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ABSTRACT

This ethnographic study used multiple approaches to try to determine the emotional experience of young children (ages 5 to 8) with chronic illnesses. Forty-six children with severe asthma and diabetes were interviewed on two separate occasions using child-centered in-depth interviews that included play-based interviewing. The study also employed indirect observation with mothers keeping a notebook of observations and also photographing relevant moments. Findings focused on children's utilization of imaginal coping, in which the child makes use of a non-literal reality, towards which the child suspends disbelief and gains a sense of serenity and trust--such as the use of a special blanket to provide comfort during treatment. Children tended to define their illness not in bodily or organic terms but in terms of the concrete suffering derived from treating the illness. Children repeatedly ascribed special powers to their comfort object or ritual acts associated with treatment procedures. Pretend play and giving symbolic importance to medication procedures were other imaginal coping strategies used by the children. Health care providers are urged to consider children's coping strategies in planning or adjusting treatments. (Contains 12 references.) (DB)

Imaginal Coping and Childhood Illness:

How Children Relate to Treatments for Chronic Illness

Cindy Dell Clark (DePaul University)

BACKGROUND

Ethnographic studies that attempt to grasp the child's point of view, particularly the child's point of view about the experience of illness, are rare (Van der Geest 1996). This ethnographic study adopted multiple approaches to understanding the child's point of view about the experience of chronic illness, among children aged 5- to 8- years old.

Over 46 young children with severe asthma and diabetes were interviewed at home on two separate occasions, using child-centered depth interviews that included play-based interviewing (Clark 1995; Clark 1996). Throughout the interviews with the child, questions were tailored to reflect the issues important to that child, to allow the child to voice their own reflections and concerns. Replica toys (of a hospital environment, and of medical implements) were used for communicating through play. Drawing (of "illness" experiences and/or fantasies about a "cure"), and picture sorts (sorting pictures of places and characters which had a “feeling” like or unlike the illness) were used to probe feelings indirectly, so that children themselves could control the revealed emotional content. In-home depth interviews with the children’s mothers were conducted separately, on the same two occasions as the child’s interview. When possible, mother and child were interviewed privately, away from each other and from other family members. The sequence of home visits took place at approximately 2 to 3 month intervals.

In addition to interviews, the study also employed indirect observation. Between interviews, each mother was asked to keep a “notebook” of observations of her child (with regard to their illness). A single-use camera was also left with the family, and the child and mother were asked to use photos to show “what it is like to have asthma (or diabetes).” These photographs were developed and brought to the second interview, as a means of probing about the illness experience in terms of what was felt to be important to the child. (Heisley and Levy 1991; Butler 1994)

FINDINGS

This presentation focuses on how children perceive their illness and its treatments, and how they deal with illness through a process called *imaginal coping*. Imaginal coping, as will be discussed in this paper, sometimes directly involved the child's treatment apparatus or medicines.

At age 5- to 8-years, children do not seem to share in the adult-derived biomedical definition of illness. Rather than defining an illness in bodily or organic terms, children defined the illness in terms of the *concrete suffering* derived from *treating* illness. For example, when young informants were asked to define diabetes ("What is diabetes?"), they often referred not to a bodily illness, but to the necessitated treatment.

Interviewer: "What is diabetes?"

> "It means you get hurt. It's boring. You have to put your finger on the machine."
> [Boy, 5]
>
> "[Having to] get shots and blood tests. " [Girl, 5]
>
> "I had to get shots and I have to prick my finger ... and I have to eat special things [like] vegetables."
> [Boy, 6]

Likewise, children suffering from severe asthma focused on concrete treatments when asked to define asthma.

Interviewer: "What is asthma?"

> "You have to take all these medications." [Boy, 8]

Interviewer: "What is asthma?" (cont'd)

> "I have to get the nebulizer. " [Boy, 6]
>
> "A medicine ... This one asthma [referring to inhaler] I put it in my mouth and sprayed it."
> [Boy, 8]

Given that children (whether they suffered from asthma or diabetes) tended to define their illness in terms of the treatment, rather than the biomedical disease concept, children related the suffering of illness to the hardships of treatment, not to the illness per se. The dilemma of coping with being ill seems to be translated, in the child's perception, into a problem of coping with the treatment regimen. (This finding agrees with an earlier ethnographic study of children with leukemia, who also became familiar with the concrete aspects of treatment without always proceeding to a stage of understanding the abstract disease.) (Bluebond-Langner 1978)

Imaginal coping is a process of coping in which the child makes use of a non-literal reality, towards which the child suspends disbelief and gains a sense of serenity and trust. This often involved the use of a transitional object (Winnicott 1971) such as a special blanket or toy (a stuffed animal, a toy car, a toy airplane, etc.) which provided comfort to the child, including during treatment. (Sometimes, kids cuddled their transitional object during the interview, when discussing the bad feelings they had about a treatment or symptom.) The comfort seemed to be derived through a combination of: 1) Cuddling or tactile comfort (especially when the child was fearful, such as during nocturnal asthma); 2) Play and ritual (such as in role reversal rituals whereby the child gave a medical treatment to a toy or playmate, during pretend play); and 3) Associated fantasies (such as imagining a toy plane can "fly away" in the nebulizer "smoke" during a boring treatment).

On repeated occasions, imaginal coping related directly to treatment regimens, as might be expected given that treatment was central to perceptions of the illness (and its hardships). Children at times asserted that a special toy could "make medicine taste better," or that play could make a child "feel better" during a treatment. The ways in which play could help a child included the cathartic enjoyment of playing at a privilege usually denied by the illness (such as playing Candyland and indulging in fantasy sweets, forbidden on the diabetic diet). Through play, the child also could gain control over a necessary regimen, by giving pretend shots, blood tests, or inhaler treatments to dolls or stuffed animals. Additionally, fantasy could provide a kind of mental escape during a lengthy treatment, such as imagining that a nebulizer was a "dragon" or that the nebulizer mask is a pilot's mask (reminiscent of the movie *Top Gun*).

Some rituals directly involved family-linked activity during a treatment routine, which the child and family had come to practice together, as a kind of “tradition.” A mother might count the time, for inhaler breathing, for the child. Or a diabetic youngster might take their shot or blood test at the same time as another diabetic family member (or in one case, a diabetic pet). Stories read during nebulizer treatment was a common ritual, with parent reading to child.

Given that treatment routines were imbedded in expressive family practices, then, it is perhaps not surprising that medication (and equipment) took on symbolic expressive importance for some children. Some young informants had developed a close emotional attachment to a particular inhaler, or to the Inspirease spacer used for the inhaler, or to some other apparatus or medicine. In a picture sort (of analogous objects), children often compared their inhaler device or blood test machine to protective artifacts, such as a teddy bear. One child compared the inhaler to a life jacket, that “helps you from water” the way an inhaler “helps you from asthma.” Medication commonly had taken on qualities of a transitional object, imbued with feelings described as being “cuddly” and “safe.”

The transitional object-like associations ascribed to medicine by children bears out the conception of another ethnographer (Van der Geest 1996) that children transform their medicines through imaginative play and interaction. This research also provides evidence for a separate hypothesis (Van der Geest and Whyte 1989), that the concreteness of medicines allow medications to take hold of an inchoate sense and turn this vague feeling into something graspable. In the case of these young sufferers of chronic illness, medicine often provides a concrete sense of safeness, amidst a potentially frightful life circumstance.

Children's imaginal coping was in many cases impeded in biomedically oriented clinical settings. Children's sense of trust and safety was often in jeopardy, when transitional objects were removed from the home (e.g. for purposes of environmental control, in asthma) or from the hospital or from the X-ray room. Medication routines were sometimes changed (for example by the medical staff at summer camp), disrupting valued rituals and the child's sense of trust, often at vulnerable times. Generally, instances when imaginal coping was honored or used to ensure medical compliance were not widespread.

DISCUSSION

The use of pretend play as a means of coping with stressful circumstances, as a form of *imaginal coping*, is not limited to chronic illness. In their work with children who are growing up in urban war zones, Garbarino, Dubrow, Kostelny and Pardo (1992) found that play helped children to cope with the trauma that comes of living with chronic community violence. It has been recorded that children played as a means of coping under Holocaust incarceration (Eisen 1988). Play has been used in hospitals, promoted by and sometimes guided by adult therapists, as a means of meeting the psychosocial needs of patients in reaction to hospitalization. (Wilson 1985)

Yet the typical experience of the young informants with chronic illness was that health care providers were indifferent to (or even interfering with) their self-initiated forms of day-to-day imaginal coping. Given that self-initiated coping likely is especially meaningful to the child, as well as imbued with familiarity and trust, health care providers would do well to consider children's own coping strategies in planning or adjusting treatments. Compliance with the heavy treatment regimen of chronic illness, as well as the child's sense of serenity, would likely benefit.

REFERENCES

Bluebond-Langner, Myra (1978). *The private worlds of dying children*. Princeton: Princeton University Press.

Butler, Lenora (1994). Autodrive in qualitative research: Cracking the ice with young respondents. *Canadian Journal of Marketing Research,* 13: 71-74.

Clark, Cindy Dell (1995). Child anthropology. In *Flights of Fancy, Leaps of Faith: Children's Mythology in Contemporary America.* Chicago: University of Chicago Press.

Clark, Cindy Dell (1996). Interviewing children in qualitative research: A show and tell. *Canadian Journal of Marketing Research,* 15.

Eisen, George (1988). *Children and play in the holocaust.* Amherst: University of Massachusetts Press.

Erkolahti, Riva (1991). Transitional objects and children with chronic disease. *Psychotherapy and psychosomatics.*

Garbarino, J., Dubrow, N., Kostelny, K. and Pardo, C. (1992). *Children in danger: Coping with the consequences of community violence.* San Francisco: Jossey-Bass.

Heisley, D.D. and Levy, S.J. (1991). Autodriving: A photoelicitation technique. *Journal of Consumer Research,* 18 (3): 257-72.

Van der Geest, Sjaak, and Whyte, Susan (1989). The charm of medicines: Metaphors and metonyms. *Medical Anthropology Quarterly,* 3(4): 345-367.

Van der Geest, Sjaak (1996). Grasping the children's point of view? An anthropological reflection. In *Children, medicines and cultures* (edited by P. Bush, D. Traks, E. Sanz, R. Wirsing, T. Vaskilampi, and A. Prout). New York: Haworth Press.

Wilson, J. (1985). Play in the hospital. In *Play interactions: The role of toys and parental involvement in children's development* (edited by C. Brown and A. Gottfried*).* Skilman, NJ: Johnson and Johnson.

Winnicott, D. W. (1971). *Playing and reality.* London: Tavistock.

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