

**Therapeutic Camps as Respite Care Providers: Benefits for Families of Children
with Disabilities**

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Abstract

This study examines the utilization of a therapeutic summer camp for children with disabilities as a respite care provider for parents of camp participants. Interviews were conducted with nine parents whose children had participated in a three day, two night camp held at a fully accessible camp facility in Texas. Findings related to four areas: the daily life of a family with a disabled child; the respite needs of these families; the value of respite care in general; the value of respite both while the child attended camp, as well as after the child returned home, and the qualities of the camp that contributed to respite. Parents reported that respite care was hard to obtain, but that it is much-needed. Parents saw the camp as a source of respite care, and that each family “did something” with the time their child was at camp in such a way as to maximize these respite benefits.

Keywords: Respite, camp, disability, children, stressors

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Introduction

With the advances in medical care over the past several decades, the issues regarding care of chronically ill children in a family and community settings have never been more pressing (Hamlett, Pellegrini, & Katz, 1992). These advances have enabled families to care for their children in the home as opposed to a hospital setting, which places increased burdens on the family as a unit, affecting such areas as family cohesion, conflict, and problem solving skills (McClellan & Cohen, 2007). Thus, it is important that these families are given as much support as possible, in order to alleviate any potential issues related to family functioning.

Several studies regarding these issues have found that respite care, where the child is cared for by someone other than the parent, has proven helpful in creating a place where parents can “recharge their batteries,” spend time with their children who are not ill, or do other necessary tasks, which could range from employment to grocery shopping (Cowen & Reed, 2002; McNally, Ben-Shlomo & Newman, 1999). Jeon, Brodaty, & Chesterson (2005) noted that respite care provided several benefits, “which included time to rest and relax, freedom to pursue other activities, improved self-esteem, feeling secure about possible breakdown of care arrangements, improvement in family relationships, and sleep patterns” (p. 300).

One area that has received limited research is the use of summer camps, specifically designed for children with chronic illness, as a provider of respite care. Meltzer and Johnson, (2004) reported that most of the research on these camps has focused on the benefits for the children, in areas such as treatment adherence and social networking. Only one study in their review had specifically examined family functioning during and after a camp for children with

cancer; that study demonstrated that maternal social interactions outside the family improved, with the change lasting for one month after the camp ended (Smith, Gotlieb, Gurwitch, & Blotcky, 1987). Meltzer and Johnson (2004) posited that mothers would report less stress related to caregiving demands once their child returned home from camp, and that mothers' general psychological distress would improve while their child was at camp. The study found that mothers did indeed have lower subjective stress levels for a month after their child returned home, and their levels of psychological distress were significantly lower for the week after the child returned home. The authors also stated that additional research is needed to examine whether their hypotheses hold true for other groups of chronically ill children, as well as in other domains of family functioning beyond mothers' psychological stress. It is important to determine whether the benefits found in the Meltzer study were relevant only to that specific group of families, or if respite care at similar summer camps also extend the same benefits. The present study seeks to examine some of these areas, as well as to extend the body of literature regarding respite care and its impact on the family as a unit.

The purpose of the present study was to examine the benefits of respite care for family functioning. The study focused on families of children who attended a three day, two night camp sponsored by a community organization utilizing a fully adapted camp in Texas run by a nonprofit organization that provides summer camp experiences for children with a range of illnesses and disabilities. A qualitative research design was utilized, including semi-structured interviews with families of recent camp participants. If evidence is found that parents do report better family functioning after their child returned home from camp, it will provide additional support for that camps should continue to offer and expand services to children and their families. This is an argument furthered by Meltzer & Johnson (2004). These authors noted that

there is financial support for respite care programs at the federal level (e.g., Lifespan Respite Care Act), as well as in over 30 states, and through Medicaid waivers. If therapeutic camps are designated as overnight respite care providers, they may be able to apply for and receive funding for existing or new camp programs.

Literature Review

Childhood Disability

There has been considerable research done in recent years that suggests that a child's chronic disability can adversely affect his or her family (Drotar, 1997; Pai, et al., 2007; Shudy, et al., 2006). It is estimated that 20 to 30% of children and adolescents in this country face a chronic disease or disabling health condition (Brown, et al., 2008). Chronic illness can be defined as a physical, usually non-fatal condition that 1) interferes with daily functioning for more than three months in a year; or 2) causes hospitalization lasting more than one month in a year; or 3) is thought at the time of diagnosis to result in either of the preceding (Pless & Pinkerton, 1975).

The psychological aspect of these diseases, and their impact on both the patient and his or her family, have become of greater interest as the survival rate and quality of life for the average chronically ill child has improved greatly due to ongoing medical advances (Hamlett, et al., 1992), and changes in healthcare, such as deinstitutionalization and the advent of managed care, have contributed to an increase in home care for children who have very serious medical or developmental issues, yet are not required to remain in the hospital for extended periods (Sales, 2003). This in turn moves a large part of the care for these children on family caregivers (usually their parents) who are often required to perform specialized medical tasks, take their child to the

hospital for evaluations, and deal with balancing finances, family life, and both psychological and medical aspects of their child's illness (McClellan & Cohen, 2007; Sales, 2003).

Research suggests that there is a need for continuing study of the ways in which a child's illness places burdens on the family unit. Children are unable to provide care for themselves when they are healthy; this situation is even more exacerbated when the child is the victim of a serious, long-term disease or disorder. Children with chronic illnesses depend on their parents to provide them with food, shelter, and clothing, as well as ensuring that they have proper medical care, and social support. Parents are often required to take their children to frequent medical appointments, and in many cases are unable to make their own decisions about proper medical care and procedures. Thus, it falls to the parents to become educated about the disorder and interact with medical and other allied health personnel. In addition, parents must manage the care of any other children present in the home, as well as allow themselves time to be "alone", to "recharge their batteries", free from worries and concerns about the welfare of the family. In many cases, it is this time "alone" that falls by the wayside. It is therefore important for research in this field to examine ways in which parents can be allowed to "recharge", and thus continue to provide for their families at an optimal level. While much of the research done in this area has focused on children with a "chronic illness", the basic principles can easily be extrapolated to children who have a disability: for example, autism, mental retardation, learning disability, or Down Syndrome.

Impact of Chronic Illness and Disability on Family Functioning

Recent research suggests that families which include a chronically ill or disabled child are at greater risk for deficits in family cohesion, adaptability, parent-child interactions, family conflict, and problem solving skills (McClellan & Cohen, 2007). In terms of family functioning,

research has shown that issues may arise in many different areas. Some of these areas include maternal mental health (Breslau, Staruch, & Mortimer, 1982); family conflict (Pai, et al., 2007) and maternal sleep and daytime functioning (Meltzer & Mindell, 2007). Other studies have also found a relationship between caregiving stress and decreased physical health for parents of children with a chronic illness (Blyth, Foerster, & Panepinto, 2006; Brehaut, et al., 2004; Cottrell & Khan, 2005). In similar studies, significantly lower levels on “quality of life” scores were reported by parents of children with cancer (Goldbeck, 2006), neuromuscular disease, renal failure and cystic fibrosis (Holroyd & Guthrie, 1986), Rett Syndrome (Laurvick, et al., 2006), cerebral palsy (Manuel, Naughton, Balkrishnan, Smith, & Koman, 2003), as well as other chronic illnesses (Florian & Krulik, 1991). Earlier studies also found that a child’s disability was negatively related to the parents’ psychological health (Hauenstein, 1990; Waddington & Buschrossnagel, 1992). Taken together, these studies suggest that there is a link between the stress of caring for a child with a chronic illness and a host of physical and emotional issues for parents.

On the other hand, some studies have found that family functioning may actually *improve* after the presence of a child’s chronic illness. One study found that fathers of young children with cystic fibrosis rated their family’s functioning significantly higher than fathers of healthy children (Cowen, et al., 1985). Blair, Freeman, & Cull (1995) found that significantly more cystic fibrosis families were rated as “good problem solvers” than the control group. Barbarin, Hughes, & Chesler, (1985) found that most of their respondents indicated that the quality of both their marriage and their overall family had improved after diagnosis of their child’s illness.

Models of Caregiver Burden

Recent research has suggested that there are several different models that attempt to account for the ways in which caring for a person with a chronic illness may affect the family as a unit. According to Pearlin, Mullan, Semple, & Skaff (1990), caregiving for a family member with a serious, chronic illness or disability can cause a “profound restructuring of the established relationship can occur...caregiving, which previously might have been one fleeting component of an encompassing relationship, can now come to be the dominant, overriding component”. Pearlin’s model was designed to describe the circumstances related to caring for an elderly patient with Alzheimer’s; however, it can easily be adapted to the needs of a family caring for a child with a chronic illness. The model outlines stressors, which related to nature and magnitude of the care demanded by a child’s needs, mediators, Mediators are the factors that determine the ways in which a person will react to stress, and are the reason why people exposed to similar stressor can, and will, react in very different ways; and outcomes, the effects of the interplay between stressors and mediators (Pearlin et al., 1990).

Patterson (2002) outlined a relational view of stress and family coping that is similar to Pearlin’s. Patterson was interested in why some families, when faced with a significant crisis (such as a child’s chronic illness), were able to “bounce back” and competently face the situation, while other families in similar situations were unable to do so. Patterson’s research suggested that families were on a “see-saw” type of mechanism, where the “demands” of the crisis were on one side, and were balanced against the “capabilities” of the family on the other, with the family’s ability to adjust being the “see-saw”. Patterson found that when faced with a significant crisis, there would be a discontinuity of family functioning, either in the direction of more positive functioning on one hand, or lesser functioning on the other. Patterson also

discovered that this discontinuity is not set in stone for each family, or even for a singular crisis, but that with the right benefits offered through what are termed “resiliency processes”, families can learn to adapt to and overcome significant crises, such as teen pregnancy, chronic illness, or divorce (Patterson, 2002).

Both of these models of family stress emphasize that it is important to not focus merely on the child’s chronic illness as a stressor within the family, but rather to examine that singular stressor as the starting point for what may become a much more extended network of issues for the family at large. In a similar way, it is important to see therapeutic summer camps as not merely a benefit for the child who attends, but also for the parents and other siblings, who may also be able to benefit from the services the camp offers their disabled child.

Respite Care

Respite care can be defined as “temporary relief for caregivers and families caring for those with disabilities, chronic or terminal illnesses, or the elderly” (ARCH, 2009). Respite care provides benefits for family members by allowing them time to “recharge”, or “take a break” from the both the physical and emotional demands of caregiving (Joyce, Singer, and Isralowitz, 1983). Botuck and Winsburg (1991) found that mothers indicated that they were “happier”, with increased feelings of well-being and less depressed mood) after the use of respite services. Mothers spent more time resting, sleeping, grooming, and had improved social personal care, leisure activities, and more social interactions when their children were in respite care. Similar findings regarding the efficacy of respite care have been shown in other studies, with respite care showing benefits in terms of relieving family stress (Joyce et. al, 1983; Marc & MacDonald, 1988; Rimmerman, 1989), improving family functioning and parental attitudes towards their child (Halpern, 1985), reducing social isolation, (Joyce et. al, 1983) and decreasing parental depression (Herman & Marcencko, 1997). Most of these studies have examined only in-home or day-care style respite opportunities; few studies have examined the utilization of overnight respite care services for families of children with either disabilities or chronic illnesses. Botuck and Winsburg (1991) was one such study, which reported positive benefits for mothers utilizing overnight respite care. The only longitudinal study of overnight respite care benefits for families of children with disabilities found improvements in psychological distress and parenting stress after one month of respite care use, with parenting stress levels returning to baseline six months later (Mullins, et al., 2002).

Therapeutic Camps

There has been an increase in the number of therapeutic camps for children with disabilities. These camps are generally operated on the same principals as a camp for children

who do not have disabilities or illnesses: they allow children to experience the outdoors, and participate in activities that are “outside the norm,” such as canoeing, climbing a challenge course, boating, arts and crafts, and other experiences. However, the difference in therapeutic camps is that they are, by design, for children with illnesses or disabilities that limit them from participating in things that children without those disabilities view as a matter of fact. Thus, staff members at these camps must always be cognizant of the specific needs of their campers and allow each child to participate as fully as he or she is able, while still allowing for safety and comfort. Only one recent study was identified that focused on the benefit of therapeutic summer camps for parents, as respite care providers (Meltzer & Johnson, 2004). That study related that these camps can, in fact, be seen as respite care providers, given that they “temporarily relieve caregivers of the daily demands of managing their child’s illness, reducing caregiving demand and improving psychological functioning while the child was at camp” (Meltzer & Johnson, 2004). However, as has previously been explained, there has been very little research on the benefits of these camps for the families of the children who participate.

Methods

Camp LIFE: Context

Camp LIFE was founded in 2004 by a Texas A&M student, a staff member and the Family Support Network, part of the Center on Disability and Development at Texas A&M University. Camp LIFE is held twice a year on the grounds of Camp For All in Burton, Texas, which has fully-accessible facilities for campers with disabilities. According to the Camp LIFE website (Camp LIFE), the camp offers activities such as horseback riding, a climbing wall,

swimming, canoeing, archery, and arts and crafts, among others. Camp LIFE serves children and adolescents (ages 5 to 21) with a wide range of disabilities.

Subjects

Parents were contacted by the Camp LIFE director, who knew the parents in her role as camp director. Having the parents contacted initially by the director was done so that the parents would feel comfortable with the study's design and potential benefits once they met with the principal researcher. Interviews were conducted with parents until saturation was reached in terms of identifying themes and opinions.

To help ensure that the participants were comfortable with all aspects of the interview process, potential participants were first contacted by the director for Camp LIFE, who had previous knowledge of and a rapport with the campers and their families; however, after the initial contact, all further communication was solely between the lead researcher and the participants. This was done to ensure that no parent felt "obligated" to participate in the study, and did so of their own accord. It was hoped that by using the director as a "gatekeeper", who saw a benefit for the study, the participants were more likely to feel comfortable with the purpose of the study, its potential benefits for their families and Camp LIFE, and felt more encouraged to ask any questions they may have about any part of the study design before the interviews took place.

Nine parents were interviewed. Two of the interviews included both the father and mother of the same child; another interview was conducted with two parents, one for each of two children. The interviews lasted approximately 45 minutes to one hour, and were held either at the participant's place of employment or in their home. Table 1 provides the pseudonyms for each

parent, the sex and age of their child, their child’s disability, and the number of times their child had previously attended Camp LIFE.

Table 1: Interviewee Background Information

Pseudonym of Parent	Sex of Child	Age of Child	Child’s Disability	Number of Times Child had gone to Camp Life
Jeff and Sarah	Female	10	ADHD/PDD-NOS	5
Ashley	Male	6	Down Syndrome	Several
Mary	Male	11	Down Syndrome	4
Michael and Erin	Female	12	Down Syndrome	5
Nancy	Male	10	Auditory	3
Rebecca	Male	13	Autism	2
Nicole	Female	9	Learning Disability/ Central Auditory Processing	1

Study Design

This study was performed using semi-structured, in-depth interviews of parents / guardians whose children had attended a session of Camp LIFE. The camp director sent out a mass e-mail to parents of previous camp participants, explaining the rationale for the present study, and requesting their participation. Another e-mail was sent out a week later, to garner further participant support. The letter from the director asked specifically that participants contact the lead researcher, if they were interested in participating. This helped avoid the issue of unintended coercion, whereby parents might feel pressured to be interviewed in the mistaken belief that a choice not to participate would perhaps limit their child’s ability to attend Camp LIFE in the future. The interviews were conducted at a time and place amenable to the

participants; most were in-home, with a few during regular business hours at the interviewee's place of employment. The interviews took approximately 45 to 60 minutes to complete.

Questions were asked to solicit information the home life of the family, the impact of the child's disability on the family, and the family's use of respite care, both previous to attending Camp LIFE, and since the date of attendance. In addition, there were questions asking how Camp LIFE might better tailor its services as a respite care provider. The interview questions were deliberately open-ended, in the hopes that participants would feel encouraged to expound upon anything that they felt was particularly important to their specific situation.

Data Analysis

Once the interview data was collected and transcribed, ATLAS.ti was used to assist in the data analysis (Lewis, 2004). The data were then examined using procedures suggested by Strauss & Corbin (1998), including the reiterative identification of categories and relationships between categories. After the data was open-coded, the transcripts were again examined, with salient codes being placed into code "families", which included codes that seemed to fit together in a thematic way. The analysis procedures were designed to "build a story" regarding how the phenomena of raising a child with a disability affects each family, both in similar and divergent ways.

This study was designed to examine several different aspects of family functioning: the daily life of a family raising a child with a disability; the family's respite needs, both met and unmet (whether camp-based or outside-care based); the value of Camp LIFE in providing respite for families in need (both during camp, as well as potential benefits remaining after the child returned home); an examination of the processes through which Camp LIFE benefits families;

and an exploration of possible suggestions provided by parents as to how Camp LIFE may be able to tailor its benefits to maximize services to both children and family members.

Results

Analysis of the transcripts of the interviews with parents led to identification of four major themes. Each of these themes and related subthemes are discussed in the following sections.

Daily Life

The first theme related to the daily life of families who were raising a child with a disability. Two sub themes were indented: Family Stressors and Benefits.

Family Stressors. Parents identified several different stressors. For example, Ashley, whose six-year old son has mental retardation, related that while all parents feel like they're "on the go" all the time, it is particularly difficult for her, given that her son is unable to explain his needs and desires, which forces her to "play detective." She felt that her family led a hectic schedule, with a lot of time spent outside the home. Another example was mentioned by Jeff, whose daughter has ADHD. He related that for his family the stress is felt most by his "non-disabled" children, as well as through the adaptations that are required to keep his daughter from becoming upset. Finally, Mary noted that were their children "non-disabled," they would be participating in after-school activities such as football or soccer, which would allow their parents time to attend to daily requirements such as grocery shopping or cooking.

Many of the parents felt frustration regarding the stressors of parenting a child with a disability; they felt "separate", with very few other people who understood their needs and wants for their children. The more likely a parent felt supported by his or her community, the more likely he or she was to feel that they were able to successfully navigate the difficulties of

parenting a child with a disability. Parents noted that it was difficult to balance care of both non-disabled siblings with disabled siblings, and that they were having difficulty in accomplishing daily living activities due to the need to care for a disabled child.

Family Benefits. Despite the stressors, parents also noted the “benefits” of raising such a child, both for themselves and for their other children, such as bringing their family “closer together.” Mary related that raising her son has provided more positive benefits than negative changes, because it has forced her and her husband to relate to each other and communicate effectively. Michael explained that after finding out his daughter was disabled, he went through a “grieving process”, but ultimately came out personally stronger for it. .These examples illustrate that while families of children with disabilities do experience some hardships and stressors that are unique to that situation, they are also often transformed in a powerful and beneficial way by that experience.

Respite Needs

There were three sub-themes related to this theme: Adult relationships, daily life (cooking, household chores, etc.), which included utilization of Texas A&M students, and special needs related to parenting a disabled child.

Adult Relationships

Several parents related that time to “just be an adult” was something that was sorely lacking in their daily lives; since their children were unable to be left at home with a neighborhood sitter, or were unable to interact with peers (to attend sleep-overs, etc.), parents often felt like they were unable to ever get a break from caring for their disabled child. She also noted the impact of her having a disabled child on her ability to relax. One mediator that helped balance the stressors was the use of respite care. It was important to parents that they were able

to take time to participate in activities with friends, and take care of other daily living tasks in order to not feel overwhelmed by the strain of raising a child with a disability.

Daily Life. Several parents mentioned that respite care was an essential aspect of managing their daily lives. In addition, parents often referred to the quality of respite care provided through local services, many of them based at the local University. For example, Mary mentioned that most of the respite care she utilized was in short time frames, enough for her to go out to eat, or shop for an hour and accomplish daily living tasks. Mary also explained something that was echoed by almost every parent I interviewed; that without respite care, things would be much more difficult for their family.

Special Needs Related to Disabled Children. Erin and Michael related that they had difficulty with respite care, because they did not feel comfortable allowing “just anyone” to care for their disabled child. This was also a common idea with other parents; parents are forced to actively look for opportunities for respite care, since the general, “call the neighbor’s child from down the street to watch him” idea was unacceptable to many of the respondents. According to Michael, this lessened the amount of respite that could be utilized. In addition, parents who were not as financially well-off faced a more difficult set of circumstances when it came to utilizing respite care; whether this was because of lack of information being provided, or the inability to pay for respite care services is unknown, but presents an interesting avenue for further study. Ashley was the only parent who stated specifically that she utilized funds and respite services from MHMR, and that she had requested funds to pay for Camp LIFE services. Ashley went on to relate that MHMR would not provide funds for Camp LIFE because, being a summer camp, it was not considered “respite care”.

In sum, parents of disabled children are, as might be expected, protective of their

children, and the way they are cared for by others. Since the usual avenues of getting “a break” (such as calling a neighbor, or regular after-school programs) were unavailable to these parents, the need for respite care was strongly felt by all of the parents interviewed. Studies have identified that respite services are one of the most sought-after and desired forms of care for families of children with disabilities, but that most programs have waiting lists (ARCH website, 2009).

Value of Having Children Go to Camp

There were two subthemes related to the Value of Children Attending Camp theme: respite benefits “while” the child was at camp, and benefits that extended to the time after the child returned home (after-camp benefits).

Respite Benefits - During Camp. A major benefit to parents while their child was at camp was that it allowed themselves to relax, or “recharge their batteries.” The respite opportunity allowed parents to spend time together as a couple, be with friends, spend time with their other children, complete household activities, like weekend projects, or to catch up on work that needed to be completed for employment situations. Rachel best summarized the benefits: “It’s great all the way around. And people that can’t understand how a family can benefit from it, I just, it amazes me. And with me having the time to have that breather and to just kind of re-energize myself, I mean that makes all the difference in the world.”

Respite Benefits - After Camp. Several of the interviewees responded that even after their child returned home from camp, benefits from respite care were extended in differing ways. Often, it was in the way in which parents felt more relaxed and better able to handle the daily stressors which come with parenting a child who has a disability. Ashley commented that because the only time her son spends “overnights” away is during camp, she very much

appreciates the relaxation and recharging time, which has to last until the next time he is able to attend camp. Parents also noted their ability to better care for their children once they returned home, because they were able to tap into the beneficial respite they received while their child was at camp.

Camp LIFE Qualities that Contribute to Respite Benefits

A fourth theme related to the camp qualities that contributed to the respite benefits. Parents felt comfortable with Camp LIFE for two reasons. First, they felt that camp provided a beneficial experience for their children, one that was enjoyable, but that also taught them valuable life skills. Camp was not simply a place to “stay and play”, but rather “fun by design”, which allowed the children to learn skills, interact with others, and gain experiences in which they otherwise not have been able to participate. In addition, participants felt that their children would be “safe” at camp, and that there was a structure and scaffolding in place in case of an emergency. Several parents mentioned that they went and viewed the camp first-hand before allowing their child to attend, and all of the parents felt that it was clean and comfortable, and that the camp administration was competent and easy to contact if needed. The belief that their children would be absolutely safe in the hands of Camp LIFE staff allowed the parents to enjoy their respite to its fullest potential.

Discussion and Implications

Discussion

All of the participants in this study reported a need for respite care, with the lack of such care being an overarching theme throughout every interview. The argument for respite opportunities was similar in almost every case. Most of the participants seemed to feel that there just were not “enough hours in the day” to get everything done, which left them feeling

overwhelmed at times. The use of local respite services was viewed as “okay”; however, the supply of those services seemed, to most parents, to be unable to meet their demands. Thus, there is a very large demand for these services, and respite care is a highly-sought-after form of service for parents of children with special needs or illnesses.

All of the parents interviewed had similar comments regarding the benefits of respite care provision in general and of Camp LIFE specifically. Each parent mentioned some aspect of respite care that was important to him or her; however, the overarching theme with their usage of this time is that they got to be “normal”; sleep in on Saturday, take their children out to a movie, have dinner with friends, or work on weekend home improvement projects. The lack of “normalcy” was referred to several times by parents when asked what they did with their respite time; for example, the ability to go out and have a quiet dinner without worrying about one’s child becoming overstimulated and anxious. As explained by Pearlin’s (1990) model of caregiver burden, the interplay between stressors and mediators is what ultimately forms the outcome for each individual, and it is quite clear from the interviews that the mediator of respite provision is something that cannot be overstated. The use of that respite to get back on track with daily living, as well as to recharge their batteries for when their child returned home, was something that every parent seemed to find of great importance. As Pearlin’s model states, stressors may take many forms, including monetary issues, inter-family strain (non-disabled siblings feeling slighted), parents feeling incompetent as caregivers, and among other issues. Respite services such as Camp LIFE seek to balance those stressors by giving parents “breathing room” and allow them to get their lives back on track. This process may be different for each family.

Respite has consistently been seen as a beneficial part of family life, and this viewpoint was upheld by this study, as well. Without rest, parents begin to grow weary and feel

overwhelmed, and the see-saw balances towards an overload of stress. When parents are allowed a chance to relax and be free from caregiving duties, however, they are able to view their life and its attendant stressors with a more focused frame of mind. This helps parents to avoid the feelings of incompetency that might arise if they were “always on the go”, without any sort of end in sight. As several parents said, they look forward to Camp LIFE all year; it provides them with a goal to reach, and helps keep stressors in perspective. Thus, once the child returns home from camp, the parents are rested and ready to again take up the daily life of raising a child with a disability. These outcomes are beneficial to both the child and parents, as well as to the rest of the family. Patterson’s (2002) model is also upheld by the need for respite care, in that it offers parents a way to become more resilient in the face of stressors related to the challenges of raising a child with a disability. Parents may easily become overwhelmed by stress if they feel that they are alone, or have no way of obtaining any help to better their situation. Here, therapeutic camps such as Camp LIFE offer both respite from daily caregiving activities, but also the idea that there are people out there who do care about your family and how you are coping with stress. This simple idea that “we are not alone” can be a powerful tool in helping parents learn to navigate raising a child with a disability.

Along with the respite benefits parents received while their child was actually at camp, a few parents mentioned that they noticed that once their child returned home, they were more likely to be patient with their child, and were better able to deal with unexpected issues, as Ashley related: “I don’t have to run and run in the yard and to the park and everywhere for at least three or four days. So that’s like, he wants to just relax... which is if he’s relaxed, we all relax”. Nancy also mentioned that she was less apt to be “annoyed” with her son after his return from camp: “So it helped me to be more patient in dealing with him. It actually helped me

appreciate some of his quirks...and it helped me to appreciate this more from a humorous perspective than from an annoyance perspective.” These “after-camp” benefits did not last for an extended time after their children returned home, but as was previously mentioned, if there was no lasting benefit (even if it is just the memory of a relaxing weekend), then there would be no desire for respite care services. The need for respite care, as evidenced by the parents interviewed in this study, is that respite (in whatever form it may take) is an integral part of maintaining positive family functioning. The respite benefits provided by Camp LIFE seemed to be greater than those of simple day-care, or drop-off activities; one suggestion for this is that the respite benefits are of longer duration, which necessarily increases the overall feelings of relaxation and “time to get other things done”, such as household projects or gainful employment. Camp LIFE provided parents with the ability to participate in a host of activities that they were normally out of reach, such as sleeping in, going shopping with friends, taking care of other children, or merely “being silly”.

But, simply having a place for children to go for a few case does not necessarily constitute respite, Parents must view the setting, in this case camp, as offering a program that fosters children’s ability to be independent, work on life skills, and have fun in a safe, non-judgmental space. The explanations given by parents as to why they were able to fully embrace and enjoy their respite experience seemed to flow from their belief that camp was a place for their children to learn and have fun; however, what seemed to be of most importance to these parents was their child’s safety, both mental and physical. Parents wanted to feel that they could drop their child off at camp and feel somewhat guilt-free about enjoying themselves, because they knew there was medical staff on site, along with “fun” activities that would occupy their child’s time. Several parents explained that the first time they took their child to camp, they were

unable to fully enjoy their respite time, as they were worried about their child; however, on subsequent camp outings, they felt much more comfortable with the overall experience, and could thus enjoy their “free time” without worry.

Implications

This study provides additional evidence that furthers the basic ideas found in respite literature; in short, that respite care is not merely a welcome change of pace for caregiving parents: it is vital to the welfare of family functioning and the family unit as a whole. As far as respite is concerned, the parents interviewed for this study were aware of both a serious need for, and inability to obtain, all of the respite services needed to improve their families’ quality of life. While day care (if available) can be helpful, the need for even a short break afforded by a three day weekend camp is also needed. However, just enabling children to “go to camp” does not necessarily ensure respite for families. Parents must feel that the camp facility, staff and medical personnel provide a safe and enjoyable experience, including learning new life skills, forming friendships, and getting to be “just kids”. Respite care is a needed aspect of holistic care for families of children with special needs. Given that providing care for a child with a disability can be a hectic, difficult, and ultimately life-changing experience, the opportunity to “recharge” is critical to the parents, and ultimately the children. Thus, Pearlin’s model (1990) is a useful way to explain how parents utilized respite care in order to adapt to stressors and issues related to caregiving.

Parents also had some suggestions for improving the impact of camp as respite care. First, parents should be able to write a short note to their child’s counselor detailing specific information they felt it was important for the camp staff to understand about their child. Being able to write such a letter would help parents feel more secure about sending their child to camp.

Being able to write a note to the child's counselor would also be useful since parents may forget or not have the opportunity to mention important issues to the counselor in the hectic atmosphere surrounding camp check-in.

Suggestions for Further Research

Future research should examine the processes by which therapeutic camps provide a safe environment for respite care to take place, since only when parents are comfortable with leaving their child at a camp will they be able to maximize their respite care experience. Exploring specific camp practices that maximize respite benefits (which in turn help increase family functioning) is vital to understanding how camps support families. While this study began to explore those issues, more research is certainly warranted in this specific area.

In addition, it is important to examine how long the benefits from respite care last after camp was over and the child returned home. This study found that respite benefits lasted for at least a few days after the child returned home, but did not examine in depth the length of time those benefits lasted, or how respite benefits gained during the child's absence were translated into benefits that were usable once the child returned home. Future research should focus on how long these "after-camp" benefits last, what benefits they provide for parents and family, and how to extend them as long as possible past the time the child returns home. Finally, future research should attempt to tease out specific information regarding age and disability type: whether a child's age influences his or her parent's ability to enjoy respite, and what effect the type of disability has on views towards and utilization of respite care services.

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