



The social life of health records: Understanding families' experiences of autism



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ABSTRACT

Outside of the epidemiological surveillance studies of autism prevalence, health records of children diagnosed with autism have not been sufficiently examined, yet they provide an important lens for showing how autism diagnosis, services and interventions are negotiated, coordinated and choreographed by families and practitioners across multiple settings. This article provides a multifaceted understanding of these processes from an ethnographic and discourse analytic perspective that reveals structural and interactional phenomena contributing to disparities in autism diagnosis and services. We consider health records as dualistic, material-discursive artifacts that are socio-interactionally co-constructed and variably interpreted, contested and utilized across home, school and clinic contexts. We chronicle several families' experiences of their children's autism diagnoses and interventions and describe ways in which health records are socially constructed, curated and placed in the middle of clinical encounters. We show how the parents in our study draw upon health records' material-discursive properties to display epistemic authority, expertise and knowledge in interactions with healthcare and school professionals involved in authorizing and planning their children's care. We describe how the parents experience the health records' clinical portrayals of their children and themselves, and how the parents' portrayals of their children are tacitly ratified or negated in the health records. The data include health record reviews, narrative interviews with parents and practitioners, and clinical observations. These data were collected between October 2009 and August 2012 as part of a larger study on disparities in autism diagnosis, interventions and services experienced by African American children with autism and their families living in Los Angeles County, California. Our analysis reveals the central role of health records in maintaining continuity of an autism diagnosis, interventions and services. This article contributes to enhanced professional awareness, parent-professional partnerships, and equity in the provision of healthcare and human services related to autism.

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1. Introduction

In the U.S., an on-going transition from paper to electronic health records (Plovnick, 2010) has resulted in a mandate for 'meaningful use,' i.e. the use of health information technology for improving the quality, safety and efficiency of healthcare, while engaging patients and families and facilitating healthcare coordination (ONCHIT, 2010). In the approaching era of electronic health records, patients' access to their health information is intended to facilitate their participation in healthcare, a development that exemplifies "both the dilemmas and productivity of actually existing

health services in rich countries" (Valentine, 2010: 951). What meanings and experiences will be engendered when patients and their families access their health records, and what impact will this have on patient–practitioner interactions, and ultimately, on the healthcare services that patients receive? How is the introduction of electronic health records expected to address health and healthcare disparities that persist in the U.S. (Feagin and Bennefield, 2014)? Paradoxically, the term 'meaningful use' does not address these questions, and we argue that neither the term nor the questions are uniquely relevant to electronic health records. It would be critical to put 'meaning' back into the 'meaningful use' mandate and to consider these questions for any kind of health records, electronic or otherwise, if we are to understand how health records figure in healthcare and what 'social life' they have.

This article addresses these questions in relation to one diagnostic category, autism, and for families who often face health and

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healthcare disparities across illness categories, African Americans (CDC, 2011). Focusing on the health records of African American children diagnosed with autism, we describe parents' experiences of reading and using their children's records. We consider health records' impact on interactions among parents and practitioners during diagnostic evaluations and intervention planning, showing how parents draw upon the material-discursive properties of records to display epistemic authority and expertise. We also consider the children's health records in relation to disparities in autism diagnosis, interventions and services experienced by underserved children and families (Magana et al., 2012; Mandell et al., 2009). Yet we do not intend to offer a "definitive race story" that "speaks only or uniquely about the experiences of African Americans" (Mattingly, 2010: 7). Rather, we provide an analytic perspective and a methodology to inquire into the complex place of health records in the reproduction of healthcare disparities for children with autism.

To this end, we aim to disrupt the assumed neutrality of the term 'meaningful use' and the illusory objectivity of health records themselves. The development of electronic health records, Berg (2004) reminds us, is "no neutral affair" because they "reconfigure healthcare practices and are deeply involved in intra- and inter-organizational and professional politics"; thus framing them only in technological terms makes "important political and organizational aspects disappear from sight" (2004: 12). Similar claims, however, could be made about paper medical records as digital scanning and storing technologies have made the boundaries between the two especially blurry. Whether the records are paper or electronic does not make much difference because it is the interconnectedness of the technological, socio-interactive, discursive and politico-economic processes that is implicated in the fact that health records are not, in any form, neutral.

The neutrality is conjured by the image of a hospital or a clinic where medical records are usually found. Our data show, however, that children's health records inhabit not only the clinical settings in which they were produced but also families' homes. These health records are organized into binders and carried from one clinical encounter to another – or scanned and e-mailed – by the parents. In the processes of their replication, movement and use they gain their meanings and significances as both material and discursive artifacts. Whether paper or electronic, the physical space inhabited by health records, be it inside a 3-ring binder or on a hand-held device, becomes pivotal in the records' co-construction and interpretation during the clinical encounter and beyond. While most studies focus on the role of professionals in the production of medical records, we examine the participation of parents in these processes, including how they experience the representations of their children in the health records; what meanings they attribute to these representations; and how they shape and negotiate what is entered into their children's health records. We view the interactive work of parents and professionals from a discourse analytic perspective, arguing that a dialogue may take place not only between people, but also between texts. Such a perspective is helpful in rendering the children's health records as simultaneously co-constructed during social interaction and *heteroglossic* (Bakhtin, 1986) because multiple voices (e.g. parents', practitioners', teachers') may contribute to a health record.

We show that while health records are perceived as objective, seemingly authorless, and always used as intended, they are highly contingent on the contexts in which they are engendered and the power relations among those by whom they are used. Our study examines health records as experienced by African American families of children with autism, who often face disparities in age at diagnosis and access to interventions and services (Magana et al., 2012; Mandell et al., 2009). We elucidate ways in which family

members and practitioners engage in the production, interpretation and use of the children's health records as certain kinds of texts and artifacts that give rise to certain kinds of experiences and actions.

Autism offers a unique view of what we call the 'social life' of health records because it may be diagnosed in multiple clinical settings. We use the term 'health,' rather than 'medical,' records because our data consist of medical, developmental, and educational records that were collected, curated and given to us by the parents of the children in our study. Autism also provides a unique view into the 'social life' of records because of widespread diagnostic disagreement, due in part to the subjective nature of the diagnostic processes (Solomon, 2010). It has been established that both at major U.S. autism research centers and at community sites there is great variability in how autism spectrum diagnoses (i.e., autistic disorder, PDD-NOS, and Asperger's disorder; APA, 2000) are assigned to individual children (Lord et al., 2012; Williams et al., 2009). Because of this variability, for several children in our study the diagnostic status and consequent eligibility for services changed over time. Moreover, some children in our study qualified for an autism diagnosis and services at one community site but not at another.

In light of widespread diagnostic disagreement, disparities related to autism diagnosis and services are especially troubling. Prevalence of autism among African American children (12.3 per 1000) is significantly lower than in non-Hispanic White children (15.8 per 1000) (CDC, 2014), a difference believed to be influenced by structural and interactional processes (Smedley et al., 2003). African American children are diagnosed later than White children, are less likely to receive an autism diagnosis on the first specialty visit, and are more likely to be misdiagnosed with adjustment disorder, conduct disorder or ADHD (Mandell et al., 2002, 2009; Valicenti-McDermott et al., 2012). These population-level findings reveal systematic delays in diagnosis, frequent misdiagnoses, and challenges to receiving appropriate services once the diagnosis is established. The promise of early diagnosis and early intervention for favorable developmental outcomes (Matson, 2007; Howlin et al., 2004) makes these statistics even more troubling. The analysis presented here is intended to contribute to health disparities scholarship by providing an ethnographic, discourse analytic perspective on the complex role of health records in how children's development and behavior are framed, and ways in which their healthcare needs remain unmet.

2. Methodology and analytic approach

This ethnographic, discourse-analytic study draws from a larger data corpus collected between October 1, 2009 and August 31, 2012 for a mixed methods, urban ethnographic study (*Autism in Urban Context: Linking Heterogeneity with Health and Service Disparities*, National Institute for Mental Health, R01 MH089474, 2009–2012, O. Solomon, P.I.) on disparities in autism diagnosis, interventions and services experienced by African American families of children diagnosed with autism. While a health records review was originally included in the study design, health records emerged during data collection as more significant than we expected in families' experiences of autism diagnosis, interventions and services. To capture this significance, we combined an ethnographic perspective with a discourse analytic approach (Wodak, 2004), which allowed us to iteratively analyze our data, moving between family members' narratives related to their children's health records and the records themselves. This process was also used to analyze other health records-related data in our corpus to identify the themes and patterns emerging across families, practitioners, and clinical settings (Solomon and Lawlor, 2013).

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