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Parent Perceptions of How Nurse Encounters Can Provide Caring Support for the Family in Early Acute Care Following Children's Severe Traumatic Brain Injury

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Abstract

Objective—A child's severe traumatic brain injury (TBI) creates a family crisis requiring extensive cultural, informational, psychological, and environmental support. Nurses need to understand parents' expectations of caring in early acute care so they can tailor their attitudes, beliefs, and behaviors appropriately to accommodate the family's needs.

Methods—In a previous qualitative study of 42 parents or caregivers from 37 families of children with moderate to severe TBI, parents of children with severe TBI ($n = 25$) described their appraisals of nurse caring and uncaring behaviors in early acute care. Swanson's theory of caring was used to categorize parents' descriptions in order to inform nursing early acute care practices and family-centered care.

Results—Caring nurse encounters included: (a) involving parents in the care of their child and reflecting on all socio-cultural factors shaping family resources and responses (knowing); (b) respecting that family grief can be co-mingled with resilience, and that parents are typically competent to be involved in decision-making (maintaining belief); (d) actively listening and engaging parents in order to fully understand family values and needs (being with); (e) decreasing parents' workload to get information, emotional support, and providing a safe cultural, psychological, and physical environment for the family (doing for), and; (f) providing anticipatory guidance to navigate the early acute care system and giving assistance to learn and adjust to their situation (enabling).

Conclusion—Application of Swanson's caring theory is prescriptive in helping individual nurses and early acute care systems to meet important family needs following children's severe TBI.

Keywords

caring; family-centered; parenting; palliative care; phenomenology; content analysis; traumatic brain injury

Severe traumatic brain injury (TBI) in children under the age of 19 years is a significant health problem in the United States resulting in the largest proportion of hospitalizations,

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deaths, and chronic morbidities each year (Asemota, George, Bowman, Haider, & Schneider, 2013; Coronado, Faul, Wald, Xu, & National Center for Injury Prevention and Control, 2010). Children who initially survive severe TBI will be cared for in emergency rooms, operating rooms, intensive care units, and possibly medical or surgical floors (*early acute care*) for days, weeks, or months following injury. Trauma to a child or young adult (< 19 years of age) and the child's subsequent hospitalization creates an idiosyncratic family crisis because most parents or guardians do not have knowledge or experience related to trauma care, disorders of consciousness, or the trajectory of recovery from severe TBI should the child survive (Patterson, 2002). Parents can be immediately constrained in their parenting role by a healthcare system that dictates how they may participate in the child's care and decisions (Fins, 2005, 2013; author et al., 2013a; author et al., 2013b; Shudy et al., 2006).

Parents will be asked to discern and synthesize a large amount of complex information. Parents will also be asked to either participate in critical decision-making processes or consent to the decisions of experts, either of which will profoundly affect their family's future (author, 2011). Yet, it is still unclear what supportive and caring behaviors parents perceive they need and expect when in this situation. How to achieve a supportive and family-centered care approach in such a complex system of interdisciplinary care, a highly technical environment, and a highly emotional situation is still poorly understood.

Most children under 19 years of age are healthy prior to their accident and their specific advanced care wishes in such critical situations may not be known or fully informed (Fins, 2013; Shapiro, 1993). Inexperience with persons with disabilities, societal biases of what it means to live with a disability, and at times misinformation from healthcare providers about ways to compensate for impairments in order to achieve a good life quality despite disability affect how able-bodied persons might envision the meaning of surviving a condition that results in disability prior to experiencing it (Bach, 2003; McMillan & Herbert, 2004). Family viewpoints on the meaning of a child's disability can also change once confronted with a child's diagnosis (Larson, 1998; Pelchat, Levert & Bourgeois-Gu erin, 2009; author et al., 2012).

An adult, typically a parent, will act as the surrogate decision-maker for the child (Heyland et al., 2003; Shudy et al., 2006). Parents will often rely on the healthcare team's knowledge and experience to assist them in synthesizing the medical information related to the child's specific health condition and prognosis, but they will often also consider other information important to the family, in order to make their decisions (Fins, 2013; Heyland et al., 2003). Factors that are known to complicate a shared decision-making approach in early acute care are that: (a) communication with the family can be disordered amongst the multidisciplinary team and the varying individuals involved can give mixed or contradictory messages to the family (Aitken, Mele, & Barrett, 2004; Bond, Draeger, Mandleco, & Donnelly, 2003; Duff, 2006; author et al., 2013b); (b) diagnostic or prognostic information may be given to the family without full transparency of all known limitations of their specificity for prediction (Bernat, 2009; Bond et al., 2003; Fins, 2013; author et al., 2013a); (c) some parents have difficulty synthesizing the array of complex information due to their literacy level (Miller et al., 2012) or a language barrier; or, (d) parent's may be lacking in self-care and be stressed, which impairs their learning (Jee et al., 2012; author, 2011; Shudy et al., 2006). In addition,

parents may perceive that they are functioning with limited decisional authority compared to physicians or third party payers (Bernat, 2009; Cegala, Chisolm, & Nwomeh, 2013; author et al., 2013a; author et al., 2013b; Stark & Fins, 2013).

In a recent qualitative study conducted by this author, parents' overall experiences in the first five years following children's moderate to severe TBI were explored following moderate to severe TBI, using descriptive phenomenology (author, 2011). Parents of children with severe TBI described their early acute care experiences and they conveyed their *caring expectations* in these encounters (how to convey informational, psychological, cultural, and environmental support). By comparing the narratives of parents of children with moderate and severe TBI, the first author and two research mentors were able to surmise that all parents came into this situation initially unaware of their caring expectations, until those expectations were not met. For instance, parents of children diagnosed with moderate TBI were generally pleased with the overall informational, emotional, cultural, and environmental support that they received from providers. When asked to articulate why the early acute care interactions were appraised as caring, however, parents tended to respond with more generic statements like "they were really nice to us" or "she/he was very helpful." Despite using probes, the interviewer found it difficult to get this group of parents to articulate specific behaviors that resulted in their caring appraisals. It was surmised that the difficulty in getting at any details in this subgroup's responses could be explained by the fact that their caring expectations were generally met in this time period, therefore this group of parents did not need to deeply reflect on their caring expectations or appraisals.

Parents of children with severe TBI, however, described many specific early acute care encounters that they appraised as either caring or uncaring. This subgroup's narratives revealed specific details on what caused them to appraise each encounter as caring or uncaring. It was concluded that the varying nature of this subgroup's early acute care encounters and the perceived disparity between parents' expectations and some of their experiences, caused this subgroup to spend more time reflecting on how encounters should be conducted in this context and what factors made particular encounters as caring or uncaring.

This manuscript is reporting parents' expectations of caring encounters specifically with nurses following children's severe TBI. Parents revealed that they believed that early acute care nurses could play a critical role in bridging their caring needs with the team, if nurses recognized this potential, had the appropriate skills, and were administratively supported through staffing ratios that reflected an appreciation for this need. We were able to inductively understand how nursing behaviors were appraised and perceived to affect the family in early acute care. We were also able to demonstrate how Swanson's theory of caring can prescriptively inform individual nursing encounters to be relevant to meeting the caring needs of each family and how the theory also informed a family-centered care perspective for this population (Holloway & Quill, 2010; Swanson, 1993).

METHODS

Protection of Participants

This analysis was conducted in accordance with all established ethical criteria for the conduct of research on humans via Institutional Review Board Approval. Written informed consent was obtained from all parent participants in the original study. The secondary analysis was in line with the original study aims and parents were made aware of this secondary analysis. Transcript data were de-identified before sharing with any mentors, so that confidentiality was maintained. Parent pseudonyms are used throughout the examples. The investigator no longer had IRB approval to have contact with participants, so the final manuscript was not shared with them, but all parents had been given the investigator contact information prior to closing the study to learn about any updates if they so wished.

Study Design

Criteria important to conducting a secondary analysis were first considered in relation to the original study in order to justify the use of these data for this study purpose (Hinds, 1997; Morse & Field, 1995; Szabo & Strang, 1997). Parents' choice of particular words, their language choices, their use of concurrent sounds or body gestures (non-verbal behaviors); their tone of speech, rhythm of speaking, emphasis on particular words (paralinguistics); and their physiologic responses while telling their stories (tensing of muscles, turning red in the face, voice shaking, or crying versus a relaxed posture, tone of voice, laughing, or relaxed body gestures while describing events), helped to convey to the interviewer that this parent group had strong positive and negative responses, months to years later, to various interpersonal encounters in early acute care. Parents also described in detail the various ways that nurses could or did help to bridge deficits in caring support with various providers. These pieces of information positioned the importance of a deeper understanding of parents' appraisals of caring with nurses following children's severe TBI.

The following research questions were asked of the early acute care data: (a) "What are the parents trying to tell us explicitly and implicitly about how they wish to be considered and treated in early acute care following children's moderate and severe TBI?" (b) "How do parents perceive caring from the nurses they encountered in early acute care?" and (c) "Do parents' narratives confirm Swanson's theory as currently described by the five caring processes or do parents' narratives expand what should be considered regarding the caring processes in this context and with this group of parents?"

Sample

The sample for this analysis consisted of 29 parents of children with severe TBI from 25 families. The original investigation enrolled 42 parents and caregivers from 37 families between 2005 and 2007 and used descriptive phenomenology to understand parents' overall experiences following a child's moderate to severe TBI in the first five years post-injury (author, 2011). First interviews were all conducted in-person between 4 and 36 months following the child's TBI ($M = 15$ months; $SD = 10$ months). Second interviews were primarily conducted by phone ($M = 27$ months post-TBI; range of 12–15 months following completion of first interviews).

Recruitment criteria for the original investigation was primarily aimed at enrolling a socially diverse group of children (i.e., ages, genders, ethnicities, geographic living locations across the United States (urban, suburban, or rural), injury severities, and time since injury) so children needed to be: (a) 6 to 18 years of age at time of TBI; (b) categorized with moderate to severe TBI by Glasgow Coma Scale Score < 12); (c) able to participate in an interview process, (d) at least 4 months and no greater than 36 months post TBI at enrollment; (e) still dependent on parent(s) or guardian; (f) conversant in English; and (g) able to assent or consent to participation, as appropriate. Children were excluded if they had an additional diagnosis of spinal cord injury or significant developmental impairment prior to injury. In the original child and parent study, at least one parent or caregiver had to also consent to be interviewed, but both could participate. Parent(s) needed to speak and understand English and consent to be interviewed separately from the child. Enrollment for the parent part of the study ceased once the investigators' concluded that: (a) several targeted attempts to recruit an ethnically and racially diverse sample of children had been attempted; (b) families were diverse in other socio-demographic factors; and, (c) parents' themes were saturated (Patton, 2002).

Data Collection

In the original study of parents' experiences, two semi-structured interviews were conducted that lasted at least 90 minutes each. Field notes were collected of both the interview context and encounters that occurred prior to the interview. Demographic information on the child, parents, and family was also collected. In the first interview, parents were asked to describe their experiences from the time they learned of the child's injury up to the point in time of the interview. As parents described particular interpersonal encounters with various early acute care providers in their interviews, parents were asked to: 1) "Tell me what made that encounter good or bad?" 2) "What particular behaviors were important to deciding it was good or bad?" 3) "What behaviors were important to you and your family at this time?" and, 4) "Was there anything that we did not ask you that you think is important for your doctors, nurses and other providers to understand about caring for you in the hospital?"

In the second interviews, parents were asked to comment on the investigator's summary of all parents' experiences and appraisals, including parents' discussions of caring behaviors in early acute care. Eliciting member feedback allowed caregivers to tell additional details and/or to clarify any part of the investigators' summary that they felt needed further discussion. In fact, the additional interpersonal experiences that parents of children with severe TBI gained over time had allowed them the opportunity to further compare, contrast, and reflect on their early acute care needs and expectations.

Data Analysis

Parents' narratives were first inductively analyzed to understand if using Swanson's theory of caring was warranted. The theory was then deductively used to categorize how caring and uncaring behaviors were described by parents. Swanson's (1993, 1999) five caring processes consist of: (a) *knowing*, which is striving to be curious and learn about, and understand what it is like for the family members to be in their particular situation; (b) *maintaining belief*, which refers to trusting in the family's capacity to work through difficult situations, make

the best decisions for their family, and find positive personal meaning in any of the challenges that the child's health condition presents to them if they are appropriately supported; (c) *being with*, which is to actively listen and be fully mindful when encountering the family in a way that shows an authentic desire to learn from and engage in helping them; (d) *doing for*, which is anticipating and assisting the family with things that they would do for themselves if they were able and knew how. A recognition by early acute care providers that parents and family are disadvantaged in such a complex, highly technical, and often fractured system of care; and (e) *enabling* involves recognizing each family's strengths and giving them the tools they need to return to a normal state of caring for themselves.

Directed content analysis (Hsieh & Shannon, 2005) was the method used to evaluate parents' transcript data describing their early acute care encounters, which were further contextualized by the investigator's field notes. Individual family examples often illustrated more than one of the five caring processes, so for the coding process, narratives were categorized in any of the five caring processes that they fit. For the exemplars, however, the main point the parent was trying to make in that narrative was used to select the caring category it most represented. Parents' narratives and the investigator's field notes were the primary sources used to clarify and negotiate meaning discrepancies (Lather, 1986; Szabo & Strang, 1997).

Transcripts of these encounters were hand-coded by the author using at least one of the five caring processes of Swanson's theory, but often the examples fit within more than one of the five caring processes. Each full transcript with examples of the investigator's coding was then shared in separate meetings with two peer mentors, who each had expertise in qualitative research. One was the caring theorist guiding this analysis (Dr. Swanson) and the other had clinical expertise in counseling families of children following TBI. These meetings spurred further discussions and questions to be sure that the investigator did not prematurely foreclose on a full consideration of parents' explicit and implicit messages about their caring.

The peer audits and the member checks with participants were implemented in order to assure that the entire analytic process honored the participants' narratives, and that conclusions were not only based on the investigators' impressions. This method opened up the analytic process to alternative ideas before final conclusions were drawn (Rolfe, 2006; Ryan-Nicholls & Will, 2009). This approach also thoughtfully considered how this data confirmed, refuted, or expanded Swanson's theory of caring.

RESULTS

PARTICIPANTS

The 29 parents from 25 families came from 9 of the 50 United States and were cared for at 14 different acute care hospitals in the United States. Parents from each family included: only biologic mothers ($n = 19$); only biologic fathers ($n = 2$); or both biologic parents ($n = 4$). Parents self-identified as Caucasian race and non-Hispanic ethnicity (93%). Yearly incomes for families were reported as: <\$20,000 ($n = 3$); 20,000 to <\$60,000 ($n = 9$); \$60,000 to <100,000 ($n = 9$); or > \$100,000 ($n = 4$). Family marital status was reported as

single ($n = 8$) or married ($n = 17$). Children's acute care hospitalizations ranged between 3 and 110 days, ($M = 31$ days). The injured children's ages ranged from 12 to 20 years of age at study enrollment, but their injuries all occurred prior to turning 18 years of age. When using the terms child or children in this manuscript, they are used to describe the children's relationship to their parent(s) and not their developmental maturity.

Parents' stories, and the way they linguistically structured their stories, (Gee, 2014) revealed how various encounters with their entire healthcare team affected the parent's identity, their roles, their ability to make informed decisions for their family, and influenced their meaning related to their family's current situation (Hinds, 1997; Sandelowski, 2011). Parents spent the most time interacting with nurses. Thus, they believed nurses were positioned to help families navigate the system and get their needs met (author et al., 2013b). Parents' narrative data is presented within each of the five caring processes of Swanson's Theory (knowing, maintaining belief, being with, doing for, and enabling) and examples are presented to illustrate important concepts conveyed about that particular caring process. Finally, an example illustrating a family who described the integration of the five caring processes in their care is presented to show how this family perceived such caring support as assisting and empowering them.

Knowing—Knowing has previously been described as a curiosity that becomes an impetus for health providers to avoid assumptions, assess thoroughly, and endeavor to learn about the family's particular situation and former identities (Swanson, 1993, 1999). This group of parents had contextually varying, but emotionally laden stories to tell about how they initially succumbed to the overwhelming feelings of losing control (e.g., flight or fight responses) when realizing their child was injured. Yet, parents also detailed how even in the midst of chaos, they subsequently began to pull themselves together, problem-solve, and move forward to act on behalf of their family. Parents perceived that early acute care providers were very good at recognizing parent's trauma and grief responses, but not always astute at recognizing parents' attempts to be *resilient* (bringing important information about the child and family, wanting to be involved, considering the positives of their current situation, and attempting to use creative problem solving). At times parents believed that some providers' even misinterpreted their attempts to be resilient as signs that they were out of touch with reality. In these situations, some providers might say or do something perceived as insensitive. Parents believed these actions were an attempt to orientate the parent(s) to a different reality as discussed in more detail in another manuscript (author et al., 2013a). An important early need for parents was to have a safe psychological and cultural space where they and their family could begin processing their initial experiences as Kerri explains:

So, the ambulance was leaving...I followed...and we, we got onto the highway and [I could see in] the window behind them, they were, [they] tried to re-resuscitate him and [pauses while tears up]. I, my, I lost all focus and I was behind the ambulance at 70 miles an hour and it was all I can do to keep it [together]. I got, I got so I notice there's all these lights [flashing around me]...I had three State Patrol [cars] after me and then they were in a speaker they were telling me to 'Pull over, Pull over' and I didn't realize that [I was driving so fast]...I lost conscious

[ness] of everything except I just wanted to get to him....I was just driving by myself and I had my two little ones in the back of the [car]....I got pulled over...I was screaming out of the window, 'That's my son. I need to get to my son'....It was a blessing for me, because that grabbed me....I lost concentration on how fast I was going....And I remember I have my children....I'm shaking and I'm realizing [what I've done], then I just turned around [to my kids]...I says, 'It's okay. I'm being pulled over because I'm going too fast and I shouldn't have done that...it's my fault, so it's good that they pulled me over.' And, uh, you know, 'We'll be okay. It's all right,'....I got to the [first] hospital, I was outside and they led me into the emergency [room]....And they didn't want me in there. This nurse got in front of me...I said 'I need to see my son,' and she said, 'No, you can't come in here.' And I says, 'Yes, you bet I am going to come in here and you're not going to get in my way. That's my son.' So, I just came in and I just hold his head and he wasn't moving and his eyes. It was the hardest thing to see, [tears up] because his eyes were open wide and there was no movement....[They told me] 'We called the helicopter and [we are going to] send him away [to the level 1 trauma hospital]'So, we took off after the helicopter left [with him]...I went in the car [with my friend]....He came out of surgery and I still was not there....and it was about 2:00 in the morning [before I got there].

Until Kerri could be understood as responding quite normally to an extremely abnormal social situation, by the nurses in the first emergency room and later in the trauma hospital where her son was transferred, she could not be adequately supported, so she could begin to decompress and moderate her anxiety. As the narrative demonstrates, Kerri had an overwhelming need to be physically and emotionally present with her son. She also needed to emotionally support her son in case he was aware or woke up, reasonably involved and informed of his medical condition and care, and included in his decision-making. Kerri was reacting quite normally to an abnormal situation so she needed a non-judgmental environment. Otherwise, she or other parents might stay in high state of flight or fight response because they might then feel threatened or shamed by the healthcare providers who are excluding them or judging them for their emotional responses.

Parents felt that some nurses and other providers working in early acute care places only witnessed the family in the early weeks after the child's injury, when the family is disadvantaged, stressed, and emotional. Parents of children with severe TBI believed this limited perspective gave many nurses a narrow understanding of parents' capacities to eventually manage and adapt to stressors if appropriately supported during this early period. Parents countered that when early acute care nurses could fully appreciate their co-occurring grief with their attempts to be resilient, nurses could then respond in ways that implicitly and explicitly communicated that the family's experiences, knowledge, and perspective were respected. Parents were able to reflect back on their overall experiences in their second interviews as they gained more insight. Parents' stories highlighted the importance of creating and implementing a *system of caring* (coordinated, respectful, inclusive, individualized, and compassionate services for the families), not only individual caring interactions between each nurse and the family as Blaine explains:

It's not the child, you know, having an injury. No, it's not that. It's, um, it's what you get from everyone else. The support and understanding and the patience...It's just the system itself.... Instead of somebody being there to help you do this, [sometimes] you're pushing them to do this.

Maintaining Belief—Maintaining belief has previously been described as holding in esteem the family's capacity to work through difficult situations to find positive personal meaning. It also includes a collaborative effort of providers to go-the-distance with the family to help them with meeting their challenges (Swanson, 1993, 1999). Parents of children with severe TBI did not want pity from their early acute care providers, because they perceived themselves as competent parents and families. What parents described that their family needed in early acute care was empathetic understanding for their need to reasonably continue to function in their family roles and remain realistically optimistic for their family's future as Alecia describes:

He had less than one percent of a chance to live, so I just kind of prayed and hoped, and just stayed at the hospital day and night, took shifts, and just kind of stayed there. He was in intensive care for a whole month, so it was a long time. And, well, after two weeks, they said, "He has fifty-fifty chance", so, you know, he's looking up. I just really wanted two things: I wanted him to know who I was, because I didn't want a vegetable; you know, just there not even knowing me. And I didn't want him to die....I didn't dare push it and sort of pray for a whole person again. I knew that was not possible, but I did want him to be coherent and know who I am. And we'd deal with the rest and you know, kind of go on from there. And my prayer is answered [as he's doing so much better than anyone ever expected], so I'm happy. You know? Challenges? Well, I guess we have them. We'll deal with them.

Parents were motivated to help early acute care providers, especially nurses, understand how important family resilience was in getting them through such a stressful period of time. Parents were often later motivated to challenge a culture espousing *negative-medical-certainty* (that the child's prognosis could be precisely predicted as negative and guaranteed) or the notion of *false hope* (no family desire for a positive outcome in the child was warranted), which several families ($n = 17/25$) encountered in early acute care (author et al., 2013a). It is not that parents wanted to be lied to, but they wanted to motivate nurses to understand the importance of not taking the family's hope away or minimizing what hope meant to them as Ariana explains:

We went back a number of months [later] just to visit and so [our daughter] could see where she had been and everything....This one nurse who was so funny....I mean he did his job and he was certainly competent technically, but, you know. He was always careful and he'd go, 'Oh, but I don't want to give you any false hope.' And he would say that forever. I'm thinking, I don't care if it's false or true, it makes no difference. So, he walks up and he goes, 'Aren't you the mother of [daughter's name], you know, and I'm standing outside in the hall and I go, 'Yes and that's her.' And his mouth just dropped, I mean truly, he said, 'That can't possibly be!'

Being With—Being with has previously been described as the act of making yourself available, mindfully present, enduring alongside the one(s) cared for, and sharing feelings with a patient or family in a way that shows an authentic desire to learn from them, connect with them, and help them. Being with also shows consideration for not further burdening the family so that the provider’s feelings become the focus of the encounter or the provider’s or facility’s needs are positioned above the patient’s or family’s (Swanson, 1993, 1999).

Hailey illustrated how her family noticed and appreciated the way some nurses actively listened to the parents regarding who their daughter was as a person. Nurses then reflected on what might be important to her daughter, if she was fully conscious and aware. They showed respect to her daughter as a person, by providing the highest level of personal grooming for her daughter alongside her medical care, even though she was in a coma. Nurses also listened to Hailey’s need to be involved in her daughter’s care, so nurses found a way to bridge the two needs:

They painted her toenails, they painted her fingernails and we had some nurses that were just really, really like almost OCD [obsessive and compulsive] about cleanliness and of course she had blood in her hair and at the time her hair was real, real long. And, um, they just couldn’t stand her hair being like that....And they would braid it so it wouldn’t get all kinked up....We shaved her legs at one time. They were getting pretty bad. That was after several weeks in ICU. I was like, we’ve got to do something with this. So the nurse just gave us a razor and said, ‘Go to work.’

Parents described their observations of how various nurses took on differing levels of interpersonal relationships with the parents in order to build a rapport with the family. The levels of interpersonal relationships ranged from acting in a social role and without a deep interpersonal connection to the family (“doing a job”), to a more interpersonal level of support where parents were viewed and treated as unique and equally valued members of the health team as Mitch explains:

They [nurses] would talk to me just like they would want me to talk to them. They would just look me in the eye and tell me, ‘This is exactly what’s going on’ and, you know, ‘We hope’ and ‘We just don’t guarantee’ and ‘This is what we know’, ‘This is what we do,’ ‘this is what we’re looking for.’ Just you know, ‘I’ve seen some people come in here a lot worse than this and be just fine later on.’ ‘There’s never any reason to give up hope’....[Later, when she was transferred to a medical surgical unit] she had some [nurses] that were just there for their check.

Parents’ consistently recognized and appreciated nurses who went beyond the medical tasks expected in their roles:

Some people do things because it’s a job and they have to do it. Some people do things because they enjoy doing it. It’s a job that they want to do. And, of course, that shows in what they do and how they provide care.

Doing For—Doing for has previously been described as performing competently as a provider, comforting the family, protecting and preserving the family’s dignity, anticipating

the family's needs, and assisting the family with things that they would do for themselves if they were able or knew how (Swanson, 1993, 1999). By maintaining the child's optimal health and personal dignity through rituals of daily care, and also doing things for the family that they would do for themselves if they knew how or could (parenting in this context), nurses protected, preserved, and assisted the parents to restore roles and routines as best as possible under current circumstances.

Kerri's previous narrative (located in knowing) provides a story to work from and discuss how a nurse can demonstrate competence in doing for the parent the things they would do for themselves if they were able or knew how. Once Kerri was allowed to be with her son and she began decompressing from her initial fight or flight response, she also needed to have her other needs addressed. She needed her physical and environmental needs addressed such as orienting her in where and how to get food, drink, rest, warmth, hygiene and use of restrooms. She also needed information on hospital parking, visitation policies, and policies on parents staying overnight. Kerri also needed her psychological needs met by being involved in her son's care and decisions as she wanted. She needed ongoing and up-to-date medical information provided about her son's specific condition, and to have his condition and care explained in a language she could understand (possibly re-explained more than once). She also needed a safe place to tell her story, ask questions, and make sense of what had happened (suspending judgment), so that she could begin to consider her family's future. Finally, she needed her cultural needs assessed and valued so that the family's experiences, beliefs, and values (religious, ethnic, or other) are addressed and incorporated into any care decisions.

Parents could be disadvantaged by certain early acute care policies (i.e., visitation, involvement in rounds, incorporation of family beliefs/rituals in decisions), by the highly technical focus and language of early acute care, and by any lack of understanding for the parents' coping responses by the healthcare team. If the family's needs were not being anticipated by their team, then nurses could coach the parents in advocacy skills; how to get what they needed within their particular early acute care system. Nurses could also intervene on the family's behalf by advocating for their particular needs with other health providers on the team. For instance, maintaining a safe psychological space at the child's bedside for the child's healing showed respect to the child and family. Nurses could honor the family's desires to enforce a policy to prevent the discussion of negative, traumatic, or insensitive information at the child's bedside as presented in author et al., (2013b).

Caring-nurse-relationships were described as connected to the family on a human-to-human level. Parents felt that caring nurses recognized parents' competence and empathized how the early acute care system of care inherently disadvantaged the family, so those nurses did whatever they had to in order to mitigate those factors, which decreased the family's workload and stress in being informed and involved in the child's care and decisions. Creating a non-judgmental and accepting environment helped the family to heal from the emotional trauma they were initially exposed to, so that they could build up their resiliency for future roles and responsibilities. Creating a safe and supportive physical, psychological, and cultural environment for the entire family decreased one family's workload by allowing them to feel that they were in partnership with their providers. As Karen illustrates, such

insights and acts allowed this parent to continue to perform in her parenting role for her child even though she was in such a foreign environment:

I can remember one of the nurses, one of her night nurses...she would try to reassure us about things...I would always be calling her and saying, 'Do this,' 'Do that,' and 'I want this done.' And obviously she had lots of other patients too and at some point I probably said, 'You know, we're probably being overbearing as parents,' and she said, 'Listen,' she said, 'You know, if this were my kid, you, you wouldn't want to be in the same room with me, because I would be there and I would be, you know, making sure this was done and that was done. You know, 'that's what you do as a parent,' so, um, she helped me in any kind of way.

This nurse involved the family because she valued that it was the parents' right to participate in their child's care, but she also gave this parent permission to be in control of aspects of the child's care, which decreased the mother's stress and concerns for her own parenting behaviors (i.e., being unfairly perceived by providers as anything but attempting to be a "good parent"). This approach ultimately increased the family's trust and sense of safety in this place.

Nursing concern for the family was also demonstrated by attentive attitudes toward changes in the child's medical condition, which should be prevented (seizures, brain storming, increased ICP, etc.) and by showing an appreciation for the family's unique knowledge and involvement in the child's care. Dismissing parents' observations or not being knowledgeable of their meaning or implications (clinical competence), led to a lack of respect for those nurses by parents. One nurse's concern and respect of this parent's astute observations and her anticipation for the family's complete needs assisted this family through the complex early acute care system in order to get their needs met. Collaboration created a trusting rapport between the nurse and the family as Ariana explains:

This one nurse was just getting ready to do his lunch, and all of a sudden [my daughter] started—[her] eyes started twitching. And, you know, to us it looked like maybe she was waking up. And so, we're sitting there getting all excited about this, and he [the nurse] says, 'Well, yeah, maybe she's waking up.' And then he left to go to lunch. Well, one of the other nurses that had paid more attention to [my daughter and was covering for this other nurse while at lunch] said, 'No, I think she's having a seizure'.... I knew she had plenty of assaults already—and I said, 'Nobody's called back. How long do we wait?' So she called them herself. And she got somebody in there right away.... Every time something came up, she'd call the doc and say, 'This is what we need, blah blah blah'—and of course, they [nurses] know so much more in terms of the minute-to-minute things that happen; what to look for and how to monitor everything.... every single one of them takes pride in their work, except perhaps that one nurse who really didn't have care for [our daughter], and thought, "Well, I'll just tell them it's nothing." But we had powerful nurses, and we had powerful advocates.

Several families ($n = 18$) also discussed their safety concerns when their child was transferred from intensive care to a medical or surgical floor. Parents described their children's medical conditions at that point in time as still medically fragile due to seizures,

brain storming, or disorders of consciousness (irritable, combative, and impaired judgment), which presented significant safety issues for the child if someone did not observe the child closely and intervene in time. Parents often felt they were entirely or mostly responsible to protect their child from injury because nursing staffing and the child's room assignment on these wards were not perceived to take these safety needs into account, or the nurses did not seem to be knowledgeable about the care of this population. The perceived responsibility for protecting the child added a burden for parents at this time and their sense that they were not in collaboration with providers for the care of the child in these places. Thus the individual nursing care or system of care was not perceived as competent or family-centered in such places as Roxie discusses:

When we were leaving ICU to go up to the floor...it was really disconcerting to me, seeing [my daughter] not getting that immediate care [she needed], you know. Like, she would have a neuro storm, and her temperature would be going up, up, up, up, and well, it wasn't their time to check on the patients, so they weren't coming and seeing what was going on. And so I would alert them, and they were like, "Oh, yeah, well, I'm going to be getting off the shift, so the next nurse will have to do it"...It seemed like they weren't prepared for that level of care needed, for these acute patients—I mean, I guess. That's how it felt. And it went on and on, you know [chuckles], every day.

Enabling—While enabling has historically been given a derogatory meaning related to co-dependencies, in the context of caring, enabling has a different meaning. Enabling has been described as giving feedback, validating family strengths, and giving family members the tools for their role in the family. One does this by informing, explaining, supporting, allowing, generating alternatives, and thinking things through with them. Such strategies support the family so the family members can eventually return to a normal state of caring for themselves (Swanson, 1993, 1999). When parents arrive in the intensive care unit they may initially feel powerless in their parenting roles because they become overwhelmed by the sight of their injured child, who is now dependent on technology. Anticipating parent needs and then coaching them in how to continue parenting in this context can help them to restore their normal family roles as Joannie and then Tori explain:

You just sit and watch your child, and [normally] you do all you can to help them, but then when certain things like this happen, you can't do anything to help them because either you don't have the expertise, or you know, it requires something else. So, it was just, it was painful.

They [nurses] did a good job understanding [our complete needs], but now that we look back, we didn't understand [all that was going on at that time] like they said, which was probably a good thing. I'm not sure whether we tuned it out? I remember the nurse in there kept saying, 'No matter what, don't leave them [physicians], just keep pressing, pressing, pressing for information and keep pushing for information.' She kept telling me that and she made us sit down and eat.

The first narrative helps illustrate the need for nurses to allow parents to get involved in the care of the child, while the second narrative illustrates how the nurses gave anticipatory guidance to the parents to prepare them in how to get involved in the care of the child. This second nurse recognized that the information system (patient rounds) that parents would encounter could be disadvantaging to them. By preparing parents ahead of time, the parents could be empowered to be able to get their information needs met and to become involved in the decision-making process for their child as they wished. By also encouraging parents to meet their physical needs, the nurse assisted these parents to keep their strength up, so they could cope with the additional stressors that they were likely to encounter while their child was cared for in the intensive care unit. Many of the nursing actions involved in doing for the parents can also enable parents by preparing them for the long-haul, giving them feedback on their strengths and weaknesses, and involving them in the child's care.

Integration of the Five Caring Processes—When nurses incorporate and integrate Swanson's five caring processes into their early acute care interactions with the family it helps them to tailor their interactions to the family perspective and needs. Carmine's story illustrates that by adapting the nurses' caring interactions to this particular family's cognitive, physical, psychological, and cultural needs and experiences, the nurses built up this family's knowledge and capacity to make decisions that were fitting with their values to act as 'good parents' on behalf of their son (informational and emotional support). Nurses also tailored activities in order to provide this family with a safe space to express their concerns, decompress from their experiences, and maintain resiliency for the future (environmental support):

My, our feelings on [certain practitioners] that we dealt with was, it must be a really tough job, and they have no bedside manner whatsoever. Maybe because they have to distance themselves from how many they lose and so, they were absolutely no help in educating us, which is what we needed. We needed some concrete things there to base our decisions on. We knew [our son's] wishes were to not be sustained for any length of time. There were questions, you know, 'Is that what we're doing right now? Are we keeping him alive?' We really didn't know any of that. So anyway, the nurses got us more on track. They were able to sketch something on a piece of paper, say, 'This is the brain.' [We asked] 'Where is the injury?' [The nurse said] 'Well, I'm not the radiologist, but I can give you a pretty good idea. We're talking,' and draw a little circle over here [on the picture of the brain]. And they certainly, later on, gave us stacks of books and pamphlets to read on brain injury, but they don't hit you with that right at first. They're much more comforting, assuring us that we can be in there twenty-four/seven if we want....Backing up what the doctor said, that, you know, 'We really don't expect him to live through the night, so,' comforting you with bringing in immediate family, if you want, to say their goodbyes, and that type of thing, but never giving up the hope. Like the doctor, his attitude was just different than the nurses. And the nurses, I don't know, we wouldn't let them [the nurses] do that and so they did not do that [convey only negative medical certainty]. They certainly stuck by that, 'Miracles happen;' 'You never know;' 'Let's wait and see what happens;' 'We're doing all we can do.' Getting us as comfortable as they can, explain[ing] all the equipment to you, and

then re-explain[ing] it an hour later, when you come back and don't remember what they told you. They were very gracious about that; very comforting to our daughter [his sister]. And then the tests start. 'Now we got to undo him and take him back for another CAT scan, there's pressure building [in the brain], there's—the ICP [intracranial pressure] levels rocketing up,' and, you know, they would alert you to, 'It's getting pretty critical again,' but again, not giving up the hope completely, just alerting you to that, urging us to 'Go get coffee, go sit down for a few minutes.'

Discussion

Family support is a transactional communication process that occurs when symbolic and interactional understandings are achieved between involved healthcare providers and the family, which reduces uncertainty over a distressing situation. When encounters are perceived to go well, a bond is created, which allows the family to re-gain mastery and control over their family roles, relationships, and well-being (Albrecht & Adelman, 1987). In the context of early acute care relationships, psychological intimacy (being with) may significantly fluctuate across all early acute care providers, based on the varying time and attention these different providers can or do spend getting to know the family (Auerbach et al., 2005).

Realistic tensions exist for expecting a deep level of intimacy from all team members (Auerbach et al., 2005; Piatt & Neff, 2012). Medical care following severe TBI is highly technical, complex, and touches on deeply emotional and morally challenging topics, where decisions must often be made quickly (Auerbach et al., 2005; author et al., 2013a; author et al., 2013b; Shudy et al., 2006). In the emergency room and while the child might be in surgery, information focused on the child's condition takes precedence, but the family may also need their physical, emotional, spiritual or cultural needs anticipated and addressed for them.

Once transferred to the intensive care unit, the providers who are involved with the family and their available time typically changes. Physicians from surgical specialties may be in surgery several hours of the day, and so their available time is immediately constrained to meet with family members. Some intensive care units have addressed this disparity by changing to a system of care where the primary physicians guiding the care are located within the intensive care unit and should be more available to the family (critical care physicians) (Meert, Clark, & Eggly, 2013; Piatt & Neff, 2012). The support needs of families of children with severe TBI are very time-intensive and at times anxiety producing because the conditions, or prognosis, that the family needs information on are often laden with uncertainty or are difficult to discuss because they evoke various emotions for all involved (Auerbach et al., 2005; Jee et al., 2012; Lefebvre, Pelchat, Swaine, Gelinas, & Levert, 2005; author et al., 2013a; Shudy et al., 2006).

Nurses are ideally positioned post-surgery to develop more intimate relationships with parents and family members (Adams et al., 2014; Auerbach et al., 2005; Bourhis, Roth, & MacQueen, 1989). Nurses can both assess families strengths for resiliency (Adams et al., 2014; Gan, DePompei, & Lash, 2012) and advocate for an environment that is supportive of

their physical, psychological, informational, and cultural needs (knowing and maintaining belief) (Adams et al., 2014). Gan, DePompei and Lash (2012) have described the importance of recognizing resilience-based factors when assessing the family system, which they point out include: a) the academic, social, and developmental history of the child prior to injury; b) effects of the brain injury on current functioning of the family within their social environment; c) protective factors within the family and their social environments; d) the family's goals, wishes, and hopes for the child and family; e) the family social history; f) the family's understanding of the child's injury; g) other ongoing changes within the family system; and, h) informational and emotional support from the early acute care professional system and the family's social community. More specific elements for nurses to assess on family resiliency within each of these factors are located within that resource (p. 633–634). The specific child factors that also contribute to family resiliency would likely be assessed at a later point in time due to the child's current medical state (disorder of consciousness).

This analysis helps to illustrate why nurses are ideally positioned to act as conduits of communication for the parents and family in early acute care (Adams et al., 2014; Bourhis et al., 1989); channeling important information in both directions, so that the family's supportive needs are considered and addressed (doing for and enabling) (Adams et al., 2014; author et al., 2013b; Shudy et al., 2006). This analysis also helps to exemplify the complex interplay between Swanson's *knowing* and *maintaining belief*, specifically inherent to conditions where death or disability is highly probable. Knowing in the context of severe TBI involves not only understanding what it means to be in the family's skin at this time, but also knowing the historical and cultural factors that have skewed the negative societal and medical beliefs about the meanings of disability and death (*socio-environmental*) (Solomon, 2012). Knowing also involves considering how the attitudes and beliefs of medical providers or others in society related to the family's situation may drastically differ from what the family believes is important, now that their loved one is suddenly in this situation. By knowing that patients and families can eventually adjust to changes and losses (Marris, 1986), nurses can become comfortable with allowing the family to express notions of optimism for the child and their family, even when the child's condition and prognosis may seem bleak for the family (maintaining belief). Simultaneously grieving and being optimistic is normal coping in this situation and does not automatically mean the parent(s) are out of touch with the gravity of the child's situation (Gan, DePompei & Lash, 2012; author et al., 2013a; Van Hook, 2008).

When nurses working with families of children following severe TBI take a socio-environmental approach to *knowing*, they position the family's context and notions of health at the forefront of care decisions and relational approaches (Purkis, 1997). Using a relational approach, nurses actively listen to family members, suspend their judgment of the family's emotional responses (simultaneous grief, optimism, stress, and resilience), deeply reflect on what it must be like for the family (i.e., empathy), and then take measures to create a psychological and cultural space that allows parents the opportunity to make sense of their current situation, so that the family can begin healing and restore their roles and relationships (Beard, 2009; Nichols, 2006; Rehling, 2008; Rutter, 2012; Shotter, 2009).

Nurses can also assist the family by coaching parents to get the information they need and by providing parents with alternative approaches to learning so that they can have their point of view heard and they can synthesize all information (medical, social, and family values) in order to make decisions in fitting with their beliefs (being with, doing for, and enabling) (Adler, Proctor, & Rosenfeld, 2013; Rehling, 2008; Schenker et al., 2013). Understanding medical information so parents can be involved in decision-making is one of the most important aspects that parents convey “a good parent” does for their child (October, Fisher, Feudtner & Hinds, 2014). By actively engaging with both the family and other members of the team, nurses can then point out family protective factors or risk factors (enabling), so that these factors can be addressed in the family’s care plan (doing for and enabling) (Gan et al., 2012; Swanson, 1993; Schenker et al., 2013; Van Hook, 2008).

Collaborative caring approaches are an important part of the palliative care movement (Adams et al., 2014; Iverson et al., 2014; Michelson, Patel, Haber-Barker, Emanuel, & Frader, 2013; Schenker et al., 2013), but the specific supportive expectations and needs for families of children following severe TBI have not been fully discussed, especially when the children are transferred out of the intensive care unit. This study provides new insights across early acute care settings to help guide the individualized and system care of families when the child survives severe TBI.

Providing for environmental needs includes not only providing for parents’ physical needs, but also considering each child’s acuity and safety needs when assigning them to an early acute care unit upon transfer out of the intensive care unit. Appropriate nurse staffing and assuring nurses competence for the care of this population are important to consider in unit assignments because preventing medical complications are important quality indicators of patient and family-centered care (Cronenwett et al., 2007; Michelson et al., 2013). Nurses need to assure that the family is not unduly burdened to stay at the child’s bedside for fear that the child will be harmed due to insufficient monitoring for seizures, brain storming, or personal injury due to disorders of consciousness (Cronenwett et al., 2007; Grant, Grinspun, & Hernandez, 1995).

Limitations

This analysis gives preliminary insight into the caring behaviors of nurses that can be important to some parents of children following severe TBI, but this sample was small and homogenous in some social demographics (ethnicity, language, and survival of severe TBI). Therefore, these parents’ viewpoints may not be representative of all families of children following severe TBI, especially those whose child subsequently dies or has poorer outcomes. More research is needed evaluating early acute care practices interacting with the family. While we heard the same themes discussed across parents and no new themes of caring were discussed prior to ending parent enrollment, the fact that this was a secondary analysis means these findings should be considered preliminary (Thorne, 1994).

Implications

Parents report that when nurses have a comprehensive understanding of the family caring needs, then nurses’ can create a partnership between the family and the team, which parents

believe plays an important role in supporting family resiliency. This collaborative effort helps the family to get their informational, emotional, cultural, and environmental needs met. We found preliminary evidence that Swanson's Theory gives prescriptive direction on how nurses can build individual relational and system partnerships with the family. A caring nurse approach creates a bi-directional bridge between the early acute care team of providers and the parents, so that supportive family-centered services can be provided in the early acute care phase, but nurse staffing ratios must be appropriately supported so that nurses have the ability to provide such demanding care to each family.

This study emphasizes the need for a palliative care approach with families following severe TBI at the moment of the child's diagnosis of severe TBI. The child not only has significant medical needs, but the entire family also has supportive needs as well. The World Health Organization defines *palliative care for children* as "the active total-care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness [or injury] occurs, and continues regardless of whether or not a child receives treatment directed at the disease [or injury]. Health providers must evaluate and alleviate a child's physical, psychological, and social distress, and effective palliative care requires a broad multidisciplinary approach that includes the family....It can be successfully implemented even if resources are limited."(World Health Organization, 2014)

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