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Article 53

Family Resilience Following Disability: Enhancing Counselors' Skills

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Abstract

Resilience is a relatively new research concept that has yet to receive the attention it needs to be adequately applied to individuals with disabilities and their families. Resilience as an approach, solution, or set of skills has scantly been applied to families dealing with the advent of disability. The information provided is intended to change this trend. Counselors can enhance their work with families living with a disability by understanding ways disability may influence family functioning and how familial coping impacts personal coping and adaptation to disability, as well as utilizing strategies to help families become more resilient following disability.

Introduction

Resilience is an area of emerging focus and importance in the counseling profession and among allied-helping professions (Hartley, 2010; 2013). However, research on resilience is still in its infancy as far as being understood and as a means of application to various populations, especially with respect to persons with disabilities and/or their families. Yet, several scholars (Stuntzner & Hartley, 2014; White, Driver, & Warren, 2008) believe resilience is an area that appears to have much applicability. To assist counselors in their understanding of resilience and enhance their ability to work with families dealing with disability, the authors define resilience, discuss factors

associated with resilience, provide information pertaining to the ways families lives and functioning change following the advent of disability, and explore strategies counselors may use when working with families.

Definition of Resilience

Defining resilience should be a simple task; however, definitions of resilience vary and have not yet been uniformly conceptualized (McGeary, 2011; White et al., 2008). The main source of ambiguity is resilience being simultaneously defined as "the process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances" (Masten, Best, & Garmezy, 1990, p. 426). For instance, Edhe (2010) referred to resilience as the "capacity to bounce back or flourish from adverse events" (p. 418). Further, Williams, Davey, and Klock-Powell (2003) described resilience as an "on-going process of development and adaptation" (p. 56). Both definitions reflect an increasing trend toward resilience being viewed as a process of healing and improved functioning that is meaningful and unique to each person, rather than as a static trait or an outcome to be achieved. With respect to persons with disabilities and their unique set of experiences, Stuntzner and Hartley (2014) defined resilience as the:

> . . . ability to learn and enhance personal skills and characteristics following the presence of a disability which can be used and refined to help them cope with their situation and disability-related experiences, improve personal insight and knowledge of their skills and potential to overcome challenging life events, and to live in a way that reflects a better quality of life. (p. 14)

Viewing resilience as a process is significant because it does not require a person or family to be experts in coping at the start of their adaptation process following disability. In fact, Stuntzner and Hartley (2014) stressed that resilience is a set of skills that can be learned and improved. Rather than a single trait or skill, it is the cumulative effect of multiple personal skills and characteristics that assist individuals in coping with their situation and disability-related experiences. In the same way that resilience has a cumulative effect on individuals, resilience can have a cumulative effect on families to emerge stronger and more resourceful following disability.

Family Resilience

Grounded in family systems theory, combining ecological and developmental perspectives, research on individual resilience can be translated into enhancing resilience in the family as a functional system (Walsh, 1996, 1998, 2013). Family resilience is based on the premise that "stressful life challenges impact the entire family and, in turn, key family processes mediate the adaptation or maladaptation of all members and the family" (Walsh, 2013, p. 66). With this in mind, scholars have noted the importance of family resilience as an approach to understand what a family does well and then to build on this base to help the family become more effective (Dillahunt-Aspillaga et al., 2014; Frain, Berven, Chan, & Tschopp, 2008; Frain et al., 2007). In particular, specific factors have been explored, discussed, and reported to be associated with resilience in individuals as well as in families. While those mentioned here should not be considered an exhaustive list of what is needed to demonstrate resilience, they are an initial starting

point to assist counseling professionals in better understanding the types and plethora of skills and approaches which may be used to enhance resilience following disability.

Factors associated with the development and promotion of resilience following a difficult or traumatic event include: (a) coping strategies, (b) spirituality (Black & Lobo, 2008; Connor & Davidson, 2003; White et al., 2008; Williams et al., 2003), (c) forgiveness (Farley, 2007), (d) adult mentorship (Walsh, 1998; White et al., 2008), (e) compassion (Williams et al., 2003), (f) social support (Black & Lobo, 2008; Neenan & Dryden, 2012), (g) effective problem-solving skills (Black & Lobo, 2008), (h) internal locus of control (Dunn & Brody, 2008), (i) personal growth and transcendence (Elliott, Kurylo, & Rivera, 2002), (j) emotional and mental regulation (Neenan & Dryden, 2012), (k) attitude and outlook on life (Black & Lobo, 2008; Neenan & Dryden, 2012), (l) purpose or meaning in the identified event (Miller, 2003), and (m) information (i.e., resources; White et al., 2008). While many of these traits and abilities may initially be considered in relation to an individualized person's process, they are also applicable to the needs of families and individual family members who encounter disability due to their relationship with a family member living with a disability. Importantly, family resilience requires the application of resilience factors to understand and improve the ways in which individual family members contribute to family processes.

Disability and Family Functioning

Historically, disability has been viewed as something that affects the lives of people living with one, and society has expected them to cope and adapt with it and the associated changes; yet, they are given little guidance or understanding of exactly how they are to do that (Stuntzner, 2012). Many of these expectations have and continue to be sent through the promotion of negative and ambiguous messages as well as invisible, hard to prove societal attitudes cast in the direction of persons with disabilities (Smart, 2009; Stuntzner, 2012). While attitudes toward individuals with disabilities have improved, people with disabilities are often subject to less humane treatment than people who do not have a disability (Longmore & Umansky, 2001). As a result, people with disabilities may encounter attitudinal, employment, learning, medical, societal, and environmental barriers—all of which have the ability to prevent them from participating in life to their fullest extent (Hartley, 2012; Hartley & Tarvydas, 2013; Smart, 2009). Thus, rather than biological conditions, it is social policies and practices that marginalize people with disabilities (Hartley & Tarvydas, 2013; Smart, 2009), which serve "to exaggerate disability and even construct disability" (Smart, 2004, p. 42). To be sure, social disadvantage is a result of both material and intangible barriers. More specifically, material barriers are comprised of high rates of unemployment, insufficient nutrition and poor living conditions, and lack of access to necessary medical and health supplies (Hartley & Tarvydas, 2013). Intangible barriers refer to dominant cultural messages of people with disabilities being perceived as diseased, broken, and in need of fixing, all of which create social disadvantage (Hartley, 2012; Longmore & Umansky, 2001).

In a similar fashion, families dealing with disability experience material and intangible societal messages, expectations, and pressures following the presence of disability with little information or education, support, guidance, and direction in how to make sense of their loved one's disability and their new set of circumstances (Kosciulek,

1994; Wright, 1983). In fact, a literature review by Frain et al. (2007) documented the long history of research supporting the pivotal role that family plays in recovery from illnesses and disabilities (e.g., Gibson & Ludwig, 1968; Gray, Shepard, McKinlay, Robertson, & Pentland, 1994; Kelley & Lambert, 1992; McCubbin, Balling, Possin, Frierdich, & Byrne, 2002). Unfortunately, while counseling professions are well aware of the importance of family in the process of adaptation to disability, there are still dominant cultural beliefs that disability impacts the individual, and thus, it is the individual who is expected to cope and adapt, not the family. As a result, families may be challenged by the fact that the process of gathering information, understanding the disability, and putting their life back together appears rather fragmented, given there is no one place for them to go to seek assistance or support (Turnbull, Beegle, & Stowe, 2001). Counselors can be of great value to families dealing with their family member's disability by helping them make the necessary transition so they can understand that (a) disability affects everyone, (b) familial changes are probable for better coping and adaptation, and that (c) they and their family member with a disability have their own processes of working through the disability.

Disability Affects Everyone

Disability is an experience that affects more than the individual; it affects everyone within the family and those who are close the person (Reichman, Corman, & Noonan, 2008). Families trying to deal with the presence of disability—whether it is congenital, acquired, or age-related—tend to initially focus on the needs of their family member and on the promotion of family stabilization (Dillahunt-Aspillaga et al., 2014; Frain et al., 2008; Frain et al., 2007). Some of this inertia and focus is expected since families are prone to numerous changes, increased demands and pressures, and unanticipated challenges often within a short period of time. However, once families get past the initial feelings and experiences encountered, they may not be prepared for some of the possible changes that lay ahead. Related is the fact that families may feel as if they don't have time or permission to focus on their own needs and issues pertaining to self-care and positive coping (Dillahunt-Aspillaga et al., 2014; Frain et al., 2008; Frain et al., 2007). For this reason, counselors need to be able to assist families in facing and addressing their own needs and concerns so they can adapt to the changes brought on by disability, heal emotionally and psychologically, and strive to put their life back together and move forward in a healthy manner.

Familial Changes Following Disability

Numerous changes often occur following the presence of disability. Families dealing with a disability must consider and face the changes brought about by disability if they are to improve their chances of coping well and becoming resilient (Dillahunt-Aspillaga et al., 2014; Frain et al., 2008; Frain et al., 2007). As to be expected, families encounter changes directly related to their loved one's disability such as those related to a person's change or alteration in personal functioning and independence. Disability-related changes that lead to alterations in a loved one's functioning may cause families to seek information and education about their family member's disability. Being able to access information and answers about a family member's disability is essential in helping families (a) be more informed about the condition, (b) know what to expect in the present

and in the future, (c) be prepared for periods of uncertainty or difficulty (i.e., reoccurrence of disability-related symptoms; Smart, 2009), and (d) feel more in control of their new situation (Wiggins et al., 1992).

Due to the fragmented nature of family coordination and services available to families dealing with disability (Turnbull et al., 2001), counselors must be aware of the fact that families may not know how or where to start the process of helping themselves. For instance, families may have questions they need answered before moving forward with their coping and healing process (Stuntzner, in press, p. 162), some of which include:

- What information do we need to know regarding our family member's disability to help us manage it and feel more capable of planning for what is to come?
- Who can we speak with in the community that is knowledgeable about the disability and its associated conditions?
- What agencies are available to provide support or information about our family member's disability?

Assisting families in the acquisition of information and support is essential. While it may help them learn more about their family member's disability and situation, access to disability-related information and support can also help families reduce stress and improve coping simply by giving an idea of what to expect and anticipate, as well as plan for the future (Rolland, 2006).

Beyond the personal changes associated with a family member's disability are the changes or, in some instances, "losses" that occur for the family. These changes are those experienced due to the family's loss of the person it used to know, familial role changes within the family (Allen, Linn, Gutierrez, & Willer, 1994), and the family's loss of previously held hopes or dreams for the future. Early on, post-disability, families may experience feelings such as grief or loss (Power & Del Orto, 2004). In some instances, they may not be aware of them or think they do not have the right to feel or express them, especially if the family member's disability is severe or time-consuming. Related to this is the reality that some families may subscribe to the well-entrenched societal belief that "they are supposed to just accept the disability and move on" without any real guidance or support. The types of loss families and individual family members sometimes experience are varied and multi-layered. Some of the possible losses families may experience include (Stuntzner, 2012, in press):

- Loss of the person they used to know
- Loss or change in the previously held relationship
- Loss or alteration of life dreams because of disability
- Loss or change in finances, medical insurances, and resources
- Loss of close friends and social support
- Loss of spirituality or a feeling of closeness to God because of disability

As previously stated, role changes and alterations in familial expectations of the family member with a disability sometimes occur following a disability. Reasons for this are many. Disability is a situation that has the potential to affect many parts of a person's or family's life. For instance, disability may affect their personal life, access or time for

leisure activities, self-concept and self-perception (Wright, 1983), family roles, sexuality and intimacy issues, employment and financial health, quality of life (Tate, Kalpakjian, & Forcheimer, 2002), as well as their future orientation or expectation toward life. Some of these changes may be related to the loss of functioning or related to personal roles and responsibilities within the family (i.e., family wage earner, intimate sexual partner). Others may be tied to the family's beliefs and expectations about persons with disabilities or their attitudes about disability and the meaning of its presence in their lives. Another dimension is that of personal and cultural perception of disability.

Personal and cultural perception of disability can be very influential in determining if persons with disabilities or their families view the disability as a positive or negative event. While it is not our intent to suggest that they ought to view disability as something desired, counselors need be aware that not all persons with disabilities, families, or cultures view the presence of disability as negative (Banks, 2003) or as a "ticket of doom" (Stuntzner, 2012). Additionally, some people and families see their situation and disability differently (Banks, 2003) or as a means to develop positive and multiple coping strategies (Taanila, Syrjala, Kokkonen, & Jarvelin, 2002). On the other hand, and also powerful, is the reality that some persons with disabilities and their families view disability as a hindrance or burden. As a result, some may be hesitant to seek outside help or support, particularly if such actions are not encouraged or condoned by cultural beliefs and practices (Rolland, 2006).

Family and Personal Functioning

Families striving to cope well and become resilient following a loved one's disability may find it beneficial to understand the ways each of them cope, including coping differences between the family member with a disability and the family. Further, each person or familial system is likely to have a different timeline in how the disability and the changes it brings to the family are processed, accepted, or integrated. Similarly, the issues of concern or ways each of their lives are affected by disability may vary or occur at different times in the coping, adapting, and learning resilience process (Dillahunt-Aspillaga et al., 2014; Frain et al., 2008; Frain et al., 2007; Stuntzner, in press).

While there appears to not be any definitive research on the comparison of coping processes between persons with disabilities compared to their families, throughout the rehabilitation literature, it is understood that coping and adaptation to disability is a very individualized process (Livneh & Antonak, 1994, 1997). From a practice standpoint, it is also noted that persons with disabilities may have different perspectives and beliefs about disability and its meaning compared to that held by their families. More specifically, it is often observed that persons with disabilities find ways to accept and move past their disabilities, yet experience barriers or negative messages from their families or those around them (Stuntzner & MacDonald, 2014). Tied to this reality is the notion that some persons with disabilities discover they hold negative beliefs and expectations because of those promoted within their family of origin (Stuntzner & MacDonald, 2014).

Due to the likelihood of varying coping processes families are likely to experience, it is important for family members to acknowledge and respect individual differences and reduce the potential negative impact of their own coping and resiliency process. Families wanting to improve their own coping and resiliency process are

encouraged to address and monitor their own process so they do not inhibit the coping abilities of their family member with a disability or that of each other. Families need to understand that their coping ability and how it is conveyed to their family member with a disability can influence his or her coping and adaptation process (see Elliott, Shewchuck, & Richards, 1999); it is important for them to understand that the two processes may influence one another.

A well-researched component of the connection between the coping and adaptation process of persons with disabilities and those close to them is the relationship and effect of caregivers and persons with disabilities (Gibson & Ludwig, 1968; Gray et al., 1994; Kelley & Lambert, 1992; McCubbin et al., 2002). While it is understood that everyone may not be placed in the role of familial caregiver, it is a common experience for families. Research clearly illustrates that the coping process of caregivers and persons with disabilities is interconnected and that both parties "may be affected by the emotional, mental, and coping process of the other" (Monin & Shulz, 2009, p. 681). For example, according to Kurtz, Kurtz, Given, and Given (1995), depression in persons with disabilities may influence the potential for it to occur in caregivers. Additionally, the caregiver's ability to practice and promote adequate problem-solving skills may influence the coping abilities of both caregivers and persons with disabilities (Elliott et al., 1999). Also of relevance is the information available about the negative effects of caregiving on the caregiver's life. Some of these include depression (Alexander & Wilz, 2010; Monin & Shulz, 2009), emotional and mental difficulties (Monin & Schulz, 2009), health issues, or reduced quality of life.

Given what is known about the relationship and connection between family coping and resilience and its influence on persons with disabilities and vice versa, counselors are encouraged to assist families in working on and addressing their own emotional and psychological concerns. By doing so, families can strengthen their own functioning as well as potentially influence, in a positive way, the coping process of their family member with a disability.

Strategies to Enhance Familial Resilience Following Disability

Despite a wealth of research documenting the critical importance of family support and adaptation following disability (Dillahunt-Aspillaga et al., 2014; Frain et al., 2008; Frain et al., 2007; Gibson & Ludwig, 1968; Gray et al., 1994; Kelley & Lambert, 1992; McCubbin et al., 2002), there is a surprising lack of empirically supported interventions. Families wanting to rebuild and become resilient following the advent of disability can assist themselves by learning about the disability and its associated symptoms, recognizing ways their lives may change, and exploring their own beliefs and expectations pertaining to living with a disability. Several of these areas have been discussed; yet, there are additional ways families can help themselves and their loved one progress toward living in a more resilient way.

Counselors can assist families in learning strategies to deal with and enhance family resilience following disability. Throughout this process, counselors may want to be mindful that change and resilience is likely to vary across familial systems and situations. Some families, like people, are going to be at different places in *believing* they can help themselves and the family move forward in a positive manner; therefore, it may

be essential for counselors to help families experience identifiable success moments as this approach aids in people "coming to believe" they can make a difference (Stuntzner & MacDonald, 2014). Counselors can be instrumental in providing additional support and encouragement as families explore their coping abilities and strategies and make decisions or take actions to promote healing.

Learning to Cope With a Disability

Learning to cope with major life-changing events is never easy, nor is it something that happens automatically. Families dealing with disability may become consumed with the immediate needs and issues in front of them and feel as if they don't have the time or the right to think about their own or their familial concerns (Dillahunt-Aspillaga et al., 2014; Frain et al., 2008; Frain et al., 2007). For this reason, counselors may find it beneficial to explore families' stress levels and ability to manage the tasks before them and their situation. Counselors may explore the importance of families giving themselves permission to tend to their own mental and emotional needs without feeling guilty or thinking less of themselves because everything they do is not focused on their family member with a disability. Additionally, counselors may help families understand that resilience and better coping is a process and something that can be learned and enhanced (American Psychological Association, 2013); it is something that can continually change the more active they become in learning skills that can help them become more resilient (Stuntzner & MacDonald, 2014).

Families wanting to move forward in a positive fashion have many options and strategies to choose from as a part of the healing process. Although not an exhaustive list, counselors can assist families by (a) exploring familial feelings and beliefs about disability or persons with disabilities; (b) allowing them to express and convey grief and loss; (c) identifying their stress and triggers when dealing with disability; (d) breaking stressors down into manageable components; (e) understanding the ways their life is affected by disability; (e) recognizing useful and applicable coping strategies that are already in place; (f) building and maintaining social and familial support; (g) learning to effectively cope with negative societal barriers, myths, and situations; (h) exploring the family vision of what a "better" life looks like; (i) learning resiliency-based skills; and (j) considering the positive side of disability (Stuntzner, in press).

Making the Decision to Heal

Given the multitude of changes that occur following disability, making the decision to heal may appear to be a daunting task. Healing is a challenging process and cannot be carried out according to a predetermined timeline. Families and individual family members heal according to individualized time frames and abilities. Nonetheless, families can make the decision to heal, and they can opt to utilize strategies that help them find meaning, acceptance, and the positive side of disability. Meaning-making and the ability to transform a difficult life event into a catalyst for a life-promoting opportunity are strategies some persons with disabilities discover and embrace as a part of the coping and resilience process (Park, 2010). Similarly, they are approaches families can use as well.

Finding meaning in the midst of difficult and challenging life events is a natural human tendency. Although not practiced universally, individuals and families striving to

cope with a disability sometimes feel the need to find meaning in their experience (Moody & Archangel, 2001). Counselors working with families may want to consider ways they can help them explore and find meaning, especially since they are surrounded by societal messages and individuals who promote the belief that finding meaning is not of value (Moody & Archangel, 2001). Such beliefs are unfortunate, because they do not give people permission to express their feelings or explore a higher purpose. Additionally, these expectations imply that families should "just move on," which is never helpful.

Beyond meaning-making are the lessons families can learn about themselves and life following disability. Many may not initially ask themselves "What can we learn from this situation?" or "How can we use the presence of disability to improve our lives or those of others in society?" However, these are questions families may consider to help them think about the positive effects of disability and life-changing experiences that await them. For example, families, when they are ready, are afforded the opportunity to learn about (a) compassion and tolerance; (b) family and personal values; (c) inner strength, perseverance, and personal character; (d) ways to enhance and further refine their coping skills; (e) thankfulness and gratitude (i.e., greater appreciation for life); (f) spirituality and the development of a stronger relationship with a Higher Being; (g) wisdom; (h) forgiveness of self and others; and (i) letting go of their personal pain (Stuntzner, in press).

Conclusion

Regardless of the beginning point in counseling, families have the ability to help themselves and to develop resilience-based skills. Such skills have the potential to improve their beliefs, feelings, and responses as they relate to the presence of a disability (White et al., 2008). Resiliency skills can also improve their overall ability to cope, especially given the fact that the more coping abilities people have the more resilient they are likely to be (Taanila et al., 2002; White et al., 2008).

Due to the fact that disability is often a complex situation with several associated issues and concerns, it is a circumstance that families may perceive as overwhelming. When this is the case, they may not know where to start or how to help themselves move forward. Counselors can be very instrumental to families by providing the necessary support, guidance, and assistance needed to assess and develop further resilience-based capabilities. Several strategies are available to families as they explore and develop their sense of resiliency. Some of the strategies counselors may use have been previously discussed; yet, also of importance is for counselors to help families recognize and use their existing coping skills and to identify which ones, current or new, are of value to them in their quest for a more resilient way of life.

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