Parent Participation: A Concept Analysis

Lisa M. Knapp

Northern Kentucky University
Purpose of the Concept Analysis

Parent participation in the care of their hospitalized child has become increasingly emphasized in the ever-changing, increasingly complex healthcare system. Although a literature review reveals an abundance of literature and study regarding parental participation, there does not appear to be a clear consensus or a clear definition of the concept. (Darbyshire, 1993). Darbyshire (1993) regards parental participation as one of the most amorphous and poorly described concepts in the pediatric nursing realm. For nurses and clinicians to provide optimal outcome care, it is essential to develop an understanding of what parent participation entails and how the characteristics of parent participation may impact the care and health outcomes of the hospitalized child. The purpose of this concept analysis of parental participation is to examine the attributes and characteristics of parental participation in the care of a hospitalized child.

Historical Perspective: Parental Participation

In the late 1800s and into the early 1900s, parents were excluded from participating in the care of their hospitalized child. Visiting hours for parents were restricted to a few hours a week. All visitors who entered a hospital, including parents, were seen as a means of introducing infections. Patients were not always able to be healed or cured of many infectious diseases. The prevailing view during the 1870s was children were better off removed from their potentially unsanitary homes and mothers who were unable to provide necessary care and treatment. The need for a parent’s love and attention appeared to be lost. (Davies, 2010)

As the 20th century progressed, behaviorism became the noted method of raising children. For example, mothers were encouraged to breastfeed their infants by the clock and not to comfort or console their infants when they cried as these behaviors would lead to a spoiled child. Nurses were remembered by pediatric patients as uncaring and lacking affection. Furthermore, parents were restricted to visiting
just a few hours a week and as a result, children’s emotional and psychological needs were left unmet and they continued to be deprived of parental presence.

In the 1940’s, the work of Bowlby (as cited in Davies, 2010) began to demonstrate the impact on a child of early and traumatic separation from a parent. Children under the age of five were impacted more than older children who experienced parental separation. Spitz, in the late 1930s, identified deleterious effects of hospitalization on children. Parents were still not permitted to regularly visit their hospitalized children. During this time, the notion of behaviorism was challenged and change was directed toward more parental involvement and recognition of the anxiety and negative consequences of separation from the parent. (Davies, 2010)

The Platt Report, published in 1959, advocated for unrestricted parent visiting and encouraged parents to engage in care of their hospitalized child as much as possible. The Platt Report also stressed the importance of nursing staff to meet the emotional needs of children. (These were the two recommendations, among several others, that pertain to this concept analysis). Interestingly, despite the published report, a survey of 636 hospitals in the United States in the late 1960s revealed only 62 percent allowed unrestricted parent visiting. (Davies, 2010)

Parent participation took a dramatic change beginning in the early 1980’s. Parents were expected to be present as much as possible, to participate in feeding, bathing, providing comfort and emotional support and provide motherly support to the child. As the hospital environment continues to evolve today, parents are continuously and progressively more involved in care of their hospitalized child. (Davies, 2010)

Current Uses of Parent Participation

Recent decades have brought a fundamental change in the parental role in the hospitalized child (Darbyshire, 1994). Today, partnership in childcare and parental involvement facilitated by nurses and health care professionals are key entities in achieving optimal outcomes for the hospitalized child (Coyne, 1995). Parents have 24 hour access to their child and are encouraged to participate in care. (Coyne, 2007). Parent participation has been shown to decrease the adverse effects of hospitalization, avoid
parent-child separation and minimize separation anxiety, and improve the quality of care a hospitalized child receives. (Coyne, 2007). Although the aim of parent participation is to provide optimal care to the child, both benefits and negative outcomes for parents resulted from parent participation (Power & Franck 2008).

Widely recognized throughout the literature are the differences parents and nurses have regarding attitudes, ideas and notions related to parent participation in the care of a hospitalized child. The majority of parents both desire and expect to participate in a child’s care (Darbyshire, 1994). Activities parents wish to participate in include feeding, bathing, toileting and providing emotional support and an atmosphere of love (Darbyshire, 1993). Parents were also found to become more involved and participate more actively the longer their child was hospitalized (Espezel & Canam 2003). Qualitative studies show many parents preferred professionals to perform technical, complex or medical care because parents lacked confidence and competence to participate effectively and safely. (Darbyshire, 1994; Coyne, 1995; Dudley & Carr, 2004) A systematic review of parent participation by Power & Frank (2008) confirmed the attitudes and behaviors of health care professionals are both impediments and catalysts to parent participation.

Parent participation lacks clear definition throughout the literature. Terms such as “parent involvement”, “partnership care”, “mutual participation”, and “care by parent” represent parent participation in the literature (Coyne, 1996). The term family centered care has been argued to be synonymous with parent participation. However, in the United States, parent participation is an element of family centered care, not a synonym for family centered care (Coyne, 1996). Family centered care involves the whole family and may, perhaps, exclude parent participation if it is not healthy for the child and family (Coyne, 1996).

**Defining Attributes**

Defining attributes of parent participation can be divided into 2 categories: tasks the parent performs and behaviors the parent exhibits. Some behaviors can also be seen roles the parent plays. Tasks can be further categorized as direct-physical care and providing emotional and spiritual support.
Examples of direct physical care include feeding, bathing, entertaining the child, and toileting. Why is the task performance such a defining characteristic of parental participation? Darbyshire (1993) reveals parents have a strong desire to be involved and feel useful. Performing tasks generates a sense of usefulness for the parents.

Distinct behaviors and roles were identified in parents who participate in their child’s care. McDonald (1969), in a study of parents’ preparation in the care of their hospitalized child, found 90% of parents nurture, encourage and provide emotional support to their hospitalized child. Roles a parent participant plays include that of care coordinator, monitor, advocator and protector (Coyne, 1996). Parents ensure their child is receiving complete care, monitor vital signs and intake and output, advocate for their child’s comfort, rest, emotional being and appropriate tests and treatments as well as protect their child from harm (Coyne 1996; Derbyshire 1993; and McDonald 1969).

Finally, there are distinct characteristics or attributes that relate to the parent, the nurse and their relationships. Coyne (1996) identifies these attributes as competency, autonomy, willingness, control and negotiation. Competency has been identified as a reason parents participate in care. Contrarily, lack of feeling competent has been identified as a reason they do not participate in care. (Coyne, 1996). Parents must be willing to learn and participate in the child’s care and the nurse or clinician must be willing teach and to allow the parent to participate. Feeling in control has been identified as not only an attribute of parent participation but also a consequence (this will be discussed later in this paper). Parents, in a study by Jones (1994), identified the ability to negotiate with the nurse as a factor in whether they participated in various parts of the child’s care. Parent participation involves a great deal of negotiation between the parent and the nurse.

Model Case

Consider a mother whose three-year-old boy is hospitalized for two weeks with a severe infection of his knee. The mother remains with the boy 24 hours a day, seven days a week. Mother performs all bathing, feeding, toileting and routine hygiene care for the boy. Mother has also learned to reposition the boy every 2 hours and actively participates on rounds and care planning with the nursing and physician
staff. Mother also provides emotional and spiritual support to the boy by rocking, holding, consoling and reciting nighttime prayers with him. Mother is able to accurately track the boy’s intake and output, as she was trained by the nursing staff. She is currently active in learning to care for the boy’s peripherally inserted central line so that the boy can be discharged to home when medically ready. The above description details a model case of parent participation.

**Additional Cases**

**Borderline Case**

Brad is the step father of seven-year-old Joel, who is currently hospitalized for chemotherapy and a low white blood cell count. Joel was diagnosed two years ago with acute lymphocytic leukemia and has been hospitalized 12 times since diagnosed. Brad stays overnight with Joel seven nights a week and while present assists or provides complete care (depending on Joel’s strength) to Joel including most physical, psychosocial and spiritual care. However, Brad must leave during the day to work, as he is the primary income source for the family. Joel’s mother visits several times a week but has three young children at home to care for which limits her ability to visit and care for Joel. Brad’s participation demonstrates a borderline case of parent participation.

**Related Case**

Caring for a chronically ill child in the home setting would be an example of a related care of parent participation. In the home, parents care for their child under different circumstances, a different setting and with different external influences. In the home, the majority of the time, there is no one to intimidate or make a parent fearful of caring for their child, as could occur in the hospital setting. Parents are more comfortable caring for their children in the home setting. Parents perform some of the same care and skills and provide psychosocial care and spiritual care as would occur in the hospital setting. However, in the home, the parent is in control versus in the hospital setting where parents feel nurses and physicians are in control for many aspects of care.

**Contrary Case**
Mary is a mother of three children whose 12 year-old has been hospitalized with osteosarcoma. Mary does not visit, does not call regularly and refuses to make decisions regarding her child’s care. Mary becomes frustrated with staff when phoned and states she only wants to know when the child’s status has changed. She will visit when time permits but wishes the staff would provide total care for her child. This is a contrary case of parent participation, meaning the parent lacks involvement, of any considerable or appreciable degree, in the hospitalized child’s care.

**Antecedents**

Illness and hospitalization are both antecedents to parent participation in the hospital setting. Also, an adult must become, in some capacity, a willing and capable parental figure or assume a parental role prior to participating as a parent. If not the biological or step parent, an adult can be a foster parent, adoptive parent or a guardian and then assume the parent role and participate in the hospitalized child’s care.

**Consequences**

Consequences of parental participation can be subdivided into positive consequences and negative consequences. Also, it is necessary to examine the consequences to the child, consequences faced by the parent and consequences perceived by the nurses caring for children who experience parent participation during their hospital stay. Jones (1994) found a hospitalized child was more cooperative, more active and less upset when parents had increased levels of participation in care. Literature review revealed no negative consequences to the child when parents participated in the child’s care.

Parent participation can have positive and negative effects on the parent. When able to participate and encouraged to participate, parents have increased competence and confidence in dealing with the child’s illness and hospitalization (Palmer, 1993). More effective education resulted when parents demonstrated increased participation in care (Ayer 1978 as cited by Palmer, 1993). Darbyshire (1993) found parents felt the hospital staff placed too much responsibility on parents who demonstrated competence, which in turn increased the stress parents’ placed on themselves to do the right thing, at the right time when caring for their child. Hopia et al., (2005) found that parents feel insecure, helpless and
have role uncertainty when they are not permitted to actively participate or are unable to participate in the child’s care.

Nurses often expect parents to participate but can exhibit both positive and negative attitudes toward parent participation. Positive attitudes include valuing parental participation and enjoyment in teaching them how to participate. Negative attitudes include feeling threatened by role-take-over and lack of control over the child’s environment and care. Difficult or strained communication between the nurse and parent was cited as a negative aspect of increased parent participation (Ygge & Arnetz, 2004). Furthermore, O’Haire and Blackford (2005) found that while nurses want to deliver optimal care, this is often difficult when conflicts arise with parents. Conflicts arise more frequently when there is a high level of parent participation.

**Theoretical Definition**

Parent participation can be theoretically defined as the act of performing activities of daily living (i.e., bathing, feeding, dressing), providing psychosocial care (i.e., comforting, consoling, loving) and spiritual care (i.e., prayers, religious and/or cultural rituals).

**Operational Definition**

Although for decades parent participation has been advocated as a philosophy of nursing care for the hospitalized child, a concrete, well-accepted operational definition is difficult to achieve because of the inability to quantify the concept. Power and Franck (2008) operationalized parent participation as the caregiving activities carried out by a parent/guardian for a hospitalized child throughout and across their entire hospitalization event. The goal of caregiving activities was to improve the physical and/or psychological well-being of the child. Caregiving activities included physical, psychological or social activities performed by the parent with or without the collaboration or negotiation with a healthcare provider.

**Empirical Referents**

Measuring parent participation has been difficult because of the lack a clear definition and the inability to quantify the elements of participation. Several tools have been used to assess and attempt to
measure parent participation. The Parent Participation Assessment Instrument (PPAI) (Jones, 1994) and the Index of Parent Participation (IPP) (Melnyk, 1994) have both been validated. Melnyk, 2004, utilized visual analog scales to determine parents’ level of physical and emotional care they performed. The Involvement in Physical Care Scale (VAS-PC), and the Involvement in Emotional Care Scale (VAS-EC) have been used in two studies to investigate parent participation (Melnyk 1994, Melnyk 2004).

Jones (1994) used a mixed method questionnaire containing a checklist of 15 aspects of care provided by parents. This questionnaire allowed for the ability to quantify care and allowed for parents to write in additional information of other care activities they performed and to what extent these activities were carried out.

**Concept Map: Parent Participation**

Figure 1 is a concept map of parent participation. Antecedents and consequences are identified. The terms parent and participation are defined and aspects of parent participation are delineated.

**Summary**

In summary, parent participation is a vital aspect of a hospitalized child’s care. Optimal patient outcomes require parents to be actively involved and engaged in the physical, psychosocial, emotional and spiritual care of the child. The psychological and emotional benefits to both the child and parent have been identified in the literature. Although there are identified negative consequences for parents who are active participants in their child’s care, perhaps some of these could be resolved with increased nurse education regarding parent needs and parent response to the hospitalization of their child. Furthermore, nurses may require education regarding how to be engage parents and meet parent needs for participation in care. Finally, further study is needed to examine priority measurable outcomes (infection rates, length of stay and newly acquired morbidity) of hospitalized children whose parent or parents are active participants in care.
PARENT PARTICIPATION

FIGURE 1: Concept Map

Antecedents

- Capable adult
- Willing adult
- Biological
- Step-Parent
- Grandparent
- Non-Biological
- Adoptive
- Foster
- Guardian
- Physical
- Feeding
  - Bottle
  - GTube
  - Fork/Spoon
- Bathing
  - Bed bath
- Tub/Shower
- Toileting
  - Diaper
  - Bedpan/Urinal
- Ostomies/Catheters
- Play
  - Toys/Games
- Read
- Psychological
- Comforting
  - Patting
- Provide Security Items
- Hugging
- Communication
  - Silence/Presence
  - Patting
- Security
- Reassurance
- Spiritual
  - Prayer
  - Rituals
  - Music

Consequences

- Parent: more secure, feel useful
- Child: more active, more cooperative, less anxiety
- Nurse: feeling threatened and loss of control; communication difficulties
- Greater collaboration
References


interventions on mothers and children. *Nursing Research, 43*, 50-55.


