

COPING WITH THE BIRTH OF AN ANOMALOUS INFANT

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Congenital anomalies are caused by a multiplicity of agents, most as yet not known. Although congenital anomalies are not frequent, their occurrence is always traumatic for the whole family. In addition to the usual adjustments related to maturational crisis that occur as a part of the normal process of parenthood, families of anomalous infants have to cope with the superimposed situational crisis.

When an anomalous infant is born, many reactions and adjustments occur. Knowledge and understanding of parental reactions will help the nurse to assess and plan appropriate interventions. This paper will examine the impact that an anomalous infant has on the family and consider ways in which health professionals can enhance a positive adjustment to the crisis of birth of an anomalous infant.

REACTIONS OF PARENTS

The birth of an anomalous infant is always difficult to accept. Expectant parents make a significant material and emotional investment toward the birth of a baby during the course of a normal pregnancy. Couples fantasize their unborn infant as a perfectly healthy copy of themselves. Each parent develops a mental picture of their baby. Each has an idea about the sex, colour of the eyes, hair, complexion and so on.

Although the anticipation is based on the model most desired, a normal child, the literature suggests that no mother is immune to the dreadful possibility that her child may not be normal. The fear of giving birth to an abnormal child is frequently expressed by pregnant women (Caplan, 1959; Goodrich, 1961). When there is a discrepancy between the expectations, hopes and wishes for a normal child, and the reality presented by the anomalous child at birth, the disappointment may be overwhelming, causing emotional trauma for the parents.

It is important for the parents, both psychologically and culturally, to produce a healthy baby. Waechter (1970) states "Our culture sets rigid standards in regard to appearance and intellectual functioning. Perfectly formed, beautiful children represent the societal ideal; therefore, any visible physical defect or intellectual impairment has unique significance as a basis for class and caste distinctions" (p. 205).

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The society in which the parents live will influence the intensity of their feelings toward their anomalous infant.

When an anomalous infant is born the mother may identify with the deformed child and feel personally responsible for the defect. Whenever the diagnosis of a physical or mental defect is made, the reactions of parents are very similar. Certain characteristic behaviours of parents observed are feelings of shock, denial, grief, anger and guilt responses, sadness, anxiety, biological inadequacy and embarrassment varying in intensity and duration (Mercer, 1974; Waechter, 1977; Waisbern, 1980). Parents react to the birth of an anomalous infant with anxiety, depression and low self-esteem regardless of the severity of the infant's abnormality (Murphy, 1982). The sources of the most serious anxiety are the threats to the parents' sense of ego integrity, self-worth and to their social status (Waechter, 1970). It is an emotionally vulnerable time for the family. Because of the emotional tragedy involved, grief reactions and the use of defence mechanisms should not be considered pathological at this time.

Grief

Most parents, professionals and authors cite shock and disbelief as a common normal initial reaction (Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975; Schild, 1971; Wolfensberger & Menolascino, 1970). "The purpose of the shock is to protect the functional ability of the self or ego from what is perceived to be overwhelming threat. Shock insulates the self from alien, unwanted, unacceptable reality allowing that reality to filter through only in manageable amounts" (Sieffert, 1978, p. 35). This reaction may then be followed by a stunned, numbed state characterized by inability to accept the defect of the infant and behaviours such as confusion, disorganization and immobilization.

Great demands are made upon the parents by the birth of a defective child; little time is allowed, however, for them to work through the feeling of loss of the perfect child before they are expected to invest their energies in caring for the unexpected defective infant (Solnit & Stark, 1961). During the mourning period the parents temporarily withdraw from their environment, withdrawing psychic energy from the lost love object in which it had been invested. Withdrawal is only the first step in the ego's attempt to cope with the crisis (Ross, 1964). Mercer (1974) observed withdrawal responses to be high during the first week and again at three months. Parents' concerns focus first on their own needs — what does the anomaly mean to them personally? They need to achieve mastery over their own feelings before they can consider the child's needs and what the defect will mean to it (Mercer, 1974).

Grief and mourning reaction may be delayed in the parents of an anomalous infant for months or even years. Kennedy (1970) quotes Siggins that "Mourning may be postponed if the ego is engaged in some other more consuming task" (p. 411). Kennedy observed variations in grief process between those mothers who were engaged in the care of their infants and those mothers whose infants were not living at home. The question may be raised if the demands of caring for an anomalous infant may encourage the postponement of a grief reaction. On the basis of his research Kennedy (1970) sees emotionally giving up the desired infant and accepting the real infant as consecutive rather than simultaneous processes.

Anger and Guilt

Feelings of anger and guilt are often observed in the parents of anomalous infants. As the shock subsides, a sense of anger grows. The feelings of failure and frustration can produce anger in the parents of anomalous infants. Anger stems from having hopes, wishes and dreams forever destroyed. The anger is initially directed at the infant as the obvious source of the frustration of the hopes and expectations which parents built before its birth. The mere thought of rejecting a defective infant creates intense anxiety in the parents. Acknowledging the rejection of the anomalous infant is most difficult for the parents. Defences are used against these unacceptable feelings (Zuk, 1962). Parents may deny the true focus of their feelings by displacement of anger from the disappointing child to themselves. The mother may experience her anger as a personal guilt. She may blame herself for what has happened to the child. The mother asks repeatedly if the problem is due to something she did or did not do. Every possibility is considered and explored in detail. As one mother said, "I don't know what I did wrong, I am trying to think if I had a cold in the first trimester; Should I have taken that aspirin?" Little things that were not thought about during pregnancy hit with devastating force when an anomalous infant is born. This emotional working through is a necessary part of adjusting to the birth of an anomalous infant.

There may be considerable anger toward the professionals or other members of the family. One woman placed the blame on what she saw as inadequate prenatal care she received. Her comments were, "My doctor did not spend much time with me during my prenatal visits; I was in and out of his office in about five minutes." These statements are expressions of feelings of frustration and hostility.

In some religious groups it is believed that malformations are God's punishment for sins committed. This may arouse guilt feelings in the mother, who searches her memory for some specific act of commission or omission (Lobo & Webb, 1970; Smithells, 1963). The mother asks "Why me? What have I done?" (Winick, 1967). The mother perceives her child's defect as a punishment for some imagined or real behaviour on her part which she felt was bad (Cohen, 1963).

Unresolved parental guilt and anger can result in overprotectiveness or guilty attachment to the defective infant and neglect of other family members (Lobo & Webb, 1970). The mother's unconscious wish that the child had never been born and her death wish for the child are countered by the dynamic opposite reaction which helps her to shift her focus to being overprotective (Ross, 1964). The neurotic devotion of a mother to her defective child is more often an expression of her own needs than a response to her child's needs (Forrer, 1969). Parents need to know that feelings of rejection and death wishes for the child are normal reactions and that acknowledging such feelings reflects a means of coping.

Many variables may influence immediate and long-term adjustment of the parents to their anomalous infant. Maturational and external situational factors influence the normal coping effort. For example, maturational factors are the kind of psychological preparation made by the parents during pregnancy for the coming child and past coping experiences with other major losses. Among the numerous situational factors are the sociological and cultural considerations, family stability, the nature and extent of the deformity, the attitudes of professional personnel at the birth of an anomalous infant, availability of community services, and the degree of energy available to parents to deal with the crisis (Butani, 1974; Waechter, 1977).

HOW NURSES CAN FACILITATE ADJUSTMENT OF PARENTS

Nursing care should be directed first at helping parents cope with their initial shock and reactions to the child's anomaly, and secondly at helping parents to become more comfortable in caring for their newborn infant. Nurses have a unique opportunity for the development of rapport and trust with parents early in their care.

Nurses working in maternity settings should have a knowledge and understanding of parents' reactions as a means of coping with the birth of an anomalous infant. This knowledge will aid the nurse to accurately assess psychosocial needs of the family, provide appropriate early interventions, demonstrate sensitivity along with an attitude of caring and warmth. The understanding and counselling provided by the nurse to the parent can facilitate a more appropriate grieving process and attachment between the parent and the defective child.

With the birth of an anomalous infant many feelings are aroused and the professional personnel must deal with conflicting emotions. Some of the questions that need to be dealt with almost immediately in the delivery room are — who is to tell the parents and how much should they be told? The impact of the birth of an anomalous infant is

so overwhelming for the health care team in the delivery room that the parents can sense that something is wrong.

Most parents prefer to be informed of the baby's condition together. Parents need to share their feelings and support each other (Irvin, Kennel & Klaus, 1982). If possible, the nurse should be present when the physician informs the parents, to reinforce the explanation. It is important that the information given to the parents be consistent. The need to confirm other people's assessments of the infant is greater when conflicting information is given to the mothers (Kikuchi, 1983). The explanations must be kept simple and in the terms that the parents can understand. Lengthy medical explanations should be avoided at this time as parents cannot absorb all the information; they are under a great deal of stress. One mother recalled that after hearing the doctor say the baby was "Mongoloid," she could not remember anything else her physician said. "The word 'Mongoloid' kept ringing in my ears, I could not think or do anything."

One of the first questions a mother asks right after delivery is the condition of the baby. It is important that the parents be told of the baby's condition as soon as possible. In a study to determine how, when, and from whom they first learned about the defect of their infant, 694 mothers of babies with various congenital abnormalities were interviewed (D'Arcy, 1968). The mothers attached great importance to the approach and general attitude of the medical and nursing staff who told them about their babies. The manner of presentation of information has a bearing on how parents will react. At a time of crisis, every word has meaning for the parents. Mothers preferred to be told the truth in simple language, and became very anxious if they were merely told not to worry. Many parents report dissatisfaction about the way they were first told of their child's handicap (Tarran, 1981). Mothers expressed a desire for truth and for an avoidance of over-pessimism or unrealistic optimism. Over-optimistic statements regarding the future of the infant may relieve a professional's tension but do not help parents accept reality (D'Arcy, 1968). Therefore professional personnel should clarify the reality of the child's condition as the parents voice each of their questions and/or fears. This reduces the distortions of perception, thinking and feeling which otherwise may occur. Parents' anxiety makes it necessary to repeat this information since they have difficulty hearing and accepting the news.

Many investigators (Berg, Gilderdate, & Way, 1969; Carr, 1970; Daniels & Berg, 1968; D'Arcy, 1968; Drotar et al., 1975; Tisza, 1962) found that the suffering was greatest for parents when there was a delay in telling them of the defect and in showing the infant to the parents. The parents imagined worse things were wrong than the actual defect. Parents need to know the diagnosis of the baby at the time of birth. During the waiting period, several parents reported a growing conviction that their baby had actually died. Upon finally seeing the child, most of the mothers felt relieved. Some of their comments were: "The idea of it was worse than the actual sight; I wondered what kind of a monster I had produced and when I saw him, he was not a monster; The suspense was worse than knowing." At the same time information overload must be avoided when conveying negative news to the parents. Realistic hope must be given. "Hope increases human strength adding to the personality's usual capacity to cope with stress" (Travis, 1976, p. 19). D'Arcy (1968) emphasizes that "the initial counselling of the mothers of malformed infants makes a deep and lasting impression" (p. 798).

This writer's observations tend to support that parents who have opportunities to see, touch and hold their anomalous child cope effectively with the whole experience. Nurses need to be sensitive and must recognize the cues that the parents wish to see their child. If the baby is badly malformed, the nurse can show the well-formed parts of the body and later show the malformed parts if the parents wish. It is important to move at the parents' pace.

With the birth of an anomalous infant there are usually no celebrations, no rituals or societal supports. There are very few flowers, gifts and cards sent to the hospital after the birth of an anomalous infant. Friends and relatives may not call or visit parents. The parents may be reluctant to send out announcements of the birth. Thus parents may experience intense loneliness during the immediate post-partum period (Irvin et al., 1982). The primary concern of the mothers of anomalous infants is for the social acceptance and support of their babies (Mercer, 1974). Demands are made on parents for providing care to their congenitally deformed infant at a time when they are experiencing emotional trauma and need for psychological support and understanding. In the early post-partum period, the nurse should attend to the mother's own dependency needs; the mother at this time needs love, warmth and acceptance. It is much easier for parents to accept their own feelings if they are accepted by professional people.

The mother has been narcissistically wounded; she may be more regressed and dependent (Waechter, 1970). Parents' sense of self-worth is improved when they see that their child is being valued by the professionals. It is important that such a positive attitude is demonstrated by the nurse right from the beginning. Small acts of kindness are clearly remembered by the parents years after the event.

To facilitate the mourning process the mother needs physical rest to increase the energy level, an opportunity to review her thoughts and feelings about the wished-for child, and a realistic interpretation and investment in the feared and unexpected child. Allowing the parents to ventilate their feelings of hostility, guilt and anxiety may help reduce their anger and leave more energy for caring for their infant.

Initially, it is hard for the parents of a defective infant to hold it, feed it, and begin to relate to the child with cuddling and love. It is not abnormal for a mother to feel repulsed by the child's obvious physical defect or feel resentment toward her anomalous child. These emotions conflict with her natural desire to love the infant. Factors that influence mother-child relationship are the mother's measure of self-esteem, degree of self-acceptance, and the amount of feedback received from the baby (Gordenk, 1976). The mother needs to identify her newborn infant both in appearance and function. She needs to compare the features of her infant with significant others (Rubin, 1961). Rubin (1963) suggests that mothers who have anomalous infants are handicapped in their attainment of the maternal role by their infant's inability to respond normally. This is why parents need help in seeing their child as a little person. It requires time for the parents to learn about their child's characteristics as an individual. The mother needs to be relieved of her feelings of guilt for her lack of motherliness. Parent-infant bonding develops over time and through experiences within the relationship of parent and child. It is important for parents to hear from the health professionals that the feelings they are experiencing are perfectly normal and that the professionals are available to help in any way they can.

Parents need time to adjust but professionals tend to become impatient with the lengthy emotional process which most parents go through with the birth of an anomalous infant and feel the urgency to do something about it (Olshansky, 1962; Sieffert, 1978). Wilker, Wasow and Hatfield (1981) observed chronic sorrow or periodic crisis rather than time-bound adjustment of parents of mentally retarded children. Allowing parents time to proceed at their own pace through the grieving process and in caring for their infant can enhance their

ability to cope. Allowing time to parents does not mean leaving them alone and walking out on them but being available when needed. This further enables the parents to actively participate in the decision-making process regarding the care of the child, thus enhancing their ability to cope with the challenge of having a child with a congenital anomaly (Solnit & Stark, 1961).

The needs of parents of an anomalous infant are extensive and ongoing. The team approach of professionals is required to assist the family. The nurse's responsibility lies in supporting parents in order to reduce their feelings of being overwhelmed and to conserve their energy for coping with the initial impact of the birth of an anomalous infant. Nurses act as role models in caring for the infant. If nurses relate warmly and with sensitivity and handle the infant like any other newborn, they do not only increase the parents' confidence in their own ability but also demonstrate to the parents a social acceptance of their infant. When the parents are ready to get involved in the care of their infant, the nurse should provide encouragement and compliment them on their achievements. The nurse can influence the relationship between the anomalous infant and the family, which in turn will affect the child's self-concept. The nurse can assist parents in the process of becoming more confident and competent in caring for and relating with their newborn. As the mother becomes more comfortable with the physical care of her baby, she may feel less threatened, less anxious and she will have more energy to cope with other tasks. This in turn will increase the parents' self-esteem, which is a major factor in the development of the maternal role. It is essential for parents to recognize their infant's strengths, however limited they might be. It is through the professional's emphasis on these strengths and positive behaviours of the infant that parents gain confidence in trusting their own positive feelings and expectations for their child's growth (Howard, 1982).

In order to facilitate the family's adjustment to having a child with an anomaly, the nurse needs to demonstrate an understanding of the feelings of parents about their anomalous infant. It is necessary to determine the concerns of the parents so that appropriate support can be given to maximize parental coping. The nurse needs to assess the family strengths and utilize family support to enhance parental coping. Parents' mutual support of each other after the birth will facilitate a positive long-term acceptance of the child (Drotar et al., 1975).

The nurse may find it difficult to work with angry parents, especially when the anger is vented on the nurse or other health professionals. However, when one understands that parental anger is directed at their own plight it becomes easier to work with the parents. An important role of the nurse is to listen to the parents' responses, to utilize the skills of therapeutic listening and observation. The nurse needs to establish an atmosphere of trust and confidence which enables parents to express their fearful questions and concerns. There are no answers to many questions but parents need to raise these questions. Parents who can openly ask questions and express concerns about their child's anomaly will be able eventually to make a positive adjustment to the birth of an anomalous infant (Howard, 1982).

If the infant is going to be hospitalized over an extended period of time or will require surgery to correct the defect, the parents need explanation regarding the nature of the defect, the overall treatment procedures, approximate times of surgery and explanations of surgical procedure and prognosis for the infant.

Nurses working in speciality clinics such as birth defects clinics provide nursing assistance for the infant and support for the family. They share their concerns with other involved professionals in assisting the family to cope with the tragic fact (Bennett, 1982).

Public health nurses, through collaboration with other disciplines and community agencies, can provide a consistent and co-ordinated support for the family. They assist the parents to cope in the day-to-day practical difficulties that parents may encounter in caring for their anomalous infant. Close follow-up of the family is recommended during the first three months after the birth of an anomalous infant (Mercer, 1974). Parents need to be informed about community resources, agencies and organizations that provide assistance to handicapped children, and that self-help groups offer parents a place to go and share their problems with others who are encountering similar experiences. Identification of available resources is often crucial in resolving the emotional turmoil of parents. Referral to the social worker for consistency and continuity of care is important. The social worker can help to co-ordinate medical and emotional support for the family after discharge from the hospital. Through time, ongoing care and support systems, parents learn to cope with the numerous tasks expected of them at this time of crisis.

It is the view of this writer that an understanding and compassionate nurse can make the difference in helping the parents cope with such an emotional experience. Nurses who are aware of their feelings and values and understand the reactions of parents to such a tragedy will be able to demonstrate a caring attitude and respect for the parents of an anomalous infant at a time when they are faced with such an emotional experience. This contribution is essential for the positive adjustment of parents to the birth of an anomalous infant.

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RÉSUMÉ

Comment composer lors de la naissance d'un enfant anormal

La naissance d'un enfant anormal est un événement traumatisant pour toute la famille. Les parents sont aux prises avec l'anxiété et la dépression et leur estime de soi diminue considérablement, quelle que soit la gravité de l'anomalie dont souffre le nouveau-né. Les besoins des parents sont nombreux et constants. L'infirmière a besoin de connaître et de comprendre les réactions des parents pour être en mesure de les aider. L'appui d'une infirmière compréhensive peut avoir un effet bénéfique sur la capacité d'ajustement des parents suite à la naissance d'un enfant anormal. Le rôle de l'infirmière consiste à aider les parents à faire face à cette naissance avec le minimum de douleur et de souffrance. Pour y parvenir, il faut aider les parents à prendre soin de leur enfant avec confiance et à accroître leur estime de soi.