4 (–15 to –1.7)</td>
</tr>
<tr>
<td><strong>Age group (y)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>21/197 (10.8)</td>
<td>49,634/214,685 (23.1)</td>
<td>12.3 (9.2 to 15.4)</td>
</tr>
<tr>
<td>40-64</td>
<td>133/406 (32.8)</td>
<td>76,795/240,084 (32)</td>
<td>–0.8 (–4.5 to 2.9)&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>65+</td>
<td>204/331 (61.6)</td>
<td>31,238/88,569 (35.3)</td>
<td>–26.3 (–30 to –22.6)</td>
</tr>
<tr>
<td><strong>Men by race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>24/60 (40.6)</td>
<td>22,226/56,004 (39.7)</td>
<td>–0.9 (–7.1 to 5.2)&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>White</td>
<td>91/314 (29.1)</td>
<td>38,832/120,672 (32.2)</td>
<td>3.1 (–1 to 7.2)&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>Other</td>
<td>9/36 (24.1)</td>
<td>5,700/36,008 (15.8)</td>
<td>–8.3 (–18.1 to 1.6)</td>
</tr>
<tr>
<td><strong>Women by race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>30/92 (32.2)</td>
<td>34,800/92,113 (37.8)</td>
<td>2.5 (–0.9 to 5.8)&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>White</td>
<td>95/388 (24.4)</td>
<td>50,373/187,541 (26.9)</td>
<td>–7.6 (–16.3 to 1.1)</td>
</tr>
<tr>
<td>Other</td>
<td>9/44 (20.8)</td>
<td>7,379/55,894 (13.2)</td>
<td>5.6 (–2.4 to 13.5)</td>
</tr>
<tr>
<td><strong>Men by age group (y)</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>18/99 (18.5)</td>
<td>20,478/77,992 (26.3)</td>
<td>7.8 (2.3 to 13.3)</td>
</tr>
<tr>
<td>40-64</td>
<td>56/178 (31.2)</td>
<td>33,928/98,778 (34.3)</td>
<td>3.1 (–2.2 to 8.5)&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>65+</td>
<td>90/133 (67.4)</td>
<td>11,957/34,606 (34.6)</td>
<td>–32.8 (–38.6 to –27.1)</td>
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<tr>
<td><strong>Women by age group (y)</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>3/98 (3.4)</td>
<td>29,155/136,663 (21.3)</td>
<td>11.5 (15.6 to 20.2)</td>
</tr>
<tr>
<td>40-64</td>
<td>78/228 (34.2)</td>
<td>42,866/141,286 (30.3)</td>
<td>–3.9 (–9.1 to 1.4)&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>65+</td>
<td>114/198 (57.5)</td>
<td>19,281/53,954 (35.7)</td>
<td>–21.8 (–29.1 to –14.5)</td>
</tr>
</tbody>
</table>

<sup>a</sup>BRFSS: Behavioral Risk Factor Surveillance System.<br><sup>b</sup>Sample size=934.<br><sup>c</sup>Indiana Network for Patient Care.<br><sup>d</sup>Sample size=548,298.<br><sup>e</sup>%Δ: mean difference.<br><sup>f</sup>Behavioral Risk Factor Surveillance System and Indiana Network for Patient Care phenotypes were determined as statistically equivalent by the two 1-sided t test method.
Table 3. Phenotype 3, overall ≥2 vitals indicated. This table depicts the full analytical results for P3 at the 80% CI.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>BRFSS\textsuperscript{a,b}, n/N (%)</th>
<th>INPC\textsuperscript{c,d}, n/N (%)</th>
<th>%Δ\textsuperscript{e} (Δ80% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>235/934 (28.4)</td>
<td>122,051/548,298 (22.3)</td>
<td>-6.1 (-8.6 to -3.7)\textsuperscript{f}</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>127/410 (31)</td>
<td>50,997/212,684 (24)</td>
<td>-7 (-18 to 4)</td>
</tr>
<tr>
<td>Women</td>
<td>137/524 (26.1)</td>
<td>71,053/335,548 (21.2)</td>
<td>-4.9 (-13 to 3.1)</td>
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<tr>
<td>Race</td>
<td></td>
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</tr>
<tr>
<td>Black or African American</td>
<td>54/152 (35.7)</td>
<td>45,513/148,120 (30.7)</td>
<td>-5 (-11.1 to 1.2)</td>
</tr>
<tr>
<td>White</td>
<td>187/702 (26.6)</td>
<td>67,594/308,224 (21.9)</td>
<td>-4.7 (-7.4 to -2)\textsuperscript{f}</td>
</tr>
<tr>
<td>Other</td>
<td>18/80 (22.6)</td>
<td>8,944/91,954 (9.7)</td>
<td>-12.9 (-19.5 to -6.2)</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>21/197 (10.8)</td>
<td>34,282/214,685 (16)</td>
<td>5.2 (2.1 to 8.2)\textsuperscript{f}</td>
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<tr>
<td>40-64</td>
<td>133/406 (32.8)</td>
<td>60,657/240,084 (25.3)</td>
<td>-7.5 (-11.2 to -3.8)</td>
</tr>
<tr>
<td>65+</td>
<td>204/331 (61.6)</td>
<td>25,699/88,569 (29)</td>
<td>-32.6 (-36.3 to -28.9)</td>
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<tr>
<td>Men by race</td>
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<tr>
<td>Black or African American</td>
<td>24/60 (40.6)</td>
<td>17,678/56,004 (31.6)</td>
<td>-9 (-15.2 to -2.9)</td>
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<tr>
<td>White</td>
<td>91/314 (29.1)</td>
<td>29,448/120,672 (24.4)</td>
<td>-4.7 (-8.8 to -0.6)\textsuperscript{f}</td>
</tr>
<tr>
<td>Other</td>
<td>9/36 (24.1)</td>
<td>3,871/36,008 (10.8)</td>
<td>-13.3 (-23.2 to -3.5)</td>
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<tr>
<td>Women by race</td>
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<tr>
<td>Black or African American</td>
<td>30/92 (32.2)</td>
<td>27,835/92,113 (20.3)</td>
<td>-4.1 (-7.4 to -0.7)\textsuperscript{f}</td>
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<tr>
<td>White</td>
<td>95/388 (24.4)</td>
<td>38,146/187,541 (9.1)</td>
<td>-11.7 (-20.4 to -3)</td>
</tr>
<tr>
<td>Other</td>
<td>9/44 (20.8)</td>
<td>5,072/55,894 (30.2)</td>
<td>-2 (-9.9 to 6)\textsuperscript{f}</td>
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<td>Men by age group</td>
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<tr>
<td>18-39</td>
<td>18/99 (18.5)</td>
<td>13,875/77,992 (17.8)</td>
<td>-0.7 (-6.2 to 4.8)\textsuperscript{f}</td>
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<td>65+</td>
<td>90/133 (67.4)</td>
<td>9,694/34,606 (28)</td>
<td>-39.4 (-45.1 to -33.6)</td>
</tr>
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<td>Women by age group</td>
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<td>18-39</td>
<td>3/98 (3.4)</td>
<td>20,407/136,663 (14.9)</td>
<td>11.5 (9.2 to 13.8)</td>
</tr>
<tr>
<td>40-64</td>
<td>78/228 (34.2)</td>
<td>33,556/141,286 (23.8)</td>
<td>-10.4 (-15.7 to -5.2)</td>
</tr>
<tr>
<td>65+</td>
<td>114/198 (57.5)</td>
<td>16,005/53,954 (29.7)</td>
<td>-27.8 (-35.1 to -20.5)</td>
</tr>
</tbody>
</table>

\textsuperscript{a}BRFSS: Behavioral Risk Factor Surveillance System.
\textsuperscript{b}Sample size=934.
\textsuperscript{c}Indiana Network for Patient Care.
\textsuperscript{d}Sample size=548,298.
\textsuperscript{e}\textbf{Δ}: mean difference.
\textsuperscript{f}Behavioral Risk Factor Surveillance System and Indiana Network for Patient Care phenotypes were determined as statistically equivalent by the two 1-sided \textit{t} test method.
Table 4. Phenotype 5, overall ≥1 clinical diagnosis or ≥1 vitals indicated. This table depicts the full analytical results for P5 at the 80% CI.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>BRFSS(^{a,b}), n/N (%)</th>
<th>INPC(^{c,d}), n/N (%)</th>
<th>(%\Delta \text{ ((\Delta)80% CI)})</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>235/934 (28.4)</td>
<td>151,645/548,298 (27.7)</td>
<td>-0.7 (-3.2 to 1.7)(^{f})</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>127/410 (31)</td>
<td>63,992/212,684 (30.1)</td>
<td>-0.9 (-11.9 to 10.1)(^{f})</td>
</tr>
<tr>
<td>Women</td>
<td>137/524 (26.1)</td>
<td>87,652/335,548 (26.1)</td>
<td>0 (-8 to 8.1)(^{f})</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>54/152 (35.7)</td>
<td>71,464/148,120 (48.2)</td>
<td>12.5 (6.4 to 18.7)</td>
</tr>
<tr>
<td>White</td>
<td>187/702 (26.6)</td>
<td>137,674/308,224 (44.7)</td>
<td>18.1 (15.4 to 20.8)</td>
</tr>
<tr>
<td>Other</td>
<td>18/80 (22.6)</td>
<td>31,158/91,954 (33.9)</td>
<td>11.3 (4.6 to 17.9)</td>
</tr>
<tr>
<td><strong>Age group (y)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>21/197 (10.8)</td>
<td>36,157/214,685 (16.8)</td>
<td>6 (3 to 9.1)(^{f})</td>
</tr>
<tr>
<td>40-64</td>
<td>133/406 (32.8)</td>
<td>74,864/240,084 (31.2)</td>
<td>-1.6 (-5.3 to 2.1)(^{f})</td>
</tr>
<tr>
<td>65+</td>
<td>204/331 (61.6)</td>
<td>38,356/88,569 (43.3)</td>
<td>-18.3 (-22 to -14.6)</td>
</tr>
<tr>
<td><strong>Men by race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>24/60 (40.6)</td>
<td>21,091/56,004 (37.7)</td>
<td>-2.9 (-9.1 to 3.2)(^{f})</td>
</tr>
<tr>
<td>White</td>
<td>91/314 (29.1)</td>
<td>37,622/120,672 (31.2)</td>
<td>2.1 (-2 to 6.2)(^{f})</td>
</tr>
<tr>
<td>Other</td>
<td>9/36 (24.1)</td>
<td>5,268/36,008 (14.6)</td>
<td>-9.5 (-19.3 to 0.4)</td>
</tr>
<tr>
<td><strong>Women by race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>30/92 (32.2)</td>
<td>30,285/88,868 (34.1)</td>
<td>1.9 (-5.1 to 1.6)(^{f})</td>
</tr>
<tr>
<td>White</td>
<td>95/388 (24.4)</td>
<td>41,094/181,412 (22.7)</td>
<td>-1.7 (-6.1 to 9.8)(^{f})</td>
</tr>
<tr>
<td>Other</td>
<td>9/44 (20.8)</td>
<td>5,959/54,954 (10.8)</td>
<td>-10 (-18.7 to -1.3)</td>
</tr>
<tr>
<td><strong>Men by age group (y)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>18/99 (18.5)</td>
<td>14,819/77,992 (19)</td>
<td>0.5 (-5 to 6)(^{f})</td>
</tr>
<tr>
<td>40-64</td>
<td>56/178 (31.2)</td>
<td>33,567/98,778 (34)</td>
<td>2.8 (-2.6 to 8.2)(^{f})</td>
</tr>
<tr>
<td>65+</td>
<td>90/133 (67.4)</td>
<td>15,011/34,606 (43.4)</td>
<td>-24 (-29.8 to -18.3)</td>
</tr>
<tr>
<td><strong>Women by age group (y)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>3/98 (3.4)</td>
<td>21,331/136,663 (15.6)</td>
<td>12.2 (9.9 to 14.5)</td>
</tr>
<tr>
<td>40-64</td>
<td>78/228 (34.2)</td>
<td>41,296/141,286 (29.2)</td>
<td>-5 (-10.2 to 0.3)</td>
</tr>
<tr>
<td>65+</td>
<td>114/198 (57.5)</td>
<td>23,345/53,954 (43.3)</td>
<td>-14.2 (-21.5 to -6.9)</td>
</tr>
</tbody>
</table>

\(^{a}\)BRFSS: Behavioral Risk Factor Surveillance System.
\(^{b}\)Sample size=934.
\(^{c}\)Indiana Network for Patient Care.
\(^{d}\)Sample size=548,298.
\(^{e}\)\(\%\Delta\): mean difference.
\(^{f}\)Behavioral Risk Factor Surveillance System and Indiana Network for Patient Care phenotypes were determined as statistically equivalent by the two 1-sided \(t\) test method.

**Discussion**

**Principal Findings**

Our study examined the prevalence estimates of 6 distinct EHR-based phenotypes to ascertain whether EHR-derived estimates are equivalent to estimates produced by survey methods. The 2 clinical phenotypes (P2 and P5) relying primarily on vital statistics data showed the closest equivalence to BRFSS hypertension prevalence estimates. This suggests that clinical variables, such as blood pressure readings, are important in classifying hypertension cases when compared to national survey data. However, clinical measurements are often missing from national surveys (eg, BRFSS). When clinical measurements are present (eg, the National Health and Nutrition Examination Survey), the survey possesses an even smaller...
sample size and is frequently more costly. Establishing robust local prevalence estimates may require local health departments to capture blood pressure measurements, which is cost prohibitive. EHR data may provide a more economical approach to the collection of clinical measurements. Additionally, EHRs can supply these measurements regularly forgoing the need for additional, specific public health data collection efforts.

Interestingly, phenotypes that relied on diagnosis code data performed less robustly. Previous studies have demonstrated the underreporting of conditions when relying on diagnostic codes alone [22-24]. Accordingly, it is possible that diagnostic codes themselves are not sensitive enough for identification of hypertension. Further, 1 possible reason for this is the type of encounter for which an individual is seen. For example, if the patient is being seen primarily in emergency or inpatient settings, a diagnosis of hypertension may not be coded, but the vital measurements would be available.

In our results, P6, which is the broadest and most sensitive definition of hypertension [21], did not align with the BRFSS at the overall population level. The hypertension BRFSS instrument item asks “has a doctor told you that you have hypertension?” [20]. This allows for variability in interpretation and may include individuals with a single elevated blood pressure incident or someone who is prehypertensive. Accordingly, it is logical that a computable phenotype using a combination of clinical data elements would be more sensitive to a diagnosis of hypertension but not to the broad question posed by the BRFSS. However, the phenotypes using a variety of clinical measurements may be a more robust measurement of hypertension for local health departments to deploy.

The results showcase the importance of the inclusion of vital statistics, which proved more sensitive for overall comparison and certain subpopulations when the CI threshold was lower. The results of P6 being associated with lower CIs were not surprising given the smaller sample sizes inherent in analyses of subpopulations. Compared to estimates from survey data, more numerous records available in the HIE or multiple EHR systems would allow for smaller CIs in estimates about subpopulations.

While not all algorithms demonstrated equivalency, 2 of the phenotypes demonstrated the potential for EHR data to provide prevalence estimates that are likely to be within 10 percentage points of BRFSS estimates. Accordingly, the use of EHR data may be a better option to estimate disease burden than costly community health surveys. EHR data have several benefits. First, EHR-derived prevalence estimates are timelier. This methodology can be implemented regularly (eg, quarterly and semiannually) to address the needs of the community compared to national surveys. National surveys are typically conducted annually and require time for postprocessing for data. These conditions result in delayed estimates, making the data untimely for certain population health questions. For certain conditions and interventions, this may prove useful for the identification of community needs as well as the timely assessment of community-level interventions. For example, we are using these methods to estimate changes in childhood obesity in multiple urban neighborhoods that received community-level interventions to address childhood obesity [25].

Second, the EHR-derived measures can be tailored to the specific needs of local health departments. Working in coordination with health care systems or HIE networks, local health departments may arrange to receive the data most relevant to their specific question rather than using proxy constructs from national data. Additionally, the EHR-based measures were manually validated and demonstrated to be of high quality, showing strong specificity and positive predictive values [21].

As reported in the results, the computable phenotypes identified a higher prevalence for the Black or African American community. Some of this variation could be attributed to the overrepresentation of inner-city health system patients within the County. However, the demographic analysis supports the premise that the BRFSS may be underrepresentative of the Black or African American population. This argument may be bolstered by the higher prevalence of subpopulations represented within the INPC demographics, both the overall cohort and the hypertension cohort. High-quality estimates, partnered with customization to local needs, will ultimately provide more robust measures for the local health departments.

Further, 1 limitation in the broader use of this methodology is most public health agencies’ lack of legal authority to require reporting of data about chronic conditions. Currently, hospitals are not required to report clinical measurements or metrics related to chronic diseases, such as hypertension, to public health authorities beyond discharge data. Discharge data primarily consist of diagnostic codes, which may not reliably capture chronic disease burden as discussed above. Currently, the reporting of these data is voluntary and, therefore, unlikely to occur given the resources, human, and technological requirements to do so on the part of providers. However, HIE networks (such as INPC) have existing infrastructures that can be leveraged to address community surveillance needs. Data are already aggregated across health care systems and providers within the community, addressing a large amount of the work required to implement surveillance of chronic conditions. This analysis suggests support for leveraging HIE networks in the community for chronic disease surveillance.

The widening use of the Fast Healthcare Interoperability Resources standard and the Trusted Exchange Framework and Common Agreement for health data exchange may also increase public health agencies’ opportunity to access EHR data [26,27]. There are still barriers to the full adoption of HIE networks into the public health environment, such as infrastructure [28] and data quality [29]. However, the COVID-19 pandemic revealed the role HIE could play in support of public health needs [17]. This is increasingly becoming important given the burden of post–COVID-19 conditions [30] and the potential increase in chronic conditions after the pandemic. Surveillance of chronic conditions is critical to public health practice. The efforts to modernize the nation’s public health infrastructure, which are currently underway, should consider the important role HIE networks can play in support of chronic disease surveillance. Admittedly, future work will involve the implementation of HIE networks in those areas of the United States where they are not currently present.
A second limitation is the inconsistent and imprecise equivalency we have demonstrated between the HIE and BRFSS estimates. The BRFSS estimates themselves are fairly imprecise even for a population of about 1 million, as in Marion County, and so make a weak “gold standard,” especially for subpopulations. Conversely, EHR data only reflect persons with health care encounters, and persons with frequent visits are more likely to have enough EHR data to satisfy some phenotype definition. With health care use varying by health status, race, age, employment, and other factors, EHR data would need adjustment for systematic biases before being interpreted as representative of the general community or subpopulations of interest. Further research would reveal what adjustments can improve how well EHR-based estimates approximate population health statistics. This study is subject to limitations related to the quantity and type of available data. Equivalence may be improved by a more complete capture of an area’s health care providers, especially in ambulatory and primary care settings. Improved data capture would increase the EHR-based prevalence estimates. Data might be weighted according to patient characteristics, such as race, age, gender, or type of health insurance, allowing estimates to be adjusted to be more representative of the general population.

As noted above, this study is subject to limitations related to data availability, namely the period for which comprehensive data was available. There have been advancements in EHR adoption and use in the period from 2014 to now. EHR and HIE adoption will continue to be advanced by data modernization activities, which have in turn been spurred by gaps identified in the COVID-19 pandemic. The data availability of important measurements such as vitals, medications, and diagnoses will likely become routinely captured and shared as part of these activities. This suggests, and more recent literature suggests, that the accuracy of computable phenotypes may improve with these advancements [31,32].

Conclusions
This study demonstrates the feasibility of using EHR-derived prevalence estimates as rough substitutes for population-based survey estimates at the community level. It highlights the importance of critically assessing which data elements to include when deriving the EHR-based estimates. Using comprehensive data sources, containing complete clinical data as well as data representative of the population, may enhance local estimates. The number of people represented in EHR data versus survey data may allow for locally accurate EHR-based measurements of subpopulations. This is critical when considering health disparities as more robust measurements for subpopulations may enable targeted public health interventions.

Acknowledgments
This study’s team would like to thank Regenstrief Data Services for their expertise with data extraction. This work was funded, in part, by the Centers for Disease Control and Prevention under a contract with the Task Force for Global Health (CFDA P93.283) entitled “Enhancing DOH Capacity for Using EHR Data for Cardiovascular Disease.” The authors further acknowledge funding from the Public Health Informatics Program and Center for Biomedical Informatics at the Regenstrief Institute. No form of artificial intelligence was used in the creation or editing of this paper.

Data Availability
The data sets generated or analyzed during this study are not publicly available due to privacy and governance concerns but are available from the corresponding author upon reasonable request and with the completion of appropriate governance.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Two 1-sided t test analyses at 80% CI.
[DOCX File, 35 KB - ojphi_v16i1e48300_app1.docx ]

Multimedia Appendix 2
Two 1-sided t test analyses at 90% CI.
[DOCX File, 30 KB - ojphi_v16i1e48300_app2.docx ]

References


Abbreviations

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
</tr>
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<tbody>
<tr>
<td>BRFSS</td>
<td>Behavioral Risk Factor Surveillance System</td>
</tr>
<tr>
<td>EHR</td>
<td>electronic health record</td>
</tr>
<tr>
<td>HIE</td>
<td>health information exchange</td>
</tr>
<tr>
<td>INPC</td>
<td>Indiana Network for Patient Care</td>
</tr>
<tr>
<td>NYC</td>
<td>New York City</td>
</tr>
<tr>
<td>TOST</td>
<td>two 1-sided t test</td>
</tr>
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</table>

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A Semantic Approach to Describe Social and Economic Characteristics That Impact Health Outcomes (Social Determinants of Health): Ontology Development Study

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Abstract

Background: Social determinants of health (SDoH) have been described by the World Health Organization as the conditions in which individuals are born, live, work, and age. These conditions can be grouped into 3 interrelated levels known as macrolevel (societal), mesolevel (community), and microlevel (individual) determinants. The scope of SDoH expands beyond the biomedical level, and there remains a need to connect other areas such as economics, public policy, and social factors.

Objective: Providing a computable artifact that can link health data to concepts involving the different levels of determinants may improve our understanding of the impact SDoH have on human populations. Modeling SDoH may help to reduce existing gaps in the literature through explicit links between the determinants and biological factors. This in turn can allow researchers and clinicians to make better sense of data and discover new knowledge through the use of semantic links.

Methods: An experimental ontology was developed to represent knowledge of the social and economic characteristics of SDoH. Information from 27 literature sources was analyzed to gather concepts and encoded using Web Ontology Language, version 2 (OWL2) and Protégé. Four evaluators independently reviewed the ontology axioms using natural language translation. The analyses from the evaluations and selected terminologies from the Basic Formal Ontology were used to create a revised ontology with a broad spectrum of knowledge concepts ranging from the macrolevel to the microlevel determinants.

Results: The literature search identified several topics of discussion for each determinant level. Publications for the macrolevel determinants centered around health policy, income inequality, welfare, and the environment. Articles relating to the mesolevel determinants discussed work, work conditions, psychosocial factors, socioeconomic position, outcomes, food, poverty, housing, and crime. Finally, sources found for the microlevel determinants examined gender, ethnicity, race, and behavior. Concepts were gathered from the literature and used to produce an ontology consisting of 383 classes, 109 object properties, and 748 logical axioms. A reasoning test revealed no inconsistent axioms.

Conclusions: This ontology models heterogeneous social and economic concepts to represent aspects of SDoH. The scope of SDoH is expansive, and although the ontology is broad, it is still in its early stages. To our current understanding, this ontology represents the first attempt to concentrate on knowledge concepts that are currently not covered by existing ontologies. Future
direction will include further expanding the ontology to link with other biomedical ontologies, including alignment for granular semantics.

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KEYWORDS

social determinants of health; ontology; semantics; knowledge representation

Introduction

Background

Ontologies are an important resource that have advanced the biomedical sciences. Originating from the philosophical domain and later incorporated into the computing and information sciences, ontologies represent and model our physical reality using semantics to describe domain entities (ie, knowledge base) [1]. These artifacts can be used to house vocabularies to generate inferences with the help of software reasoners such as HermiT [2], ELK [3], and FaCT++ [4]. Logically structured vocabularies can be used with reasoning tools to implement problem-solving software in clinical settings. In addition, biomedical researchers have advanced and wielded ontologies to be used in applications for artificial intelligence, natural language processing, information retrieval, and indexing (eg, data integration, harmonization, and exchange) [5]. Some impactful examples of ontologies include the Systematized Nomenclature of Medicine–Clinical Terms [6] and Gene Ontology [7], which are hosted on the National Center for Biomedical Ontology [8] and the OBO Foundry [9]; for example, the National Center for Biomedical Ontology BioPortal is an open repository of >700 biomedical ontologies [8], whereas the OBO Foundry hosts interoperable biomedical and health ontologies that share a common framework [9]. All the OBO Foundry–approved ontologies are built upon the Basic Formal Ontology (BFO), a common upper-level ontology, for interoperability and reuse. More than ever, there is a strong need to use ontologies for social health behavior sciences with the downstream goal of harmonizing biological and behavioral data [10].

Social Determinants of Health

Since the early 19th century, the public health community has sought to determine how social determinants are associated with behavior, health outcomes, and health inequalities [11]. Factors such as social position can influence an individual’s health status and thus lead to disease-inducing behaviors [11]. The link between social determinants and disease is a central point for public health research [11]. Over the years, public health researchers have classified these determinants as social determinants of health (SDoH). SDoH have been described by the World Health Organization as the conditions in which individuals are born, live, work, and age [12]. These nonbiological factors influence health outcomes in terms of health status, well-being, mortality, and life expectancy.

SDoH encompass many different areas, such as social and political context, governance, physical and living environment, community, safety, education, occupation, income, cultural and social values, biological and behavioral factors, wellness, food, and the health care system [12]. These categories can be represented by 3 levels of organization: macrolevel, mesolevel, and microlevel determinants [12]. Macrolevel determinants consist of socioeconomic hierarchies that govern access to resources in society through policy making [11]. Mesolevel determinants include concepts such as environment, neighborhood quality, occupation, and crime. This intermediate level is also concerned with psychosocial risk factors such as a stressful environment, the quality of social networks, and high physical or social demand [11]. Finally, microlevel determinants describe individual interactions, behaviors, lifestyle, and genetics [11]. Associated with these determinants are health inequalities, or the unfair and avoidable differences in health status among individuals [12], including inequities caused by structural or systemic factors.

Research Objective

The overarching goal of this research was to develop a biomedical ontology to model and represent knowledge on SDoH. More specifically, this work attempted to provide a broad spectrum of concepts ranging from the macrolevel to microlevel determinants focusing on social and economic characteristics as well as social-related health policies. By developing an ontology for SDoH, we can standardize the current scientific knowledge of this area based on a lightweight literature review and consensus from domain experts. Accomplishing this may help provide a computable ontology artifact that can link health data to concepts involving SDoH and advance informatics methods and tools to understand the impact each determinant has on human populations. In addition, modeling SDoH may also help to reduce existing gaps in the literature through explicit links between the determinants and biological factors. This in turn can allow researchers and clinicians to make better sense of data and discover new knowledge through the use of semantic links.

Existing relevant ontologies usually focus on biology and biomedicine; however, the scope of SDoH expands beyond the biomedical level (ie, microlevel) and relates to aspects that are not necessarily biology based, such as economics, public policy, social factors, and so on. Some of the more mature ontologies, such as the ones hosted on the OBO Foundry, have some interoperability due to a shared framework, but there remains a need to connect the heterogeneous SDoH concepts within the biomedical level and elucidate meaning from the knowledge. We therefore put forth the following research objective: using ontological methods, we can represent, formalize, and connect concepts pertaining to social, policy, and economic factors of SDoH. The output of this effort is an initial ontology artifact that models the social, policy, and economic concepts and their relationships in composing the scope of SDoH to build future work. To accomplish this, we (1) analyzed the literature on the 3 aspects and the aforementioned concepts within these aspects.
and (2) produced an evaluated ontology artifact that reflects the intricate connections of the social and economic concepts of SDoH. This final experimental ontology artifact will be logically consistent with evaluation from domain experts and reasoning tools, grounded from a review of the literature to determine high-level concepts that stretch across SDoH, and aligned with a shared framework for biomedical ontologies to enable interoperability and reusability.

**Methods**

**Overview**

A brief yet comprehensive review was conducted to develop ontology terminology that effectively captures the concepts related to SDoH. This review served as a foundation for structuring and defining the key elements within the ontology. The literature reviewed aimed to examine how human health is affected by nonbiological factors that are associated with SDoH. The concepts were curated in concept map drafts from the review of SDoH, and the determinant of health model was used as a guide for concept development [13]. Later, we used Web Ontology Language, version 2 (OWL2) [14], the BFO [15-17], and semantic reasoners to construct and validate the ontology artifact.

**Review of Social and Economic Factors Impacting Health**

Peer-reviewed articles were searched and evaluated by the primary author on PubMed from September 17 to October 8, 2021. Boolean operators and MeSH (Medical Subject Headings) terms were used to refine literature searches conducted using the advanced search feature on PubMed. Multiple concepts and relationships were combined through Boolean expressions, that is, “Social determinants of health AND (health policy OR health care system),” to broaden the search. Certain phrases were enclosed in parentheses to isolate parts of the search query for precision and specificity. MeSH terms with regard to SDoH were provided by PubMed and used to construct the queries. A summary of each search is described in Table 1.

<table>
<thead>
<tr>
<th>Level</th>
<th>Search query</th>
<th>Results, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Macrolevel</td>
<td>“Social determinants of health AND (health policy OR health care system OR health disparities)”</td>
<td>721 (25.45)</td>
</tr>
<tr>
<td>Macrolevel</td>
<td>“Income inequality AND welfare AND health policy”</td>
<td>10 (0.35)</td>
</tr>
<tr>
<td>Macrolevel</td>
<td>“Environmental determinants of health AND climate change”</td>
<td>216 (7.62)</td>
</tr>
<tr>
<td>Mesolevel</td>
<td>“Work OR socioeconomic position AND (health inequalities)”</td>
<td>300 (10.59)</td>
</tr>
<tr>
<td>Mesolevel</td>
<td>“Socioeconomic outcomes AND (housing OR food)”</td>
<td>291 (10.27)</td>
</tr>
<tr>
<td>Mesolevel</td>
<td>Food OR poverty AND (health inequalities)”</td>
<td>250 (8.82)</td>
</tr>
<tr>
<td>Mesolevel</td>
<td>“Social determinants of health AND (crime rate OR domestic violence)”</td>
<td>14 (0.49)</td>
</tr>
<tr>
<td>Microlevel</td>
<td>“Social determinants of health (gender OR age OR ethnicity OR race OR inequalities OR education)”</td>
<td>1031 (36.39)</td>
</tr>
</tbody>
</table>

Articles of interest must have met the following criteria: free full text available, publication date <10 years ago, and published in English. With accessibility in mind, free full text was included as an eligibility criterion. Older publications may have been relevant to this paper but were not considered because they may not reflect current knowledge. Thus, the publication date was set to <10 years ago. As English is the primary language of all authors of this study, it was included as an eligibility criterion for the literature search. Finally, the article type must have been a book or document, systematic review, journal article, observational study, case report, or clinical study. Collectively, the search queries yielded a total of 2833 nonduplicate citations. The first step of the inclusion and exclusion process involved removing articles that did not incorporate, or relate to, the MeSH terms identified in the search queries within their abstract or title. After this evaluation, of the 2833 articles, 2750 (97.07%) were immediately excluded, and 83 (2.93%) remained for a second assessment. Articles that did not precisely align with the research topic were once again removed. As a result, of the 83 articles, 56 (67%) were excluded, and thus 27 (33%) articles remained. Of these 28 articles, 9 (33%) were included for the macrolevel determinants, 10 (37%) addressed the mesolevel determinants, and 9 (33%) focused on the microlevel determinants. The inclusion and exclusion processes are depicted in Figure 1.
Figure 1. Iterative process for gathering the articles of interest. The PubMed searches produced 2833 nonduplicate citations; by applying the inclusion and exclusion criteria described in the main text, we removed 2805 (99.01%) citations, leaving 27 (0.95%) articles for review.

Ontology Design and Development

The review helped us capture some basic salient high-level knowledge that we can encode into ontology from concept maps. The motivation is to gain a bird’s-eye view of SDoH and proceed from a top-down approach in developing the experimental ontology. We developed iterative multiple concept maps using draw.io [18] to identify concepts and relationship links among the concepts. Our analysis of the concept maps revealed 4 generalized relationships that bridged the various concepts: type of, part of, dependency, and causal. Figures 2-5 reveal the final drafted concept maps.
**Figure 2.** Determinants that impact health outcomes and behaviors. Dotted concept ovals indicate additional child concepts that are further described in Figures 3-5.

**Figure 3.** The relationship of concepts associated with macrolevel determinants. Concepts were derived from literature keywords, such as “health policy,” “income inequality,” “welfare,” and “environment.” Dotted concept ovals indicate additional child concepts.
Figure 4. The relationship of concepts associated with mesolevel determinants. This map displays the most detailed network of relationships and was formed from the following keywords: “work,” “work conditions,” “psychosocial work factors,” “socioeconomic position,” “socioeconomic outcomes,” “food,” “poverty,” “housing,” and “crime.” Dotted concept ovals indicate additional child concepts.

Figure 5. The relationship of concepts associated with microlevel determinants. Key elements of this map were gathered from keywords such as “physiology,” “gender,” “ethnicity,” “race,” and “behavior.” Dotted concept ovals indicate additional child concepts.

The part of relationship is illustrated with a forked link connection and indicates that 2 concepts were part of each other; for example, this is demonstrated in Figure 2 between the concepts “Macrolevel determinants” and “Social determinants of health,” where macrolevel determinants are one part (meronym) of the composition of SDoH (holonym). A dependency relationship was demonstrated as a dotted-line link connection and referred to concepts that were dependent on each other. This can be seen in Figure 3 between the concepts “Behavioral health” and “Mental health status,” where an individual’s behavioral health is dependent on the status of their mental health.

A causal relationship was represented as a thick line link connection and described 2 concepts that had a cause-and-effect relationship. An example of this is demonstrated with the concepts “greenhouse gas” and “extreme high temperature,” where there is a causal relationship between greenhouse gas and increased temperatures. Finally, a type of relation was illustrated as an open arrowhead similar to Unified Modeling.
Language notation. This was used to represent inheritance, or parent and child concepts. All child objects inherit the functionality specified by the parent. This included relationship types; for example, as seen in Figure 2, the concept “Health outcome” was described to have a causal relationship with “Vaccine,” where “Vaccine” could have child entities such as “COVID-19 vaccine” and “Influenza vaccine.” As health has a causal relationship with vaccine, it also shares this relationship with its child objects.

**Ontology Encoding and Natural Language Evaluation**

Items from the visualization concept modes were authored as an OWL2-based ontology [14] using the open-source ontology editor, Protégé [19]. Natural language translation was used to produce statements from the ontology for evaluation using Hootation, an experimental software library that extracts ontology axioms and produces human-friendly natural language statements for expert evaluation [20]. Statements were represented as sentences based on ontology class axioms and object properties; for instance, Hootation produced existential-type statements for subclass axioms such as “Every bus ride is a type of transportation method.” The evaluations were used to determine whether classes and their relationships were expressed correctly. To assess the quality of the ontology, 4 evaluators were asked to assess each statement on an Excel (Microsoft Corp) spreadsheet. Two of the evaluators are social behavioral scientists (ie, social work), and 1 of the evaluators is a biomedical ontology scientist. Furthermore, each evaluator was asked to rate a statement as (1) “Yes, this is accurate,” (2) “No, this is not accurate,” or (3) “Do not know if this is accurate.” The Results section discusses details of our analysis from the collected evaluation data.

**Alignment With the BFO**

To ensure semantic interoperability, we aligned our ontology with the BFO [15,17,21]. The BFO is an upper-level ontology that models entities using metalevel categories based on philosophical realism [16]. It is a widely regarded standard framework for creating biomedical and health reference ontologies that enable sharing, interoperability, and consistency with other ontologies by way of the metalevel categories and properties. To advance this work further, we aligned our exploratory ontology with a few of the metalevel concepts from the BFO. Currently, we have made some early attempts to align the object properties with OBO Foundry properties.

Earlier, we identified 4 basic relationships that connect the concepts from our ontology model. We reviewed the BFO model and identified object property relationships that semantically correspond with our 4 relationship connections. The OBO Foundry’s part of or has part (BFO_0000050 [22]) object property was used to reflect the part of relationship [23]. The OBO Foundry’s causally related to (RO_0002410 [24]) object property reflected a causal relationship, and the OBO Foundry depends on (RO_0002502 [25]) object property was used to reflect the dependency relationship [23]. Naturally, the type of relationship was handled by OWL2’s SubClassOf axiom.

In addition to the identified property relationships, we settled on classifying the concepts using the 2 basic categories continuant (BFO_0000002 [26]) and occurrent (BFO_0000003 [27]). A continuant is defined as “an entity that persists, endures, or continues to exist through time while maintaining its identity” [26], essentially an entity or object. An occurrent is defined as “an entity that unfolds itself in time or it is the instantaneous boundary of such an entity (for example a beginning or an ending) or it is a temporal or spatiotemporal region which such an entity occupies_temporal_region or occupies_spatiotemporal_region” [27], basically an event or process. Each of the concepts in our model was classified into these 2 very basic classes from the BFO. Classifying these concepts into these BFO categories helped leverage the aforementioned property relationships because they were dependent on whether the connecting concepts were aligned with the BFO concepts.

We used ROBOT (a recursive acronym for “ROBOT is an OBO Tool”) [28], an OBO Foundry command line software tool, to perform development tasks with OBO Foundry ontologies. We extracted the 2 BFO categories, and the 3 object properties (along with their corresponding axioms via the STAR [situation, task, action, and result] method) using ROBOT to generate a light import of the essential BFO terms. The exported import was used to encode alignment of the concepts in our ontology with the BFO, and FaCT++ [4] was the software reasoner of choice, due to its fast performance, to test whether our ontology model was logically satisfiable. The finalized reviewed ontology, named 3M (microlevel, mesolevel, and macrolevel) Ontology, was published in our GitHub repository [29].

**Results**

**Overview**

The literature search identified several topics of discussion for each determinant level. For macrolevel determinants, topics included health policy, income inequality, welfare, and the environment. For mesolevel determinants, the selected articles investigated areas such as work, work conditions, psychosocial work factors, socioeconomic position (SEP), socioeconomic outcomes, food, poverty, housing, and crime. Among all 3 levels, the highest number of articles for discussion were available for mesolevel determinants. Finally, the articles found for microlevel determinants examined gender, ethnicity, race, and behavior. In the following paragraphs, we discuss SDoH in detail.

**Policy Making**

Social policies and programs, fair employment and working conditions, and living environment are all likely to have the greatest impact on SDoH [30]. Social protection measures, increased coverage and quality of early years care, parental employment support, and gender equality in employment and education may improve early childhood development and even help to reduce child poverty. Affordable housing can be met through minimum housing standards and government actions [30]. Air quality legislation may have some benefits on air pollution and overall living [30]. The effects of climate change may be reduced by improving early warning systems and extreme weather preparedness.
Without action, climate change has the potential to raise agricultural prices, and this may threaten food security in low-income regions [31]. Families and individuals with low-income status are most susceptible to climate-related diseases such as malaria. Providing universal health care coupled with climate resilience measures is needed to reduce climate change impact on those with low-income status [31]. Bouzid et al [32] point out that several systematic reviews discuss diseases associated with climate change, but more focus should go toward the management of droughts, floods, air pollution, and food safety. The lack of research in these areas is likely due to the unpredictable nature of, for example, floods and government bodies that are primarily concerned with disaster response rather than research [32].

**Policy Outcomes and Interventions**

Health policies are fundamental for health and safety and are designed to improve quality of life. The most common types of implementation measures used to assess health policy outcomes include acceptability, feasibility, appropriateness, and compliance [33]. Well-tested quantitative measures are not used enough, and this may directly affect policy outcomes [33]. Most policy intervention tools at the school, district, state, or province level assess wellness policies from high-income countries such as the United States. Data from a systematic review showed that low- and middle-income countries lacked policy intervention initiatives [34]. Similar studies have investigated the relationship between income inequality and subjective well-being.

Evidence on the impact of social assistance on human health remains unclear [35]. Not enough articles discuss the differences between social assistance recipients and nonrecipients [35]. There is a lack of strong methods and study designs to evaluate the health effects of policies mainly in part due to insufficient data. Population-based health surveys do not provide enough information on respondent characteristics [35]. The available methods used to evaluate policy interventions require researchers to identify instances of large-scale policy change when social assistance programs are hardly ever affected by big changes. Instead, areas to be looked at are tobacco, food labeling, greater income redistribution, and labor market regulations [35].

A systematic review assessed randomized social experiments on social policy interventions for health outcomes in the United States and found that investments in early life, income support, and health insurance interventions may hold the potential to improve mental health and health in general [36]. The authors’ power analyses suggested that the models that were used were underpowered to detect health effects and outcomes. The authors noted that policy-related experiments should focus on design to accurately measure the relationship between health outcomes and policy interventions.

**Income Inequality and Low SEP**

According to a meta-analysis, income inequality was not influenced by measures used to assess subjective well-being or geographic region [37]. Instead, the level of country development, more specifically job opportunities, may be linked to income inequality in low- and middle-income countries. This serves as an indicator to government policy makers that reducing income inequality may lead to an improvement in subjective well-being [37]. While income inequality may have some effect on well-being, political economy may also influence population health. A systematic review revealed that there is a gap in the literature on many aspects of political economy, and it is unclear whether there is a relationship between political economy and population health [38]. Although there is no evidence, it seems that social democratic states with higher public spending tend to have better population health, but there is still no significant relationship between welfare state type and health inequalities [38].

In addition to income inequality, a low SEP may also contribute to poor health outcomes. There is consistent evidence that individuals who have a low SEP are often associated with hospital death and poor-quality end-of-life care [39]. Individuals with a poor education and who resided in impoverished neighborhoods were most likely to die in the hospital, receive acute-based care, and not receive specialized palliative care [39]. Future research on end-of-life interventions should consider SEP and its effects across the social strata [39].

**Physical Environment and Health**

A systematic review conducted by Lago et al [40] analyzed the relationship between health and physical environment, lifestyle, and social and economic conditions. On the basis of their evidence, the authors concluded that the main factor linking socioeconomic status and health was income. Individuals with a higher level of income, as opposed to those with lower income, were associated with a lower chance of negative health outcomes [40]. The current association between income distribution and health is the general conclusion because individuals belonging to a lower social class have been shown to have worse average health. Different variables such as education may also play a role in determining health status because it is usually correlated to individuals’ social class [40]. Warmth and energy interventions may lead to improvements in respiratory health, mental health, and overall health for individuals with low-income status. Studies that targeted existing chronic respiratory diseases linked to inadequate warmth were most likely to see health improvement [41].

A mixed methods study demonstrated that energy performance interventions reduced energy use and helped raise indoor temperatures [42]. Despite there being a lack of evidence that suggests that energy performance investments improve health, data did show that improvements in social and economic conditions are better for overall well-being and health [42]. Economic conditions such as a low SEP are linked to poor health outcomes [42]. Individuals with a low SEP had an increased risk of cardiometabolic disorders and mortality according to Petrovic et al [43], who examined the role of health behaviors in socioeconomic equality in health. Behaviors such as smoking, alcohol consumption, physical activity, and diet were considered, as well as health outcomes such as cardiometabolic disorders and mortality. Of all behaviors examined, smoking contributed to the most social inequalities in health. The authors conclude that health behaviors may contribute to socioeconomic
inequalities, but this is dependent on population and study characteristics [43].

**Impact of Food Availability on Nutrition**

Individuals with low- and middle-income status are subject to food scarcity and poor nutritional health [44]. Supplementary feeding had a positive effect on weight and growth in low- and middle-income countries and was most beneficial to individuals who were poorly nourished. There were moderate positive effects on psychomotor development and mixed evidence on improved cognitive development [44]. Groups with lower income tend to select energy-dense diets that do not consist of vegetables or fruit [45]. Fats, refined grains, and added sugars are less expensive than nutrient-dense foods [45]. As a result, there may be a link between high obesity rates and low-cost calories [45]. Pregnant or postnatal women had an increased intake of fruits and vegetables after being enrolled in a food subsidy program [46]. Mean birth weight was slightly higher in 2 high-quality studies [46]. There is currently not enough evidence on the true impact of food subsidy programs for both children and adults [46].

**Work Conditions and Occupational Health**

Currently, no data suggest that workplace health promotion programs (WHPPs) increase socioeconomic inequalities in health, and there is not enough quantitative data on the ability of WHPPs to reduce social inequalities [47]. WHPPs seem to be the most helpful for working individuals who have a low SEP, but most of the programs were equally effective for groups from lower and higher socioeconomic backgrounds [47]. Most studies on working conditions supported the notion that adverse working conditions can mediate the association between SEP and well-being [48]. Studies that examined occupational categories or employment grades as indicators of SEP had the strongest findings in comparison to those that used education or income [48].

There is strong evidence that both physical and psychosocial factors are the cause of approximately one-third of the socioeconomic inequalities in health [49]. Despite limited longitudinal studies, cross-sectional evidence consistently showed that both physical and psychosocial work factors contributed to socioeconomic differences in self-rated health. Work factors may also play a role in inequalities, but there is not enough evidence to determine specific types of work factors [49]. In comparison to men, women experienced worse working conditions and higher job insecurity and also experienced poorer self-perceived physical and mental health [49,50]. Employed men had less emotional support, worked longer hours, and faced higher physical demands; however, they also held higher job statuses and had greater levels of effort-reward imbalance [50]. Although men were subject to more physically demanding tasks, women reported more musculoskeletal symptoms [50]. Health disparities between genders may stem from less favorable working conditions experienced by women [50]. Women are more commonly exposed to repetitive movements with low loads and awkward working positions than men [50]. Anthropometric differences in bone mass, fatty tissue, and muscle may also influence these health outcomes [50].

**Socioeconomic Factors and Domestic Violence**

Employment, income, social class, ethnicity, race, and living conditions all make up socioeconomic factors that may contribute to domestic violence [51]. The highest frequency of violence against women is found in a family environment, with the spouse being the most common perpetrator, and is most prevalent in low-income countries [51]. Individuals who experienced sexual dissatisfaction, unsatisfactory environmental conditions, and mental disorders tend to partake in acts of violence [51]. Certain countries have established laws to better protect women, but there needs to be an integrated approach for both national and international government organizations to achieve social change [51].

**Discrimination and Poor Health Outcomes**

The literature has shown a significant relationship between poor health and racism and a relationship with even higher significance between poor mental health and poor physical health [52]. Health outcomes indicated an association between racism and suicidal ideation, planning, and attempts. Depression was the most reported health outcome and had the same magnitude of association as racism [52]. Health care providers with different training, experience, and specialty backgrounds may hold implicit bias against racial and ethnic minority people [53]. A systematic review revealed that bias is associated with patient-provider interactions rather than health outcomes [53]. This indicates that patient-provider interaction can mediate the relationship between provider bias and patient health outcomes [53].

Institutionalized racism refers to the macrolevel systems, social forces, institutions, ideologies, and processes that interact with one another to cause inequities among racial or ethnic groups [54]. Although public health literature mentions the term *institutionalized racism*, it does not always engage with the concept or dive deep into the mechanisms through which health injustice is perpetuated [54]. To better understand racial and ethnic groups considered disadvantaged, the term should be explicitly mentioned in public health research as a central concept of health inequities [54]. Disparities in the neonatal intensive care unit exist in structure, process, and outcomes and generally disadvantage infants from racial and ethnic minority groups [55]. Hispanic and Black infants are most likely to receive care in poor-quality hospitals. In addition, hospitals serving racial and ethnic minority groups are underresourced and may lack quality improvement infrastructure. Quality improvement initiatives may have the best effect on populations considered disadvantaged who experience poor-quality care [55].

**Gender Attitude and Sociocultural Norm**

There may be several factors that can shape gender attitudes in early adolescence. In a study conducted in 29 countries, data demonstrated that young adolescents from varying cultures all express similar stereotypes and gender attitudes [56]. A gender study demonstrated that adolescents commonly endorsed norms that perpetuated gender inequalities such as masculinity established on toughness and skills or femininity based on physical appearance and shaming of sexuality [56].
Sociodemographic characteristics such as gender, race, immigration status, and age cause a variation in the results; however, family and peers are the central influences in building gender attitudes [56].

**Statistical Analysis**

Initial metrics from the ontology exhibited 245 classes, 47 object properties, and 346 logical axioms. Four evaluators independently reviewed 232 statements, specifically SubClassOf axioms, produced by the Hootation natural language translation software. Each statement was categorized as a 0 or a 1 to indicate expression accuracy. Statements that were not accurate were annotated as 0, and accurate statements were annotated as 1. Unsure responses were annotated as 0. The levels of agreement for each evaluator were calculated using a web-based program called ReCal3 (“Reliability Calculator for 3 or more coders”) [57]. Intercoder reliability was assessed through an average pairwise agreement and an average pairwise Cohen κ value [58].

Individual levels of agreement were as follows: evaluator 1=54%, evaluator 2=58%, evaluator 3=56%, and evaluator 4=76%. The average percentage agreement in terms of the average number of shared responses was 60.85% (SD 10.13%). The pairwise agreement also demonstrated that evaluator 2 and evaluator 4 had the highest similarity (74.14%) among shared responses, and the lowest percentage for shared responses was between evaluator 1 and evaluator 3 (48.71%). The pairwise agreements between evaluator 1 and 2 (56.47%), evaluator 1 and 4 (70.26%), evaluator 2 and 3 (60.35%), and evaluator 3 and 4 (55.17%) were recorded. The relationship among these results is demonstrated more accurately through the average pairwise Cohen κ value (0.19), which determined the interrater reliability. The results are presented in Table 2.

**Table 2.** Evaluation of subclass accuracy in percentage. Evaluators were asked to rate expression accuracy with 0 (no and unsure) and 1 (yes). The individual levels of agreement and disagreement are shown for each evaluator.

<table>
<thead>
<tr>
<th>Evaluator</th>
<th>Agreed (yes(^a); %)</th>
<th>Disagreed (no(^a) and unsure; %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evaluator 1</td>
<td>54</td>
<td>46</td>
</tr>
<tr>
<td>Evaluator 2</td>
<td>58</td>
<td>42</td>
</tr>
<tr>
<td>Evaluator 3</td>
<td>56</td>
<td>44</td>
</tr>
<tr>
<td>Evaluator 4</td>
<td>76</td>
<td>24</td>
</tr>
</tbody>
</table>

\(^a\)Yes indicates the evaluator denoted a knowledge statement from the ontology was true, whereas, no indicates the evaluator assessed it to be false and unsure for if the statement was unknown to the evaluator to be true or false.

The average Cohen κ value was extremely low (0.19), as was the pairwise Cohen κ value for evaluators 1 and 3 (−0.04). The other Cohen κ values between evaluators 1 and 2 (0.12), evaluators 1 and 4 (0.38), evaluators 2 and 3 (0.19), evaluators 2 and 4 (0.44), evaluators 3 and 4 (0.04) were recorded. The statistical analyses helped identify concepts that required revision or omission. Statements that were classified as 0 were reviewed for analysis and possible error. Concepts with high levels of disagreement were revised, and new concepts were added to create a more logically structured ontology.

**Discussion**

**Principal Findings**

The ontology that was developed attempted to model the macrolevel and mesolevel conceptualizations of SDoH in more detail. Interpretations from the literature demonstrated that macrolevel factors are crucial determinants of health and health inequities. Individuals considered disadvantaged are almost always at risk for poor health and poor health outcomes. The main drivers of health inequalities seem to be a lack of education, affordable housing, basic housing needs, income, and access to health care. More specifically, women and racial and ethnic minority people are subject to these determinants, and this is the same for individuals living in low- and middle-income countries. Data from the articles also identified gaps in the literature for current research on low- and middle-income societies. Moreover, policy outcomes determined by SDoH can be measured in many ways; yet, there is little quantitative data on their validity. Finally, findings from the literature provided a solid foundation of knowledge and analysis that guided the design and development of the ontology.

Each of the 3 determinant levels interacts with, and dynamically influences, the other 2; therefore, delineation among the micro-, meso-, and macrolevel determinants is not always clear [59]; for example, the primary effects of discrimination are microlevel factors, such as the imposed psychological context from the individual enacting the discrimination and the individual experiencing it. However, the act of discrimination also has effects on the meso- and macrolevel determinants. The willingness of providers to live and work in underserved communities is considered a mesolevel factor, while the ability of the health care system to create recruitment and retention policies is a macrolevel factor. For an adequate transformation of these complex systems to occur, there will need to be an emphasis on the interactions among the levels and their interdependence [60]. Our work is imperative to the understanding of the ontology of SDoH because it will further the scholarly understanding of public health, lead to the development of necessary policy and interventional changes, and reduce the gap in health care literacy.

The statistical analyses from the evaluations were used to create a revised version of the ontology with a broad spectrum of knowledge concepts ranging from the macrolevel to microlevel determinants. Interpretation of the statements varied, and this may have posed a potential challenge for proper ontology evaluation; for example, the average Cohen κ values indicated that there was no effective agreement, implying that statements from the ontology were not accurate. The low levels of
agreement were mostly attributed to poor labeling and poor association between class and subclass axioms. Poor labeling referred to items that were not specific enough (eg, burnout → job strain, translated to “every burnout is a job strain”). Poor associations among expressions were found to be untrue or mislabeled (eg, poor → income inequality, translated to “every poor is an income inequality”). Personal opinions on statement evaluations were considered but not always incorporated for revision; for example, the concept poor energy performance was not understood by the first 3 evaluators, but it was cited in the literature and described poor energy efficiency in homes, such as poor heating or poor insulation [42].

After some iterative revisions of the ontology, we imported the minimal BFO concepts and property relationships discussed earlier into the Protégé environment and encoded the concept alignment with the BFO terms. We used the FaCT++ reasoner to perform a check of the logical consistency of our final aligned ontology model, and it revealed no inconsistent axioms. At the time of this writing, the core ontology exhibited 383 classes, 109 object properties, and 748 logical axioms, and we included an import of the Simple Knowledge Organization System ontology for additional annotation properties [61]. This preliminary ontology is currently hosted on GitHub [62]. Figure 6 shows a screenshot of the ontology in the Protégé tool with all essential concepts aligned (by assertion and inference) with the BFO categories and properties.

Figure 6. Screenshot of the experimental ontology in Protégé with alignment with Basic Formal Ontology concepts and properties.

Determining the accuracy of ontology concepts may help to produce a well-structured ontology. Moreover, appropriately addressing SDoH is fundamental for improving health and reducing long-standing inequalities. Modeling concepts transform metadata into a knowledge domain, which facilitates new knowledge discovery. By linking this ontology of SDoH
with other biomedical ontologies, researchers can make use of shared data for data exchange and information integration for biomedical tools such as computer-aided reasoning or decision support applications, enhance existing ontology knowledge bases, produce precise definitions of SDoH concepts in natural language, and provide a better understanding of the terminology associated with SDoH to reduce gaps in the literature.

Several concepts exist beyond the macro-, meso-, and microlevel determinants, which are included in the final version of the ontology. Concepts that impact or contribute to SDoH include academic degree, access to food, access to health care, behavioral health, discrimination, distance to medical resources, economic growth, economy, employment status, environmental determinants, exposure to crime, disease, food security, gross domestic product, gender attitude, gender identity, health inequities, health literacy, health outcomes, health services, health care coverage, history of incarceration, income, individual behavior, media culture, medical conditions, military service, national employment rates, nutritious diet, patient engagement, patient safety, personal health management, quality health care interventions, quality of life, sexual activity, sexual orientation, social class, social constructs, and vaccine. Each of these items contains additional subclasses (Figures 2-5).

**Macrolevel Determinants**

Class axioms for the macrolevel determinants included government programs, health care system, income inequality, macroeconomic conditions, macroeconomic policies, multisectoral approach, public policy, social security benefits, and social welfare. Each of these classes has been broken down further, as illustrated in Figure 3. Government programs, social security benefits, and social welfare were created to assist individuals who belong to a low social class, have a secondary-level education or less, and who are unemployed or work minimum wage jobs [30]. Both national and local governments intend to improve overall health by formulating macroeconomic policies and implementing multisectoral action initiatives to develop comprehensive strategies for addressing SDoH, promote inclusion and transparency in decision-making, and adopt equity-focused approaches in planning and resource allocation [30].

Currently, the US federal government mandates several public policies to improve the quality of life through the drug policy, agricultural policy, water policy, and energy policy [12]. Macroeconomic conditions such as employment and inflation can help regulate the economy, but these are highly dependent on current national employment rates [38]. Likewise, fiscal policies may help to reduce government spending, control debt, and regulate taxation, which in turn controls the economy [38]. Findings from the literature are reported on adult populations and rarely focused on children.

**Microlevel Determinants**

Over 50 microlevel determinants were identified as biological factor, bodily function, human physiology, individual factor, individual lifestyle, nutrition, participation in physical activity, and physical fitness. Each of these concepts has subclasses that are illustrated in Figure 5. The relationship between individual factors such as education and health is complex. Low educational attainment may result in poor health. Cognitive disabilities and health conditions may affect educational outcomes, which in turn affect health literacy [63]. Low health literacy is associated with poor health outcomes and mortality. Individuals who do not understand the severity of their health conditions are less likely to seek medical care [63]. Poor operation of bodily functions may also result in undesired health outcomes. Likewise, poor management of diet and nutrition can affect physical fitness [45]. Individuals with a low SEP are subject to food insecurity and often malnourished [44]. Their inability to purchase food or healthy food options reflects their diet and nutritional status, resulting in illness [44].

Another microlevel factor that disrupts healthy living is discrimination. Individuals who are discriminated against for their race, gender, sexual orientation, disability, or age may experience depression and suicidal ideation. Discrimination that occurs in a hospital setting is prominent against African American and Hispanic individuals and results in poor or delayed treatment [53]. Negative gender attitudes may elicit aggressive behavior and lead to domestic or physical violence [56]. Attitudes toward gender may be attributed to sociocultural norms or individual beliefs; for example, individuals living in low- and middle-income countries with a high poverty rate often express toxic masculinity [56].

Individuals who identify as lesbian, gay, bisexual, transgender, or queer are targets for discrimination, bullying, isolation, and violence [64]. This is true even in the health care system, where
transgender women are commonly admitted as men, despite them expressing their gender [64]. Similarly, the normalized societal attitude toward individuals with disabilities is often exclusionary [64]. As health systems are often not designed with the needs of individuals with disabilities in mind, these individuals frequently face challenges, requiring them to navigate and challenge established norms [64]. Overall, findings from the literature emphasized that microlevel factors play a large role in human behavior and health outcomes.

Conclusions

In this paper, we examined the range of social and economic factors covering SDoH and modeled these aspects using ontology-based methods and tools to create a representational artifact. With this artifact, data and resources can be linked and aggregated to address clinical research that could analyze the link between the aforementioned factors and possible biological factors sourced in published bioinformatics ontologies. To our knowledge, this is the first ontology to focus on knowledge concepts that are not addressed by current biomedical ontologies for SDoH. The latest version of this ontology is available on GitHub [62] for public early release and future updates. Overall, this preliminary work is a demonstration of the possibility to model these heterogeneous social and economic concepts that can be aligned with the greater body of biomedical ontologies. However, the social and economic scope of SDoH is expansive, and although the ontology is broad, it is still in its early stages and could be expanded further with more granular social and economic concepts. Future consideration will be given to developing specific subdomains that can act as federated modules that can integrate with this ontology. Finally, we will include further aligning of this work with the BFO, using more precise semantic properties to accurately reflect the relationships among the concepts, which will provide further alignment with the existing validated biomedical ontologies.

Acknowledgments

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Data Availability

The data sets generated during and analyzed during this study are available in the 3M Ontology repository [29].

Conflicts of Interest

None declared.

References


17. Home. Basic Formal Ontology. URL: http://basic-formal-ontology.org/ [accessed 2024-03-04]

18. Untitled diagram. draw.io. URL: https://app.diagrams.net/ [accessed 2024-03-05]


22. part of. OLS Ontology Search. URL: http://purl.obolibrary.org/obo/BFO_00000050 [accessed 2024-02-27]


24. causally related to. OLS Ontology Search. URL: http://purl.obolibrary.org/obo/RO_0002410 [accessed 2023-09-17]

25. depends on. OLS Ontology Search. URL: http://purl.obolibrary.org/obo/RO_0002502 [accessed 2024-03-04]


29. 3M ontology. GitHub. URL: https://github.com/UTHealth-Ontology/3M [accessed 2024-03-05]

30. Key policies for addressing the social determinants of health and health inequities. World Health Organization. 2017 Aug 03. URL: https://www.who.int/publications/i/item/9789289052658 [accessed 2024-03-04]


62. 3M Ontology. GitHub. URL: https://github.com/UTHealth-Ontology/3M [accessed 2023-09-17]


Abbreviations

- BFO: Basic Formal Ontology
- MeSH: Medical Subject Headings
- OWL2: Web Ontology Language, version 2
- SDoH: social determinants of health
- SEP: socioeconomic position
- STAR: situation, task, action, and result
- WHPP: workplace health promotion program

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