

The process of empowerment in mothers of chronically ill children

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As a result of advances in scientific knowledge and technology, the number of children living with chronic illness is ever increasing. The burden of responsibility for the care of these children falls increasingly on the involved parents and, particularly, on mothers. In spite of the challenges that chronic childhood illness presents, many families are able to adapt to their situation and develop a sense of control over their lives. A sense of control has been associated with the notion of empowerment. Following a theoretical analysis, empowerment was conceptualized as a social process of recognizing, promoting and enhancing people's abilities to meet their own needs, solve their own problems, and mobilize the necessary resources in order to feel in control of their own lives. To understand the concept of empowerment from an empirical perspective, a fieldwork study was undertaken to describe the process of empowerment as it pertains to mothers of chronically ill children. This paper presents the process of empowerment that occurred in these mothers. Four components of the process of empowerment emerged: discovering reality, critical reflection, taking charge, and holding on. As a result of the study, empowerment was reconceptualized as largely a personal process in which individuals developed and employed the necessary knowledge, competence and confidence for making their voices heard. Participatory competence — the ability to be heard by those in power — was the outcome of this process. Although the unique finding in this study suggests that the process of empowerment was largely intrapersonal, there was a relational element in the process. Clearly, the intrapersonal and interpersonal processes of empowerment are intertwined.

INTRODUCTION: HYBRID MODEL

The concept of empowerment has not been empirically studied within a nursing context. Because it reflects a process, it is difficult to operationalize and no single measure can capture it adequately (Rappaport 1984). Using the hybrid model of concept development (Schwartz-Barcott & Kim 1986, 1993), a fieldwork study was conducted to further refine the concept of empowerment in relation to mothers of chronically ill children (Gibson 1993). The

hybrid model interfaces theoretical analysis with empirical observation and is composed of three phases.

In phase 1, the initial, theoretical phase, the concept of empowerment was searched for in the literature and analysed for meaning and measurement. In the second phase, which overlapped with the first, field research methods (participant observation and in-depth interviewing) were employed to collect qualitative data for further analysis of the concept. In phase 2, a fieldwork site was chosen, major questions to guide the research were formulated, cases

were selected, and data were collected and analysed Phase 3 interfaced the theoretical analysis with insights gained from empirical observations during the fieldwork phase (Schwartz-Barcott & Kim 1986)

Setting

Phase 2 of the study took place over a 12-month period on a neurological unit in a 350-bed children's hospital in the north-eastern part of the United States of America Participant observation and in-depth interviewing methods were employed Participant observation is especially applicable for exploratory and descriptive studies that examine processes, relationships among people, continuities and patterns over time, and the immediate sociocultural context within which daily experience is grounded A holistic examination of the phenomenon is stressed as well as the importance of the context, setting and participants' frame of reference (Keith 1988, Lofland & Lofland 1984)

The goal of the in-depth interviews was to elicit the participants' interpretations of their experience by capturing how the world is perceived, understood and experienced by those whose lives are a part of it The use of interviewing with observation enhanced validity as it assured that the truth in observations was checked with the active questioning of the interview situation and *vice versa* (Chenitz & Swanson 1986, Schatzman & Strauss 1973) Participant observation also provided opportunities for prolonged contact with participants to validate aspects of the data and ensure the rigour of the study (Sandelowski *et al* 1989)

Sample

The criteria for sample selection included parents who had a child with a chronic neurological condition and who were considered by the professional staff on the unit to have a sense of control or degree of mastery over their situation However, identifying potential parents to participate in the study was a real challenge as many of the children's health care needs were very complex, the social issues for many of the families were overwhelming, and the parents clearly were very stressed

The final sample consisted of 12 mothers, ranging in age from 25 to 49 years, of neurologically challenged children, who ranged in age from 11 months to 16 years The limitation with this non-probability or judgement sampling is that it allows no way of knowing precisely the degree to which the sample corresponded to the universe it represents However, the focus of the study was to look at response patterns rather than the way behavioural traits or special individual characteristics are distributed in a known universe whose systematic nature is either taken for granted or ignored (Hornigmann 1970) Therefore, the sample was justified as appropriate to search for patterns

that occur in consideration of empowerment in mothers of neurologically challenged children

Most of the mothers were interviewed several times Therefore, multiple interviews had the advantage of enhancing optimal understanding and saturation as well as establishing validity in the interpretations of data analysis (Strauss & Corbin 1991)

Data analysis

The data were analysed in relation to the research questions and proceeded simultaneously with data collection All elements of data — transcribed interviews, field notes and memos — were read and re-read so that the researcher was fully immersed in and intimate with the data prior to intensive analysis Each interview was examined in detail and coded independently Initially, coding labels were chosen to reflect the actual words of the participants to avoid premature abstraction and distortion of meaning Categories were created from the interpretations of what the participants said The antecedents, context, contingencies and consequences were considered in relation to the categories

Memoranda were written in relation to various themes in the data and enabled the researcher to move from the data to a conceptual level (Miles & Huberman 1984) As Aamodt (1991) noted, this transformation of data from one level of analysis to another required a sense of awareness and an intuitive sense of the whole of the data

The themes reflected only the content of the interviews To capture the process of empowerment, the interviews were re-written in a chronological sequence The mothers' stories were written in a descriptive manner with little, if any, interpretation to avoid premature interpretation and explanation (Schwartz-Barcott & Kim 1986) The stories captured the mothers' feelings, responses, patterns and perspectives (Taylor & Bogdan 1984)

Following the hybrid model approach of concept development, a model case was selected that best represented the process of empowerment Subsequently, each interview was examined in relation to the model case and embellished aspects of the process Although each mother's experience was unique, there were remarkably consistent patterns During data analysis, there was an intense and intimate interplay among the researcher, the mothers, the data and the emergence of the process of empowerment As well, theoretical notes and memoranda were studied and integrated into the analysis Definitions of empowerment and its outcome were refined The pre-condition, influencing factors and consequences of empowerment were examined An analytic description of the process of empowerment follows

THE PROCESS OF EMPOWERMENT

A conceptual model of the process of empowerment in mothers of chronically ill children is visually depicted in Figure 1. The model reveals the mothers' commitment to, bond with and love for their child, which motivated and sustained the process of empowerment. Frustration was a powerful force that permeated the process and was a critical factor in helping the mothers to *discover reality*. Furthermore, frustration evoked ongoing cycles of *critical reflection* which subsequently enabled the mothers to *take charge* of their situation and, then, to *hold on* to their sense of power — even during changing circumstances. *Participatory competence* was the outcome of the process.

Although the process of empowerment is presented in a sequential manner in this paper, reality as it is lived and perceived is not entirely captured since, in the human experience, multiple events and processes occur simultaneously. The process of empowerment is iterative and interactive rather than linear in development. The components of the process of empowerment are interdependent and overlapping. However, this dynamic process can be analysed more clearly when considered sequentially — one component at a time. Consequently, the presentation of the process of empowerment which follows is more clearly delineated with discrete phases.

Precondition of the process of empowerment

As noted, the notion of empowerment was studied in mothers of neurologically challenged children. Although the children varied in the age at which they were diagnosed, the majority were diagnosed within the first 6 months of life. In all cases, the mother had developed a

strong bond with her child. The mothers' deep love of, real commitment to, and responsibility for their child, to ensure that their child received the best care possible, motivated and sustained the process of empowerment.

COMPONENTS OF THE PROCESS OF EMPOWERMENT

Discovering reality, diagnosis and post-diagnosis

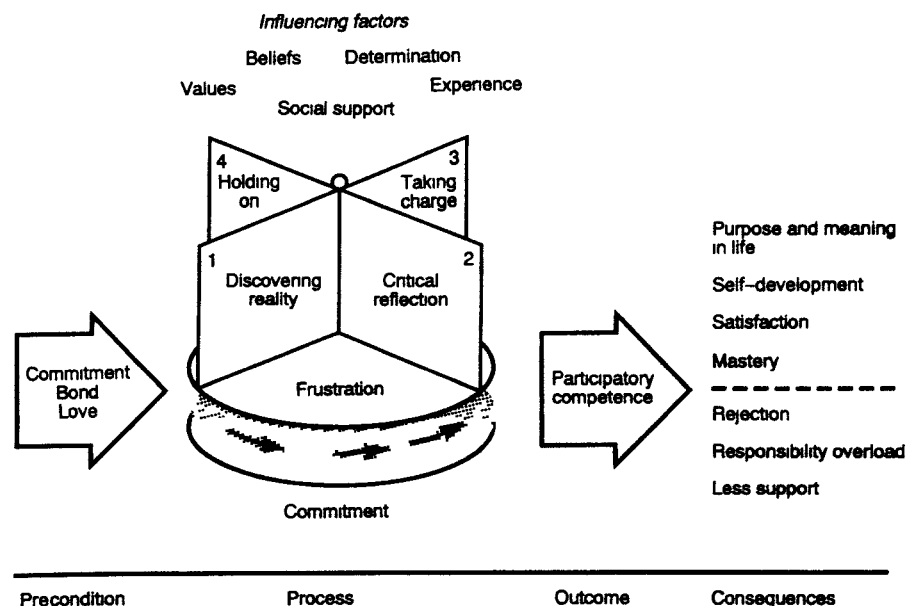
The mothers' responses to the diagnosis of a chronic neurological problem in their child were enigmatic. In the first phase of the process of empowerment, 'discovering reality', the mothers responded emotionally, cognitively and behaviourally.

Emotional responses

Many of the mothers realized that there was something wrong with their child. Although the diagnosis legitimated their concerns, they, nevertheless, were bewildered, shocked and confused, as well as frightened, anxious and angry. Because they did not believe or could not comprehend the implications of the diagnosis, they were unable to grasp the reality of the diagnosis and envision the future realistically. The ramifications of a long-term health problem in their child were incomprehensible. Nevertheless, the diagnosis initiated a grief response in the mothers.

When the child was diagnosed as an infant, mothers found it difficult to believe the negative realities that the child's health problem entailed. They believed it was too early to predict a child's potential when the infant was naturally helpless and dependent. When the child exhibited delays in development, they hoped that the child was 'slow' and would 'catch up'. They were driven by a sense

Figure 1 A conceptual model of the process of empowerment in mothers of chronically ill children



of hope and optimism that their situation would be different or would improve. Two mothers admitted to being very sceptical and were determined to prove to the doctors that they were wrong.

Marta's words best capture the myriad of emotional responses of many of the mothers. She was the mother of an 11-year-old boy who was severely retarded as a consequence of viral encephalitis contracted in the neonatal period. She related

It was not until Peter was 2 years old that reality finally hit. That definitely was the worst time. I was depressed. I cried a lot. In fact, my older son drew a picture of me and, in the picture, I was crying. I realized, then, all he saw his mother do was cry. I felt envy for the first time in my life. I avoided people with normal children. I felt it was just not fair. This was an awful feeling for me as I never knew envy before. I hated how I was feeling. I was real angry and jealous.

Although all of the mothers described a feeling of emotional turmoil and upset in the early months following the diagnosis, they fully invested themselves in caring for their child. Most of the mothers did not dwell on their grief responses. Yet, the mothers experienced a range of feelings as part of the process of accepting the situation and realizing that crucial aspects of the situation could not be changed.

Cognitive responses: the quest for information

Following the diagnosis, the mothers in this study felt very unsure and uncertain. During that time they were most receptive to outside help. They embarked upon a quest for information in order to understand their situation. They sought out as much information as possible — from books, pamphlets, doctors, nurses or other mothers in similar situations.

In the early stages they believed everything that was told to them was the truth. They relied on health care professionals to make sound decisions. The physician, in particular, was considered to be the ultimate expert. There was a strong sense of trust in people who provided care to the child. They expected that health care professionals would make the right decisions and would be available to them. Initially, they were more recipients of care rather than active participants in care. Because of their unfamiliarity with and inexperience of the situation, external sources of information were authoritative.

The mothers always had a strong need for information, to explain the child's aberrant health status, plans and rationale for care, and what they could do to help the child. Even when the information was distressing, the mothers felt a degree of comfort in knowing what was happening. Throughout the interviews many mothers recalled their anxiety and frustration when they did not understand what was happening.

Behavioural responses

Mothers assumed responsibility for the child's health and, in so doing, they did everything possible for their child. Many of the mothers reported that in dealing with their situation they merely were doing what was required. One mother simply said 'You just deal with things as they come'. In the mothers' minds, there was no choice. When applauded for their efforts, they simply responded that they were doing the only thing that they could do. There was no other option for the mother who loved and desired the best for her child. Simply not caring did not occur to her. The mother's own feelings of sadness, remorse and anger were channelled into an attitude that was described by many mothers as 'making the best of the situation as there is nothing else I can do'. In so doing, the mothers learned to see the positive aspects of their situation. Betty, the mother of a 16-year-old boy with neurofibromatosis who sustained a devastating stroke following surgery, commented

I really believe that if somebody has a positive attitude, that if it's going to go one way or the other, if there's a choice there, and they are positive about it, I really think you know, it's going to help them in the long run.

The mothers in this study did not think a lot about how they managed. Anna, a mother of a 7-year-old boy with a recurrent brain tumour, related 'You just don't think about these things'. In a similar observation, Benner & Wrubel (1989) have noted that coping strategies are seldom developed in a purely deliberative and conscious manner. People may have very little access to or understanding of their coping practices. Coping is their way of being in the world and understanding themselves.

Through caring for the child, mothers learned about their child. They discovered the unique personality characteristics of the child (particularly, if the child was diagnosed as an infant) and were able to discern the effect of the illness or chronic health condition on the child. They actively watched the child's responses and they noted the child's patterns and variations.

Mothers constantly monitored the child. Most of the mothers recorded information in a journal or on a calendar to keep a record of events the child experienced, progress, treatment and responses. Consequently, they were very cognizant of any change in their child. They were quickly able to discern problems and interpret symptoms and, possibly, recognized solutions that would work for their child. Clearly, mothers knew their child. This knowledge of the child integrated the biopsychosocial aspects of the child as well as the totality of all of the child's experience. The mother's knowledge was not only empirical but also intuitive.

As noted in the findings, initially, the mothers were unsure and uncertain. Because the situation was unfamiliar to them, they had nothing with which to compare

their assessments and experiences. Some mothers, intuitively, felt all was not well with their child — only to have their concerns minimized. Feedback from doctors and even family members led mothers to believe that they were over-protective or overly concerned. Because their concerns were not legitimated, they felt frustrated, confused and uncertain.

The role of frustration in the process of empowerment

Frustration was a predominant theme in all of the interviews. Mothers encountered numerous frustrations within the family, with the health care system, as well as within themselves.

Frustrations within the family mothers carry the burden

A dynamic developed in family relationships whereby the majority of caretaking activities were assumed by the mothers. Most of the mothers reported the frustration felt because the child's health care needs were primarily their responsibility. Because the fathers did not have the same investment in terms of the caretaking responsibilities for the child, their confidence and expertise in relation to the child's chronic health problem did not develop commensurately with the mothers'. Therefore, the burden of the child's health care needs fell on the mothers. The mother, even if she was working outside the home, took the child to the various appointments with doctors and stayed with the child during hospitalization. Many indicated that they did not receive the support they needed from their spouses.

The mothers were annoyed when their husbands did not want to listen to them while they talked about the child's health problem and the frustrations with the health care system. They speculated that their husbands did not like to see them upset or else they wanted to pacify them. Two mothers noted that all they wanted was an opportunity to talk. They did not want a solution from their husbands — they just wanted an opportunity to vent their feelings and be heard. When the mothers' attempts to share their innermost feelings were met by evaluation, reassurance or misunderstanding, they felt very much alone with their plight. Anna, the mother of a 6-year-old boy with a recurrent brain tumour, captured it best:

Ninety-five per cent of the time, things are fine but I do get frustrated and annoyed at him. I find it frustrating to try to tell him things and he says 'Don't worry, everything will be fine'. It's just like I don't have anything to worry about. He does not recognize my feelings and I find that so frustrating.

Alaina, the mother of a severely handicapped 13-year-old girl, further explained:

[My boyfriend] knows now to listen to me. He knows all I need to do is vent. He used to give me advice and he sensed I did not like that so he said to me at one time 'You don't want me to give you any advice, do you?' and I said 'No, all I want you to do is let me vent'.

Clearly, the child's health problems created tension between many of the mothers and fathers.

Two of the mothers were divorced. Both stated their marriages would have ended ultimately, but the presence of the chronic health problem in their child accelerated the demise of the marriage. Yet, both mothers were currently supported by men who willingly shared the responsibility of care for the child with the chronic health problem. They were able to discuss the situation with these men and felt that they were being listened to as well as supported. Lack of support and understanding from family members for many of the mothers was both frustrating and disappointing.

Frustrations with the health care system

Through the course of caring for the child, negative changes in the child's health status elicited concerns or anxieties in the mothers. Because of their concern and uncertainty as to what to do, they sought help from health care professionals. Mothers experienced strong feelings of frustration, particularly with physicians, when their concerns were minimized, negated or ignored.

Mothers described many kinds of irritations related to health care. Waiting was frustrating: waiting for the doctors or nurses to attend to the child — in the emergency department, in the hospital unit, or in the clinics, waiting for answers to questions, waiting for the child to heal or progress, or waiting for the child to have seizures when this was part of the diagnostic process. Travelling in and out of a large, congested city added to aggravations. Repeating the child's health history over and over as well as educating new residents were very irritating.

Also frustrating was not having answers to solve the child's health problem. Another dissatisfaction was the conflicting opinions of different doctors so that mothers felt uncertain as to what to do. Other aggravations related to fragmented specialization. What was also very difficult was not knowing or understanding what was happening to the child.

As well, mothers experienced frustrations when prescribed medications and treatments did not work as anticipated. Finally, another disappointment for one mother was that traditional medical care could not provide any hope for her child.

Frustrations with self

Additionally, mothers experienced frustrations with themselves when their customary ways of coping no longer were effective. One mother noted that she had to stop

focusing on herself — her sadness, envy and anger — and deal with her situation and make the best of what she could not change

Clearly, frustration was a predominant theme in all of the interviews. The frequency, intensity and duration of various frustrations evoked ongoing cycles of critical reflection which ultimately enabled the mothers to develop a sense of personal power and helped them to face reality.

Critical reflection

The escalation of frustrations forced the mothers to evaluate themselves and examine their situation critically. Unquestionably, their self-interests were threatened. Frustration, clearly, was a catalyst for growth and change and initiated the empowerment process.

Meanwhile, mothers developed confidence in their knowledge of and abilities to care for the child. They eventually came to the realization that they knew their child better than anyone else. They fully examined their situation to understand and determine wherein their difficulties lay and what they could do about them, in terms of their attitudes and behaviours. Throughout the process, they evaluated what was important for the child as well as for the family. They established priorities as they became acutely aware of their values, goals, wants and needs. As one mother reflected:

If anything good has come out of this, I smell the roses a lot more. I was a workaholic before and made time for the kids at the end of the day. Now the kids come first. The work is always there. I spend more time with my family — they come first.

The process of critical reflection was necessary for them to be able to take charge of their situation in a proactive manner and to develop a sense of personal power. Through the process of critical reflection, mothers became aware of their strengths, abilities and resources.

All of the mothers employed a positive style of thinking by making downward comparisons which enabled them to see their own situation more favourably. All of the mothers pointed out how the hospital experience made them realize how much worse their own situation could be. A focus on the positive aspects of the situation did not minimize in any way what the mothers lived with. Yet, their comfort and familiarity with their own situation made the situations of others seem worse. Furthermore, mothers learned to appreciate the inherent goodness within their situation. Mothers converted the energy from such negative emotions as frustration and anger into positive energy and problem-solving to make their situation better. All of the mothers noted how much they had learned to appreciate what they had and not to take aspects of life for granted anymore.

Through the process of critical reflection, the mothers

also searched for a purpose or found meaning in their plight. One mother explained:

I know Peter has taught me what is most important. I see parents having such great expectations and demands of their children. I want to say 'Just enjoy your children for what they are'.

Younger (1991) discovered, in accepting the reality of the situation, individuals reorganize the meaning of life. Furthermore, they finally realize that events cannot be changed. Therefore, they relinquish their hopeless expectations and become free from longing for what has been lost. They accept what cannot be changed and make a conscious decision to move forward.

Nevertheless, the mothers realized that, inevitably, there would be happenings that were not planned which must be managed. Diane, the mother of an 18-month-old boy with myelomenigocele, said 'I'm learning to realize that getting upset doesn't change anything'. The mothers learned to control their emotional responses, to feel less stressed and, therefore, to conserve energy. They acknowledged that, from their travails, they were stronger, more efficacious and more purposeful. Therefore, through cycles of critical reflection, mothers developed an increasing awareness of their strengths as well as the confidence to be assertive and to act upon their needs. During the process, there seemed to be either a dramatic turning point or a demarcation that had some significance to the mothers which triggered a conscious response of their taking hold of their situation and then taking charge.

Taking charge

Once the mothers were aware of their strengths and were confident in their knowledge of their child, they took charge of the situation. No longer did the mothers subordinate their perspectives and judgements to those of others. As Belenky *et al* (1986) contend, the orientation to authority shifts from external to internal as women learn to listen to their own voice. The mothers learned to assert themselves and, in so doing, their growing sense of confidence was reinforced.

Taking charge entailed (a) advocating for the child, (b) learning the ropes to interact efficiently with the health care system, (c) learning to persist to get the attention they needed for the child, (d) negotiating with health care professionals so that opinions and requests were heard, and (e) establishing a partnership in which there was mutual respect and open communication between the health care professionals and the mothers as well as commitment to a common goal.

Advocating for the child

Mothers saw themselves as an advocate for their child. Because their child was so dependent upon them for care,

the mothers felt compelled to speak on their child's behalf because they realized that no one else would

Learning the ropes

One mother explained 'It's a matter of learning the ropes' to deal efficiently with the health care system. Her 18-month-old child with myelomeningocele experienced nine surgical operations since his birth. She noted 'I've learned a lot and I'm learning to get it right'. One mother of a child with a complex seizure disorder learned to call the doctor or the nurse practitioner or to alert the epilepsy team that her child was coming into the emergency department. In so doing, she did not have to wait for hours and recite the child's history to a resident or a doctor who not only was unfamiliar with the child but who may not understand the uniqueness of the child's regimen.

Learning to persist

The mothers relentlessly continued to assert themselves and to advocate for their child. Many of the mothers learned to write down their questions so that they were assured of getting the information they wanted. Some also requested another medical opinion. One young mother of a 5-month-old baby met with the departmental chief to get the action she needed for medical care for her child. Some mothers enlisted the support of nurses because they believed that if the doctors would not listen to them they would listen to the nurses. With time, even the mothers who considered themselves to be shy, became more comfortable with, and assertive in, their interactions with the doctors. There was a consistent theme of 'never giving up'. The mothers persevered to get the best care they could for their child.

Driving negotiation in the hospital setting

All of the mothers reported that the hospital experience was very stressful. Mothers found it very difficult to have a sense of power in a setting where the practice model was hierarchical and medical needs were placed as primal. Yet, the mothers, in their own way, initiated changes in their interactions with health care professionals and most became adept at making their voices heard. Clearly, the mothers were the driving force for negotiations with health care professionals. Because they firmly believed that they knew their child the best, they did not surrender their power passively to physicians or to anyone else.

Establishing partnerships

Mothers wanted a partnership with the health care team — in terms of being an associate, a collaborator and an active participant in the child's care. Although mothers needed up-to-date information concerning the health status of the child, they wanted respect and acknowledgement for their assessments, opinions and suggestions in terms of the child's health problem. They wanted their

abilities and expertise to be recognized so that they could be a full participant in their child's health care. The frustrations the mothers repeatedly acknowledged related to not being heard.

Contingent on establishing partnerships was the need for each party to acknowledge the expertise of the other. The mothers acknowledged the expertise of the doctors and other health care professionals. However, it was not always apparent that the doctors respected the mother's expertise in knowing her child.

Therefore, integral to the process of empowerment was being able to achieve a goal in co-operation with others. Keys to successful partnerships were mutual respect and open communication between the mother and health care professional. The mothers in this study derived a sense of satisfaction when there was a mutual exchange with health care professionals and a commitment to a common goal. Alana, the mother of a severely retarded 13-year-old daughter, stated it well:

Working as a team is best — the doctor knows the diagnosis but the mother knows the child. Both perspectives are important. It is important that the team is open and receptive to ideas. Working as a team really makes a difference. I have every confidence that my child would get the care she needs but I believe she would be in the hospital longer without my input.

Nevertheless, the mothers acknowledged that they did not want total control of the situation. In situations which were unfamiliar to them, they relied on the expertise of the health care professionals. Yet they wanted opportunities for discussion so that they were fully aware of the situation. What they also wanted was recognition for their insights, suggestions, abilities and skills in caring for their child. In other words, they wanted to be heard. Alana said it best:

I like my opinion to be listened to. I don't really want total control but I want the doctors and nurses to be open to listen to me.

Holding on

The final phase of the process of empowerment was 'holding on'. As a result of the mothers' awareness of their strengths, competencies and capabilities, they were able to maintain their own sense of power even during changing circumstances. Although the mothers experienced feelings of disappointment, frustration and anger, their core abilities endured. In 'holding on', the mothers developed a sense of personal control in terms of regulating their own responses. Through ongoing cycles of critical reflection, the mothers became cognizant of the dynamics within situations and, therefore, they tried to be understanding and patient when outcomes were not what they anticipated. Consequently, they continued to persist with their efforts to attain a desired outcome, established new time frames

in which to evaluate the situation, or else developed alternative strategies

All of the mothers were remarkable in their perseverance and persistence. Those mothers who were more able to hold on to their power experienced a sense of satisfaction from knowing that they were doing all they could. Other mothers were dependent on being heard in order to hold on to their power.

Many of the mothers were involved with other activities, such as work, school, recreation, or support groups. Such involvement provided a balance in their lives that renewed their energies to deal with their situation and sustained their ability to 'hold on'.

OUTCOME OF THE PROCESS OF EMPOWERMENT

The phases of discovering reality, critical reflection, taking charge and holding on indicate that the process of empowerment was largely intrapersonal. The mothers developed and employed the necessary knowledge, competence and confidence for making their voices heard. In becoming empowered, mothers developed confidence in their knowledge of their child and in their decision-making for their child. Decisions were consistent with their goals and their own sense of meaning. Mothers became a voice of authority and were able to collaborate effectively with health care professionals. Thus, the mothers had a personal sense of taking charge and an ability to be assertive and to take action consistent with their values, beliefs, goals and needs.

The mothers were empowered when they were full participants in their child's care — in working towards mutually agreed upon goals for their child with health care professionals — and when they were heard. The mothers did not want to dictate to health care professionals what should be done for the child. They also did not want the physicians to agree with their requests or suggestions without some confirmatory dialogue. What these mothers needed most in order to be empowered was to be heard by the health care professionals.

Therefore, the outcome of the process of empowerment in this group of mothers was conceptualized using Kieffer's (1984) language of *participatory competence*. Kieffer defined participatory competence as an abiding set of commitments and capabilities. In this study, Kieffer's definition was refined and redefined as the ability to be heard by those in power. The group of mothers in this study who attained participatory competence, (a) had developed sound knowledge of their child, (b) were competent in caring for their child and in making decisions consistent with what they knew of the child, and (c) had developed confidence in communicating what was best for the child.

Although the three indicators reflect personal competence, there is a relational aspect of empowerment in

being heard. In being heard, the mothers perceived that health care professionals were receptive and responsive to what they had to say and that their expertise was recognized. Mothers who attained participatory competence were associates, collaborators and participants in their child's care.

The mothers' ability to hold on to their own sense of power was not contingent on an attainment of participatory competence. Mothers could still have a sense of personal power even when they were not heard. However, the mothers who were the most empowered attained participatory competence. Therefore, the relational or interpersonal aspect of empowerment provided greater empowering capability. On the other hand, one mother attained participatory competence without demonstrating a sense of personal competence. Yet, in being heard, this mother was provided with an opportunity for dialogue which ultimately enhanced the care of her child.

CONSEQUENCES OF THE PROCESS OF EMPOWERMENT

For all of the mothers in the study, empowerment was very much a learning process. Self-development was enhanced as the mothers tapped into their strengths and capabilities. Mothers gained new competencies, felt stronger and became more efficacious. In essence, they had gained a sense of mastery of their situation. Clearly, the mothers experienced transformative change within themselves. The mothers found meaning within their experiences. The ability to find meaning in their situation enabled the mothers to have a positive orientation towards life. They integrated their experiences — their disappointments, shattered dreams and successes — to find a sense of purpose in them and to reach out to help others.

Not only did the mothers seek fulfilment in helping others in similar circumstances, they also channelled their energies into school, work or recreation. In investing in other activities and relationships, the mothers found alternative sources of satisfaction to make up for what they had lost. The mothers were remarkable in their abilities to transcend their difficulties and to move forward. Most of the mothers were able to plan for the future. All of the mothers derived a sense of satisfaction when they became fully aware of their personal competencies and, even more, when they were heard.

Nevertheless, the process of empowerment resulted in some negative consequences. Negative consequences of participatory competence occurred even when the mothers felt heard. At times, health care professionals were unwilling to share their power and they rejected the mothers' input and suggestions. On the other hand, when the health care professionals recognized the mothers' competence, they placed too much responsibility on the mothers to make the right decisions and to assume the total care of

the child Too much responsibility was stressful for the mothers, particularly in unfamiliar situations Furthermore, mothers who were deemed to be empowered did not receive the support they required to deal with the stressors that occur as a result of hospitalization Clearly, health care professionals need to be sensitive to the negative effects of empowerment

INFLUENCING FACTORS IN THE PROCESS OF EMPOWERMENT

Factors that influenced the process of empowerment were both intrapersonal as well as interpersonal Intrapersonal factors included the mothers' values, beliefs, determination and experience Social support was the interpersonal factor that influenced the process of empowerment

Values

The mothers' values were implicit influential factors in the process of empowerment The values of the child, of mothering, and of a sense of family were salient in this study

Beliefs

The mothers' beliefs were influential factors in helping them to deal with their difficulties All of the mothers in the study had beliefs that the future could be influenced Their beliefs for a hopeful future were reflected in their positive, optimistic and forward thinking orientation towards life The mothers also trusted their own abilities to care for their child as well as the health care system to provide their child with the best health care possible Some of the mothers expressed belief in God or in a higher power that helped them

Determination

The mothers' strong will and motivation to ensure that their child received the best care possible reflected their determination All of the mothers were remarkable in their persistence and perseverance to do everything that they possibly could for their child

Experience

The mothers' past experiences were potent influential factors in the process of empowerment Experiences within their family of origin, from work situations, and from educational contexts, all influenced how the mothers managed the challenges engendered in having a chronically ill child Additionally, all of the mothers learned through their experiences of caring for the affected child As Kieffer (1984) noted, there was no other substitute for learning through experience

Each of the aforementioned intrapersonal factors needs further in-depth research to determine its influence on the process of empowerment Given the unique finding in this study, that the process of empowerment was largely intrapersonal, future research is needed to determine what personal factors are most salient

Social support

All of the mothers benefited from the support they received This support came from many sources — spouse, family, friends, health care professionals, and other mothers in similar situations

The mothers profited from the support that they received from health care professionals Specifically, information about the child's health status, plans for care and future projections were important to all of the mothers They felt supported when they saw that the health care professionals were acting in the child's best interest Mothers who were less confident benefited from the support of nurses who acted as advocates on their behalf Furthermore, mothers appreciated acknowledgement from health care professionals for their unfailing efforts in caring so well for their child

Additionally, many of the mothers benefited from respite care for their child They appreciated this relief which provided them with an opportunity to balance their lives Furthermore, all of the children in the study were well linked with services in the community, such as early intervention, physical therapy and home care

Most of the mothers in the study derived support from another mother in a similar situation There was giving as well as receiving of support as the mothers shared their experiences with each other, encouraged one another and learned from one another Clearly, the mothers experienced a real sense of being understood and of connection through their association with other mothers

In understanding the process of empowerment, an important consideration is the interconnectedness of the person and the environment The process of empowerment takes place in a context, which includes interactions with others Positive interactions with others are encouraging, strengthening and edifying On the other hand, lack of support and understanding is frustrating, disappointing and minimizing Yet, paradoxically, both positive and negative support influenced the process of empowerment in this study The conflicted support, which was manifest in feelings of frustration, was a catalyst for constructive action The interactions — both positive and negative — with others were foundational for critical reflection Then, the mothers were able to take charge and move forward

Unlike Kieffer's (1984) and Lord & Farlow's (1990) findings, most of the mothers in this study did not have a facilitator or external enabler to mentor them along their path to empowerment In fact, only one mother identified

any one particular person who was influential along the way. A nursery school teacher was very influential in involving this mother in meaningful employment as well as in linking her with other mothers in similar circumstances. Future research that focuses on social support will provide an understanding of what, when and how support is efficacious during the empowerment process.

CONCLUSIONS

The process of empowerment has been described from an empirical perspective as it specifically pertained to mothers of neurologically challenged children. Although the generalizability of the findings is limited, the nature of the research methodology employed to describe and define the process of empowerment and its outcome has analytical generalizability in which the theory that is generated can be used to examine other situations (Hutchinson 1990). Attempts to examine other situations from the theoretical perspective presented in this paper as well as endeavours to research the concept within different contexts are strongly recommended.

The conceptualization of empowerment that emerged from this study is remarkably distinct from the conceptualization of empowerment that has been depicted in the literature. A pervasive finding in the study was how alone and isolated the mothers were — which contrasts with other studies in which a sense of community was critical to personal empowerment. Nursing interventions directed at facilitating a connection with others in similar circumstances, as well as research efforts to understand the process of empowerment in mothers who have such support, will shed further light on the phenomenon of empowerment in mothers of chronically ill children.

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References

- Aamodt A (1991) Ethnography and epistemology generating nursing knowledge. In *Qualitative Nursing Research: A Contemporary Dialogue* (Morse J ed), Sage Publications, Newbury Park, pp 40–53.
- Belenky M, Clinchy B, Goldberger N & Tarule J (1986) *Women's Ways of Knowing: The Development of Self, Voice, and Mind*. Basic Books, New York.
- Benner P & Wrubel J (1989) *The Primacy of Caring: Stress and Coping in Health and Illness*. Addison-Wesley, Reading, Massachusetts.
- Chentz C & Swanson J (1986) *From Practice to Grounded Theory: Qualitative Research in Nursing*. Addison-Wesley, Menlo Park, California.
- Gibson C (1993) A study of empowerment in mothers of chronically ill children (doctoral dissertation, Boston College, 1993). *Dissertation Abstracts International* 94-02789.
- Honigmann J (1970) Sampling in ethnographic field work. In *A Handbook of Method in Cultural Anthropology* (Naroll R & Cohen R eds), Columbia University Press, New York, pp 266–281.
- Hutchinson S (1990) The case study approach. In *Advanced Nursing Science Through Research (volume II)* (Moody L ed), Sage Publications, Newbury Park, pp 177–213.
- Kieffer C (1984) Citizen empowerment: a developmental perspective. *Prevention in Human Services* 3(2/3), 9–36.
- Keith J (1988) Participant observation. In *Methodological Issues in Aging Research* (Schae K, Campbell R, Meredith W & Rawlings S eds), Springer, New York, pp 211–230.
- Lofland J & Lofland L (1984) *Analyzing Social Settings*. Wadsworth, Belmont, California.
- Lord J & Farlow D (1990) A study of personal empowerment implications for health promotion. *Health Promotion* 29(2), 2–8.
- Miles M & Huberman A M (1984) *Qualitative Data Analysis: A Sourcebook of New Methods*. Sage, Newbury Park.
- Rappaport J (1984) Studies in empowerment: introduction to the issue. *Prevention in Human Services* 3(2/3), 1–7.
- Sandelowski M, Davis D & Harris B (1989) Artful design: writing the proposal for research in the naturalist paradigm. *Research in Nursing and Health* 12(2), 77–84.
- Schatzman L & Strauss A (1973) *Field Research: Strategies for a Natural Sociology*. Prentice-Hall, Englewood Cliffs, New Jersey.
- Schwartz-Barcott D & Kim H S (1986) A hybrid model for concept development. In *Nursing Research: Methodology, Issues and Implementations* (Chinn P L ed), Aspen Publishers, Rockville, Maryland, pp 91–101.
- Schwartz-Barcott D & Kim H S (1993) An expansion and elaboration of the hybrid model of concept development. In *Concept Development in Nursing: Foundations, Techniques, and Applications* (Rodgers B L & Knaf K A eds), W B Saunders, Philadelphia, pp 107–133.
- Strauss A & Corbin J (1991) *Basics of Qualitative Research: Grounded Theory, Procedures and Techniques*. Sage Publications, Newbury Park.
- Taylor S & Bogdan R (1984) *Introduction to Qualitative Research Methods*. John Wiley, New York.
- Younger J (1991) A theory of mastery. *Advances in Nursing Science* 14(1), 76–89.

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