Social Science & Medicine 90 (2013) 32–39

Contents lists available at SciVerse ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

How healthcare provider talk with parents of children following severe traumatic brain injury is perceived in early acute care

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ARTICLE INFO

Article history:
Available online 28 April 2013

Keywords:
United States
Place
Provider–parent interaction
Communication
Culture
Severe traumatic brain injury
Ethnography of speaking

ABSTRACT

Healthcare provider talk with parents in early acute care following children's severe traumatic brain injury (TBI) affects parents' orientations to these locales, but this connection has been minimally studied. This lack of attention to this topic in previous research may reflect providers' and researchers' views that these locales are generally neutral or supportive to parents' subsequent needs. This secondary analysis used data from a larger descriptive phenomenological study (2005–2007) with parents of children following moderate to severe TBI recruited from across the United States. Parents of children with severe TBI consistently had strong negative responses to the early acute care talk processes they experienced with providers, while parents of children with moderate TBI did not. Transcript data were independently coded using discourse analysis in the framework of ethnography of speaking. The purpose was to understand the linguistic and paralinguistic talk factors parents used in their meta-communications that could give a preliminary understanding of their cultural expectations for early acute care talk in these settings. Final participants included 27 parents of children with severe TBI from 23 families. We found the human constructed talk factors that parents reacted to were: a) access to the child, which is where information was; b) regular discussions with key personnel; c) updated information that is explained; d) differing expectations for talk in this context; and, e) perceived parental involvement in decisions. We found that the organization and nature of providers' talk with parents was perceived by parents to positively or negatively shape their early acute care identities in these locales, which influenced how they viewed these locales as places that either supported them and decreased their workload or discounted them and increased their workload for getting what they needed.

Introduction

Early acute care (from initial hospital admission to discharge into rehabilitation care) of children following severe traumatic brain injury (TBI) requires extensive talking with parents to inform them and involve them in decision-making for the child. Parents' lack of knowledge about TBI means they need healthcare providers (henceforth referred to as providers) to thoroughly explain the child's injuries, treatments, secondary responses to injuries and treatments, and the range of potential outcome trajectories for the child (Jee et al., 2012; Madrigal et al., 2012).

The precipitating hospital factors that can complicate ideal communication in early acute care settings includes: a) the intersection of high technology and complex medical conditions, which encourages providers to prioritize technical skills and minimize interpersonal skills (Jee et al., 2012); b) minimal communication instruction given to providers to prepare them for managing their own and others' emotions (Gillotti, Thompson, & McNeilis, 2002); c) the multiple and divergent disciplinary roles involved in the care of the child and family, and the lack of organizational structure to promote respectful interdisciplinary communication that results in a unified message to the family (Boos, Okah, Swinton, Wolff, & Haney, 2010; Institute of Medicine, 2001); and d) providers' attempts to protect themselves from chronic exposures to encounters where they may believe there is no 'good outcome' or 'good news' to give the family (Meadors & Lamson, 2008; Roscigno et al., 2012). In addition, the family's cognitive, emotional, and behavioral states following the child's injury make their processing information and learning particularly difficult and time consuming. Parents may become overwhelmed or hampered by medical jargon, the amount of new information they must process quickly, the descriptions of procedures that seem barbaric (i.e., drilling holes in the skull or

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http://dx.doi.org/10.1016/j.socscimed.2013.04.017

taking a bone flap out of the skull and freezing it), or they may react emotionally to discussions of negative possible outcomes (Jee et al., 2012; Ularntinon et al., 2010). Taken together, perceptions of provider talk with parents following children's TBI becomes a critical human factor that can strongly shape how parents frame the caring or uncaring nature of the locales where such talk experiences occurred.

Background

Early acute care settings have physical characteristics that define their use (high use of technology), but they also have human cultural characteristics that define and shape how these settings are used and experienced (e.g., outsiders must get permission to enter or stay). Gustafson (2001) explained that a particular setting, such as an early acute care unit, takes on meaning to parents and families as the unit is experienced physically, psychologically, spiritually, and culturally. That unit is also influenced by the broader social context in which it is situated (e.g., the unit within the hospital and the hospital within a community, state, and country). How parents and families experience the space's physical, social, psychological, and cultural characteristics related to the care of the child and the care of the family directly and indirectly shape how the parents and families identify with these units as *places*.

Due to advances in early medical care, more children are surviving TBI in recent years and children's long-term outcomes are heterogeneous and based on a number of injury, medical, and social factors (Anderson, Godfrey, Rosenfeld, & Catroppa, 2012). Culturally competent, effective, and timely talk with parents is known to be a critical factor in building trusting relationships with families (DeLemos et al., 2010). It involves creating mechanisms by which all providers and the family can be knowledgeable of, and have input into, the plan of care. It also involves creating a means for provider disagreements to be discussed away from the family, so that a unified message is given to parents that shows respect between all providers (Gordon et al., 2009; Hoonakker et al., 2008). Given the minimal research on this topic with this population, and the problems translating research knowledge into practice (Institute of Medicine, 2001), early acute care providers may still lack a complete understanding of how their talk processes or policies can trickle down to affect parents' perceptions of the caring or helpful nature of early acute care units. Parents' retrospective orientations to their early acute care talk experiences are important because they give insight into how they perceive involvement in their child's care, what information they needed, and how they coped with various encounters both initially and long-term (Bronner, Peek, Knoester, Bos, Last, & Grootenhuis, 2010; Revenson & Lepore, 2012; Ularntinon et al., 2010).

In a larger investigation using descriptive phenomenology to explore 42 parents' overall experiences following children's moderate to severe TBI (37 families), Roscigno and Swanson (2011) noticed strong language tones and detailed provocative stories in the *meta-communications* (talk about talk) of parents of children following severe TBI. These parents often felt constrained and misunderstood during the process of receiving early acute care. This was in contrast to the experiences of parents of children with moderate TBI, who most often felt understood, but gave vague specifics about what was good or helpful when probed. Overall differences in the tone, detail, and genre of each group's meta-communications signaled that there was something different about each group's subjective orientations to the early acute care talk experiences and places. We reasoned that exploration of the talk about talk from parents of children diagnosed with severe TBI, including the language parents used and their corresponding behaviors, would provide important preliminary information to improving care delivered in these settings. The aim was to explore and discover what parents were trying to tell us explicitly and implicitly about the talk in these settings. Cummins, Curtis, Diez-Roux, and Macintyre (2007) claimed after conducting a synthesis of published literature, that the findings from the research they synthesized has shown causal relationships linking people's orientation of settings (i.e., place) to their health. The inductive approach we took is a critical first step to acknowledging parents complete talk needs in order to create future family-centered places that are sensitive to their perspective and experiences.

Methods

Ethical approval for this secondary analysis was obtained from the University of Illinois, Chicago; and the University of North Carolina, Chapel Hill, as well as two clinical recruitment sites, which are not identified to protect the identities of all systems of care described by parents. Written informed consent was obtained from all participants. Transcript data were de-identified. A copy of this manuscript has been shared with the involved parents, for whom contact information was still current ($n = 20$ of 23 families). We did not have permission, however, to interview parents for feedback.

Participants

In the original study, forty-two parents from thirty-seven families were recruited from across the United States from 2005 through 2007. Recruitment strategies included: personal solicitation at a northwestern children's hospital; advertisement on two TBI related websites; local advertisements; and mailed invitations to targeted participants in a regional southeastern brain and spinal cord injury program and a northwestern hospital's trauma registry. Recruitment was aimed at enrolling a diverse group of children, which we believed would then reflect a diverse group of parents with varied experiences.

Inclusion criteria of children were that they: (a) were 6–18 years of age at injury; (b) diagnosed with moderate to severe TBI; (c) had no other neurologic impairment; (d) had the ability to consent/assent and participate in an interview; (e) were within 4–36 months of their injury; (f) dependent on their parent/guardian; (g) were conversant in English; and, (h) at least one parent/guardian who was also willing to be interviewed separately. Recruitment continued until the sample reflected reasonable diversity in child's injury severities and family social demographics, and the themes of both children's and parents' experiences were saturated.

Since parents of children with moderate TBI gave vague specifics about why talk in early acute care met their expectations, they were not included as comparisons. The transcripts from the 29 parents of children with severe TBI were initially evaluated to make sure they met our inclusion criteria: (a) discussed in detail their talk with providers in the early acute care period; and, (b) discussed the meaning they interpreted (cognitively, emotionally, or behaviorally). Two families were excluded because of a lack of sufficient detail, but both parents were in agreement with the other parents' appraisals of what was important for early acute care talk discussed in second interviews.

Data collection and preparation

All families were interviewed initially in-person by the first author. Second interviews were done by phone ($n = 19$ families) or in person ($n = 3$ families), and one parent declined to participate in the second interview. The investigator had prolonged engagement with families at the first interviews, beyond the interview (Patton, 2002). Thus, the investigator believed that phone interviews would