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Symbolic Interactionism: A Perspective for Understanding Parent-Nurse Interactions Following the Birth of a Child with Down’s Syndrome

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The birth of a child with Down’s syndrome is a challenge to parental and societal expectations. Feelings of shock, sadness, confusion, denial, fear, anger, guilt, and helplessness may be evoked. In this paper, the impact of stigma on individuals with Down’s syndrome and their families will be reviewed to clarify why interactions between parents and others need to be explored. Next, the central concepts important to the symbolic interactionist perspective will be reviewed. Then, qualitative data from an ongoing study of 90 parents of children with Down’s syndrome (ages 3 months to 18 years) will be presented to illustrate how symbolic interactionism can be applied to the care of children with Down’s syndrome and their families. Finally, implications for nurses working with families that include a child with Down’s syndrome will be addressed.

The birth of a child with Down’s syndrome is a challenge to parental and societal expectations. Generally a child’s birth is considered to be a time for celebration, and parents expect to be proud of their newborn child (Parks, 1977). While some

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prospective parents express concern about the health and normalcy of their unborn child (Glazer, 1980; Light & Fenster, 1974; Rubin, 1972; Sherwen, 1981), the actual birth of a child with a disability is usually an unexpected event (Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975; Parks, 1977; Van Riper & Selder, 1989). An overwhelming sense of failure may take the place of the pride new parents expected to feel after months, possibly years, of hoping and planning (Waechter, 1977). Feelings of shock, confusion, sadness, denial, fear, anger, guilt, and helplessness may be evoked following awareness of the child's diagnosis (Childs, 1985; Drotar et al., 1975; Horan, 1982; Mary, 1990; Walden, 1989).

According to McCann (1987), this other-than-expected birth experience often creates tremendous anxiety, a sense of helplessness, and an overwhelming feeling of responsibility on the part of nurses toward the parents. In an attempt to deal with their own discomfort, nurses and other clinicians may avoid interacting with parents and may actually increase or prolong parental feelings of uncertainty, meaninglessness and powerlessness (Cooper, 1991; Darling, 1988; Seligman & Darling, 1989; Van Riper & Selder, 1989). In addition, because relatives, friends, and co-workers may be uncertain about how to respond, societal rituals surrounding the birth (e.g., people coming to the hospital to see the newborn-infant, people sending or bringing cards and presents) may be altered (Holaday, 1989; Roberts, 1984).

A theoretical perspective that may help nurses to work more effectively with families following the birth of a child with Down's syndrome is symbolic interactionism. Symbolic interactionists are primarily concerned with discovering how people define and experience their world. The underlying premise of this perspective is that the subjective aspects of a situation must be explored because the meanings people assign to situations ultimately organize their behavior (Stryker & Statham, 1985). Rather than merely reacting to the environmental forces that impinge upon them, people interpret or define their situation based on the symbolic meanings they have learned through interaction with others and their beliefs about the importance of the situation as defined (Burr, Leigh, Day, & Constantine, 1979).

An individual's definition of the situation includes an assignment of positions to the other individuals in the situation, thus setting up expectations concerning their behavior. An individual's definition of the situation also includes an assessment of self, including the assignment of positional identities to oneself (Stryker, 1967). Based on the individual's definition of the situation, the individual perceives, makes judgments, and initiates action (Schvanveldt, 1973). Behaviors cannot be understood or interpreted unless one is aware of how people define their situation (Knafl & Deatrick, 1990).

According to the symbolic interactionist perspective, parental responses following the birth of a child with Down's syndrome need to be interpreted within the context of the parents' interactional histories prior to the child's birth and interactions with the child and others (clinicians, relatives, friends, and co-workers) following the child's birth (Seligman & Darling, 1989). By influencing how parents define their situation, these social interactions also influence how parents respond
to their child and how they deal with the ongoing challenges associated with parenting a child with Down’s syndrome.

In this paper, the impact of stigma on individuals with Down’s syndrome and their families is reviewed to clarify why parent-other interactions need to be explored. The central concepts important to the symbolic interactionist perspective are also reviewed. In addition, qualitative data from an ongoing study of 90 parents of children with Down’s syndrome (ages 3 months to 18 years) are presented to illustrate how symbolic interactionism can be applied to the care of children with Down’s syndrome and their families, and implications for nurses are addressed.

Impact of Stigma

Although societal attitudes toward individuals with disabilities have become more positive, many people in our society continue to stigmatize individuals with Down’s syndrome and their families (Fine & Asch, 1988; Pueschel, 1985; Seligman & Darling, 1989; Springer & Steege, 1980; West, 1984). According to Goffman (1963), stigmatized individuals possess an attribute that makes them different from others. This attribute is deeply discrediting, and it is incongruous with society’s stereotype of what a given individual should be. A discrepancy exists between the expected and the actual. This discrepancy can impact upon the person’s social identity. The person is thought of as not quite human (Goffman).

Ainlay, Coleman, and Becker (1986) noted that people qualify as stigmatized only within the context of a particular culture or social situation. Stigma is a reflection of culture itself, not a property of individuals. When individuals fail to meet the expectations of a particular culture or social group because they possess undesirable or unexpected attributes, they are stigmatized (Saylor, 1990). The normal and the stigmatized are not persons, but perspectives (Goffman, 1963).

In addition to specifying which characteristics are desirable and which are undesirable, society also teaches how to react to stigmatized individuals. People learn how to respond to individuals with disabilities by watching and listening to others in their social group (Saylor, 1990). Although social responses are not always negative, common responses toward individuals with disabilities include stereotyping and restricting or terminating social relations (Stafford & Scott, 1986). Individuals with disabilities are often avoided because they remind others that everyone is vulnerable and life is not always predictable (Katz, 1981). Giedeman and Roth (1980) described children in America who have disabilities as “the unexpected minority.” According to Giedeman and Roth, “to grow up handicapped in America is to grow up in a society that, because of its misreading of the significance is never entirely human in the way it treats the person within” (p. 301).

Goffman (1963) suggested that not only are stigmatized individuals credited and relegated to a morally inferior status in American society, but their close associates
come to bear a "courtesy stigma." Just as family members vicariously share the pain and uncertainty associated with a member's chronic illness or disability, they also vicariously experience the psychosocial threats associated with the illness or disability (Barbarin, 1986). Family members are often subjected to the same negative social responses as the stigmatized person (Goffman). Courtesy stigmas, like personal stigmas, may result in the restriction or termination of social relations (Stafford & Scott, 1986; West, 1984).

Prior to their child's birth, most parents of children with Down's syndrome have had limited or no past experience with individuals with disabilities. In general, these parents have been exposed primarily to the stereotypes and stigmatizing attitudes toward individuals with disabilities that pervade our culture (Seligman & Darling, 1989). Initial interactions with clinicians, both nurses and physicians, may influence how parents respond following awareness of their child's diagnosis. Many clinicians have had little or no contact with individuals with disabilities either in their training or in their personal lives (Seligman & Darling). Because clinicians share the values and expectations of their particular social group, they too may accept the societal belief that intelligence, beauty, and physical perfection are morally best (Saylor, 1990). Some clinicians find it difficult to work with individuals who have illnesses or disabilities that cannot be cured (Myers, 1983). For example, in a study by Darling (1979), one physician said: "I don't enjoy it . . . I don't really enjoy a really handicapped child who comes in drooling, can't walk and so forth . . . Medicine is geared to the perfect human body. Something you can't do anything about challenges the doctor and reminds him of his own inabilities" (p. 215).

Clinicians who hold stigmatizing attitudes toward individuals with disabilities may find it difficult to understand that a child with Down's syndrome may have a positive impact on his or her family. In a study by Blackard and Barsch (1982), parents and clinicians differed significantly in their responses to a questionnaire about the impact of children with disabilities on their families. When compared to parental responses, responses of clinicians overestimated the negative impact of the child on family relationships. In a recent study by Cooley, Graham, Moeschler, and Graham (1990), 48% of the genetic counselors believed that the problems associated with parenting a child with Down's syndrome outweigh the benefits, while only 6% of mothers and 17% of nurses agreed.

Symbolic Interactionist Perspective

Although no one description of the symbolic interactionist perspective is universally accepted, similarities do exist among the various orientations. The central concepts discussed by most symbolic interactionists include: (1) society (2) self, and (3) mind.
Society

Blumer (1967) described society as symbolic interaction. According to Blumer, symbolic interaction refers to the distinctive and peculiar character of interactions that take place between human beings. Rather than merely reacting to the actions of another individual, humans interpret or define these actions. The way an individual responds is based on the meaning that the individual attaches to the situation. Mead (1934) defined meaning as the imaginative completion of an act or the mental picture of actions or experiences symbolized by an object or event. According to Mead, meaning is implicit wherever there is present a specific triadic relationship constituted of a conversation of gestures: a gesture by one person, a response to that gesture by a second person, and the completion of the social act initiated by the gesture of the first person. A gesture is any part of an act that comes to be an indication of parts of the act yet to happen. Stryker and Statham (1985) suggest that social interaction and meaning are interdependent; meaning is shaped in and by social interaction, and meaning shapes the course of interaction.

Society does not exist as a static entity, but is continuously created and recreated as people interact with each other. Stryker and Statham (1985) described the fundamental image of social reality as “a flow of events involving two or more interacting persons” (p. 314). No two individuals interpret their social reality in the exact same way, but social interaction is made possible by taking the role of others (Mead, 1934). Taking the role of others is a process by which a person puts himself or herself in the place of the other person and responds as that other person is presumed to respond. Others can be generalized others (e.g., other new parents) or significant others (e.g., spouse, friend, mentor). An individual generally gives highest priority to the responses of significant others (Stryker, 1967). By taking the role of others, individuals can see themselves as others see them, and arouse in themselves the responses that they might call out in others (Meltzer, 1967).

The accuracy of role-taking depends on how well meanings are shared (Stryker & Statham, 1985). When the meaning of an event or situation is not shared by the individuals who are interacting, a critical problem may occur. The individuals may find it difficult to anticipate or predict the actions of each other. A solution to this problem lies in the emergence of significant symbols (Stryker & Statham, 1985). Significant symbols are symbols that mean relatively the same thing and imply relatively the same set of subsequent behaviors to the individual who produced the gesture and the individual who perceives it (Stryker, 1967). It is somewhat doubtful whether any symbol will imply the same behaviors to any two individuals.

While some symbolic interactionists do not use the concept of role, because they believe that it denies that behavior patterns and norms emerge in the course of interactions, the majority of symbolic interactionists use the concept of role. According to Burr et al. (1979), roles are integrated sets of social norms that are understood to be societal expectations regarding how one should or should not behave at specific times and under specific conditions. Rose (1962) used the term
role to refer to a cluster of related values and meanings that guide and direct an individual's behavior in a certain social setting. Rose suggested that an individual is likely to play many different roles in the course of a day, and role-playing constitutes much of the individual's behavior.

Self

Mead (1934) considered the ability of human beings to act toward themselves as they might act toward others as a central mechanism by which human beings deal with their world. For example, human beings can get angry with themselves, they can rebuff themselves, they can argue with themselves, they can bolster themselves, and they can plan what they are going to do. To state that human beings can respond to their own gestures implies that human beings possess a self (Meltzer, 1967). According to Mead (1934), the self is "that which is an object to itself" (p. 140). Stryker and Statham (1985) described the self as a social structure that emerges from social interaction. The self is established, maintained, and altered in and through communication (Stone, 1962). The evolution of self is gradual and continual (Stryker, 1967).

The evolving self includes the physical self and the complex social self. The physical self refers to one's body and its various characteristics. Cooley (1967) described the social self as the reflected or looking-glass self. According to Cooley, "the thing that moves us to pride or shame is not the mere mechanical reflection of ourselves, but an imputed sentiment, the imagined effect of this reflection upon another's mind" (p. 217). Mead (1934) identified the 'Me' and the 'I' as two interacting components of the social self. The Me component is comprised of the attitudes, definitions, and expectations of others (Meltzer, 1967). The I component represents the spontaneous, creative, and unorganized aspects of human behavior (Meltzer, 1967; Stryker & Statham, 1985).

Mind

"The concept of mind refers to a mental process or activity, not a physical entity such as the brain" (Manis & Meltzer, 1967, p. 301). The brain is necessary for the emergence of mind, but social interaction or individuals in society using their brains, not brains per se, make the mind (Troyer, 1967). According to Mead (1934), minded behavior arises around problems and it involves a temporary inhibition of action while the individual tries out various approaches to the problem in his or her imagination. This inhibition of action implies that the individual constructs an act, rather than responding in a predetermined manner (Meltzer, 1967). Through a process of internal conversation, the individual is able to address self from the standpoint of the generalized other. The individual is able to present to the
self, tentatively and in advance of overt behavior, symbolic representations of different possibilities or alternatives to future action. The individual is able to imagine or think about possible consequences. Animals lack introspective abilities, so they are unable to engage in this type of abstract or reflective thinking, (Meltzer, 1967).

Application of Symbolic Interactionism to Practice

In this section of the paper, qualitative data from a study of 90 parents of children with Down's syndrome (between 3 months to 18 years of age) are presented to illustrate how nurses can apply the perspective of symbolic interactionism to the care of children with Down’s syndrome and their families. Among other self-reported assessments of the perceived impact of initial and ongoing interactions of parents with others (physicians, nurses, other children, and society in general), parents answered open-ended questions regarding how they first learned of their child’s diagnosis and the initial responses of clinicians and others following awareness of their child’s diagnosis.

Shattered Dreams and Expectations

During the prenatal period, parents construct a mental image of their infant. This mental image or fantasy infant is composed of real infants, family photograph infants, and dream infants (Horan, 1982). Interactions with friends, relatives, and co-workers help to shape this mental image (Seligman & Darling, 1989). In addition, the image is reflective of self and significant others (Solnit & Stark, 1961). Because this fantasy infant originated in the self-concept and its specific attributes are derived from a society that values health, beauty, and wholeness, an infant with Down’s syndrome will most likely be viewed as very discrepant from the fantasy infant (Horan; Walden, 1989; West, 1984).

Mental images or expectations regarding the birth experience are socially constructed during the prenatal period. The media tends to portray birth as a very beautiful, exciting experience. Parents are bombarded by advertisements that include pictures of happy new parents and perfectly formed infants who look like the “Gerber baby.” Prepared childbirth classes tend to prepare parents for the “typical” birth experience. Although the possibility of encountering unexpected events (e.g., preterm delivery, emergency cesarean section) is generally addressed in class, the possibility of giving birth to a child with a disability is seldom mentioned. Most parents expect that the end product of the birth experience will be a healthy, nondisabled infant (Murphy & Pueschel, 1975; Seligman & Darling, 1989).

According to the symbolic interactionist perspective, the birth of a child with Down’s syndrome may, at least initially, symbolize shattered dreams and expecta-
tions regarding the fantasy child, the birth experience, and the future of their family. One mother wrote:

When a child is conceived, a dream is born. The dream images a healthy, strong, and clever child who with confidence and success, fulfills a parent's desire to bear a child . . . When we received the news that she had Down's syndrome, it was as if the child of our dreams had died. I can remember spending hours thinking back on my pregnancy and asking what caused this to happen. Asking questions like, what did I do to deserve this? I can remember my greatest concern initially was who will take care of this child if something happens to us and what will she be able to do. I can remember thinking I never wanted to have another child. Instead of being happy when I left the hospital, I can remember it seeming to be the worst day of my life. I can remember going to the grocery store and looking at every baby and toddler to see what they were doing. I can remember attending church for months and not being able to sing a hymn.

Another mother recalled her initial feelings after her husband informed her of their child’s diagnosis:

When he finally broke it to me, I felt my whole world crumbling in around me. All my dreams for my little girl were shattered in that very instant. My husband and I held each other and cried.

The incongruence between expectations and reality may alter initial parent-child interactions. Healthy, nondisabled infants provide cues that guide parents in initiating, modulating, and terminating interactions (Quinn, 1991). Because they often have marked hypotonicity and show delays in onset of eye contact (Berger & Cunningham, 1981), children with Down's syndrome may be less able to provide clear signals to their parents. Parents may assume that the infant's atypical response is due to their own failure as parents. This sense of failure as a parent may be generalized to a sense of failure as a person, and parents may temporarily distance themselves both physically and emotionally from their infant to avoid further discomfort (Edwards & Saunders, 1990).

Nurses can do much to influence the outcome of parent-child interactions, but they need to recognize that the quality of these interactions will affect the parent's self-confidence (Edwards & Saunders, 1990). Parents who are forced to interact with their infant before they are emotionally ready may develop feelings of disappointment, guilt, inadequacy, uselessness, and profound sadness. For example, one mother recalled how painful her initial interaction with her son was:
A nurse said, "You must bond and touch him. Put your hand into the incubator and touch him." I just sobbed. She then forced me by physically taking my hand and making me touch my baby and stroke his face. I am crying as I write this, it is painful still.

A similar experience was reported by another mother. She said:

One nurse who cared for the babies in the nursery seemed to push our daughter on us. I, emotionally, was not capable of caring for her and did not want to nurse her.

The following quote illustrates that some parents may be afraid to express negative feelings about this other-than-expected birth experience because they are worried that nurses and other clinicians will label them as bad parents.

I cried a lot in the hospital, yet I had our baby with me every second. I worried that the nurses would think I was a terrible mother because I cried so much. I told that to a nurse and her reply was, "It's because you love him so much that you are crying." I felt that they didn't doubt me.

Being Told

Parents' perceptions of how they were informed of their child's diagnosis may have a major impact on how parents define this other-than-expected parenting experience, how they interact with their child, and how they respond to the ongoing challenges associated with parenting a child with a disability (Darling, 1979; Halpern, 1984; Springer & Steele, 1980). One father said, "We happened to have an excellent physician who really helped set the tone on how we feel about our child." A mother of a 2-year-old reported a similar experience. She said:

The pediatrician entered the room and sat down with us, held our hands, and explained the best that he could what having such a child meant. He reassured us that this was a time for celebration, that she would make us happier than we could ever imagine and that the only thing that made her different was that one (lousy) chromosome. She would be able to do anything she wants (read, write, talk, walk, etc), it might just take her a little longer than most. But, give her time, you'll see . . . After his talk with us, I didn't cry anymore. I no longer felt sorry for myself.

In contrast, a mother of a 1-year-old boy commented on how scared she felt after talking to the physician. According to this mother
The only choices the doctor gave me were: (1) I would take him home and love him. (2) Put him in an institution. (3) Order them to cut off his food supply . . . What no one told me and I desperately needed to hear, was that these children generate more love than is imaginable. I was scared to death of my baby . . . for the first few months, I felt suicidal.

Pueschel (1985) reported that there has been marked progress over the past decades in the approach to counseling parents following the birth of a child with Down's syndrome. Nearly one-half of the parents in a survey of 285 parents of children with Down's syndrome born between 1950 and 1972 (Pueschel & Murphy, 1976) were dissatisfied with the initial counseling they received from physicians. Many of the parents described physicians as abrupt and unsympathetic, often recommending that parents place their child in an institution. In a second survey, this time of 139 parents of children with Down's syndrome born between 1973 and 1982 (Pueschel, 1985), 65% of the parents reported that they had received appropriate, supportive counseling following the birth of their child with Down's syndrome. Pueschel stressed that although the comparison of data from the two surveys shows significant statistical differences, there is still a need for further improvement in parent counseling. Thirty-five percent of the parents in the later study were dissatisfied with initial counseling because they perceived the physician as unkind, blunt, and unsympathetic.

The present study included parents of children with Down's syndrome born between 1973 and 1991 (66% were born after 1982). The results of this study support Pueschel's (1985) suggestion that some clinicians need to improve the strategies they use when counseling parents following the birth of a child with Down's syndrome. Less than one-half of the parents reported that the initial information they received was accurate and encouraging. Over one-third of the parents in this study described the initial information they received as pessimistic and discouraging. The following quotes illustrate that even though attitudes toward individuals with disabilities have become more positive, some parents are still being given inaccurate information in a cold, pessimistic manner. According to a mother of a 13-year-old:

The doctor we had chosen to be the physician for T. came into the room at about 7 a.m. and told me “your baby is mongoloid. I do not take care of retarded children. You need another doctor.” I asked, “Who?” He mentioned someone my other daughter had seen awhile back. When my husband returned at about 8:30 a.m., this other doctor then came in. She told us T. would never move, never talk, be a total vegetable, and should be put in an institution. When we said, “No, we'll keep her, she's ours,” she asked our ages and we told her. Then she pointed to my husband and said, “This is your fault.”
A mother who delivered her infant in the emergency room of a small rural hospital in 1988 recalled how she first learned of her child’s diagnosis of Down’s syndrome:

The emergency room physician came in while I was still being cleaned up from delivering. He walked over, looked very quickly at me, then away, and said, “You have a mongoloid baby; that means she’s mentally retarded, she has extra chromosomes and looks different. You have any questions?” My response was, “Not right now.” He left immediately, I lay there trying to figure out what in the world was going on and was trying to remember the newer used term for mongoloid.

Even more recently, a mother who underwent an amniocentesis in 1989 was given very negative information by her physician:

The doctor who told us, tried to convince us to get an abortion. He said that there was no guarantee that the baby would not be a “vegetable” and that having a handicapped child was going to be very hard on us and our family.

According to the symbolic interactionist perspective (Blumer, 1967), individuals respond to the action of others based on their own interpretation of what the other person said or did. Thus, how parents respond to the news that their child is other-than-expected will be based on the meaning(s) that parents attach to the situation. Understanding the parent’s interpretation of what the person informing them said or did is crucial to understanding initial and ongoing parental responses.

Even if the mother and father are told about their child’s disability at the same time, they may respond very differently based on the way in which they interpret the situation. For example, one mother recalled how her initial response differed from her husband’s initial response:

My husband burst into tears, his face got red. I could see the pain he was in. I had a few tears fall down my cheeks. The rest of the day I comforted him. I was the strong one taking care of him.

This mother went on to report that two weeks later her husband was the strong one, giving her the support she needed. She noted that they “went through the shock at different times.”

**Initial Responses by Clinicians**

According to symbolic interactionists, role-taking gives the person an opportunity to view the situation from another person’s perspective. Clinicians and parents
often have very different life experiences, thus they may differ in how they define the birth of a child with Down’s syndrome. Clinicians may find it very difficult to take the role of the parent of a child syndrome, and parents likewise may have difficulty understanding the clinician’s point of view (Seligman & Darling, 1989).

Clinicians may assume that the birth of a child with a disability will make parents feel inadequate, depressed, embarrassed, or angry. Rather than provide parents with support, guidance, and empathy, clinicians may search for signs of dysfunction. While clinicians may define their efforts as monitoring vulnerable individuals and their families, parents may define the efforts of clinicians as prying and judgmental. Parents may feel that they are being watched and analyzed. One mother reported:

After he went through his reasons why he knew our son had Down’s syndrome, he said, “Are you two always this calm? Why don’t you react!” I guess because my husband and I didn’t cry or say anything. Both of said to each other afterwards, we should have said to that doctor, “What do you want us to do or say, ‘Send him back, we don’t want him?’” He left us feeling guilty.

Another mother recalled having a similar experience:

I felt that they expected me to fall apart. Which I didn’t. The feeling I got from everyone was that I should at some time soon fall apart and when this didn’t happen, that they felt there was something wrong with me or that I had no feeling at all. I’m the kind of person who takes what life gives and makes it work for you. To me, my baby was here, I loved him, what he had or didn’t have, there was no way to change that. For me to fall apart would make things worse for the rest of my family.

Clinicians often assume that the new family wants increased privacy, and they may move the mother to a private room or a room at the end of the hall. This act, which was intended to be supportive and caring, may be perceived by parents as stigmatizing and isolating. One mother who was put in a private room because of her unstable health status recalled:

I was put in isolation because of the shock, and my blood pressure was low. I didn’t find this out until long after I was home. I thought during the time I was in isolation that my family rejected me for having this child. I lost track of time for 3 to 4 days. I wish someone would have explained this to me. I felt all alone.
According to another mother:

I was put in a private room farthest from the nursery. I never got to know other mothers. It may have prolonged the sadness.

Some clinicians avoid emotion-laden encounters with new parents in an attempt to deal with their own feelings of uncertainty and inadequacy. The following two quotes illustrate that some clinicians may avoid interacting with parents, or avoid talking about the child's diagnosis of Down's syndrome.

No one discussed the situation. They seemed afraid to discuss it. Looking back now I wish someone had given us some information. I knew they cared, they were just afraid to talk.

Not one nurse ever mentioned Down's syndrome. As I left the hospital four days after my son's birth, a nurse handed me a book and said, "You might need this."

Parents who believe that they are being watched, analyzed, isolated, or avoided may enter a state of anomie, that is, they may feel both powerlessness and meaninglessness in relation to this other-than-expected birth situation (Darling, 1988; Seligman & Darling, 1989). Parents may not only start to question the value and worth of their newborn child, but also their own capacity as a parent and their own status in society.

Some parents believe that all clinicians should be experts on Down's syndrome. They may find it very difficult to interact with clinicians who seem inadequately prepared to deal with children with disabilities and their families. One parent wrote:

It was a sad experience. As a young adult, I felt I knew more about Down's syndrome than the attending physician or our family physician.

Parents may be unable to take the role of a clinician, and thus unable to understand why some clinicians have difficulty interacting with parents in a sensitive, caring manner. In addition, the fact that many clinicians find it difficult to address the emotional needs of parents does not go unnoticed by parents. According to one mother:

No one volunteered any helpful information. I had to ask. They were concerned about our physical health, but not how I was handling anything emotionally.

Another mother noted:
I would have liked the nurses to have been more personable with me, instead of acting cool towards me. I am really a nice person, but most nurses were afraid to get close.

A third mother gave some suggestions for nurses. She wrote:

Do not force a mother to bond or touch until the mother decides that it is time. Take the time to sit down and say you understand the emotions and feelings that we must be going through. Look at whether our needs and emotions are being addressed, not just the medical care of our baby.

**Redefining the Situation**

While parents may initially view the birth of a child with Down's syndrome as a tragedy, their opinions may shift dramatically once they become acquainted with the child. Getting to know the child as a person first, then a person with a disability, may help parents to redefine the situation. One mother reported that the birth of her child broadened her family's world. According to this mother,

All of us have learned to look beyond face value. Before our son was born, there were no disabilities in our very large family. I think it at first shook our perfect world but now in 3 years our world has broadened. We have all watched something wonderful grow out of what was initially felt as a tragedy.

Another mother noted that her definition of the situation changed over time. She wrote:

We have sad days and happy days. Mostly happy. Our son has really showed us what love is, unconditional love, and what is really important in this life on earth. He is helping us to set our priorities. I do remember feeling numb for about two weeks. Crying a lot. But day by day I became more accepting of the situation.

Clinicians can play a major role in helping parents to define their situation more optimistically. The following quotes illustrate how the response of a nurse can help parents view the situation more optimistically.

I was crying one day after my son's birth because I had not yet seen his eyes open. A few hours later a nurse came rushing in my room with my son in tow. She was smiling. She had hurried to bring him to me while his eyes were open. She had paid attention to something
said and had made a special effort to make me feel better. There was one nurse who gave us a hug and said, "You'll do just fine. Take him home and love him. That helped to bring us where we are today.

If parents receive little or no encouragement to rework their initial definition of the situation, they may never redefine the situation or the process of redefining may be very lengthy. According to one mother,

They generally ignored me and avoided talking about my daughter. They didn't realize what I wanted and needed was someone to say, "Now she's here, it's time to go on." Instead they made time stand still. I couldn't move ahead.

Implications for Nurses

In order to provide appropriate interventions to parents and other family members following the birth of a child with Down's syndrome, nurses need to gain some understanding of how members of the child's family define the situation. Symbolic interactionists argue that meanings and values are the most direct cause of an individual's behavior. Understanding how family members define the experience of raising a child with Down's syndrome will help nurses to assess the responses of family members and provide individual and family interventions that are timely and relevant.

Nurses need to look beyond the outward behavior of family members and explore what feelings and perceptions are directing the behavior (Edwards & Saunders, 1990). It should not be assumed that a mother who quickly sends her infant back to the nursery is rejecting her infant. This mother may have difficulty moving into the parental role because she is frightened and unsure of what is expected of parents of children with Down's syndrome. Through their actions, nurses can help parents to see that the child with Down's syndrome is a child first and needs many of the same things that nondisabled children need.

It is important also for nurses to gain some insights into possible discrepancies in definitions within a family. Parents and other family members need opportunities to express and discuss openly both negative and positive feelings regarding this experience. Nurses can help family members understand that each person will define the situation somewhat uniquely, and this definition will constantly be changing and evolving.

For some parents, it may be helpful to talk to other parents of children with Down's syndrome. Many communities have Parent-to-Parent groups that will arrange a match between the new family and another family that includes a child.
with Down's syndrome. In addition to parents who identify what is expected of them in their new role as parents of a child with Down's syndrome, talking to other parents during parent-to-parent visits or at a support group meeting gives new parents a chance to validate their thoughts and feelings. New parents also find it reassuring to see that there are parents of children with Down's syndrome who have continued to grow and develop in spite of, or because of, the birth of a child with Down's syndrome.

Most new parents, but especially those who find it too difficult to talk to clinicians and other parents, will find it beneficial to read accurate, up-to-date books (e.g., *Babies with Down's Syndrome: A New Parents Guide* by K. Stray-Gunderson) and other publications (e.g., *Down's syndrome: Papers and Abstracts for Professionals*). Reading factual information in terms that they can understand helps parents to acknowledge their new reality. National (e.g., National Down's Syndrome Congress, National Down's Syndrome Society) and state organizations (e.g., Down's Syndrome Association of Wisconsin) are excellent sources of information.

Nurses need to be aware that their own definition of the situation may differ from how family members define the situation. In order for nurses to become more effective in their interactions with new parents of children with Down's syndrome, nurses need to become more effective in their ability to take the role of a parent of a child with Down's syndrome. Nurses can improve their role-taking abilities by: (a) exploring their own attitudes regarding individuals with Down's syndrome and their families; (b) becoming aware of their own limitations (e.g., difficulty dealing with sensitive issues, difficulty showing emotions); (c) keeping pace with not only the advances in medical science regarding individuals with Down's syndrome, but also significant changes in educational, vocational, and recreational programs open to individuals with disabilities and their families; (d) interacting with individuals with disabilities on a more frequent basis; (e) reading personal accounts written by parents and siblings of individuals with disabilities; and (f) attending support group meetings.

In summary, nurses may find the symbolic interactionist perspective very helpful when they work with families following the birth of a child with Down's syndrome. Once nurses gain insight into the feelings and perceptions that are guiding the behavior of family members, nurses will be able to address issues that family members consider to be important. Rather than work in opposition, or in parallel, nurses and family members can work together on goals that are individual or family specific. When family members begin to feel empowered, the child, the family, and the nurses will benefit.

**Acknowledgement**

This paper is dedicated to the memory of Robert Phillips, a friend, who willingly shared his definition of the experience of parenting Melissa, who has Down's syndrome.
References


Down’s Syndrome Association of Wisconsin, P.O. Box 23384, Milwaukee, WI 53223.

Down’s Syndrome: Papers and Abstracts for Professionals, 200 Rabbit Road, Gaithersburg, MD 20878.


National Down's Syndrome Congress, 1800 Dempster Street, Park Ridge, IL 60068–1146.

National Down's Syndrome Society, 141 Fifth Avenue, New York 10010.


