8-31-1999

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Recommended Citation

Butler, Kimberly Olvera, "Family Communication and Competence Among Siblings of Pediatric Oncology Patients" (1999). *Master's Projects*. 838.

DOI: <https://doi.org/10.31979/etd.qbt2-yvc2>

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FAMILY COMMUNICATION AND COMPETENCE AMONG SIBLINGS OF PEDIATRIC ONCOLOGY PATIENTS

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August, 1999

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Abstract

Pediatric oncologic diseases are a leading cause of mortality and morbidity among children. The chronicity of the treatment requires the family to adjust their daily routines to care for the ill child. The changes are experienced by all the family members: the ill child, the parents, and the well siblings. The literature reflects variable effects on the well sibling. There has been limited research that evaluates the effects of family interaction patterns. This pilot study examined communication within the family and sought to determine if communication, as measured on the Parent-Adolescent Communication Scale, correlated with competence, as measured on the Child Behavior Checklist Youth Self-Report.

Purpose: The purpose of this pilot study was to lay the groundwork for studying a possible relationship between family communication patterns and competence of well siblings in families with a child undergoing treatment for cancer

Hypothesis: The researcher hypothesized that healthy siblings of pediatric oncology patients would have higher competence, as measured on the Child Behavior Checklist Youth Self-Report Form, if the family had open communication patterns with limited problems, as measured on the Parent-Adolescent Communication Scale.

Family Communication and Competence Among Siblings of Pediatric Oncology Patients

Personal Interest

Review of the Literature

Possible outcomes

- Feelings of Isolation/Disconnected
- Low self-esteem, sense of self worth
- No one to talk to
- More empathy for others
- Increased sense of value of one's life

Mediating Factors

- Having someone to talk to
 - Information on the plan of care
 - Explanation of what is happening
 - Sharing of feelings, fears, concerns
- Feeling Special

Theoretical Framework: Circumplex Model of Marital and Family Systems

Flexibility:

Cohesion:

Communication: facilitates movement in the other dimensions

Evaluated by listening skills, speaking skills, self-disclosure, clarity , & tracking

Purpose and Hypothesis:

Participants:

- Diagnosed in the last year ALL, AML, NHL, Hodgkin's, Osteosarcoma
- Living with patient
- Between the ages of 11-18
- English Speaking

Methodology

- Questionnaires Mailed--coded
- Stamped envelope provided
- Participants awarded \$10.00
- N=21, n=8

Instruments

Parent-Adolescent Communication Scale

Circumplex Model

Measures degree of openness and extent of problems in family communication

20 item, 5 point Likert scale

Child Behavior Checklist, Youth Self-Report

Family Resiliency Model

Competence = social competence + activity competence + academic competence

Findings

Competence scores of well siblings not significantly different than established norms

No correlation between family communication and competence

Discussion

Limitations

Sample size

Participants

Recruitment

Interviews: Clinic visit or home visit

Multiple cancer research centers

Expand inclusion criterion

Methodology
recruitment - telephone
correlation - sample too small
ask qs

Abstract

Pediatric oncologic diseases are a leading cause of mortality and morbidity among children. The chronicity of the treatment requires the family to adjust their daily routines to care for the ill child. The changes are experienced by all the family members: the ill child, the parents, and the well siblings. The literature reflects variable effects on the well sibling. There has been limited research that evaluates the effects of family interaction patterns. This pilot study examined communication within the family and sought to determine if communication, as measured on the Parent-Adolescent Communication Scale, correlated with competence, as measured on the Child Behavior Checklist Youth Self-Report.

Family Communication and Competence Among Siblings of Pediatric Oncology Patients

Pediatric oncologic diseases are leading causes of mortality and morbidity among children. The American Cancer Society estimates that 8,000 new cases of childhood cancers were diagnosed in 1997, and 8,700 new cases in 1998 (Cancer Facts, 1998). The chronicity of the treatment requires the family to adjust their daily routines to care for the ill child which includes care at home, frequent medical appointments, and multiple inpatient admissions. The changes are experienced by all the family members: the ill child, the parents, and the well siblings.

Review of the Literature

Research findings reveal variable effects on the well sibling of a child with cancer. The literature has also begun to examine different coping mechanisms and predictors of adjustment.

Negative Effects

Cairns, Clark, Smith, and Lansky (1979) found there were significant differences between the healthy child and the ill child. The well child had more feelings of being isolated, feelings that their parents were overprotective and indulgent of the ill child, fearful of confrontations with other family members, and fearful of personal failure.

Spinetta (1981) hypothesized that the well siblings suffer at least as much as, and probably more than, the patients. It was found that the well siblings' emotional needs were met at a significantly lower level compared to other

members of the family. Self-concept scores were lower. Furthermore, well siblings viewed their parents as more emotionally distant.

Kramer (1984) interviewed well siblings of pediatric oncology patients to gain a description of how the illness affects the well child. The negative consequences included: 1) emotional adjustments including feelings of lower self worth, anger, frustration, and guilt; 2) separation with feelings of loneliness, isolation with inadequate supports; and 3) difficulties related to the treatment regime including fear, anxiety, and embarrassment.

Siblings were interviewed by Koch-Hattem (1986) to get the well child's description of their experience since the diagnosis of the ill sibling. Well siblings did not exhibit a change in their behavioral expression of depression such as change in appetite or desire to attend school since the diagnosis of the ill child. However, there was a significant change in the affect of well siblings; a higher incidence of feeling bothered, sad, and scared since the diagnosis. The author goes on to suggest further research that could identify mediating factors in the well child's response such as self-esteem, extent of family involvement, and socioeconomic status.

Walker (1988) interviewed siblings using open ended questions and psychosocial evaluations through puppet play, drawing, story telling, and sentence completion test. Three areas of stressors were identified: loss, fear of death, and change.

Additional qualitative research was done by Martinson, Gilliss, Colaizzo, Freeman, and Bossert (1990) to describe the effect on the well sibling having a

sibling with cancer. Well siblings were interviewed yearly for a total of three interviews. They were asked five open-ended questions. It was found that the siblings did not see themselves as a, “competent member of the family” and that there were limited opportunities to talk with someone about their feelings. The authors concluded that well siblings need information about the ill child’s disease and treatment, need to feel important, and need someone to talk to about their fears.

Bendor (1990) utilized a group process to identify the unmet psychosocial needs of the well siblings. The school-age group expressed feelings of deprivation, displacement, injustice, anger, loneliness, and vulnerability. Adolescents expressed feelings of vulnerability, fear of death, and feelings of burden for the sick sibling’s physical and mental health.

Evans, Stevens, Cushway and Houghton (1992) evaluated whether the level of well sibling’s knowledge of the illness and treatment correlated with psychological adjustment which was operationalized as the incidence of behavior problems and social competence on the Child Behavior Checklist. Multiple instruments were used, including the Child Behavior Checklist and two tools developed by the researcher: Sibling Illness Questionnaire and the Family and Social History Questionnaire. The research used a combination of both qualitative and quantitative methods. The Sibling Questionnaire identified that well siblings were preoccupied with the illness, often felt sad, and many had no one with whom to talk. One third of the siblings were talking to no one about their feelings

and only one quarter could talk with their parents. The relationship between communication and social competence was not evaluated.

Wang and Martinson (1996) examined factors that contributed to the presence or absence of behavioral problems in Chinese siblings of children with cancer when compared to the standardized norms. There were significantly more behavioral problems and fewer social competence behaviors in Chinese siblings compared to established norms.

Positive Effects

Kramer (1984) found positive outcomes through content analysis of interviews with well siblings. The well siblings were found to have increased empathy for others, a sense of value in one's life and health, and increased family communication.

Evans et al. (1992) found that sibling knowledge (as measured on the Sibling Illness Questionnaire) did not correlate with behavior problems but did correlate with an increased level of social competence. The authors went on to question which came first, social competence or increased knowledge.

Illes (1979) not only found negative effects, but also found positive effects of having a sibling with cancer. In the 1979 qualitative study, positive outcomes included increased empathy for parents, respect for the ill child, and improved self-concept.

Havermans and Eiser (1994) reported that healthy siblings perceived their lives to be affected as a result of their sibling being diagnosed with cancer.

Siblings reported an increased empathy for others and a greater value of life.

Predictors of Sibling Adjustment

Iles (1979) asked siblings of pediatric oncology patients how the illness of their sibling affected them. Through a semi-structured interview siblings were asked, "What helps?" Five things were identified: 1) to talk with someone, 2) to know if something big was going to happen, 3) to have explanations of what was happening, 4) to know what is happening, and 5) to feel special. This points out the need of the siblings to have straight-forward, open, honest communication and a sense of value in themselves as an individual.

When Kramer (1984) asked, "What helps?", the well siblings suggested: 1) more frequent hospital/clinic visits, 2) more information about the disease and its treatment, 3) open and honest communication, 4) greater involvement in the ill child's care; 5) at-home care during sibling's hospitalization, and 6) passage of time. The author recommended encouraging open communication, providing information, and encouraging participation of the well sibling in daily care activities.

Walker's 1988 work also developed a taxonomy of coping efforts. Coping behaviors included: wishful thinking, talking to others, seeking attention, and solitary play. Further research was recommended to identify the relationship between different coping activities and outcomes.

Heffernan and Zanelli (1997) also studied the coping mechanisms of well siblings. They compared the coping mechanisms identified by the sibling and

those identified by the mother. Both the mother and the siblings reported the utilization of new behaviors, including an increased sensitivity to others.

Birenbaum (1989) studied families with a dying child. Family communication, as measured by the Parent-Sibling Communication instrument, was correlated with the number of behavioral problems and the level of social competence, using the Child Behavior Checklist. The questionnaires were completed before the death, two weeks after, four months later, and 12 months after the death of the ill child. It was found that the better the family communication, the higher level of social competence among the well siblings. Furthermore, Parent-Sibling communication was inversely related to behavior problems among the well siblings.

We are presented with a complex picture which presents a wide variety of aspects upon which researchers might focus. The effects on the well sibling are multi-dimensional; there being both positive and negative effects. One might want to look further at mediating factors such as family cohesion, family cultural differences, socioeconomic status, social support, individual and family resiliency, education, and information.

Communication is repeatedly mentioned in the literature as a possible mediating factor. Birenbaum (1989), Walker (1988), Kramer (1984) and Iles (1979) all identified open, honest communication, or someone to talk to, as something that helps. This pilot study builds on their work by examining the relationship between competence and family communication. Family

communication was measured by the Parent Adolescent Communication tool based on Olson's Circumplex Model of Marital and Family Systems.

Theoretical Framework

The Circumplex Model of Marital and Family Systems (Olson, 1983) has been developed to examine how family systems cope. Family cohesion, flexibility and communication are the three dimensions of the Circumplex Model.

Cohesion is described as the emotional bond between family members. Four levels of cohesion are identified; from disengaged, to separated to connected emmeshed.

Flexibility is the amount of change in leadership, role relationships, and rules. Four levels are identified from rigid, to structured, to flexible to chaotic.

Optimal functioning occurs when there is a balance; when the family is operating in one of the central levels. There is a curvilinear relationship between cohesion and flexibility, with family functioning. Either too much or too little cohesion or flexibility can be seen in dysfunctional family systems.

Communication is the facilitating dimension in that it facilitates movement in the areas of cohesion and flexibility so that a balance can be achieved. Communication is essential for negotiation to occur within the family dimensions of cohesion and flexibility as the family goes through changes. The family's communication is evaluated as a group, as opposed to individual evaluations. Communication is evaluated in regard to listening skills, speaking skills, self-disclosure, clarity, and continuity tracking.

Purpose and Hypothesis

The purpose of this pilot study was to lay the groundwork for studying a possible relationship between family communication patterns and competence of well siblings in families with a child undergoing treatment for cancer. The researchers hypothesized that healthy siblings of pediatric oncology patients would have higher competence, as measured on the Child Behavior Checklist Youth Self-Report Form, if the family had open communication patterns with limited problems, as measured on the Parent-Adolescent Communication Scale.

Methodology

Participants

Subjects were recruited throughout the oncology patient population at Packard Children's Hospital at Stanford. English speaking families with a child diagnosed in the last year with acute lymphoblastic or acute myelocytic leukemia, osteosarcoma, Hodgkin's or non-Hodgkin's lymphoma, and currently in treatment, and with a sibling living in the home between the ages of 11-18 were sent a questionnaire. A total of 21 families were identified and sent questionnaire packets. A reminder postcard was sent two weeks after the initial mailing. The parents were instructed that the children should complete the questionnaires without assistance. Participants were awarded a \$10.00 gift certificate for their participation.

Of the 21 questionnaires sent out, 8 were returned completed. One was returned with the incorrect address. One was returned partially completed, unable

to be scored. The siblings' ages ranged from 12-14, including four girls and four boys.

Setting

The parents completed a consent form, a demographic information sheet and the parent form of the Parent-Adolescent Communication Tool. The siblings completed Parent-Adolescent Communication Tool and the Youth Self-Report form of the Child Behavior Checklist. All the information was returned in a provided stamped, addressed envelope. To maintain confidentiality, all questionnaires and demographic information had the names removed and were assigned a code.

Instruments

The Parent-Adolescent Communication Scale evaluates the degree of openness and extent of problems in family communication (Barnes and Olson, 1985). The theoretical background of the instrument tool is that of the Circumplex Model of Marital and Family Systems. The tool is a 20 item, 5-point Likert scales. The scale has been widely utilized in the family communication literature. Alpha reliability range from .78-.87. Test-retest reliability is .78-.77.

The Child Behavior Checklist (Achenback & Edelbrock, 1983) evaluates total competence as the sum of social competence, activity competence, and academic competence. The Youth Self Report (YSR) form was utilized. The subjects complete the YSR independently. It is written at the fifth grade reading level. Test-retest reliability is $r = .79$. The theoretical framework is that of family resiliency model.

Analysis and Findings

Total competence scores on the Child Behavior Checklist ranged from a *t*-score of 37 to 64, with a mean of 52.2. Comparing the research subject's scores to the established norms, using the *t* test for independent groups, there was no significant difference between the two groups.

Pearson's correlation coefficient was utilized to evaluate the presence and strength of a correlation between family communication and competence among the siblings. No correlation was found.

Limitations

The sample size is too small to demonstrate a statistical relationship between the two variables. Further research is needed to more fully understand the moderating effects of family communication on sibling outcomes. However, this pilot study does suggest several issues that will need to be addressed when conducting research on this population.

Discussion

This pilot study identified several issues related to recruiting families for participation when they are experiencing so much stress. Perhaps only those families that are functioning well had the time and energy to read, complete, and return the questionnaires. Of note, the researchers did receive phone calls from three families expressing an interest in participating in the study as soon as their child was well. None of these families returned the questionnaires. Furthermore, the researchers spoke with four families during an inpatient admission. They, too, expressed interest, but noted the difficulty of participating as they were currently

separated from the well sibling and understandably had their attention focused on the hospitalized child. One of these families ended up participating. It seemed the families saw the value and had the interest in participating in the research, however, were too stretched to put one more thing on their plate.

Future research needs to be completed which will reveal the effects on families who have been under represented in the research. Greater participation may be achieved by having the questionnaire administered in an interview format. The researchers may foster greater participation if the research is presented in person. The time a family is waiting for a clinic visit might be a more convenient and less disruptive time for families. Also, making home interviews available may increase participation of some families.

In order to find a statistically significant relationship a larger sample size is needed. Multiple cancer research centers could be included to increase the number of participants. Expanding the inclusion criterion to a wider variety of ages, diagnosis, and languages would provide additional potential participants.

There is evidence that some well siblings do experience difficulties and that the degree of distress might be reduced if we better understand those factors that make a difference. If we, as professional practitioners, are to provide comprehensive and sensitive care to the entire family, we need to further research factors that may be mediating factors in the well child's response.

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