

CLINICAL CARE UPDATE: CHILDREN AND FAMILIES

Parents of Children with Emotional Disorders: Issues for Consideration and Practice

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ABSTRACT: Parents with children who have serious emotional disorders face significant personal and family issues in their parental role. Professionals providing services to these families must be sensitive to a variety of issues if they are to provide an empathic context when these families are seeking help. This paper will explore the stress these families incur, the loss they experience, and the resources needed for coping and the preservation of family integrity. Practice implications will be addressed.

INTRODUCTION

Professionals who provide assessment, treatment, and support to parents with a child who has a severe emotional disorder must examine the assumptions that are held about these families. These assumptions can hinder the development of a partnership between the practitioner and family members seeking help. It is often difficult to identify these

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families since there is no agreed upon definition as to what defines a child or adolescent as severely emotionally disturbed.

A definition proposed by the Child and Adolescent Service System Program (CASSP) of the National Institute of Mental Health (Lourie & Katz-Levy, 1986) describes these children as having long-term chronic emotional problems characterized by the existence of a functional disability, in need of multi-agency services, and the presence of a diagnosed mental illness in duration of at least one year. Gould, Wunsch-Hitzig and Dohrewend (1981) estimated that 11.8% (7,500,00) of the under 18 population suffer from some type of emotional handicap and are in need of mental health services. National estimates are 12 percent or 7.5 million children in need of mental health treatment with about half of these children considered to be "seriously emotionally disturbed" (Institute of Medicine, 1989). The burden to these families and the services that they require are enormous.

The purpose of this paper is to explore how families with children who have serious emotional disabilities can be engaged in services provided by mental health professionals. Specifically, this paper will examine how professionals can establish a working relationship with these families by creating an empathic context for their work. This can be established if the professional understands and acknowledges the stress these families incur in parenting a child with an emotional disorder, the personal loss they experience related to the hopes and expectations for their child, and the resources they need to preserve the family.

SETTING THE STAGE: AN EMPATHIC CONTEXT

Creating an empathic environment or context for the establishment of a working relationship is viewed by some (Kohut, 1982; Wolf, 1988) as the core of the helping process. Wolf (1988) defines empathy as a process of listening and perceiving in a certain way so as to grasp some aspect of the person's inner experience. People need to feel understood and that their needs and desires are comprehended by an important person in their life. When professionals can communicate this level of understanding to families, an opportunity is created for a working relationship built on empathy and respect.

Traditional approaches to families (structural, strategic, communication) run the risk of initially disrupting the empathic context of the relationship between the professional and the family. If we assume families are the cause of a child's difficulties then this perspective will

influence what we are able to see and hear as the families attempt to express their needs and concerns. These approaches tend to focus on the assessment of the family dynamics or family communication patterns and their relationship to the child's emotional disorder. Interventions are then generated from this perspective.

For example, family members may experience the assessment process and the associated interventions as blaming them for the child's problems rather than as looking at the symptoms that the child or adolescent is presenting and try to understand the effect that these symptoms or behaviors are having on the family. This is not conducive to the creation of an empathic relationship. Often, family members will feel frustrated, misunderstood, and alienated from the practitioner. When these feelings are experienced, family members are left with no choice but to protect themselves from the practitioners who are there to work with them. As practitioners, we often label this behavior as resistant or defensive, which further creates distance in the working relationship. How can we remain in contact with the various family members when our approach to them is creating distance in the relationship we are attempting to establish?

If we approach our work by being curious about what is happening to this family system because of the child's behavior then we will be able to see how this system is adapting and coping as a response to the behavior. This view provides an opportunity for a different type of connection to families and sets the stage for a parent-professional partnership. As practitioners, we can be there for family members in a manner that communicates that they are understood and that this setting is safe to discuss the issues that would be helpful to their family and the child with the presenting problem. We want to limit the amount of reactivity present in the parent-professional interaction so that an opportunity can be created to establish a working partnership. This can occur by limiting the distance between the practitioner and the family seeking help. Specific issues need to be taken into consideration and addressed to help create and facilitate this partnership.

A CHILD WITH AN EMOTIONAL DISORDER: THE IMPACT ON FAMILY

As practitioners, it is important that we understand the impact that having a child with an emotional disorder has on the family that is seeking our help. If we can sensitize ourselves to the issues these

families experience and the needs that arise because of their experience, we will be in a better position to stay present to their struggles and provide the services and resources they need. It is important to consider the following issues to facilitate an empathic context and working partnership for our work.

1. *A family does not anticipate the onset of a severe emotional disorder in one of its children.* This occurrence is non-normative in that it is unexpected. Normative events allow a family to anticipate change and make the necessary arrangements that will allow the family to adjust to the new set of family demands. Families with children and adolescents who have serious emotional disabilities do not anticipate raising a child who is disabled. The event is involuntary in that it is not chosen, anticipated or expected to be part of the family life-cycle. It has been documented with adults who are mentally ill that "the onset of mental illness in a family member produces a state of crisis in the family" (Hatfield, 1987, p. 64). This upheaval and state of crisis for parents with children who are diagnosed as having a serious emotional disorder disrupts communication patterns, family roles, and living patterns for the family. The marital unit, sibling and parental relationships are all affected by the needs and behaviors of the child. How these variables are influenced will vary from family to family. How the family organizes around this crisis situation can, and often does determine the future course for family adaptation and development.

2. *These children present a unique set of developmental challenges to which families must adapt and adjust.* For example, cognitive and emotional development of a child with a serious emotional disorder does not follow predictable developmental stages. This can create persistent tension that disrupts family homeostasis and can keep the family in a constant state of change. Increased caretaking needs of the child or adolescent will exceed developmentally expected demands. Obtaining emotional support, economic resources, respite care, and community services to help with the increased responsibilities can be problematic. These factors create additional stress in the family system and often tax the family's ability to cope and respond to the needs of all of the family members.

In addition to the unanticipated developmental changes, the overall family life cycle is disrupted. Parents anticipate that they will move through stages of predictable parental roles. They anticipate an increased interaction and independence in their relationship with their children. In the case of parenting a child with an emotional disorder, these roles are altered to accommodate a child's inability to fulfil their promise in life.

3. *Parents experience a loss as they begin to understand their child's disability.* Parental expectations are often in conflict with the child's abilities and needs when confronted with the reality of the child's handicap. This conflict between ability and expectation continually disrupts the family life cycle (Duvall, 1962) and presents continuing issues of loss for all family members.

For example, during school age years, parents face discrepancies between their child's actual capabilities and the functioning of the child's peer group. The initial diagnosis of a child's disability confronts the family with the discrepancy between their hopes for the child and the child's actual abilities. This discrepancy between their child's developmental capabilities and the child's peers increases a sense of being isolated from other families. Opportunities are often missed to share the joy and pride of parenting with their peers.

As the child ages, the body will change often with minimal changes in cognitive and emotional abilities (Myer, 1986). Expectations related to physical abilities and involvement in outside school activities are often not met. These changes often serve as a continual reminder to parents of the loss of their dreams and expectations for their children, and their altered role as parents in their children's lives.

4. *Parents of these children are faced with long term support issues that extend and modify the parenting role beyond expected years.* These delays reverberate to the family. The parents' own developmental tasks related to aging may be postponed due to the care needs of the child (Myer, 1986). Retirement plans, vacations, and grandparenting expectations are disrupted. Parents will have a difficult time anticipating when their roles will change, how to encourage normal separation activities and how to deal with the emotional ties to their children. These questions will consume inordinate amounts of time and raise pragmatic as well as legal questions that will need to be addressed. If siblings are involved, they will also be affected by these parental struggles and their role in relation to the sibling suffering from the emotional disorder.

Research by Breslau and Prabucki (1987) indicate that the siblings of a child with a disability experienced increased rates of psychiatric impairment such as higher levels of aggression, increased depression, and social isolation when compared to siblings who did not have a brother or sister with a disability. There is also some indication that the depression and isolation increased for siblings when they were younger than the child with the disability.

Pueschel (1986) suggests that the stresses on the sisters and brothers of a child with a disability are similar to those of their parents. These

siblings may compete for parental and family resources, assume increased responsibility for caring for the sibling with the disability, have fears about becoming disabled themselves, and may face or experience greater parental expectations related to their own abilities.

As parents come to understand how their parenting roles are altered, they will also need to be mindful of how the child's disability will affect the other children in the family. This will influence parental decisions related to time, how family resources are allocated, sibling expectations, and the level of emotional support they will have available for their children.

5. *Families vary in their response to stress.* One of the key factors in understanding this response is the organizational structure of ones' family prior to the introduction of a stressful event into the family system (Lewis, 1986). When confronted with a crisis, a family responds to preserve the integrity of their structure. However, in the case of severe and chronic stress, the initial family coping response may be taxed beyond the capabilities that exist in the current structure.

Lewis (1986) observed that "families containing a child with a chronic, severe psychiatric disorder almost always presented with a dysfunctional or severely dysfunctional pattern." His observations are consistent with the research of Erickson (1968), and Miller and Keirn (1978), which indicate that parents with handicapped children experience a stress reaction related to parenting these children. This may explain why these parents are often assessed as maladjusted by professionals. Focusing too quickly on pathology or family dysfunction often alienates the family or creates a sense of powerlessness in relation to the treatment process. An approach that looks for dysfunction as its primary perspective often ignores the family's attempts to cope as well as the reality of the situation in which the family is embedded.

Lewis (1986) has noted that as families deplete their ability to maintain the homeostatic structure of the family, the structure begins to change. A well functioning, flexible family can move to rigidity. If the stress persists, the family structure may appear mildly to severely disordered and chaotic. The stress incurred from the problems associated with parenting a child with a severe emotional handicap is real and will influence and alter the family structure. The family must continually restructure in order to preserve some sense of family integrity and as a means of family self protection.

Family stress theory is useful to examine the impact a child or adolescent with a severe emotional disability has on the family. Theorists (Mederer & Hill, 1983) have researched families undergoing normative and non-normative stress, the resulting crisis, and efforts to cope

and adapt. They have sought to answer the question of what characteristics, traits, or qualities make some families less crisis prone and give them stronger regenerative power. McCubbin and his associates found that in general, "families with more internal resources and stronger interpersonal and community support systems cope more successfully with stressful events" (Slater & Wikler, 1986, p. 387).

Hill's (1949) ABCX model of family reaction to stress looks at the potential disorganization stress can cause a family undergoing a crisis. In this model three variables are assessed to understand how a family will respond to a crisis (the X event) and the impact of stress on the family resulting from the crisis. These are the events themselves (the A factor), the resources available to the family (the B factor), and the family's perception of the precipitating event (the C factor). If a family does not have resources to draw on, both internal and external, and their perception of the situation offers little hope, then this family will experience heightened levels of stress when attempting to cope with a child with an emotional disability. Different members of the family will experience this process differently depending on the resources and perceptions they bring to a given situation.

Among the most notable expansion of Hill's work has been the work of McCubbin and Patterson (1983). They looked at a family's effort over time to recover from a crisis situation. Experience with past crisis events are added to the current situation to account for stress beyond the event itself. This can lead to a pile up of demands on the family, which are often too much for the family to handle, creating a continual process of family reorganization.

6. *Families will need a range of coping strategies and resources to manage the stress in their lives.* Coping strategies are effective when they prevent hardships from resulting in emotional stress (Pittman & Lloyd, 1988). Pearlin and Schooler (1978) found that a range of responses were more effective than any one response in reducing the level of stress experienced. The lack of resources, psychological, financial, and environmental, increased the probability of families' experiencing increased stress. They also found that in parental and marriage domains, self reliance was more effective than seeking help. For parental strains, effective coping was found to be the "conviction that one can exert a potent influence over one's children" (LaVee, McCubbin & Olson, 1987, p. 859).

Self reliance and a belief that one can impact the environment in which the child resides appear to be important variables associated with family coping. Families with children who are emotionally handicapped seek information and resources to cope with their children's

changing environment as well as adapting to it (Pearlin & Schooler, 1978). This desire for resources and information often runs counter to mental health professionals who have tended to assist families with intrapsychic phenomena. More recently, the emerging emphasis on parent-professional collaboration (Friesen & Koroloff, 1990) has focused on increasing family skills, working in partnership, and securing resources for families in order to increase the coping responses necessary in parenting a child with an emotional handicap.

Building on the work of McCubbin and his colleagues (1980) and a coping and adaptation model (Hatfield, 1987) it is possible to define the variables that affect family coping and specify appropriate interventions. Three variables emerge which affect a family's ability to cope with stress. These are the resources that individuals bring, the family's internal resources, and the support of the extended family network. Research indicates a positive relationship between the existence of these variables and successful family coping (Slater & Wikler, 1986).

Dunst and Trivette's (1987) social systems model of family functioning seeks to empower families with the skills and resources necessary to meet their needs. The role of the professional is to help identify family strengths, listen to the family's perceived needs, identify the social support available (informal and formal), and create opportunities for the family to mobilize and adapt as the needs of the child and environment change. This model of intervention focuses on developing family self reliance. The emphasis is on a partnership between the professional and the family. To accomplish this, Dunst and Trivette propose twelve principles of empowerment. These principles recognize the value of mutual respect, proactive responses, reciprocity, and promotion of problem solving skills.

PRACTICE IMPLICATIONS

In the initial interviews with these families clinicians should be advised to approach the assessment process with a level of understanding that acknowledges the disruption in family life that these families experience. Often they are in a state of crisis and all hypotheses about family functioning should be tentative. Questions that are able to convey an understanding of this disruption, the crisis they are experiencing and the unexpectedness of this situation in their lives are more likely to facilitate an empathic context for current and future work. In

addition, it is important that clinicians recognize the loss these families are experiencing and realize that there is no ritualized process in our society to facilitate the grief associated with mental illness (Hatfield, 1987). By taking into consideration how this grief affects family structure and functioning, practitioners may position themselves to help these families adjust to the many changes in their lives.

Clinical assessment and intervention efforts for families who are experiencing severe and chronic stress can be enriched by focusing on the nature of the stress itself. The family structure the professional sees at the time of crisis may be a structure that is essentially functional. This structure is working in some manner to keep the family safe from the overwhelming stress the family is experiencing. However, it may be distorted by the chronicity of the pile up of demands experienced by adapting to a child who has serious emotional disabilities. The interaction between this stress and the family's resources impacts the resilience of the family and its ability to stay on track and meet family demands.

It is important that practitioners acknowledge to themselves and with these families that they are aware of the extreme stress families are experiencing and that this stress has or is contributing to a change in family interactions. A place to begin is by asking all family members to describe the changes that have occurred in the family since they noticed the difficulties their child was having. It is important to ask what changes have occurred. How have these changes affected you, your children and your partner? How do you and your partner support each other? What do you need from us? What would be helpful now? These questions can communicate to the family that the clinician is concerned about the entire family, that this is a difficult situation, that the family is responding the best way it can, and that the clinician is concerned about what sort of help they are looking for. These questions will also begin to give the practitioner some indication of where the strengths of the family system are in order to build on these strengths in future sessions.

Siblings need to be acknowledged and encouraged to participate in the family sessions. Their unique needs, fears, feelings, and how things have changed for them should be discussed. Depending on the age of the sibling or their willingness to talk at this time, the clinician may need to verbalize in a general sense what other siblings experience as a way to encourage conversation and normalize their experience. It is important for the practitioner to remember that the lack of conversation by siblings may be related to a number of factors. Siblings may not want to

increase the burden to their parents by expressing their needs, they may not know how to make sense of what they are feeling, and may feel guilty for discussing family issues with a stranger. Your ability to be empathic can set the stage for their involvement.

If we can keep in mind that family members need support from each other and from others in the community we may be able to help reduce the sense of blame they experience for the current difficulties in their life. We may be able to see the strengths that they possess in their attempts to preserve the functioning of their family. Statements from the practitioner that can identify this situation as stressful and acknowledge the family's strengths in its attempts to manage this stress can help the family externalize the problem and feel understood by the practitioner. Statements that can convey empathy for their current situation will enhance the working relationship between the family members and the professional.

Practitioners must be willing to discuss openly with families what is known about their child's emotional handicap. Parents need this information in order to make sense of what is happening to their child and to enhance their ability to cope with this situation. If practitioners do not have the information or are not clear themselves about the diagnosis or appropriate interventions then they must be willing to discuss this openly with the family. In these situations it will require that the practitioner either refer the family for additional help, search for additional resources, or consult with experts in the field to secure and provide this information to the family.

Parents must be encouraged to discuss the meaning that they attach to their child's illness in their lives and how it has changed their lives and their thinking about the future. This requires an openness in the parent-professional relationship built on trust and empathy. Professionals will continually need to assess their own beliefs and assumptions about mental illness to establish and maintain this forum for discussion. This is seen as an ongoing process in the therapeutic relationship.

In order to manage the stress in their lives, families will need a range of community resources. Practitioners must ask the various family members what they need to help dilute the stress in their lives. When we ask these questions, we must also be willing to listen to their response. Parents may need help with arranging respite care, applying for entitlement benefits, securing some flexibility in appointments, advocacy on behalf of the treatment needs of their child, or help in negotiating and coordinating services. Working with these families

requires more than a knowledge of family systems or dysfunction. It requires an understanding of how these families will receive services that preserve the integrity of the family and minimize additional stressors on an already overstressed family system. As practitioners, we must assess how active we are willing to be and how this activity relates to our theoretical orientation, style of helping, and agency policies that influence our role in the helping process.

SUMMARY

Mental health practitioners have the opportunity to expand the manner in which we work with parents who have children with severe emotional disorders. By incorporating an orientation that considers the stress these parents are experiencing, the losses they encounter, coping strategies utilized and in need of development, and the community resources that are needed, an empathic context can be established and maintained that will contribute to a parent-professional partnership. It will be helpful to these parents to assess the health of the family, to understand how the family has reorganized around the stress, and the attempts made to cope with the various demands on family life. In this way, intervention has the possibility of healing rather than of labeling an already stigmatizing event.

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