Counseling Families of Children with Communication Disorders

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When a child is diagnosed with a communication disorder, family members often are confused and in shock. They are not prepared for the challenges associated with a long-term communication disorder, and family-focused resources are not readily accessible. The sense of loss related to the diagnosis may provoke a grief reaction, which, if not resolved, could lead to depression and other problems for the family and the child. The authors explore two types of grief: stage and episodic. They also discuss the importance of the role of the speech–language pathologist in recognizing and understanding the family's grief and facilitating positive strategies for dealing with it.

Over the past 5 years, there has been an increase in the percentage of individuals ages birth to 21 years who need special education services (Office of Special Education and Rehabilitation Services [OSERS], 2002). These increases are significant in that the overall population of children in this age range decreased during the same time period. In addition to the growth of children with disabilities, a similar growth has occurred in the number of children from culturally and linguistically diverse families. OSERS has only been collecting data on race and ethnicity since 1998/1999, but the trends have indicated an underrepresentation of Asian and Hispanic children receiving special services and an overrepresentation of African American children in special education.

The 1997 amendments to the Individuals with Disabilities Education Act (IDEA) have made family involvement a mandated program component for serving children under age 6 years. Although schools are not required to develop family service plans for children ages 6 to 21 years, best practice has indicated that an ecological approach to service necessitates an interface between the child's home and school environments. Strong family involvement is especially important for children from culturally and linguistically diverse families in order to offset the potential bias in assessment as well as intervention (Baca & Cervantes, 1998). As part of the team of specialists who work with a family throughout the phases of diagnosis and intervention, speech–language pathologists (SLPs) need to understand the impact on the family of a sense of loss that may accompany a communication disorder diagnosis and how best to assist with coping strategies (Stone, 1992). The SLP functions as a counselor and educator whose role is to help the family adapt (American Speech-Language-Hearing Association [ASHA], 1999).

The ASHA scope-of-practice guidelines for SLPs (2001) acknowledge the importance of counseling and working with families. Despite the fact that the number of children needing speech and language services and the diversity of those children has increased, little change has been noted in training programs in regards to the curriculum content and experiences relative to counseling (Culpepper, Mendel, & McCarthy, 1994). Professional training programs state the need for counseling but do not adequately prepare graduates in this area. Likewise, continuing education events for practicing SLPs have not increased substantially in the last decade (Rollin, 2000).

The intent of this article is to better prepare SLPs for the potential trauma and persistent sense of loss families experience when a child is diagnosed with a significant communication disorder. An overview of loss and grieving theory in relationship to death or terminal illness sets the stage for dealing with loss in response to a communication disorder diagnosis. This overview is followed by a discussion of episodic grief and its suitability for describing the process families go through when a child has been diagnosed with a communication disorder. Finally, how episodic grief may affect the therapeutic relationship is examined, and specific suggestions for recognizing and dealing with a family's grief are provided. Appreciation for the complexity of episodic grief associated with a communication disorder diagnosis equips the SLP to be a better resource and change agent for families.

LOSS/GRIEVING THEORY

Loss occurs when family members experience a major change in habits, roles, relationships, or environment (James & Cherry, 1988). In general, loss disrupts a person's natural coping strategies and results in a grieving process aimed at resolution. Grief is a dynamic, complex, and psychosocial process produced by forced change. Schneider (1984) described grief as holistic in that it involves physical, cognitive, behavioral, emotional, and spiritual dimensions. As shown in Table 1, a number of symptoms from various dimensions may coincide with grief and further complicate the resolution process (Lehmann-Norquist, 1999; Powers & Singer, 1993). Grief over what was, should have been, or could have been—as well as what must change in the future—is a natural response to loss that is somewhat prescribed by society.

Current research on families adapting to stress and grief reactions has been examining family coping styles in an effort to determine whether a family exhibits a general coping strategy or specific strategies for different events, such as having a child with a disorder (Ferguson, 2002). Researchers have described two types of coping strategies: *event-focused problem-solving* and *self-focused emotional adaptation* (Carver, Scheier, & Weintraub, 1989). Coping strategies that fall under the heading of event-focused problem-solving are characterized by the family taking actions that address the source of the loss—in this case, the event experienced by their child. Family needs receive little attention. Self-focused emotional adaptation strategies center on a family's efforts to resolve emotional reactions to the loss. At the same time that essential actions are taken for the child, the family's needs in terms of stress and grieving are receiving attention. Knowledge of both coping styles is important for understanding the multifaceted dimensions surrounding the grief process.

Movement through any situation producing grief is considered healthier than stagnation. Some families appear more able to deal constructively with stress than others. It may be that a family's coping style is determined in part by how family members define the problem, how they handled prior types of stress, and how family dynamics have changed over time (Ferguson, 2002). Problems tend to occur when a family spends too much time with a specific emotion or fails to put the loss in perspective. Table 2 presents various family reactions to having a child with a communication disorder and the accompanying potential risks. Green (1995) warned that normal grief can turn into clinical depression if it is left unresolved. During times of severe stress, individuals are least likely to utilize effective coping strategies to move through their emotions. Family coping strategies are a complex phenomenon, one that deserves continued research.

Two terms for differentiating loss in reaction to death versus loss resulting from the diagnosis of a disorder have emerged in the literature. In the case of death or terminal illness, the term *stage grief* is used. For families experiencing the loss of normal communication or ability in a family member, the term *episodic grief* is more apropos. Unfortunately, individuals and families have minimal preparation for dealing with grief of any kind (James & Cherry, 1988). Both types of grief are described so as to augment the SLP's knowledge base.

Stage Grief

Traditionally, grief in response to death has been conceptualized as a series of stages that are identifiable by the emotions experienced. *Acceptance* means that the family has detached from the pain and reality of losing a loved one. As few as three

TABLE 1. Common Symptoms Accompanying Grief and Stress

Physical	Mental	Emotional	Spiritual
• Sleep disturbances • Appetite disturbances • Indigestion • Headaches • Tightness in chest/ hollowness in the stomach • Lump in throat • Immune system breaks down	• Short-term memory loss • Difficulty concentrating • Confusion • Preoccupation with the diagnosis • Routine takes effort • Difficulty making decisions	• Overwhelmed by the many feelings that occur at once • A sense that an expression of emotion may get out of control • Wide mood swings that may be moment to moment initially • Short fuse	• Wh– questions • Anger at God • A change in beliefs and values • Loss or strengthening of faith • A need to find meaning in the diagnosis of the communication disorder

TABLE 2. Descriptions of and Explanations for Family Reactions to Stress Associated with a Communication Disorder

Feeling	Symptom	Definition	Value	Risk
Shock	Feeling of numbness, confusion, & bewilderment	Nature's anesthetic, as it numbs the senses	Prevents being overwhelmed by the situation/reactions, cushions the blow, & allows completion of daily living tasks	Inhibits complete understanding of the communication disorder and may delay decisions about services
Denial	"This can't be happening to me."	Refusal to accept the diagnosis	Temporarily relieves painful feelings and provides time to regroup until reality is tolerable	Results in isolation or a continual search for a different opinion, prevents forward movement, & interferes with seeing the positive
Anxiety	Feeling of being all alone and totally responsible for all decisions; insecurity	Concern and fear of unknown	Discomfort forces redirection of energy to more positive action	Need to be an expert on the disorder; constant search for the best answer
Anger	"Why me?" or "Who is at fault?"	Resentment that hopes and dreams are no longer probable	Allows release of emotions, opens the door to acceptance, & begins focus on present	Heightens stress and interferes with constructive problem-solving
Guilt	"If only I had . . ."	Dwelling on what cannot be changed or controlled	Little, if any, value	Results in relationship problems & continued search for cause
Depression	Feeling of great sadness/disconnection	Anger turned on self	Indicates some degree of acceptance	Leads to abnormal isolation/indecision/ health problems
Acceptance	Content in knowledge that action is being taken	Acknowledges the communication disorder as reality	Empowers and facilitates rebuilding of life one step at a time; recognizes positive aspect & contribu-	Complacent that the worst is over

stages (Powers & Singer, 1993) and as many as seven stages and accompanying emotions (Kubler-Ross, 1969; Schneider, 1984) have been described as belonging to this type of grief resolution. There is a common core (see Table 2), which begins with a *period of disbelief and initial awareness.* This may be followed by a *reactional phase* that serves to limit the awareness and acknowledge the need to heal. Eventually, a time of *constructive action,* described as acceptance, gaining perspective, or transforming loss, emerges, in which the weary "travelers" return home.

Unless there are complications, the stage approach implies that the emotions and reactions most likely will occur primarily during the culturally defined mourning period. The impact is somewhat limited in scope, depending on the relationship to the deceased. Mourners initially are preoccupied with the immediate tasks necessary for addressing the stressful event, such as those involving making burial arrangements and decisions about disposition of personal effects. Numerous support systems immediately are activated. Support groups, newsletters, pamphlets, and other resources are readily accessible to guide families through the process. Later, the immediate family role changes from one of making arrangements to one of adjusting to the absence of the valued member. During this time, the family's internal and external subsystems invariably are altered. A typical time period alloted by society for resolution to occur is 1 to 3 years. Beyond that time frame, grief related behavior may be viewed as dysfunctional coping.

All cultures have implicit expectations for acceptable grief behavior in reaction to death (Green, 1995; Werner-

Beland, 1980). These expectations are typified in the various types of clothing, rituals, attitudes, and acceptable periods for mourning. Failure to adhere to these cultural mores may contribute to unresolved or complicated grief resolution (Schneider, 1984; Shipley, 1997).

The stage approach for describing the grief process related to death is accepted and understood by society. It is viewed as a necessary and natural response to loss. Many funeral homes and places of worship automatically assume responsibility for supporting the family. Less information and support are readily available to family members who are dealing with the emotions related to having a child with a communication disorder. The term *episodic grief* is more applicable to this situation.

Episodic Grief

The concept of episodic grief was introduced more than 30 years ago in the counseling literature specific to families of children with mental retardation. Since then, anecdotal reports have become available, but more research is needed concerning the universality of the process, the factors affecting the process, and strategies for individualizing grief resolution. Most of the communication disorders literature has been written from the perspective of families with children who exhibited congenital deafness (Shontz, 1965), cleft palate, or acquired disorders such as pediatric traumatic brain injury (TBI; Luterman, 2001; Wade et al., 2001). For the purpose of this article, discussion will focus on episodic grief resulting from an initial diagnosis of a communication disorder in a child. The episodic approach to loss explains how family members may cope with the loss of a "perfect" child who is seen as an extension of themselves. This approach has also been referred to as *chronic sorrow, mobile mourning,* or *recurrent sadness* (Davis, 1987; Powers & Singer, 1993). Although the term *episodic grief* does not do justice to the complex issues associated with how families adapt to stress, it does capture the transitory aspect of an adaptive process.

It has been estimated that 70% of family members who experience a sense of loss in response to a disability will have moderate to severe emotional reactions (Powers & Singer, 1993). Initial reactions experienced by families may be similar to the emotions described for stage grief, but the process differs in consequential ways. The primary difference is that episodic grief is a prolonged process with no predictable end and perhaps no complete resolution (Powers & Singer, 1993; Roth & Worthington, 2001). Most important, it tends to be revisited at critical life junctures (Williams, 1993). Having a child with a communication disorder is not expected. It often necessitates a change in plans as the family members adjust their views of the future for their child and how they will operate in that future. Recent research has suggested that the stress reported by families may be a general indicator of overall family stress and patterns of stress management, as opposed to disorder-specific stress in reaction to a situation involving the child with the disorder (Baxter, Cummins, & Yiolitis, 2000). Further research is needed to more clearly explain the dynamics of episodic reactions in families.

In researching this topic, we uncovered an essay by Emily Perl Kingsley, "Welcome to Holland" (1987; see the Appendix). In this essay, a parent draws an analogy between a voyage to an unexpected destination and the birth of a child with an unexpected disorder. Mrs. Kingsley based the essay on her experience as a parent of a son with Down syndrome. The Kingsley analogy is appropriate to use for understanding the reactions of families of children with other types of disorders, including communication disorders. Planning a voyage encompasses travel itineraries, shared roles of family members, and tips for successful travel. Having children also involves planning similar to that associated with an exciting voyage. The major difference when a child has a communication disorder is that these plans and "itineraries" have to be modified, which is unexpected. Rarely does the "trip preparation" include tips for coping with a disorder. The roles and responsibilities of the "travelers" are altered, and the final destination is changed. SLPs should view themselves as one of many "travel guides" for this type of family journey.

Kingsley (1987) described the never-ending pain that accompanies an altered itinerary involving a child with a disorder, especially as other travelers continue to talk about their "trips to Italy" with nondisabled children. In a follow-up to Kingsley's essay, Cathy Anthony (2003) described how she had to relocate her family to "Holland." She also described still stomping her feet and crying out in protest. Her frustration episodes generally were precipitated by changes in the disorder or in routine life transitions that were different from those for families who did not have a child with a disability. Many families, as well as SLPs, are not well equipped to understand or deal with episodic grief and the recurring sense of loss inherent in a diagnosis of a significant and long-standing communication disorder. As Kingsley (1987) and Anthony (2003) recounted, these "relocations" require the family to learn new languages, establish new friendships, and appreciate the value of their change in plans. Unlike stage grief, the parameters for episodic grief are less well defined, more pervasive, unanticipated, and cyclic.

The most apparent explanation for episodic grief is that the source of loss remains and by necessity requires ongoing care. Powers and Singer (1993) stated that in this situation families may not even associate their feelings with grief because there has not been a death. In this case, mourning is related to the ongoing challenges of communication, not to the person. Grieving should not result in emotional detachment from the person with the communication disorder, but rather should result in detachment from the disorder. This entails a shift in focus from the mourner or self in bereavement to the person with the communication disorder. It produces a more diffuse and ambiguous sense of loss compared to that felt in death and is more conducive to event-focused problem-solving.

Episodic grief stems from repeated modifications in family routines over time that are experienced with a long-term condition. Out of necessity, families make adjustments in order to accommodate specific service needs, locate additional financial resources, seek related services, make decisions based on the dynamics of the disorder, and handle strained marital and family relationships. Social support systems change due to the ongoing nature of the challenge, cultural expectations, and the comfort level of friends and family (Rivara et al., 1992), thus creating a feeling of social isolation.

It is often forgotten that siblings and extended family members share in the grief process, even though they too had different expectations for their relative and for their interactions with that person (Luterman, 2001; Powell, 1998; Ross, 1991). Brothers and sisters may experience problems with school, health, social relationships, and behavior as a result of the shift in family dynamics. Relationships and lives that were stressful prior to the communication disorder may be exacerbated by the accompanying new demands (Wade & Taylor, 1996).

Some researchers have speculated that gender also plays a role in how grief reactions should be experienced or are perceived according to society (Beach Center on Disability, 2001; Jenkins, 1996; Luterman, 2001; Mallow & Bechtel, 1999). In a survey of parents whose children had developmental delays, Davis (1987) found that mothers were more susceptible to episodic grief because the responsibility for dealing with time-management crises often was relegated to them. Fathers reported more grief related to comparisons between their child and the society's conception of the typical child.

To further complicate matters, societal expectations for episodic grief are vague as compared to those in the case of death (Davis, 1987). At first glance, it appears that Western cultures appreciate family reactions to the loss of "normalcy" in a child. This acceptance functions to reinforce the culture's value of and standard definition for what is "normal." Society allows for the nature of grief to vary, depending on the severity and visibility of the communication disorder (Green, 1995; Huang, 1993). Both Kingsley (1987) and Anthony (2003) referred to a "journey of time." However, the amount of time society allows for episodic grief is unclear. Too much time spent grieving may be interpreted as a weakness or self-indulgence, whereas too little or no grieving can be viewed as "strength of character."

The "permission" to grieve and the conditions for grief related to a communication disorder are tempered by popular opinion in Western cultures that stresses the positive nature of disabilities. The interplay between the sense of loss and the celebration of ability is not clearly understood (Powers & Singer, 1993). Ultimately, family members are placed in a difficult position because they may not be ready to perceive the event as positive and in turn may not be validated by society in regards to grieving fully the recurring bouts of loss.

Most of the available information about the grieving process in relation to a communication disorder has been gleaned from clinical reports, anecdotal profiles, and small studies of a specific type of communication disorder in which grief is dealt with as an aside. In his book on counseling, Rollin (2000) included sections related to family reactions as he discussed counseling needs for each specific communication disorder. He noted the emotions reported by parents when a child is born with a cleft palate or cerebral palsy and the resulting psychosocial influence on the family system.

In a study dealing with TBI, Rivara et al. (1992) found that the quality and quantity of the coping strategies applied differed with the severity of the disorder. Other studies found that with severe TBI, family coping strategies tended to deteriorate in the first year posttrauma (Wade et al., 2001; Wade, Taylor, Drotar, Stancin, & Yeates, 1996). If, however, the family members actively addressed their grief emotions early in the process, their risk for later dysfunction was lowered. The presence of behavior problems beyond communication that often accompany TBI disorders also added significant threat to the family's coping strategies (Burgess et al., 1999). Continued efforts to examine how various types and severities of communication disorders affect episodic grief are critical for our knowledge base and in regards to the types of services families may require.

In essence, grief over a communication disorder is complex and not well documented. The process appears to be dependent upon family circumstances, cultural expectations, gender, and the nature of the disorder. It is characterized by feelings of loss similar to those in stage grief; however, research and anecdotal reports have suggested that there are critical differences. To summarize, grief resulting from a communication disorder is likely to be episodic, the source of loss remains, the focus is not on the mourner, the progression of the disorder is unpredictable, societal expectations are somewhat ambiguous, and the relationship between each family member and the child dictates specific types of grief behavior. For all of these reasons, it is important to have a well-informed "travel guide" along for the "voyage."

GRIEF AND THE THERAPEUTIC RELATIONSHIP

Continuing with our voyage analogy, it is easy to appreciate the value of travel insurance, reputable travel agencies, qualified guides, detailed directions, satisfying accommodations, and accessibility to resources such as transportation, funding, and emergency health care for a successful trip. Likewise, qualified SLPs, accredited agencies, access to services, and productive child–clinician and family–clinician relationships are important ingredients for successful intervention. Neither set of elements guarantees success, but both sets do increase the chance for positive outcomes.

Rollin (2000) listed six factors that influence a family's ability to resolve grief related to a communication disorder:

1. the mental health of family members
2. the nature of the marital relationship
3. coping strategies of each member
4. the severity of the communication disorder
5. access to information
6. intervention team effectiveness

Werner-Belan (1980) suggested that prior experience with and attitudes about disabilities also may affect grieving, even though little empirical evidence supports this theory. Thus, counseling should take into consideration the context of the family's overall life situation. The SLP's goal in counseling is to help the child and family recognize grief symptoms, acknowledge the role and nature of grief, identify healthy strategies for dealing with grief-related behavior, activate constructive coping strategies, and seek professional counseling as warranted.

Without qualified "tour guides," the family's "relocation to Holland" may not be as positive as Kingsley's (1987) and Anthony's (2003). Research into the role of family support for recovery of posttrauma patients indicated that lack of family involvement is likely to result in depression for the child and hinder progress (Dalton, 1994; DePompei & Williams, 1994). Unresolved grief or dysfunctional coping by the family may contribute to atypical developmental dimensions for the child with a language disorder. Rollin (2000) stressed that although a causal relationship between developmental problems associated with communication disorders and the family system has not been proven, it deserves further attention.

Kubler-Ross (1969) emphasized the importance of a persistent, nurturing therapist for helping a family overcome anxiety in the case of death. This suggestion is even more appropriate for communication disorders, given the chronic and recurrent nature of episodic grief and the potential for changes in the speech and language service provider over time. A disruption in service providers may precipitate stress and cause disequilibrium for the family because there has been a major change in the therapeutic relationship.

Powers and Singer (1993) described four indicators, or "red flags," reflecting dysfunctional grief management. The first flag is a family member's negative self-assessment of her or his ability to handle the grief. Another indicator is the degree to which the person is perseverating on a specific grief behavior. Failure to experience diminished intensity of emotions and behaviors is a third warning sign. Finally, the presence of prolonged, serious psychological problems, as described in Table 1, is the fourth signal.

The impact of grief associated with communication disorders cannot be underestimated (Davis, 1987), nor can the impact of recurring grief reactions be ignored. Both situations are normal, but they do have the potential to interfere with rehabilitation of the child if not acknowledged and managed. In a study of 96 children with moderate to severe TBI and 96 children with orthopedic injuries (Wade & Taylor, 1996), parents reported that they did not receive the types of supportive counseling they needed in the early stages of the disorder. The authors speculated about the absence of counseling services and suggested that families may fail to voice their emotional needs or may not recognize the importance of acknowledging those feelings.

MAKING THE BEST OF "HOLLAND"

Most of the resources on episodic grief are not readily accessible to or suitable for families unless a specific problem, such as a hearing loss or speech difficulty, is present. The analogy of a voyage to Holland with numerous excursions in the new home seems useful for families coping with episodic grief. An SLP may be called upon to educate families about the changed itinerary and help them visualize a positive alternative travel plan (Conoley & Sheridan, 1997). An SLP "tour guide" often is the link that enables the family to forge new partnerships with strangers and seek ongoing support and services (*Highway to Healing*, n.d.).

As families move through episodic grief, SLPs should consider the following guidelines as a resource for serving families. This information has been compiled from a variety of sources (Alper, Schloss, & Schloss, 1994; Barry & Hardman, 1994; Cox-Gedmark, 1980; Davidson, 1999; "Feelings and Reactions in Spinal Cord Injury," 1998; Luterman, 2001; Oates, 1981; Simons, 1987; Ty-Murray, 1998).

1. *Assess the amount of information that the family can handle at any given time and be sensitive to how much time is available for resolving the specific emotion being experienced concomitantly with making necessary service decisions* (Tanner, 1980). The impact of an initial diagnosis of a communication disorder is often devastating and inhibits the processing of any other information presented at that time. The family members' priority is to seek help for their child. They need information pertaining to the nature of the communication disorder and services available.

Unfortunately, this is the first time the family is at risk for beginning a pattern of dealing with emotions that may lead to unresolved grief (Leahey & Wright, 1987). Feelings of shock, denial, anxiety, anger, and guilt may not be recognized by the family as acceptable reactions to the diagnosis or as associated with a grief process. Personal coping strategies may not permit emotional adaptation. Reassurance that the time spent understanding behavioral reactions is critical. The SLP should strive for a balance between implementing positive coping strategies and taking actions that are appropriate for the child.

Establishing baseline indicators for stress reactions and type of coping strategies applied provides a monitor from which to make relevant referrals and facilitate positive outcomes. The best approach for fully assessing the grief domains is a multifaceted and dynamic one incorporating family self-reports and observations. Rivara et al. (1992) found significant differences between family and service provider evaluations of the negative effect of a child's TBI on the family. Carver et al. (1989) developed a self-report tool for families to use for documenting their coping strategies. This tool addresses three domains: problem-solving action, emotional adaptation, and avoidance. Another tool, the *Brief Symptom Inventory* (Derogatis & Melisaratos, 1983), also has been used to research the psychological coping strategies of parents. An example of an item from one of these tools is the following: A person is asked to rate how well this statement reflects his or her behavior: "I make a plan of action." "I feel lonely." "I never feel close to another." "I have restless sleep." Typically, the items are clustered into domains reflecting behavioral reactions to the event and perceptions of resources available and utilized.

2. *Supply concrete information about the communication disorder and service delivery systems.* Feelings of guilt occur when family members believe that the communication disorder could have been prevented or that it is their fault. If a cause can be determined, it may be easier for some families to move forward (Beach Center, 2001). In reality, most communication disorders in children are caused by factors beyond one's control (Centers for Disease Control, 2001), which contributes to heightened fears and anxiety about how best to facilitate recovery. Accurate information concerning all aspects of the disorder will enable family members to be more active team participants and, it is hoped, will reduce problems leading to dysfunctional coping (Huang, 1993). Support groups, Web sites, and printed literature should be provided early in the process and referenced as needed.

3. *Emphasize not only the progress being made but also the strengths of the child.* Part of episodic grief includes acceptance of the disability as well as the child. The child's role in the family is as important as his or her performance levels of communication skills. Although such acceptance may result in an additional challenge to the family's acknowledging the positive, it is paramount for the well-being of the child. It also provides an opportunity for family members to receive credit for their roles in the child's life and serves to build the family's confidence in being able to cope.

4. *Provide information about coping strategies so as to establish a level of cognitive understanding.* Adopting a proactive stance toward the emotions associated with stress and transition has been strongly recommended (Wade & Taylor, 1996). Although Table 2 includes a succinct overview of the process, using the analogy of a voyage may be more meaningful for the family and the client. Visuals often help individuals grasp the nature of the process. By acknowledging the value of emotions associated with a communication disorder, the SLP opens lines of communication for a positive working relationship (Briggs, 1998; Wade et al., 2001). Reviewing how the family or others have experienced similar stress in the past reinforces the idea that the most recent transition or crisis will be survived as well. This information may provide insight into the positive coping style of the family, irrespective of the disorder. Stressing the importance of all family members' maintaining good physical and mental health to best help the child and others reinforces their understanding of the process. Using humor and talking with other persons dealing with the same types of problems are important for learning to live with the new reality. The SLP can affirm the family's tenacity in surviving each stressful episode or side trip while highlighting the positive things that have resulted from "living in Holland."

5. *Use role playing and active listening strategies.* Positive facilitators learn to maintain a balance between empathizing with the grief behavior and confronting behavior that appears to be dysfunctional. Role playing often provides a springboard for sharing difficult feelings with others, letting emotions out in an acceptable manner, and dealing with individuals who are not in the same circumstances. Active listening conveys empathy, which communicates support, rather than sympathy, which communicates pity (Jenkins, 1996). SLPs should avoid statements such as, "I know how you must feel." A more supportive response might be, "Let's talk about those feelings." As a trusting relationship grows, both the SLP and the family will be more comfortable in dealing with the tough times.

Using a journal to record feelings and events also creates a platform for discussion. It can be useful in tracking the progression of grief as well as the progress of others. A journal may be more beneficial for mothers, who seem to experience episodic grief more often and with more intensity (Briggs, 1998). The SLP may learn more from a journal than from other types of communication, especially if circumstances limit family involvement with the service provider.

6. *Learn about the family's culture as it pertains to disability and grieving* (Battle, 1997; Huang, 1993). The SLP must maintain a proper perspective, be positive and flexible, and avoid being judgmental about the behaviors exhibited by family members or their manner of expression (Beach Center, 2001). Although some behaviors may be barriers to forward movement in one culture, they may be necessary in another. What appears to be denial in one culture may be a positive coping strategy for other cultures. The view of what constitutes a communication disorder, the role of family members in decision-making, the culture's expectations for acceptable interventions, and the appropriate target for anger or guilt are likely to vary among Western and Eastern cultures, Native American cultures, and certain religious cultures. The SLP should be careful not to underestimate the significance of cultural mores.

7. *Monitor the indicators or red flags that signal dysfunctional coping and make referrals as appropriate.* Anxiety and insecurity are natural reactions to grief. Parents may feel as if they are the sole decision-makers, and the burden is heavy because the consequences are great. Conoley and Sheridan

(1997), for example, emphasized the importance of counseling for families who are responding to the child with TBI. SLPs can redirect this type of energy into more positive activities, such as searching for resources and support groups, that help in changing attitudes and beliefs about the communication disorder. If symptoms of depression are observed, the SLP may probe to determine whether or not the family can identify this as a coping strategy while also realizing the importance of moving on. If feelings such as anxiety, denial, and the need for the "optimal solution" are extreme and overwhelming, physical and psychological harm is possible. Mothers are especially susceptible to the negative effects of prolonged social isolation and depression (Rivara et al., 2001). Siblings may benefit from the services of a school counselor when a comprehensive counseling and guidance program is available (Barnes, Friehe, & Radd, 2003). The SLP should be alert for statements that represent a refusal to accept what has happened, persistent daydreams about how it should be, an inability to handle the situation, or heightened marital tension (Carver et al., 1989). The value and risks of the various emotions listed in Table 2 may be an objective aid for families to use in identifying "red flags."

8. *Be prepared to educate others about the complexity of coping with stress.* If families become angry at or begin to blame various agencies for not providing sufficient services for the child, the SLP may need to educate other members of the service team about the episodic nature of stress. As more research regarding patterns of family stress and ways of coping becomes available, SLPs will have to adjust the information provided to families. Judgmental attitudes about the family may be hard to avoid, but knowledge of the complexity of the process is essential for team effectiveness. Frequently, little or no attention is given to family members other than the parents. Counseling for grandparents and siblings certainly is appropriate, given the intent of a family-centered service plan. Again, the voyage analogy is beneficial for use when conducting an inservice for other professionals and may be a visual aid they can use in providing services to the family.

9. *Create an accessible and consumer-friendly resource bank.* Accessible information on how to cope with stress throughout the life span, family patterns of adaptation, and family support services (including marital, individual, and family counseling) is central to a holistic continuum of services. Lists of child-friendly service providers of dental care, medical services, childcare, education, funding, and recreation also are important. Professionals may be unaware of or not have easy access to materials that could assist in easing stress in the family.

CONCLUSION

The study of episodic grief in response to a communication disorder deserves more attention. Episodic grief plays a central role in the intervention process for the child and family, and as such, it deserves more attention in training programs and in the research arena. Clearly, SLPs need family-friendly resource materials and tools for tracking the progress of family members who are experiencing stress. Further research delineating predictor variables that contribute to successful and unsuccessful resolution of episodic grief; examining those coping strategies that result in positive, family-focused outcomes; expanding knowledge of cultural norms; and exploring the cyclical nature of coping with stress related to various types and severity levels of communication disorders in children is warranted.

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AUTHORS' NOTES

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2. Mary Friehe is now at the University of Nebraska–Omaha. Alison Bloedow is now at the University of Wisconsin–River Falls, and Stacey Hesse is now at the University of South Dakota.

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APPENDIX: "WELCOME TO HOLLAND"

I am often asked to describe the experience of raising a child with a disorder—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this . . . .

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around . . . and you begin to notice that Holland has windmills . . . and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy . . . and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

The pain of that will never, ever, ever, ever go away because the loss of that dream is a very very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

—Emily Perl Kingsley