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Planning with parents for seriously ill children: Preliminary results on the development of the parental engagement scale

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ABSTRACT

Objective: The objective of this study was to develop a clinically relevant tool to assess parental engagement in decision making and planning for seriously ill children during palliative care consultations. Although little is known about the structure and process of planning meetings between parents and providers, less is known about the nature of parental engagement as it relates to decision making ability in pediatric end-of-life care. Using attachment and caregiving as a framework, this study clarified important dimensions of parental engagement.

Method: Using a multi-phase, template-matching technique, both literature and pediatric palliative care consultation data were analyzed, iteratively reviewed, matched, and categorized to create a measure of parental engagement. The attachment paradigm serves as the theoretical framework for the study, which focuses on parental engagement in decision making as a caregiving system function. Attachment and related literatures as well as coping and pediatric palliative care literatures were used in the initial conceptual sampling phase.

Results: The study yielded two groups of findings. The first set of findings centered on the findings of the literature and consultation template-matching phases of the work. These two phases yielded a conceptual model of parental engagement as a psychobehavioral complex consisting of three dimensions: *information-centered dialogue, insightful participation, and achievement of a collaboratively agreed-upon plan.* The final phases consisted of creation of a 9 point Parental Engagement Scale, scoring of the consultations, and establishment of initial inter- rater reliability at .80. Psychometric testing continues.

Significance of results: Parental engagement in decision making is a critical area for study and intervention. If we can support parents in their caregiving executive functions while understanding the psychological and emotional underpinnings of the caregiving system and parental engagement itself, we can move inquiry forward in understanding parental needs for intervention during this most profoundly challenging time.

KEYWORDS: Pediatric palliative care, Parental engagement, Parental coping, Parental decision making, Collaborative planning

INTRODUCTION

Parental decision making in the case of serious childhood illness occurs in a context in which both protective and executive roles of the parent are simultaneously elicited and challenged in the most formidable ways. Relative to this, clinical experts emphasize the importance of support for parents and caregivers in pediatric palliative care (Himelstein et al., 2004; Byrne et al., 2010). Parents whose children receive a diagnosis of serious life-limiting illness experience destruction of their previous reality (Clarke-Steffen, 1993) and the shattering of psychological assumptions regarding stability (Cohen, 1993a). Feelings of helplessness emerge in the face of something they cannot control (Clarke-Steffen,

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1993) as well as fear of losing the child (Cohen, 1993b). Grief reactions are paramount concerns in parents facing the serious illness of a child and providers are urged to recognize the prolonged nature of many of these reactions. Not surprisingly, the traumatic stress model has been used as a conceptual framework for understanding parental experience and behavior in cases of serious childhood illness (Stuber et al., 1998; Kazak et al., 2005).

These parents' decision-making activities occur within a complex medical landscape characterized by varied and evolving perspectives and practices that include the development of the integrated model of palliative care, multiple treatment options, and increasing opportunities for experimental interventions. Parents struggle with enormous amounts of new and unfamiliar information that bring substantial uncertainty (Mishel, 1983). Uncertainty, along with the tendency toward heuristic bias or psychologically based default-type patterns of decision making in high-intensity situations such as the serious illness of a child, are well documented in the literature, and although support for dual processing in the face of complex problems remains (Evans & Over, 2010), the concern with heuristic bias in pediatric palliative care reflects the cognitive struggle inherent in parents' experience (Mishel, 1983; Santacroce, 2003: Feudtner, 2007; Feudtner et al., 2010).

While parents grapple cognitively with the intricacies of the information presented to them, they are also strained affectively (Feudtner et al., 2010). Their emotions can change in intensity and duration over relatively short periods of time in association with a number of variables, often related to the child's condition.

At the same time parents are meeting considerable real-time challenges in cognitive and affective dimensions, they are continuing to function as key members of much larger relationally based parent–child systems: the caregiver and attachment systems. These often nuanced psychological systems relate to the parent's past and current states of mind regarding themselves and others, their particular relationship with the child who is ill, and their relationships with healthcare providers. This forms a matrix or psychological field within which the parent operates and which fuels parental behavior throughout the course of the child's illness and beyond.

Attachment theory provides a specific model for parental coping in the case of childhood illness, which considers the uniqueness of the parent–child relationship as it frames the parental struggle to come to grips with the illness of a child. By considering the totality of the parent–child experience as an essential whole, namely, the attachment/caregiving system, we begin with an integrated framework for the study of the parent–child experience and parental decision making in serious childhood illness. The tool development study described here is part of a series of studies using the attachment framework and planned by our team (Methods to Analyze Palliative Services in Pediatric Advanced Care; MAPSPACT), which is providing a separate research infrastructure in parallel with the evolving clinical services of the Morgan Stanley Children's Hospital of New York (CHONY) Pediatric Advanced Care Team (PACT) within Columbia University Medical Center (Byrne et al., 2010).

A recent phenomenological analysis of transcribed narratives from initial consultations conducted during the first year of this PACT's services yielded themes consistent with the concepts discussed throughout the pediatric palliative care and attachment literatures. Themes included: pervasive parental uncertainty; decision making halted by the hope for more information; negative affects of anger, fear, and sadness in the search for options to protect the child from suffering; parental need for comforting; complexities of child–parent–multiple provider communications; and fear of abandonment (Byrne et al., 2010). In these themes we see threats to the protective and executive functions of the caregiving system, which are ominipresent in serious childhood illness.

From an attachment perspective, parental decision-making activities reside at the intersection of parental coping and caregiving systems. Parents are attachment figures for their children, a role which is especially crucial during periods of threat or crisis, such as the illness of a child (Marvin & Pianta, 1996). As attachment figures operating within the caregiving system, they are expected to engage in actions, including decision making, which maximize the welfare of the child. In serious pediatric illness, parents may perceive inability to protect the child, thereby facing an emotional crisis marked by inability to cope with or "come to terms" with the situation facing them (Hinds et al., 1996; Miedema et al., 2010). This inability of a parent to cope with a child's illness has been studied in very specific ways by attachment researchers and shown to have a negative impact on caregiving behaviors (Marvin & Pianta, 1996). In contrast, this same body of work indicates that parents who are psychologically able to deal with the reality of their child's illness are resolved with regard to their children's diagnoses. Furthermore, these studies of young, chronically ill children have demonstrated higher rates of secure attachment profiles in resolved parents and their children, compared with unresolved caregiver/child dyads (Marvin & Pianta, 1996; Barnett et al., 2006).

Parental resolution of a child's life-threatening diagnosis is a complex achievement. It reflects internal psychological models of the child, the child's medical condition, and the parent as caregiver within the context of the attachment relationship (Pianta et al., 1996). Resolved parents articulate their distress, but do so in a manner that indicates their realistic grasp of the situation as a whole. They can acknowledge their child's emotional and physical needs as well as their own and manage their emotions to the degree that is necessary to accomplish their caregiving tasks. They may require much support, but they manage to succeed in the internal integration of this profoundly challenging experience.

Another characteristic of well-functioning caregiving systems, which has implications for parental decision making, is a specific type of reflective stance toward the child. Parents who function reflectively treat their children as psychological agents with needs and desires of their own. These parents can reflect upon their own as well as their children's internal experience and mental states (Sharp & Fonagy, 2008). This ability, known as "parental reflective functioning", is composed of the cognitive construct of perspective-taking along with the emotional process of being able to internally "hold" and regulate the child's emotions without becoming overwhelmed (Slade, 2005). Parental perspective-taking extends to the ability to take the perspective of others, e.g., the treatment team. This is a related cognitive process, although not the specific attachment- based complex termed "parental reflective functioning" as developed by Slade (2005). Both perspective-taking and reflective capacity contribute to parental coping and decision making as they pertain to the child and others.

Although stemming from different branches of inquiry, parental resolution (Pianta et al., 1996) and reflective functioning (Slade, 2005), as well as the general construct of coping (Lazarus & Folkman, 1984; Folkman & Moskowitz, 2004), all address the connection between cognitive operations and emotion regulation in the management of stress and challenge. In the case of parental resolution and reflective functioning, these challenges occur within the context of the attachment relationship and require continual attention to or consideration of the child. Management operations include appraisals, attributions, expectations, inferences, and emotion regulation/problem solving strategies. Some of these operations, for example, attributions and expectations, are also components of current definitions of parental engagement (Randolph et al., 2009).

This article describes preliminary work on the development of a clinically relevant instrument for assessing parental engagement in pediatric palliative care decision making. Parental engagement, defined here as a psychobehavioral construct, denotes not just parental presence but effective participation. Engagement is often accompanied by emotional distress and cognitive uncertainty requiring much support, but is nonetheless successful in moving the decision-making process forward for the good of the child. Engagement is composed of cognitive, emotional, psychological, and behavioral processes. It takes place within the context of the attachment/caregiver system and is impacted by multiple factors. Therefore, the scheme presented here for measuring parental engagement is based on attachment-related precepts as well as empirically and clinically identified parental characteristics, including cognitive uncertainty and affective valence.

METHOD

Aims

The aim of this methodological research is to develop a tool for reliable *in vivo* assessment of parental engagement in planning and decision making, in particular for seriously ill children in the context of provider/family meetings. The context for assessing parental engagement in pediatric palliative care is most often the team meeting, which is held among family members and clinicians for the purpose of sharing information and planning for the child's care. The clinical significance of family meetings as the formalized central planning hub is recognized. This is a noteworthy research context in that, as Feudtner (2007) emphasizes, very little is yet known about the conduct of family meetings, despite their critical importance.

Design and Procedures

Instrument development protocol proceeded from deductive conceptual reasoning and literature review, to inductive structured coding of narrative consultation data, to categorizing of the central components of observable and naturalistic parental behavior to create scale dimensions, and through to reliability scoring. Data gathered in this study were part of a larger project that was approved following full review by the Institutional Review Board of the Medical Center. After the initial deductive process in which a conceptual template was developed, final categorization for dimensions in this coding scheme were arrived at through an inductive process in which related phenomena were clustered and categories integrated in an increasingly refined manner (Hsieh & Shannon, 2005).

Directed content analysis was employed across four phases: (1) identification of important concepts and consensus in the existing attachment and pediatric palliative care literatures; (2) analysis of pertinent parental operations and behaviors evident in one year's consultation narratives; (3) an integrative process of construct refinement; and (4) initial reliability testing. This particular method of directed content analysis (Hsieh & Shannon, 2005), also known as deductive category application (Mayring, 2000), is typically used to inform the development of coding schemes by providing information about concepts or variables of interest and their relationships. The four step approach is oscillating in nature, moving from deductive literature review to inductive narrative analysis while making iterative comparison of findings. Therefore, rather than being truly stepwise in a linear way, this process was actually circular in that it entailed continual, comparative validation and revision until final dimensions were decided upon. For the major dimensions, descriptions were clearly established and sub-classifications outlined along with operational definitions of each.

The first phase consisted of a review and identification of important concepts from the palliative care and attachment literatures. Concepts and phenomena taken from the pediatric palliative care literature, as discussed in the Introduction, include parental cognitive understanding, uncertainty and struggle, positive and negative affective valence and emotional struggle, coming to terms with the reality of the situation, and achievement of actual decision making and planning. Specific concepts identified from the attachment-related literatures were taken from the parental resolution of diagnosis and reflective functioning models as discussed previously. They include evidence of parental psychological movement forward in the decision- making process by showing organization and coherence of speech and an ability to move past the present to the future, reflection on or consideration of thoughts and feelings of child and self, perspective taking, realistic appraisal of situation and child, and the ability to sufficiently manage emotion so that caregiving system functions can be managed.

Selection and coding of consult narratives comprised the second phase. All initial consults from the PACT's first year of service were reviewed. These included the same interviews analyzed qualitatively in the previously described study by Byrne and colleagues but for the purposes of this tool-development study, a different type of categorical content analysis was done. As reported for the qualitative study, these initial consultations had been held at the request of the family or their child's physicians for the purpose of information sharing, support, and decision-making activities. Most often one or both parents or primary caregivers, and the child's referring and specialty physicians, were in attendance along with members of the PACT team. Because all consult narratives predated this research effort, they provided a sample of clinical consults representative of the early interactions of the PACT team at CHONY without the limitations or benefits of structured research interview techniques. They do not reflect any *a priori* research question, method, or design formulation. This was beneficial to the instrument development study in the sense that the consults captured the natural resonance of the clinical narratives.

Thirty-eight of the 43 total consultations were analyzed for the purposes of this study. The five consultations that were excluded did not fit the inclusionary criteria of the study, which required caregiver input in the consultation narrative so as to allow for analysis. This was critical to the attachment-based caregiving system focus of the study. Three were relevant to patients who were near 18 years of age or older and had little or no parental involvement. Two additional consultations were excluded when caregiver absence resulted in lack of parent input in the narrative. Two within the remaining group of 38 families were adoptive families. The decision was made to include these in the study analyses based on current attachment research, which highlights both the development of positive attachments at all stages of the adoption continuum and the importance of parental states of mind in the formation of adoptive parent–child relationships (Steele et al., 2008, 2010). These findings are congruent with findings regarding biological parents' mental states, child attachment, and resolution of diagnosis, thereby providing a satisfactory conceptual basis for these parents' inclusion.

The parent sample was predominantly Hispanic (63%). Other groups represented included White, African-American, African, Pakistani, and Southeast Asian parents. Of those parents that identified themselves with a religion, they named Christian, Muslim, Hindu, and Jehovah's Witness faiths. Parents ranged in age from their 20s through their 50s.

Patients in the study sample ranged in age from 18 days to 18 years of age and their parents were making most of their treatment decisions. Ages can be categorized as follows: birth to 6 months ($n = 14$); 6–12 months ($n = 4$); 12–36 months ($n = 5$); 36–60 months ($n = 5$); 6–12 years ($n = 4$); 13–18 years ($n = 6$). As reflected in the breakdown, the largest cluster occurred in the combined youngest age groups (0–12 months; $n = 18$), while the toddler, preschool, school- age, and adolescent groups were similar in size ($n = 4$–6).

There were 22 males in the patient sample and 16 females. Children had been diagnosed at ages ranging from 24 weeks' gestational age to ~12 years of age. Time from diagnosis to consultation ranged from 18 days to 11 1/2 years. Diagnostic categories included congenital conditions often related to extreme prematurity composed of severe cardiac, pulmonary, and gastrointestinal conditions as well as genetic disorders. Additional medical conditions included cancer, neurological devastation, and HIV/AIDS.

The coding of narratives followed a structured approach characteristic of creating coding categories from content analysis of open-ended questions (Hickey & Kipping, 1996). Notably, from early in the iterative analysis process, clear congruence emerged between the interview material and preexisting concepts found in the literature. Initially, parental or team members' words and phrases regarding parental feelings, behaviors, actions, needs, and perceptions, which had relevance for any of the above concepts, were bracketed and coded according to the relevant concept. Any interview material or reviewer impression regarding parental engagement in the planning meeting that could not be easily yoked to a concept from the literature retained its status as a significant parental item of interest and continued to be evaluated as the iterative process moved forward. Objective information regarding the child's medical status, that is, diagnosis and physical examination findings, were noted but not coded. Initial identification of coding units took place over the course of multiple readings of the narratives by J.K. who has experience in content analysis methodology.

In the third phase, these units were then grouped through an iterative process, and larger categories or dimensions were derived along with operational definitions and observable, behavioral indicators of each. In this analysis, they were evaluated as to how they reflected the relative presence and aspects of the identified dimensions, and they were assigned numeric weights. Last, a scale was created with a sum value of 9 points. This final coding scheme reflects both process and behavioral considerations across all domains, and does not silo various aspects of parental experience in simplistic ways, but rather groups them in integrated, observable categories. Throughout the process, the coding scheme was refined as both authors conferred on the establishment of the larger categories. This was important, as it contributed to interpretive reliability, which relates to uniformity in coding (Burns & Grove, 2009).

The final phase of coding scheme development included the actual scoring of initial consultation interviews using the dimensions and items in the new tool, and the establishment of preliminary interrater reliability levels. All interviews were scored by the first author (J.K.), who has experience in attachment-related coding systems. This includes reliability in administration and coding of the Reaction to Diagnosis Interview for pediatric illness (Pianta & Marvin, 1992a, 1992b) as well as in the Reflective Functioning Coding Scales (Fonagy et al., 1998) for use with the Adult Attachment Interview (George et al., 1985). A subset was scored independently by the second author (M.J.), who has conducted attachment-based research for >10 years. Interrater reliability levels were 80% on initial coding of this subset of interviews, with 100% reliability upon conferencing to agreement. Expert content validity checks were then conducted with three clinical experts in pediatric palliative care, two who are not members of the clinical or research teams, and one who is a clinical team member but has not worked on this study. Further work on scale development continues, and will provide additional data regarding psychometric properties.

RESULTS

Three final dimensions of parental engagement were derived, which were conceptually linked with the relevant extant literature and also integrated and reflected the information that emerged from the consultation narratives. These dimensions are *information-centered dialogue*, *insightful participation*, and *achievement of a collaboratively agreed-upon plan*. Conceptual and operational definitions, exemplars for high and low scoring, and suggestions toward dimension subcategories to be used in scoring, are described in the following sections.

Dimension No. 1: *Information-Centered Dialogue*

Information-centered dialogue was the first dimension or category identified as fundamental to parental engagement in decision making in the family meeting. Regardless of cultural and language differences or emotional distress, this was evident in those interviews in which parents were actively involved in the planning for their child. These interviews were characterized by parental questions, input, and information sharing surrounding their child's medical condition and various treatment options, risks, and alternatives. Parental uncertainty was evident, often coinciding with an active effort on the part of the parents to gather, share, think about, and make sense of information. This active effort was a predominant feature of those interviews in which a parent scored high on this dimension. For example, one father of a 2-year-old with severe congenital pulmonary disease and multiple other co-morbidities wanted to be given a system-by- system review of all risks and benefits of any possible interventions that may be presented. He was actively involved in planning and serving as a conduit for information sharing with his wife, who was at the bedside of the child. For this couple, this arrangement worked well and they were able to move forward in this aspect of engagement in the planning process. In another example of *information-centered dialogue*, one mother was able to recount in painful, but necessary and appropriate detail, the story of her child's illness and treatment history as well as her clear understanding that the child's illness was terminal. Yet another mother was able to report discussions with her child's physicians in detail, and ask clear, pertinent questions regarding what to expect as the child moved through the illness trajectory toward impending death.

Parents who did not engage well in *information-centered dialogue* asked few questions and shared little information. One of the parents could not remember the name of her child's diagnoses or the primary treating physician. Another remembered very few specifics of her many conversations with medical providers. Yet another relayed only general information followed by the nonspecific question regarding her terminally ill infant, would the baby "be fine?" In one case a mother did not readily share critical information regarding medication compliance in her young adolescent daughter and it was only after much discussion that this was established. This sort of omission, regardless of parental motivation, makes it almost impossible to move forward in the planning process.

Dimension No. 2: *Insightful Participation*

Insightful participation was the title given to the second dimension of parental engagement. This category addressed most proximally the complex psychological caregiver system nexus and included three pertinent subcategories or items: evidence of parents' ability to take into account others' perspectives or viewpoints; their ability to consider their children's thoughts, emotions, or needs as they exist separately from their own; and their ability to acknowledge their own emotional status and or needs.

These subcategories emerged from the consultation narratives and provided concordance with the attachment-related precepts of interest, namely, parental resolution and reflective functioning. Both subcategories dealing with child and parent thoughts and emotions addressed these concepts, including the assumption of forward psychological movement requiring a certain level of parental emotion management. It is important to note that just as we are not assessing parental resolution here through the well-developed construct and coding scheme (RDI) presented by Pianta and Marvin (1992a, 1992b) we are also not confusing the first two subcategories with the well-established and disseminated measures of parent development interview (PDI) (Slade et al., 1994) or reflective functioning scales (RF) (Fonagy et al., 1998), which have prescribed scoring protocols and defined, specific schemata. Rather, we see the subcategories described here as informed by these constructs at a general conceptual level, but operationally quite distinct in their elemental nature. In contrast with the rigorous assessment protocols of the RDI, PDI, and RF, our subcategories are simply descriptive and capture the spontaneous, observable, sometimes general, and most-often partial, constituents of such complete constructs. Parental perspective- taking was also addressed in this dimension regarding parental dealings with the treatment team.

Examples are provided across the spectrum of this dimension. On the higher end, one mother of an adolescent poignantly described how sad she was, but that she felt a sense of satisfaction that she and her husband had been able to give their child a good quality of life and positive sense of self-esteem despite the illness. She went on to describe their strong support system and the ways that this support helps them to deal with the stress of their child's illness. This is an example of *insightful participation* that simply and eloquently highlights the ability to consider the psychological experience of her child, herself, and her husband. Another mother was clearly able to articulate her emotional struggle with anger and guilt, looking back on decisions that she had made, even though they were appropriate at the time. She displayed *insightful participation* in what is only one of many profound statements made by parents in these interviews, when she conceded "but I know I can't predict the future". This ability to contemplate her own limitations as a parent with balanced perspective in the context of temporal change contains elements of both parental resolution and reflective functioning.

Examples of parents' ability to articulate their emotional status included one mother's revelation that she was "afraid of the moment" (of her child's death), a father's admission that he was extremely anxious and close to "snapping" as he and his wife welcomed any and all support offered by the team. Many others were able to give voice to their sadness, some while enumerating the coping resources available to them and the impact this experience was having on other members of the family.

At the lower end of this dimension, we noted that other parents seemed stuck in their emotions, not able to acknowledge or to report them with ownership or agency. For example, one mother was visibly angry as she alternately focused on a previous miscarriage and blamed the medical providers for "covering up mistakes" with her currently ill child.

Throughout the interview she made no open acknowledgment of her clearly observed affect. Still others avoided the topic as in the example of the mother who told the team that she didn't like to talk about "it" adding that she liked to focus on "better things." It is of note that this mother also denied any sadness or anxiety on her ill adolescent daughter's part. This speaks to the third component of this dimension which is the recognition of the child's thoughts, feelings, and needs as separate from those of the parents.

Parents who were able to see their child's needs as separate from their own often simultaneously expressed their sadness, hope for some measure of treatment success, and the equally powerful wish that their child not suffer as a result of the illness or intervention. For example, requests that all reasonable measures be taken but that a child not suffer were common in this group of parents. In another example of viewing the child's needs as separate, parents of an adolescent male in the latter stage of his illness took every precaution to involve him in all decisions and allow him to make final decisions regarding his medical care.

Conversely, in one particularly stark example of parents who did not show evidence of viewing their child's needs as separate from their own, a mother and father focused solely on a tracheostomy that had been done years before. They attributed their child's multiple congenital comorbidities and developmental delay to the procedure. As they remained fixed in this negative attribution pattern, they could not see any future for their child and could not entertain any discussion of his current needs or past history and life until then. They could not discuss their child as a person, needing instead to find expression for their own emotional conflict and inability to reconcile themselves to the actual circumstances of his birth and medical status.

Dimension No. 3: *Achievement of a Collaboratively Agreed-Upon Plan*

The third and last dimension identified in the coding scheme addressed the actual achievement of a plan. It was obvious from consultation narratives as well as from the literature, that at some point all processes converge toward the goal of making decisions in the best interests of the child. This is a discrete outcome as well as part of the engagement process, which at the categorical level, serves as a clear behavioral marker of successful parental involvement in planning. This is a dimension that allows for examination of relative levels of success by highlighting the integration and regulation of parental cognition and emotion in the attainment of this important outcome.

This final integrative dimension culminates in the achievement of a clear plan for the child's care. It is here that parents integrate and process information, as they display effective involvement and forward movement. Parents who were able to arrive at this goal once again displayed an active stance, similar to that displayed in the first dimension surrounding information-centered dialogue. The difference between these first and last categories, however, lies in the implication that a certain level of both emotion and information processing is occurring in the latter and has been integrated psychologically, perhaps indicative of resolution.

Parents who accomplish relatively high levels of collaborative planning display active exploration of options, discussion of logistics, and final concurrence on a mutually agreeable plan, despite uncertainty. All parties involved understand that this plan may change as circumstances change, but again we see overall movement forward as the parent sufficiently manages cognitive and emotional challenges and ultimately negotiates a vital caregiving system function.

In one noteworthy example of parental achievement of this goal, parents of a 36-week-old infant with life-threatening cardiopulmonary anomalies met with the team, including the social worker, on a regular basis. They had their infant christened shortly after birth, because of his grave status, and decided on surgery with a full understanding of the risks involved. While waiting for the surgery, the mother spoke with the social worker about possible funeral arrangements for the baby. The mother was described as anxious regarding the impending surgery, and sad at the anticipation of losing her child. Yet, despite the emotional pain and fear, she and her husband were able to navigate these psychological waters and make clear, collaborative plans for the baby's care and treatment.

In numerous other examples parents made sound, informed decisions that they were able to articulate to the team. In one case, parents understood that there were no further medical interventions that could be offered to them but asked that feedings be continued and that all comfort measures be taken. This was agreed upon with the team. Many other parents, faced with the same profound reality, were equally able to articulate their requests for palliative measures and worked on the specifics of this with the team.

In some cases, parents had great difficulty arriving at a plan, regardless of team guidance, explanations, provision of information or support. One mother struggled with a realistic understanding of her child's long-term needs and could not discuss a reasonable plan. Although she made an effort to discuss options, she remained at an impasse and could not seem to move past it. In another family, the parents could not engage at all, despite numerous and thoughtful efforts by the team to help them participate in discussion about their child's treatment. Repeated attempts were made to arrange meetings convenient to either or both parents at places in close proximity to their child's hospital room. Each time the parents could not engage, for example, the mother was overcome with emotion or the father left the room. Neither parent could make their wishes known because of intense, debilitating emotion and avoidance. With no collaborative plan agreed upon, the team reported continuing efforts at communication.

Relationship of Parental Engagement to Clinical and Demographic Variables

It is interesting to note the demographic and clinical variables that did not appear to impact parental engagement and were not identified as dimensions in these preliminary tool- development data. Neither diagnosis nor time since diagnosis seemed relevant to engagement. Various levels of parental engagement were displayed in similar frequencies across diagnoses, which included congenital cardiopulmonary anomalies, neurological conditions, cancers, HIV, and cystic fibrosis. The same was true of time since diagnosis, which was defined as the period from the time of diagnosis to the time of the initial PACT consultation. Both high and low levels of parental engagement were evident across the time span, with both occurring throughout the continuum. In addition, there were no systematic differences evident in engagement scores based on language or cultural differences.

DISCUSSION

The work reported here provides conceptual grounding and early empirical evidence for the examination and measurement of parental engagement in decision making within pediatric palliative care populations. The results of this initial study indicate that parental engagement can be examined as a psychobehavioral complex expressed during a common clinical scenario, the care planning meeting between the family and members of the treatment team. These early findings indicate that elements of parental engagement do not appear to be bound by parental demographic factors or child factors such as diagnosis, or time since diagnosis. Rather, similar to much of the work seen in the attachment literature on parental states of mind, it may be that engagement is fueled to a substantial degree by internal parental cognitive and affective operations, which are impacted differentially by external factors.

The method used here, although clearly delineated, allowed for a certain level of flexibility in the application of deductive and inductive methods. This is commonly seen in the very early stages of scale development in clinical domains. This was necessary in that the task at hand required the review, assessment, and final integration of two bodies of literature as well as the empirical data. The final dimensions were integrative in that they subsumed concepts taken from attachment theory and related constructs as well as phenomena discussed in the pediatric palliative care literature, and both were validated in the consultation data. These consultation data served as the final arbiter in the process. The coding scheme derived through this procedure reflects a holistic approach, which attempts to address parental engagement as a complex phenomenon, which is related to parental psychological processes, but can be measured through external indicators.

Interestingly, there were similarities noted in some of the concepts reviewed in the pertinent literatures. For example, the palliative care literature talks about parental "coming to terms" with the reality of a worsening clinical picture in the recurrence of cancer in a child (Hinds et al., 1996). This construct signifies the parents' struggle to deal with their emotions and participate in decision making while preparing for future possibilities and evidencing acceptance as well as hope. Although it bears some similarity to the concept of resolution in attachment literature, it does not address psychological operations, that is, internal working models, which provide a roadmap for this outcome. In addition, the concept of resolution, as part of the larger attachment framework, can serve as a foundational construct for further investigation in this line of inquiry. The same is true of the literature on emotional struggle. We see this throughout both bodies of work, which describe the emotional challenges parents face. Again, the attachment literature provides a clear, systematic approach to measurement of how this emotional struggle works for or against parents' movement through the difficulties they must face. In the area of cognition, there were fewer areas of direct overlap, but the issues of cognitive struggle, cognitive mastery, and metacognition in general are replete throughout the consultation data and resonate with the respective literatures.

Although the three dimensions identified for tool construction are separate for analysis and measurement purposes, they are interrelated conceptually to some degree. For example, certain aspects of achievement of a final collaborative plan are also seen in *information-centered dialogue* (specifically, discussion of information), as well as in *insightful participation* (the perspective taking component). The coding scheme, although numerically straightforward and designed for ease of use, incorporates the complexity of the engagement process so that activities are operationalized not only as they are behaviorally evidenced but also as they function to generate complex parental caregiving activities.

LIMITATIONS

Primary study limitations had to do with sample and measurement issues. The convenience sample for the narrative consultation coding phase was small and taken from one integrated pediatric palliative care service in which the cultural group was predominantly Hispanic. Although these early results indicate that ethnicity may not impact parental engagement, we need to investigate this on a larger scale to make any conclusions. Similarly, there were peaks in parental engagement scores for the upper and lower child age categories. We view interpretation of this with caution, given the relatively small sample size.

Additional limitations are related to the sample size, which limited analysis by diagnosis and time since diagnosis to description and frequency counts only. A larger sample size would have allowed for subset analysis of possible differences in parental engagement based on these variables. Review of the attachment-based resolution of diagnosis findings differ across these variables (Marvin & Pianta, 1996; Barnett et al., 2006; Schuengel et al., 2009). A larger study in our population might determine any statistical associations as they pertain to parental engagement.

Measurement concerns centered around the consultation protocols. First, this study included a secondary analysis of consultations previously conducted and transcribed for clinical purposes. Therefore the method (consultation protocol) and measurement (consultation structure and content) were not controlled. Although the PACT team follows a guideline for conducting and recording consultations, which was clear in the reports, not all interviews were uniform in approach or structure. The post-hoc nature of the study precluded any solutions to this methodological concern. On the other hand, the naturalistic quality of the interviews provided an ecologically valid context for this initial deductive and inductive iterative inquiry.

CONCLUSIONS

In summary, the work described here, as part of our larger effort to clarify parental processes in pediatric palliative care, will move knowledge development in this field forward both conceptually and clinically. We have identified the conceptual underpinnings, derived the essential dimensions, and begun to operationalize the items and scoring criteria that comprise a quantifiable scale measuring parental engagement. Work continues to refine the items and perform additional psychometric testing. By using this approach and measuring parental engagement in decision making as a psychobehavioral complex as understood within the attachment framework, we can identify parents and families differentially at risk. Intervention to achieve engagement can then be targeted to those areas along the engagement continuum in which a parent may have difficulty. In the case of pervasive problems, we can intervene in attachment-informed ways that address unresolved trauma and grief and parental working models. For all parents, attachment-guided intervention has the potential to support caregiving systems to the benefit of parent and child and achievement of family-provider collaborative decision making under the most stressed circumstances. All this remains to be investigated by our team and others as we move forward in this valuable area of inquiry.

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