

Social Construction of the Patient Through Problems of Safety, Uninsurance, and Unequal Treatment

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The purpose of this research was to study how the Institute of Medicine discourse promoting health information technology may reproduce existing social inequalities in healthcare. Social constructionist and critical discourse analysis combined with corpus linguistics methods have been used to study the subject positions constructed for receivers of healthcare across the executive summaries of 3 different Institute of Medicine reports. Data analysis revealed differences in the way receivers of healthcare are constructed through variations of social action through language use in the 3 texts selected for this method's testing. **Key words:** *corpus linguistics, critical theory, discourse analysis, health information technology, inequality, social constructionism, social justice*

THE PURPOSE of this research is to interrogate how some aspects of the discourse constituting the currently proposed National Health Information Infrastructure (NHII) may reproduce existing social inequalities in healthcare, by embedding them as unquestioned presumptions in seemingly neutral discussions of information technology. Specifically, the focus of this analysis is the possibility that existing barriers to healthcare for racialized¹ populations may be replicated in policy-level information requirements determinations contained in the Institute of Medicine Quality Chasm series,¹ also known informally as the Patient Safety reports. The

problematic consequences of social inequality and disparity due to socioeconomic status and racialization* of populations in the United States healthcare system are well described elsewhere.^{4–7} For the same reasons, the possibility that such consequences could be “frozen in” to the NHII, even if only inadvertently, would be equally problematic.

To study the implications of the information requirements determinations in the Institute of Medicine Quality Chasm series, corpus linguistics and critical discourse analysis

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*In postcolonial studies and in cultural studies, racialization refers to the concept of “race” as a social construction rather than a universal, essential or foundational category of biology or culture.² The term *race* is used for social purposes in classifying humans into groups who differ on a physical, biological, or genetic basis, usually endorsing an assumption of a theory of unchanging human types that are fundamentally different from each other.³ A *racialized population* is a group of people assigned a set of characteristic differences through social processes based on a theory of “race.” The expression *racialized population* is preferred in postcolonial and cultural studies because it points to this theory of difference and to the assignment process.

methods were used to compare the discursive construction of subject positions for receivers of healthcare across 3 different Institute of Medicine executive summaries. The 3 executive summaries selected as data for this project are those from *To Err Is Human*,⁸ released as part of the Quality Chasm series¹; from *Coverage Matters*,⁹ released as part of the Insuring Health series¹⁰; and from the Institute of Medicine stand-alone report on the unequal treatment of racialized populations,³ titled *Unequal Treatment*.¹¹

In a parallel study, analysis of surface features of these data samples demonstrated differences in the social action of language used in the 3 Institute of Medicine report series, attesting to the benefit of using critical discourse analysis combined with corpus linguistics to study official documents of this type.¹² The most notable findings of a preliminary report were the lack of overlap in the research discursive space created by each executive summary and marked stylistic differences in the framing of the 3 health quality problems in the opening paragraphs of each respective Institute of Medicine report executive summary.¹² In the present study, the same samples are examined using the same methods, to interrogate ways that the “official language” of these documents discursively construct receivers of healthcare.

BACKGROUND AND SIGNIFICANCE

The NHII is described as “an initiative set forth to improve the effectiveness, efficiency and overall quality of health and healthcare in the United States . . . [composed of] a comprehensive knowledge-based network of interoperable systems of clinical, public health, and personal health information that would improve decision-making by making health information available when and where it is needed.”¹³ Because it was designed to be built in multiple parts over a 10-year period beginning in 2004, the NHII does not currently exist as a coherent, singular entity, or completed institution. At this time, it is primarily consti-

tuted as a discursive object in the texts produced by the Institute of Medicine,¹⁴ as well as by a variety of other stakeholders such as regulatory agencies, policy experts and politicians across the ideological spectrum, health information vendor Web sites, and so on.

The 2003 American Medical Informatics Association Spring Congress¹⁵ outlined a social justice agenda for health informatics by calling for the development of health information technologies that bridge the digital divide while supporting improved healthcare outcomes for both vulnerable and underserved populations. The white paper reporting on this congress outlined barriers for health information technology development for vulnerable and underserved populations, offering policy, funding, research, and education and training recommendations to overcome these barriers.¹⁶ One policy recommendation specifically relevant to the present research was to “increase National Health Information Infrastructure to address specific risks for underserved populations, as well as preventive health education networks.”^{16(p453)}

A primary assumption in this research was that the Institute of Medicine literature, promoting the deployment of health information technology, contributes to a policy-level health information requirements determination¹⁷ for the NHII. Although that connection is not explicitly made in those reports, the reports are widely used in planning information systems for healthcare and can thus reasonably serve as suitable surrogates for policy-level information requirements determination for healthcare in the United States. According to Yadav,¹⁷ an information requirements determination is a vital step in the construction of an information system during which the information needs and usage of an organization are surveyed and disambiguated to develop a clear plan—a requirements specification—that will be used to guide the development of the information system. Since there is no single healthcare organization in the United States, the information needs related to healthcare overall are necessarily heterogeneous, and thus crafting

an information requirements determination should be of paramount importance in attempting to build an NHII. Yadav calls for a “thorough analysis of an organization before specifying design requirements”^{17(p4)}:

1. Identify and remove (if possible) inconsistencies within an organization.
2. Identify a reasonable set of measures of effectiveness for the organization and its information to support these measures.
3. Determine design requirements for an organizational support system (Yadav’s expression for an information system) to match the information requirements and the characteristics of the organization and the management.

The overarching question about texts such as the Quality Chasm series, then, is: how much do they reflect, or obscure, the social justice agenda outlined by the 2003 AMIA Spring Congress?

EPISTEMOLOGICAL AND METHODOLOGICAL COMMITMENTS

Addressing that question properly requires taking a critical stance, while doing so in a methodologically rigorous way. Hence, this research was conducted from a social constructionist and critical theoretical point of view, using discourse analysis and corpus linguistics methods. Although these approaches may be familiar to many readers, they are less commonly used in health informatics research, and their relevance for the present project may not be immediately clear. Therefore, a brief overview of these approaches—and their importance here—follows.

Social constructionism

According to Crotty,¹⁸ social constructionism is an epistemology that guides selection of research methods as well as the interpretation of results of research. Burr¹⁹ further described social constructionism as an antiessentialist, antifoundationalist epistemic point of view that considers language use as a

form of social action, and outlined the “family resemblances”^{19(pp2–5)} of social constructionism as follows:

1. A critical stance toward taken-for-granted knowledge.
2. Assumption of historical and cultural specificity.
3. Assumption that knowledge is sustained by social processes.
4. Assumption that knowledge and social action go together.

Constructionist approaches are frequently used to demonstrate how knowledge is constructed through ideologically inflected social relations, rather than discovered from neutral research. Constructionist approaches reject the notion that knowledge can be simply “known” in an objective, value-free manner. Although the methods adopted for this research have an objective cast, placing them within a constructionist frame helps ensure that the results have a critical value that exposes the problematic social relations behind them.

Critical theory

When using critical theory, the research product is a critique of some existing order. Critique is distinguished from criticism from a neutral position, in that critical theorists question the ability to achieve a neutral position and are especially concerned with the circumstances within which knowledge is constructed.²⁰ There, critique is defined as a “sustained criticism of an argument . . . from a specific point of view”^{20(p76)} of a discursive text or practice. Thus, a researcher engaging in critique takes an articulated or specifically stated political position with respect to the object of study and during the critical research process. Critique is used to expose contradictory tendencies²¹ and foregrounds the structuring of knowledge around an array of ideological and social relations.²² The assumption of social constructionism is a keystone of critical inquiry, but critical theory goes beyond simple constructionism to articulate the development of knowledge for

supporting action that promotes freedom¹⁸ and is frequently used in emancipatory projects with social justice goals.

WHO NEEDS SOCIAL JUSTICE? DISCURSIVE CONSTRUCTION OF THE SUBJECT

The concept of "subject position" is key to linking these considerations together with the actual people who move through health-care systems. Subject position is a poststructural concept associated with critical theory, cultural studies, and discourse analysis, which views individual humans as "multiforming and fragmentary . . . not unitary and integrated."^{23(p95)} It is important to differentiate between the empirical concept of a "subject" who is a member of a control group or treatment group in an experimental study and a "subject position" in critical or poststructural theory. The concept of subject position is at odds with the commonsense notion that people are autonomous self-defining entities with individual identities that are the source of their actions and beliefs.²⁴ The process of construction of subjectivities in this sense is the means by which ideologies are constructed, enacted, transmitted, and reproduced over time. Althusser argued that "there is no practice except by and in an ideology," and "there is no ideology except by the subject and for subjects."^{25(p115)} Critical theory holds that fragmentary individual humans, as well as groups, are constructed by subject positions through representations of humans and groups of humans in texts and discursive practices, including normalizing practices imposed by the use of computer software. Critical theory assumes that subjects are both produced by and contribute to the constitutive and ideological social processes reflected in texts, discourses, and discursive practices.²⁰ Althusser considered ideology an "essential feature in the reproduction of social relations"^{25(p199)} and introduced the concept of ideology as *interpellation* or the hailing of individuals as con-

crete subjects²⁵ or vehicles to express ideology. The individual's response to the hailing is at the same time their enlistment into and their recognition or acceptance of their place in the dominant ideology.²⁰

Critical and social constructionist discourse theory assumes that any single specific human or group of humans may actually occupy, or perform, or have imposed upon her or them, a number of different and possibly competing subject positions, such as "elderly," "African American," "female," "patient," "stakeholder," "end-user," and so on.²⁶ Labels such as these represent some of the ways patients may be classified or hailed into subject positions for any given ideological purpose in healthcare, or with respect to normalizing processes in health information technology designed to facilitate healthcare delivery. The study of the representation and positioning of subjects (eg, as in "elderly African American female patient") within a discursive structure may reveal latent ideological assumptions about people that are socially and historically contingent, taken-for-granted, inaccurate, and/or unjust.²⁷ Such representations of subjects, embedded as they may be in uncritical understandings of how subjects are "constructed into" their roles in healthcare systems, are likely to lead to inadequate and/or unjust information requirements determinations for information technology projects ostensibly designed to assist the people forced to take on such roles.

Discourse analysis

Discourse analysis focuses on language use as social action and the ways in which language use influences or constitutes knowledge development and representation.²⁸ Discourse analysis is thus often used to identify systematic language-based bias, ideology, and taken-for-granted and historically contingent assumptions that underlie—or result in—systemic institutional social injustice.^{29,30} Jaworski and Coupland note that academic study and knowledge production are "based on acts of classification . . . defining

boundaries between conceptual classes ... labeling those classes and the relationships between them."^{28(p4)} They also hold that discourse analysis evolved in response to the rise in the information age, in response to 2 conditions: first, the "weakening in confidence in traditional ways of explaining phenomena"^{28(p3)} and second, the commoditization of language through communications media.

Both of these conditions underlie the analysis of problems like the reproduction of inequities in the construction of subjects, in that healthcare systems are now so complex that supraindividual, structural approaches are required to understand how they work, and communications media are now required to make them run with any semblance of smoothness. On the latter point, healthcare information science is fundamentally concerned with the development of classification systems to facilitate computerized data and knowledge management; therefore, discourse analysis is particularly appropriate for social justice research projects in health informatics. Further, health informatics is specifically concerned with encoding health knowledge, information, and practices into machine-readable format to enable deployment of information technology in the interest of improving healthcare and medical decision making. Discourse analysis should prove especially useful in identifying latent, inaccurate, and unjust ideological assumptions in the texts and documents used to plan the information systems that instantiate such deployments. It can also identify the traces of such assumptions in the surface characteristics of the information systems themselves—from the levels of data structures through to the graphical user interfaces used in the practice of care management.

Corpus linguistics

Corpus linguistics is a methodology employed to study how language is used for achieving communicative goals in large collections of naturally occurring texts called

corpora.³¹ Computerized linguistic analysis of corpora includes the construction of keyword-in-context concordances that facilitate the identification of association patterns³² in language use in specific texts. A concordance is an index or list of lines containing all instances and contexts of use of a node (or target) word,³³ which can be used to study language use as social action through the analysis of word frequencies and clusters, keyword lists, word collocations, and so forth. Stubbs³⁴ and Hunston³⁵ have both outlined ways in which computer-assisted corpus linguistic methods can enrich discourse analysis by automating some aspects of close textual analysis of patterns of language use in large corpora. Combined with the discourse analysis principles and theoretical stances described above, corpus linguistics can be used to expose patterns in the rhetoric used in healthcare information system descriptions, to help establish whether ideologically charged assumptions are present therein.

METHODS

Data

The Institute of Medicine report series "Quality Chasm" was selected because these texts include strong recommendations regarding the use of health information technology in improving healthcare safety and quality¹ and are widely quoted in literature supporting the deployment of health information technology in general, and the construction of the NHII in particular.¹⁴ The Insuring Health report series¹⁰ and the stand-alone report *Unequal Treatment*¹¹ were selected because they are also from the Institute of Medicine and outline specific social justice problems in United States healthcare. Insuring Health is concerned with the consequences of the social justice problem of "uninsurance," or less euphemistically, the lack of insurance coverage and therefore lack of access to healthcare in the United States. *Unequal Treatment* is a stand-alone report from the Institute of

Medicine on the unequal treatment of racialized populations regardless of insurance coverage or access to care. These reports were published by the Institute of Medicine contemporaneously with the Quality Chasm series, between 2000 and 2005, and form a large corpus of naturally occurring texts from one of the leading health policy advisory organizations in the United States.³⁶

The executive summaries of the first report in each of these series were selected for the data analysis. Frequently, the executive summaries of the first reports are often all that decision makers read, and executive summaries tend to emphasize or highlight the authors' "take home" messages precisely to cater to that pattern of surface-level information consumption. Furthermore, because the authors—by definition—consider those "take home" messages to represent the most important things they have to say about the matter, they constitute a good window into the authors' agendas regarding the matters at hand, including their unquestioned presumptions and critical omissions. Finally, an exclusive focus on the executive summaries of these reports serves to limit the scope of this project.

Data management and processing

All texts of *Coverage Matters*, *To Err Is Human*, and *Unequal Treatment* were purchased from The National Academies Press³⁷ in both paper and digital PDFs to facilitate comparison of surface features of all the texts, and to facilitate random checking of agree-

ment between the 2 formats. The PDFs were converted to Rich Text Format in batches, using Convert Doc (Softinterface, Inc)³⁸ in preparation for analysis using corpus linguistics tools. Headers repeated on each page of all 3 executive summaries were removed to keep them from skewing word frequency counts. Oxford WordSmith Tools 4.0³⁹ was used initially to create keyword-in-context concordances of the 3 separate executive summaries.

FINDINGS

Table 1 shows the results of the word frequency analysis for all the executive summaries described above, using keywords representing receivers of healthcare in the texts. The first round of concordances for each text was produced using the truncated keyword *patient**. The sentence "Uninsured persons may be charged more than patients with coverage . . ." (p5) in the concordance from *Coverage Matters* led to a second set of concordances for all 3 texts using the truncated keyword *person**, and a third set for the truncated word *consumer**. The words *person*, *patient*, and *consumer* are all used to refer to receivers of healthcare in these 3 executive summaries. Table 1 includes the number of times each word is used in each text, along with the total number of words in each text. There is no direct statistical correlation between word usage, intended meaning, and any inadvertent meaning production³⁴; however, such frequencies point to node words

Table 1. Word frequencies^a

Keyword-in-context	Coverage Matters	To Err Is Human	Unequal Treatment
Patient*	2	81	129
Person*	27	2	3
Consumer*	3	7	1
Total word tokens	4764	5139	7729

^aThis table shows the number of times each truncated keyword appears in each text, according to the keyword-in-context concordance. Each line represents a set of concordances. The words *person*, *patient*, and *consumer* are all used to refer to receivers of healthcare in these executive summaries. Each carries a somewhat different connotation.

Table 2. Word cluster lists^a

To Err Is Human		Unequal Treatment	
Cluster	F	Cluster	F
for patient safety	8	racial and ethnic	6
patient safety and	6	minority patients and	5
to patient safety	6	are more likely	5
patient safety to	5		
to improve patient	5		
on patient safety	5		
improve patient safety	5		
center for patient	5		
in patient safety	5		
improving patient safety	5		

^aWord clusters from concordances of executive summaries from *To Err Is Human* and *Unequal Treatment* using keyword patient*. No word clusters resulted from the patient* keyword-in-context concordance for *Coverage Matters*. F refers to number of times the word cluster is repeated in the text.

that represent likely signposts for identifying ideological social action through language use.

Oxford WordSmith Tools also generates word cluster lists for each concordance if there are significant word clusters repeated throughout the texts. These are shown in Table 2. Given that *To Err Is Human* is often referred to as the “patient safety” report, it is no surprise that word clusters including variants of “patient” and “safety” are repeated throughout the text. The same can be said for the cluster result for *Unequal Treatment*, which examines unequal treatment of racialized populations.

Discussion

The keyword-in-context concordance enabled detection of differences in the words and phrases used to refer to receivers of healthcare in the 3 policy report executive summaries. *To Err Is Human* and *Unequal Treatment* predominantly use the word “patient,” and far less frequently “person” and “consumer.” The most notable result of the keyword-in-context concordancing was the small number of times that the word *patient** is used in *Coverage Matters* compared with the number of times it is used in the other

2 texts. *Coverage Matters* draws a sharp distinction between an “uninsured person” and a “patient,” even though an individual can be both. Each word carries a somewhat different connotation. The sentence from *Coverage Matters* discussed in the results section above actually distinguishes between “uninsured persons” and “patients with coverage,” reporting that uninsured persons often pay more for medical care than patients with coverage.^{9(pp48,49)} This distinction between “persons” and “patients” is curious and contradictory, given that if “uninsured persons” are “paying more than others for medical care,” those same persons must have also been “patients” at some time.

Deeper exploration of these keywords yields interesting distinctions of meaning and interpretation, and therefore social action through language or discourse. One of the top current definitions for “person” in the *Oxford English Dictionary Online*⁴⁰ is “an individual human being,” a canonical usage likely to be shared by most if not all policy makers. A “person” is one of the most general words that can be used to describe an individual human being. It is difficult to think of a more vague substitute for the word “human.”

A top *Oxford English Dictionary* definition for the word “patient” is much more specific:

"a person receiving or registered to receive medical care." Earlier *Oxford English Dictionary* definitions for the word "patient" are "a sufferer" and "a person who suffers from injury or disease." This definition is delineated as "archaic" by *Oxford English Dictionary*, but it was the definition specifically used in the author's own nursing training and is a very useful construct in clinical work with chronically mentally ill patients. A "patient" is a very specific kind of person, engaged in very specific social relations. As "sufferer," a patient garners recognition of a painful condition and perhaps compassion. Even under the more generic definition of "a person receiving or registered for healthcare"—again, a canonical usage likely to be shared by policy makers—a patient is entitled to specific rights and expectations from healthcare providers and the healthcare industry.

The word *consumer* has entered healthcare vocabulary with the commoditization of healthcare as an industry and has economic overtones of one who consumes wastefully, as opposed to one who suffers, as suggested by the word "patient." *Oxford English Dictionary* defines a "consumer" as "he who or that, which consumes, wastes, squanders, or destroys." *Oxford English Dictionary* definitions of "consume" include "to make away with, use up destructively," "to destroy," "to decompose," and "to spend, especially wastefully, to waste, to squander." This is a troubling characterization of receivers of healthcare. The *New Dictionary of Cultural Literacy* defines consumer as "one who purchases a good for personal use."⁴¹ This definition of consumer is less pejorative for receivers of healthcare but raises a host of new questions. Most healthcare costs are paid for by health insurance corporations contracted by employers to benefit employees. Which "consumer" of the healthcare good is prioritized in the healthcare industrial complex? If a consumer of healthcare is one who purchases healthcare for personal use as 1 definition states, then whose use is prioritized in the design of healthcare information technology? The answers to these and other questions suggested

by these varying subject positions most definitely affect the design of health information systems and the NHIL, as the following discussion indicates.

Insurance companies, for which healthcare is a commodity bought, sold, and bargained for, have an incentive to reduce the cost of healthcare to increase profits. Insurance companies are known to cut their costs by threatening to withdraw their business from healthcare providers who do not meet their price demands. This practice has resulted in hospitals increasing their charges for people without health insurance such that patients without insurance pay more for healthcare than patients who have insurance.^{42,43}

For the employer, the healthcare good is an affordable insurance product, which the employer uses as an enticement for retaining strong candidates for employment. Companies shop for insurance with affordable premiums based on their own fiscal position. The size of the company has a profound effect on its ability to offer health insurance as a benefit to its employees. Those companies who can offer insurance may be limited by their fiscal circumstances with respect to the quality of healthcare they can purchase. As more companies move their jobs overseas,⁴⁴ this leaves fewer employers in the United States offering employment including health insurance benefits, the traditional means by which American citizens have achieved access to healthcare.⁴⁵ Furthermore, those companies who maintain their United States operations complain that they cannot compete with companies who have moved most of their operations overseas, and they continue to reduce their benefit packages for Americans.⁴⁶

The healthcare good for the persons who actually receive the care applied directly to their physical bodies is care that is safe, effective, and timely. Quality of care has been defined as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."^{47(p21)} Timely, safe, and effective healthcare is something that is often out of

reach for those who do not have health insurance or whose insurance coverage is limited. People without health insurance are blocked from routine wellness care and often end up receiving care on an acute and emergent basis for conditions that might have been avoided with routine wellness care.⁴⁸ This is costly for the emergency health facilities and the community at large.⁴⁹

Because healthcare insurance in the United States is paid for predominantly by private insurance, which is supplied as a benefit of employment, the label of “uninsured person” may be suggestive of one who does not work. However, except for children, this is not the case; most uninsured persons in the United States are employed but do not receive health insurance as a benefit of employment.⁵⁰

The word clusters (see Table 2) revealed in both *To Err Is Human* and *Unequal Treatment* were predictable. However, their identification through the use of keyword-in-context concordancing demonstrates that this approach—combined with critical and social constructionist discourse analysis—has the potential to expose subtle differences in social action through language use even in very small corpora.

CONCLUSION

In this study, the combination of critical and social constructionist discourse analysis with corpus linguistics methods has proven to be adequate for investigating textual data for discursive signs of the social action of lan-

guage in creating subject positions in the selected Institute of Medicine report executive summaries. The automation of corpus linguistics methods does not replace human interpretation in discourse analysis but provides systematic ways to find language use patterns of interest to this research.

The results show differences in language use for describing and constructing the subject position for “receivers of healthcare” across 3 Institute of Medicine executive summaries. If these distinctions between “uninsured persons” and “patients” unintentionally or covertly enter the policy-level requirements specification for the NHII, the needs of receivers of healthcare who are uninsured may not be adequately represented in an NHII that is designed primarily for “patient safety.” This might simply be due to inattention (or underattention) to healthcare inequality issues during the process of codifying the information technology aspects of the NHII, but whether the problem is due to commission or omission is largely irrelevant from a policy point of view.

More research is needed to establish the degree to which the language of the executive summaries discussed here actually represents a problem in the way subjects of the healthcare system are being constructed through policy formulations. The safe, effective, and socially just deployment of health information technology requires explicit delineation between the good insurance corporations and individuals who have healthcare applied directly to their bodies. Their interests may not always coincide.

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