

Intergenerational Relationships When a Child is Blind

by

Martha J. Haylor, RN, MN

A Master's Research Project

Presented to

Oregon Health Sciences University

School of Nursing

in partial fulfillment

of the requirements for the degree of

Master of Science

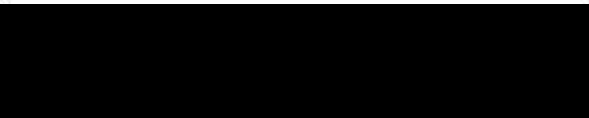
June, 1991

This project was supported by the ADAMHA Clinical Training Grant MH17172-03 (1985-1986) and the Professional Nurse Traineeship Program, Grant Nos. 2 A11 NU00250-11 (1986-87).

Approved:



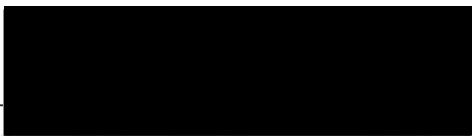
Sheila M. Kodadek, R.N., Ph.D., Associate Professor, MRP
Advisor



Joanne E. Hall, R.N., Ph.D., Professor, First Reader



Barbara Limandri, R.N., DNSc., Associate Professor, Second
Reader



Carol A. Lindeman, R.N., Ph.D., F.A.A.N., Dean, Oregon
Health Sciences University School of Nursing

ACKNOWLEDGEMENTS

It has been my tremendous good fortune to once again have had the opportunity to participate in a project where the intelligent and creative minds of women have been at work. This paper is the product of the work but it captures only a small part of the energizing experience of having worked with a good committee. To Dr. Sheila Kodadek, Dr. Joanne Hall, and Dr. Barbara Limandri, I have benefitted not only from your great thinking but also from your guidance and nurturance along the way.

To my family of today, Sally and Jamie, thank you for just being here and all the good things that members of caring families give one another.

TABLE OF CONTENTS

CHAPTER	PAGE
1 INTRODUCTION	1
Review of Literature	3
Purpose and Research Questions	9
2 METHODS	10
Sample and Procedure	11
Data Analysis Procedure	11
3 ANALYSIS OF FINDINGS	13
Grandparent-Parent Interactions	13
Grandparent-Grandchild Interactions	17
Coping Strategies	18
Family Legacy	19
SYNTHESIS OF FINDINGS	20
Congruent Involvement	21
Incongruent Involvement	22
Incongruent Uninvolvement	23
Congruent Uninvolvement	24
4 SUMMARY	25
Implications for Research and Practice	26
REFERENCES	29
ABSTRACT	33

CHAPTER 1

Intergenerational Relationships When a Child is Blind

The birth of a child with severe visual impairment impacts the entire family. In turn, the way in which the family copes and manages this situation impacts the child who is blind as well as the health of the family unit. Much of the research investigating family responses to a child with a chronic or handicapping condition has identified the parents or siblings in the family as the unit of analysis with little or no attention given to the impact of such an event on the grandparents of the child or the impact of their responses on the family unit. Uphold and Harper (1986) have indicated that studies of intergenerational family relationships during health and illness hold much potential for informing nursing theory, practice, and research. In particular, intergenerational family research provides insight into the transmission of health beliefs and values between generations as well as the nature of interpersonal relationships as families cope with the long term disability of one of its members.

Changes in demographics, advances in medical science, and a shift in philosophy regarding long term care for children with handicapping conditions suggest that attention to intergenerational relationships is an important area for nursing inquiry. With longer life spans an increased number of people are experiencing grandparenthood and will spend an

increased number of years being a grandparent (Barranti, 1985). At the same time, advances in medical technology mean that children with chronic and handicapping conditions are more likely to live longer than in the past. Today, children with disabilities most often are cared for at home by their families rather than in institutions. As a result, grandparents of these children have an increased opportunity to know their disabled grandchild and their grandchild to know his or her grandparents.

Historically, when multigenerational families shared a common home or lived in close proximity to one another, the family values, beliefs, and idiosyncracies may have been easier to detect as they were passed from one generation to another. Although many different types of grandparent/child/grandchild relationships are evident today in American culture, the impact of the previous generation on the next may find more subtle expression and therefore be less obvious to the nurse working with families than in the past. The aim of the research reported below was to bring to the foreground the tacit intergenerational relationships in families who have a child with severe visual impairment. In uncovering and reporting the meaning, relevance and importance of intergenerational relationships and their impact on families it is hoped that the nurse's sensitivity and attention to these meanings is heightened and practice is influenced accordingly.

Review of Literature

The literature related to grandparents and the grandchild with a developmental or physical disability is very limited (Berns, 1980), with no identifiable literature that specifically addressed the concerns or responses of grandparents of a blind grandchild or their impact on the child's immediate family. However, four major studies, conducted by researchers from a variety of disciplines, have contributed significantly to the current understanding of grandparenting in families of children without physical or developmental disabilities.

Kivnick (1982, 1983, 1985) focused on the meaning of grandparenthood and its relationship to the well-being of the individuals experiencing it. Based on qualitative analysis of intensive semi-structured interviews with 11 grandparents, a structured questionnaire regarding the meaning of grandparenting was developed and subsequently administered to 286 grandparents. Five simultaneously existing dimensions of grandparenthood were identified :

- a) Centrality. Degree to which grandparenting practices, and the contribution of the role to personal identity and meaning in life are of central importance to the grandparent.
- b) Valued elder. Importance grandparents place on passing on traditions and concern about how grandchildren will remember them;
- c) Indulgence. Attitudes that culturally seem to go along with the grandparent role of lenience and tolerance of grandchildren;
- d) Immortality. Aspects of immortality achieved through descendants;
- e) Reinvolvement. Extent to which grandparenthood provided a vehicle for relating to aspects of one's own life history.

Kivnick (1985) has continued to conceptually elucidate the dynamic nature of grandparenthood and its contributions to individual mental health by considering the interrelationships of the meaning of the role, the characteristic behaviors of the role and the degree of satisfaction of the role.

Kornhaber and Woodward (1981) considered the grandchild's perspective in their research with 300 grandchildren aged 5 to 18 years, thus identifying five grandparent roles. These five roles were:

- a) Historian. Grandparents were a source of historical, cultural and family information and wisdom for grandchildren.
- b) Mentor. Grandparents taught grandchildren things not learned anywhere else within an atmosphere of acceptance.
- c) Role model. Grandchildren learned about aging, future grandparenting roles, and intergenerational relationships from their grandparents.
- d) Wizard. Grandparents involved in the lives of their grandchildren stimulated imagination and creativity.
- e) Nurturer. Grandparents served as the second line of care providers for their grandchildren.

Kornhaber and Woodward (1981) concluded that direct grandparent/grandchild relationships served to broaden the social support system for children and were crucial to the health and well-being of children. Based on ongoing research and clinical experience, Kornhaber (1985) has expressed increasing concern that these important grandparent/grandchild involvements are threatened by social and cultural changes that result in constricted intergenerational relationships.

Wood and Robertson (1976), identified four different styles of grandparent involvement with their grandchildren: a) those interested in the moral development of their grandchildren, b) those concerned about providing a role model for their grandchildren, c) those focused on the personal relationship with their grandchild, and d) those with a ritualistic, impersonal, and distant type of relationship with their grandchild.

Neugarten and Weinstein (1964) investigated three aspects of psychological and sociological dimensions of the grandparent role: a) the degree of comfort with the role, b) the importance or significance of the role, and c) the style of enacting the role. Data were collected using semi-structured interviews from 70 grandparent couples living in close geographical proximity to their children and grandchildren. Five styles of grandparenting were identified through inductive analysis: formal, funseeker, surrogate parent, reservoir of family wisdom, and distant figure. Formal grandparents maintained the boundaries between parenting and grandparenting and followed the prescribed cultural roles of grandparent. Fun seekers were those grandparents who enjoyed an ongoing relationship with their grandchild centered around mutually enjoyable activities. Surrogate parents were most often grandmothers who assumed caretaking responsibilities for grandchildren at

the request of their mother. The reservoir of family wisdom grandparents were similar to the historian described by Kornhaber and Wood (1981) and the valued elder identified by Kivnick (1982, 1983, 1985). The description of the distant figure grandparent was congruous with those grandparents described by Wood and Robertson (1976) as impersonal and distant.

Two aspects of grandparent/grandchild involvement are addressed by these studies: the amount of involvement and the style of involvement. Three of the four studies speak to a level or intensity of involvement with grandparenting by those experiencing it. Kivnick (1982, 1983, 1985), Neugarten & Weinstein (1964), and Wood and Robertson (1976) address level of involvement in a global sense by investigating the concepts of centrality, comfort and importance of the role, and grandparent focus of personal or distant relationship with their grandchild. Kornhaber and Woodward (1981) do not address the level of grandparent involvement, but rather focus exclusively on the way in which grandparents are involved in their grandchildren's lives.

The different meanings or styles of grandparenting address the way in which grandparents are involved indirectly or directly with their grandchildren. Those styles or meanings that imply indirect involvement are related to the transmission of intergenerational values such

as valued elder and immortality (Kivnick 1982; 1983, 1985), historian (Kornhaber & Woodward, 1981), nurturer/surrogate parent (Kornhaber & Woodward, 1981; Neugarten & Weinstein, 1964), role model (Kornhaber & Woodward, 1981; Wood & Robertson, 1976), and reservoir of family wisdom (Neugarten & Weinstein, 1964).

Direct grandparent/grandchild involvement is evident in the meanings and styles of grandparenting described by researchers, such as indulgence (Kivnick 1982; 1983), mentor and wizard (Kornhaber & Woodward, 1981), promoter of moral development (Wood & Robertson, (1976), and fun seeker (Neugarten & Weinstein, 1964).

The level of involvement, as well as the direct and indirect grandparenting styles are personally and culturally constituted. Neugarten and Weinstein (1964) provided evidence for this statement in that the surrogate parenting style was most often the experience of grandmothers, while the formal and distant figure styles were most often the experience of grandfathers. The researchers do not address the question of whether these styles are mutually exclusive. However, they are presented as if they were the predominant style expressed by the participants.

With rare exceptions research has not focused on the relationships of grandparents with their adult child and grandchild who is disabled. In a descriptive study Harris, Handleman, and Palmer (1985) explored intergenerational

perceptions of the experience of caring for an autistic child. When differences in these perceptions existed, grandparents were consistently more positive or less burdened in their views of the autistic child's behavior, the impact on their son or daughter and their relationship with their adult child. From a clinical perspective Berns (1980) has offered suggestions for grandparents regarding accessing knowledge and strategies for grandparent-family involvement with the birth of a handicapped child.

In summary, the literature regarding grandparenting has centered around the roles of grandparents in the extended family system, the meaning of grandparenting for those experiencing it, and the styles of grandparenting. The literature indicates that grandparent/grandchild relationships are potentially rewarding and important sources of human affection for grandparents and grandchildren. It is also clear that many styles of grandparent/grandchild involvement are found in American culture. The literature regarding intergenerational relationships when a grandchild is disabled is extremely limited. Missing from the research are investigations that examine the family context within which styles of grandparenting and discrepancies in perspectives are embedded.

Purpose and Research Questions

The purpose of this research project was to describe from the parents' perspective the meaning of intergenerational relationships when there was a blind child in the family. Specifically, the research questions were: 1) How do parents of blind children describe grandparent responses to their blind grandchild? and 2) How do parents perceive grandparent responses to affect the family? This report was drawn from a larger qualitative descriptive study conducted by Kodadek and Haylor (1988) which was designed to explore parents' perceptions of the experience of caring for a blind child.

CHAPTER 2

Methods

The qualitative social research methodology described by Lofland and Lofland (1984) was used for this study. As described by Emerson (1983) this "qualitative strategy analysis framework" focused on the interactional strategies used by individuals in the phenomenon of interest. The goal of the method was to move from the topical and substantive concepts of strategy or situation to a conceptual level (Emerson, 1983; Lofland & Lofland, 1984). Intensive interviewing has been described by Lofland and Lofland (1984) as a "guided conversation", the purpose of which is to stimulate rich, deep descriptive data used to "discover the informant's experience of a particular topic or situation" (p. 12).

To facilitate systematic data collection for the study, an open-ended interview guide was developed. Questions were organized around topical categories related to the diagnostic period, daily care for the child, family decision-making, social and health care professional interactions, and impact of the child's blindness on the family. Although parents were not specifically asked about the response of grandparents to the blind child, all parents interviewed volunteered information about such responses suggesting how important grandparent reactions were to them.

Sampling and Procedure

A sample of 12 families (12 mothers and 8 fathers) from the Pacific Northwest were recruited through ophthalmologists. Two of the mothers were unpartnered and two fathers declined to participate. Children with visual impairments ranged in age from 6 months to 6 years, with a mean of 2.8 years. Nine of the 13 visually impaired children were impaired due to retinopathy of prematurity and only one child was without other health problems. The high percentage of children with retinopathy of prematurity also meant that most families in the sample had had an extensive neonatal intensive care experience.

Interviews were conducted in the family home with one exception when the family came to the investigators' offices. Both investigators participated in interviews and each adult family member was interviewed by a different investigator. Whenever possible interviews for mothers and fathers were conducted at the same time.

Data Analysis Procedures

All interviews were audio tape-recorded and transcribed verbatim. The transcripts were analyzed using two primary strategies: interpretive analysis and the qualitative data analysis strategy recommended by Lofland and Lofland (1984). Interpretive analysis took place at several levels. After each interview, the researchers conducted an initial analysis in the form of debriefing with one another.

Initial impressions and hunches were shared and documented for further validation, clarification, or refutation based on the interview transcripts. Each interview was read and reread in order to get and maintain a sense of the whole family picture prior to more focused topical analysis. Memos of recurring themes and processes also were generated at this time. The development of matrices for topical and subtopical analysis was undertaken to further clarify identified phenomena (Lofland & Lofland, 1984).

help and comfort. Tangible aid was defined as palpable goods and services. Non-supportive interactions were those in which the parent perceived that some important aspect of their own or their child's being was denied or avoided by the grandparent.

Emotional support and respite. Grandparents provided emotional support in the form of empathetic listening, comments and activities that were perceived as comforting and caring, recreation, and the offer of a home away from home. The ability to listen empathetically or say and do things that were comforting and caring were not restricted to those grandparents who lived close by, but rather were considered by parents as essential to good relationships regardless of geographical proximity.

When grandparents lived close, parents enjoyed a variety of recreational activities such as going out to eat, playing cards or just visiting. Trips to the grandparent's home were mentioned by some parents as opportunities for a break from the daily routine within a caring, nurturing atmosphere. These supportive activities with grandparents were helpful in restoring energy for parents who were "drained" by their ongoing daily attempts to provide a nurturing environment for a blind child (Kodadek & Haylor, 1990).

Tangible assistance. Tangible assistance from grandparents was demonstrated in the form of direct

financial aid, provision of professional services, child care, and assistance with special health care needs of the visually impaired child. Grandparents had supplied airline tickets when the parents of one child were searching for a cure for the blindness; a house owned by the grandparents was given to another child's family to live in; grandmothers provided babysitting for the blind child and/or siblings; and one grandfather had provided bookkeeping services to help manage the financial aspects of extended health care costs and money loans.

The surrogate parent/nurturer role (Kivnick, 1982, 1983, 1985; Neugarten & Weinstein, 1964) was very evident in one of the study families. A grandmother came to help out with the household when the baby was born and continued to live with the immediate family. The baby slept in the grandmother's room and she took care of him during the night so the rest of the family could rest. The child's mother was more involved in the child's care during the day but the grandmother remained a central caregiving figure.

Advice-giving by grandparents received mixed reviews from parents. As suggested in the literature, grandparents have traditionally seen themselves or been viewed by children and grandchildren as a source of wisdom and information (Kivnick, 1982; Kornhaber & Woodward, 1981; Neugarten & Weinstein, 1964). Data from this study suggested that grandparents of blind grandchildren continued as a source of

knowledge regarding parenting and child development. Parenting advice was difficult for the parents if the grandparents did not appreciate the special challenges presented by the child's blindness or other health care conditions. For example, the mother of a child who eventually required gastrostomy feedings was told by her mother to "Just let him go hungry. Babies will eat if they get hungry enough."

Non-supportive interactions. In some instances, grandparents were unable to provide emotional support. The inability of grandparents to provide support to their children seemed related to the grandparent's coping strategy or the family legacy. In the following excerpt, the grandmother's coping style of denial made it difficult for her daughter to share her concerns:

I think it would have been nice if somebody had said, 'yeah, it's alright to cry, go ahead and cry.' But my mom is real unrealistic and she just refuses to see that bad things are happening. Or she's always got a quick fix for whatever's going wrong. So with her, I couldn't [cry]. You can't really be that way with her. You can't say, 'This is terrible I want to cry.' Because immediately she's got all these solutions and it just makes it worse then.

Reluctance on the part of grandparents to provide respite care for their blind grandchild was attributed by parents to one of three things: a lack of desire, a willful avoidance, or uncomfortableness with some aspects of the blind child's care or needs. Parents responded with understanding for grandparents who could express their feelings of awkwardness

with small infants, or for those who did not understand the different developmental advancement of blind children. Willful avoidance on the part of grandparents was experienced as hurtful and presented problems for the immediate family unit.

Grandparent-Grandchild Interactions

Parents were unanimous in expressing their thoughts about how their visually impaired children should be treated by grandparents as well as others. Parents believed that it was in their child's best interest to be treated without pity, in a manner that was developmentally appropriate and in a way that allowed for the special circumstances produced by the child's visual impairment. In the following excerpt a mother describes a typical interaction between her visually impaired child and her parents:

My parents treat her normally. It's just she's another kid. They'll do special things with her as far as sitting down with her and reading or explaining something to her, but I've also seen them do that with the others [children in the family].

In contrast, another mother describes the response of her husband's parents to their blind son.

My husband's parents are totally different. [About her son their attitude seems to be] He is a blind child. He can't do anything. That type of thing, so that is kind of hard to deal with. Because you have to stop them and say, 'Hey, he's not a poor blind child because he picks up on that right away. And then he knows how to use the emotions to get what he wants.'

The opportunity to be physically present with the child seemed to influence the grandparent's ability to have

comfortable interactions with their grandchild. The importance of having contact with the blind child is exemplified in these excerpts:

It's the blindness that is the problem with him (grandfather). I can remember one day Janet was sitting in a chair, and my husband said something to her and she responded to him. You could tell [the grandfather] was just shocked. He finally realized that she has a brain. You know, she can hear what you are saying, she can think. And then after that, I caught him watching her a little bit more. And you know, he'll just really stand back and kind of observe her. But see, now he'll play with her and he teases her, and talks to her all the time. And treats her like a child finally.

We visited family in Nevada and they said that they were so glad that they got to meet John because they would have felt pity for him if they had never met him. But after meeting him they just thought he was so neat and that everything was going to be okay.

Coping Strategies

The impact of a blind grandchild on grandparents was most evident in parental descriptions of how grandparents seemed to cope with the experience. As might be expected, coping expressions were individual and no one coping strategy was mentioned by all parents. A variety of grandparent coping strategies were observed by parents including: a) expressions of sadness, b) avoidance of the blind child and sometimes the family unit, c) denial of the finality of the diagnosis, d) denial of feelings, e) finding meaningful roles with the child and family, f) worry, and g) reaching out to other families of children with developmental or physical disabilities.

For one grandmother, finding a meaningful role for

herself with the blind child and his family had provided new meaning for her life also.

Joey has brought his [grandmother] out of a real depression that she had before. [She had very few interests in life prior to Joey's birth.] And now, it's kind of comical because she says she will take care of him until he talks back. I was kind of surprised but she participated in the CPR class and she did it wonderfully well. She does not have to sleep in Joey's room but she wants to. It is like therapy for her. And especially when my mom just had cataract surgery not too long ago. We joke about the blind leading the blind, because the two of them couldn't get across the room together almost. And so it has been good for her in a sense. You always look back and say, 'well, gee, why us? Why me?' There is the proof [the answer].

Family Legacy

The concept of family legacy is used to address experiences from the parent's childhood, attitudes, beliefs, or characteristics of grandparents, that are passed on to the next generation, or that are still operating in the older generation and impacting the blind child's family. Evidence of the family legacy was apparent in parental descriptions of initial concerns about telling the grandparents of the child's diagnosis, and in those discussions attributing present difficulties with grandparents to the social and cultural background of the grandparents.

You think of your child as being handicapped, and not being a whole person. Well, they are as whole a person as anybody else. But you are fighting a lot of old ideas, archaic ones. My family is old country. Some of the relatives back East, it leaked that he was blind. Their response was, 'what institution is he going into?' You know, that's what happened in the old country.

Parents also described the values and beliefs that had been modeled for them by their parents that had been helpful in their own coping with the diagnosis of blindness in their child. This father shares his strategy for considering a decision regarding experimental surgery for his child:

You really do have to put a lot of trust and faith in the doctors, but that doesn't mean that you have to put all your faith in what gets said. I mean you've got a brain too and so my recommendation is to use it. Consider the expert opinion but also consider what you think too. I mean, you know most people are pretty smart. I grew up with that attitude. My parents are that way, so I learned it from them. And, of course, I recommend that way of thinking.

The mother of one child in the study had two siblings who were blind. She related stories of her growing up that now were very helpful in thinking about the parenting career of caring for a blind child. The opportunities to have had role models, see the struggles and accomplishments of blind individuals, and exposure to the constant description required of parents of blind children were viewed as resources that she could draw on as she thought about the future. She related the following story of how her father described vacation sights to her siblings.

My dad explained...he said that Crater Lake looked like a mound of mashed potatoes with gravy in the middle of it. When we went to the Redwoods, we took my (siblings) and we walked hand-in-hand around the circumference of the tree. That's how they saw the tree. So you know, I tell my son everything.

Synthesis: A Typology of Grandparent Responses

Three types of grandparent response to a blind grandchild were identified based on a qualitative

matrix analysis of the interaction of the four subcategories of grandparent-parent interaction, grandparent-grandchild interaction, grandparent coping style, and the family legacy. The concept of congruence is used in describing each of these types to connote the apparent balance between the needs of the grandparent and the needs of the family. The second term in each type label identifies the overall connection the grandparent has with the child and family.

Congruent Involvement

The pattern of congruent involvement describes a style of interaction between generations within the family that is characterized by balance and smoothness. Within these families grandparents found outlets to meet their coping needs while at the same time found ways to attend to and support the needs of parents and grandchildren. Parents viewed these grandparents as having found meaningful expressions for their involvement with the family and the blind grandchild. Grandparent-grandchild interactions were based on the grandparents' understanding of the special developmental and social characteristics of children with a severe visual impairment. Grandparent love and discipline came in the form of emphasizing the "normal" or "regular kid" aspects and were viewed positively by

parents. The family legacy was one that valued differences and acceptance of visually impaired persons. There was a feeling of comfortableness and a philosophy of "getting on with life" apparent within the generations of these families.

Incongruent Involvement (Time-to-warm-up families)

The second type of intergenerational style, incongruent involvement, describes families in which parents expressed concern not about the desire of grandparents to be involved, but rather a comfortableness with actual involvement. Overall, there were many indications that these grandparents wanted to be supportive of the parents, wanted to have meaningful relationships with their grandchild, wanted to be able to cope in a manner that did not create sadness or further demands on those around them, and wanted to be open to reevaluating any existing negative stereotypes about blind individuals. This style was labeled incongruent because there was an intergenerational imbalance between what was needed or wanted and what the individuals were able to do in the present.

Two themes were apparent from the data that partially explained the imbalance: a) the blind child's immediate family was very busy meeting the care demands of day-to-day life and for a variety of reasons was not

available as a resource to the grandparents in helping them come to know their grandchild or find meaningful grandparent roles; and b) grandparents, unable to cope with their sadness or distress of having a blind grandchild, were not as available to their grandchild or the needs of the family.

Incongruent Uninvolvement

The intergenerational style of incongruent uninvolvement was the most difficult for parents of blind children in this study. The imbalance in this type of uninvolvement was a result of either an intrusive grandparent presence, or a parental disappointment at the grandparents seemingly lack of interest in the family. In either case the grandparents were perceived by the parents as unavailable to the real needs of the parents and family. Grandparent-parent interactions related to the blind child were superficial in nature, with parents sharing diagnosis and treatment information but interactions were characterized by an overall tone of tension. Parents expressed concern over their inability to understand the grandparents' response and what they could do to make relationships better. Grandparent-grandchild interactions were either very limited or inappropriate in nature. One grandfather was observed giving a toy to the sibling of a blind

child in the blind child's presence. When the blind child asked what was given to the sibling, the grandfather said, "Nothing," and told the sibling to be quiet. The family legacy in this family was one characterized by stereotypes of blind individuals as less capable and holding less potential to live a full, productive life.

Congruent Uninvolvement

There were no data to support a fourth type of grandparent-family response, congruent uninvolvement; however, it is the logical fourth possibility given the three intergenerational relationships observed. This type of family response could be similar to the concept of emotional cut-off described by Bowen (1985) in which adult family members of one generation emotionally or physically distance themselves from their parents in an attempt to cope with unresolved issues of differentiation. This style of family involvement may be more familiar to mental health clinicians and may require a different research strategy for empirical description.

CHAPTER 4

Discussion

The nature of intergenerational relationships has been identified as one of several significant factors determining the overall family coping strategy (Kodadek & Haylor, 1990). Families who functioned most smoothly were characterized by intergenerational relationships that were mutually supportive. Evidence from this analysis suggested that grandparents were deeply impacted by the diagnosis of blindness in a grandchild. In turn, the visually impaired grandchild's family was concerned and influenced by the grandparents' responses to the disabled grandchild. Intergenerational relationships were viewed by some families as an valuable resource, and by others as an additional demand on the family.

The data suggested that just as grandparents with non-disabled children find different ways of being involved in their grandchildren's lives, so did these grandparents. Grandparents in this study were indulgent, nurturing, playful, wise, involved or distant: descriptors consistent with conceptualization in the area (Kivnick, 1982; Kornhaber & Woodward, 1981; Neugarten & Weinstein, 1964).

This study provides beginning insight into the family and cultural context in which grandparent roles

are played out, and a flavor for the experience of grandparent response to a child with severe visual impairment. Within a context of initial deep sadness, limited knowledge about the expected growth and development of blind children, a disruption to the expected life course of one's adult child, and varied stereotypes of blindness, the dimensions or types of grandparents take on different meanings. As grandparents came to understand the meaning of blindness and their grandchild they often shifted from an uninvolved, emotionally distant, or formal style to one that included storytelling, play, and protection.

Implications for Research and Practice

Research. The results of this study should not be considered exhaustive, but rather a beginning interpretive analysis of issues that deserve further study. Data were gathered from the perspective of the parents only and the question deserves more extensive phenomenological study. Further study based on data collected from parents, grandparents, and grandchildren would add depth and clarity to this analysis.

Nurses working with these families would be a valuable resource in identifying and describing the existence of congruent uninvolved families. A research strategy such as that employed by Benner (1984) in which nurses would reflect on their clinical practice

with these families would facilitate further understanding of the complexity of intergenerational relationships.

Practice. The data from this analysis suggested that families who experienced a grandparent as uninvolved may need nursing support. Intervention could take place in a number of ways: with the immediate family of the blind child, with the grandparents, with the grandparent and grandchild, or with a combination of these approaches. For those grandparents who want to be involved but are having difficulty finding a way to do this, education regarding the differences in child development or the opportunity to talk privately with the nurse may provide the possibility for addressing unique key issues. For those families in which grandparents seem unable or unwilling to involve themselves in their grandchild's life, the nurse may need to work with the family as they work toward resolution of the hurt and anger often experienced under these circumstances. For some grandparents, repeated exposure to the blind grandchild provided the opportunity for grandparents to come to know their grandchild as a human being who happened to be blind rather than a blind grandchild.

Based on the clinical experience of the author, subsequent to this study, it can be said that some

grandparents are deeply saddened by their blind grandchildren. With the passage of time and unresolved grief, the prospect of knowing how to address the intergenerational distance that may be present becomes even more difficult for grandparents and parents.

Nurses are often privileged to experience vulnerable moments with families. With sensitive and thoughtful care that incorporates family meanings, nurses have many possibilities to facilitate smooth functioning among generations in the family.

References

- Barranti, C.C. (1985). The grandparent/grandchild relationship: Family resource in an era of voluntary bonds. Family Relations, 34, 343-352.
- Benner, P. (1984). From novice to expert: Excellence and power in clinical nursing practice. Menlo Park, CA: Wesley-Addison.
- Berns, J.H. (1980). Grandparents of handicapped children. Social Work, 25, 238-239.
- Bowen, M. (1985). Family therapy in clinical practice. New York: Jason Aronson.
- Emerson, R.M., (Ed), (1983). Contemporary field research (pp.93-105). Boston: Little, Brown & Co..
- Harris, S.L., Handleman, J.S., & Palmer, C. (1985). Parents and grandparents view the autistic child. Journal of Autism and Developmental Disorders, 15(2), 127-137.
- Hagestad, G.O., & Burton, L. (1986). Grandparenthood, life context, and family development. American Behavioral Scientist, 29(4), 471-484.

- Haylor, M.J., & Kodadek, S.M. (1988). Parents' perceptions of grandparent response to a blind grandchild. Paper presented 3rd Annual Beta Psi Chapter Sigma Theta Tau Research Conference, Portland, Oregon.
- Kivnick, H.Q., (1982). Grandparenthood: An overview of meaning and mental health. The Gerontologist, 22(1), 59-66.
- Kivnick, H.Q. (1983). Dimensions of grandparenthood meaning: Deductive conceptualization and empirical derivation. Journal of Personality and Social Psychology, 44(5), 1056-1068.
- Kodadek, S.M. (1985). Parents' perceptions of the experience of caring for a blind child. Grant proposal. Portland: Oregon Health Sciences University, School of Nursing, Office of Research Development and Utilization.
- Kodadek, S.M., & Haylor, M.J. (1988). Parents' perceptions of the experience of caring for a blind child. Final report. Portland: Oregon Health Sciences University, School of Nursing, Office of Research Development and Utilization.

- Kodadek, S.M., & Haylor, M.J. (1990). Using interpretive methods to understand family caregiving when a child is blind. Journal of Pediatric Nursing, 5(1), 42-49.
- Kornhaber, A. (1985). Grandparenthood and the "New Social Contract." In V.L. Bengston & J.F. Robertson (Eds.), Grandparenthood (pp. 159-171). Beverly Hills, CA: Sage.
- Kornhaber, A., & Woodward, K.L. (1981). Grandparents/Grandchildren: The vital connection. Garden City, New York: Doubleday.
- Lofland, J., & Lofland, L. (1984). Analyzing social settings: A guide to qualitative observation and analysis. Belmont, CA: Wadsworth Publishing Company.
- Neugarten, B., & Weinstein, K. (1964). The changing American grandparents. Journal of Marriage and the Family, 26, 199-204.
- Uphold, C.R., & Harper, D.C. (1986). Methodological issues in intergenerational family nursing research. Advances in Nursing Science, 8(3), 38-49.
- Wood, V. (1982). Grandparenthood: An ambiguous role. Generations, 22, 22-23, 35.

Wood, V., & Robertson, J. (1976). The significance of grandparenthood. In J. Gubrium (Ed), Time, roles and self in old age. New York: Human Sciences Press.

Abstract

Title: Intergenerational Relationships when a Child
is Blind

Author: Ma

Approved:

Sheila M. Kodadek, R.N., Ph.D., MRP Advisor

This report was drawn from a larger qualitative descriptive study conducted by Kodadek and Haylor (1988) which was designed to explore parents' perceptions of the experience of caring for a blind child. In this paper, parents' perceptions of grandparent responses to the child are explored in depth. Twenty parents from 12 families were interviewed using an open-ended interview guide. Taped interviews were transcribed and analyzed using interpretive analysis and the qualitative data analysis strategy recommended by Lofland and Lofland (1984).

Analysis revealed four sub-topical categories or themes around which parents described grandparent responses to a child with severe visual impairment: parent-grandparent interactions, grandparent-grandchild interactions, observations of grandparent coping, and the family legacy or evidence of the transmission of intergenerational values. A qualitative matrix using the four qualitative themes produced a typology of grandparent involvement with the family: congruent

involvement, incongruent involvement, and incongruent uninvolvement. Implications for nursing research and practice are identified.