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The Effects of Respite Care on Care Providers of People with Disabilities

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THE EFFECTS OF RESPITE CARE ON CARE PROVIDERS OF PEOPLE WITH DISABILITIES

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By Sara L. Masten
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THE EFFECTS OF RESPITE CARE ON CARE PROVIDERS OF PEOPLE WITH DISABILITIES

Sara L. Masten

University of Nebraska at Omaha, 2002

Advisor: Dr. Frank Brasile

Respite care has been an intervention used by families taking care of a member with a disability for many years to provide the caregivers with a break from the daily care-taking duties of taking care of a family member with a disability. Though research has been conducted on this topic in a variety of areas (ie: needs for and availability of respite services), measurable outcomes and personal benefits is one area that has not been the focus of much investigation. Thus the purpose of this investigation was to examine the impact of a respite care program on levels of perceived life satisfaction and leisure involvement of caregivers.

The sample (n = 55) for this study consisted of caregivers of individuals with disabilities who participated in a week-long respite care intervention. The Diener Satisfaction with Life Scale was administered to this group both prior to and post the respite care intervention. Also as part of the investigation a listing of personally chosen activities were rated by the caregivers to determine if differences in type and intensity levels of activities participated in varied between pre and post respite care.

Results indicated that personally perceived life satisfaction increased significantly post respite care. It also was observed that while the types of activities participated in pre and post respite care were similar, the intensities in which these activities were participated in increased during respite.

Implications from this study include the possibility of providing pre respite care leisure education to the caregivers to increase their awareness about the benefits of leisure and possibilities that exist for them. Also, through this same intervention, some family leisure education could be examined to provide caregivers with ideas about how to expand the opportunities for their entire family, including the member with a disability.

Dedication

This work is dedicated to my husband, Brent, who has pushed me to work through this project. He has continued to support me and my desire for further education throughout our marriage. I could not have completed this project without his support.

Thank you.

Acknowledgements

I would like to acknowledge the contributions of those individuals who helped make this work possible. I have been fortunate to have three supportive individuals on my committee. Thank you to my committee chair and advisor, Dr. Frank Brasile. I would also like to thank Dr. Richard Stacy for suggesting that I turn what used to be a research proposal into this project. Also thanks to Dr. Bruce Horacek.

I would also like to recognize the support provided to me from the caregivers and participants of Easter Seals Nebraska. They were my true source of inspiration for completing this project.

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Chapter One

Introduction

Respite care services have provided temporary relief from providing care for people with disabilities for many years and has been identified as a high priority for families repeatedly throughout literature (Folden & Coffman, 1993; Hall, 1996; Freedman & Boyer, 2000).

Taking care of a family member who has a disability can be very demanding work. Unlike work, caregivers do not have the option of taking the day off or leaving early. Taking care of a family member with a disability is not something that is done only when the time is available. It is something that must be done on a consistent, regular basis. Living with someone who has a disability can be a full time job, leaving the caregiver with little time to take care of personal needs and wants.

Caregivers who are able to take a break from the daily regime of taking care of their loved one are themselves receiving some form of respite care, if respite care is a term used to define a temporary break from the daily care taking duties.

Although it seems there are would be many values to this service, little research has been conducted to determine the measurable outcomes or effects respite care has on caregivers.

Rationale

In a health care environment that stresses the importance of outcome measurement, the area of respite care is lagging behind. Much has been written about how important respite care is to caregivers, how it is used, the different types available and the lack of availability there is to receive quality respite. However, very little research has been conducted related to caregiver benefits.

With all the rationalization about the need for this service to families, one would assume respite care would be available in abundance. Unfortunately, there is a noted shortage of this valuable service and its benefits for the caregiver (Hall, 1996; Treneman, Corkery, Dowdney, & Hammond, 1997). Thus, there appears to be a need to better understand why families believe this service is so important to them. In other words, what are they gaining from the respite care experience?

Research Questions

The research question posed is: "What are some measurable effects of respite care on the caregiver?" More specifically, is there a difference in the type and intensity levels of personally chosen activities participated in by the caregiver during the respite care? Also, is there a difference in the degree of self-reported life satisfaction of the caregiver after the respite care in comparison with prior to the respite care?

These questions can be examined through examining aspects of times of care providers prior to the respite care and to then compare them with after the respite care. . Therefore, this study will focus on these important measurable outcomes.

Purpose

To examine the impact of a respite care program on levels of life satisfaction and levels of activity involvement of caregivers.

Research Objectives and Hypotheses

Research Objective 1: To examine the differences in the type and intensity levels of participation in personally chosen activities among caregivers prior to and during a one-week long respite care program.

Hypothesis 1: There will be no difference on reported selected activities among the caregivers pre and post respite participation.

Hypothesis 2: There will be no difference on reported levels of intensity of participation in reported selected activities among the caregivers pre and post respite participation.

Research Objective 2: To identify reported levels of life satisfaction of caregivers who participate in a structured respite care program.

Hypothesis 2: There will be no difference on reported levels of life satisfaction for respite caregiver participants pre and post respite program participation.

Definitions

For the purpose of this study, some of the terms used frequently throughout the text are defined as the following:

- Respite care: A temporary vacation or break given to those who care for one or more individuals who are ill or disabled. Frequently respite care is provided at the home or the facility of the respite workers (burlingame & Skalko, 1997).
- Disability: A physical or mental impairment that substantially limits one or more of the major life activities (burlingame & Skalko, 1997).
- Life Satisfaction: The degree of life satisfaction will be determined by administering the Diener Satisfaction with Life Scale. This is a five question survey that examines an individual's perceived level of life satisfaction.
- Personally Chosen Activity: Any activity used to fill the time not spent taking care of a family member with a disability.

Delimitations

This study will look at the life satisfaction of caregivers who receive six days and five nights in succession of respite care provided by Easter Seals Nebraska at Catron-Camp and Retreat Center in Nebraska City, Nebraska. Perceived levels of life satisfaction will be examined to determine if a change evolves between the time prior to and the time immediately following these days of respite care. The personally chosen activities of the caregivers will also be examined to see if a difference exists in activities participated in and at what intensity levels between their time prior to and their time during respite.

Assumptions

One assumption of this study is that the program participants will have corresponding types of disabilities as those participants who did not take part in the survey. Other assumptions include that the families will have comparable demographic information including, but not limited to, socioeconomic status, number of family members and age of care receiver. Another assumption is that no extraneous events will be occurring during this time period that will have an impact on the results of the study.

Limitations

This study has some obvious limitations, the first being that a self-report survey was used. Along with self-report comes relying on participant's honesty on the survey questions. Another limitation is that some of the results may be biased. For one, respondents could be more interested in respite care than the caregivers who decided not to respond to the survey. Also, caregivers may have responded with extremely positive results, hoping that with the results of this study more respite care programs or additional funding may become available. Therefore, it is possible that respondents may have exaggerated the actual effects of the respite care service. These limitations are invariable when doing a survey-type measurement. One must rely on the information the respondents provide. The last and most obvious limitation is related to the potential imperfection of the instrument used.

Significance

This study's objectives seem appropriate because respite care has been promoted to be an important program in supporting families that have a member with a disability. Respite has been recognized to be beneficial in relieving stress, which may lead to burned out caregivers. It is hoped that results from this investigation will aid in providing credence to some of these alleged outcomes and as such lead to a better understanding of the value of respite care to those who help to financially support respite care.

Chapter Two

Literature Review

Introduction

Over the last decade there has been an important focus placed upon respite care and there have been a number of studies done regarding respite care. Past research has examined areas ranging from expressing the needs for respite care, to perceptions of respite care, to the usage of respite care. Others have focused their attention on the various family support systems available to caregivers of disabled family members. The one common theme throughout these studies is how respite care is defined. More specifically, one article defined respite care as "those family support services that provide temporary relief from the rigorous physical and emotional demands involved in caring for a family member with a disability" (Botuck & Winsberg, 1991, p. 43). Herman & Marcenko stated: "Respite establishes an environment where the potential exists for parents to address their own needs" (p. 465). While one of the focal points has been on the definition of respite care, another has been on the provision of this service.

Fujiura and Braddock estimated that approximately 85% of people with mental retardation and other developmental disabilities live with their families, many for their entire lives (cited in Freedman & Boyer, 2000). As this original research could not be obtained to be examined, if this data is assumed to be true, it seems plausible that respite care would be an important support system needed by families that have a member with a disability living in their home. However, despite recent growth in the development of family support services such as the attainability, cost and use of respite care, little research examining the measurable outcomes and effects of this service has been conducted. Therefore, if there is a desire to continue and potentially expand this program, research must be conducted that examines these valuable measurable outcomes.

Respite Care as a Support System

Respite is a highly valued family support service and the one most often provided by community agencies. Family supports are services, resources and other types of assistance that enable individuals with disabilities of any age to live with their families. Of the varying types of family support available, respite care has been found to be utilized the most frequently, followed by case management and support groups (Freedman & Boyer, 2000).

Types of Respite Care

There are a variety of types of respite care services available. All of these services can be categorized into either in-home or out-of-home care. Respite care can take on many forms, lasting for an hour or two to more than a week, yet the primary purpose of all forms of respite care is to provide a break from the daily care-giving duties. The specific types of respite care, compiled from Folden & Coffman (1993), can be grouped into in-home and out-of-home services. Some examples of in-home respite care services include sitters, companions, homemaker services, home health aides, parent trainers and nursing services. Examples of out-of-home respite services include residential facilities, private family homes, parent co-operatives, group homes, day care programs and school programs.

Needs for Respite Care

A study conducted by Warnock and reported in the *Report of the Committee of Enquiry into the Education of Handicapped Children and Young People* indicated that approximately 20% of the school population has special educational needs and that 1 - 2% of all children nationally have severe and complex difficulties (cited in Hall, 1996). It is likely that these numbers will grow considerably with the major improvements in medical enhancements. People are living to be older and others are simply surviving circumstances that killed individuals years ago. All of these elements lead to the realization that respite care will be needed now more than ever before (McGrother, Hauck, Burton, Raymond, & Thorp, 1993).

In 1990, it was estimated that between 1.8 and 2.2 million children with disabilities had mothers in the workforce (Fewell, 1993). Given this, it is no wonder that respite care is in such high demand by caregivers. Taking care of an individual with a severe disability is exhausting work both physically and emotionally. Many people with severe disabilities need assistance with every area of their daily lives including bathing, dressing, toileting, eating and transferring.

Many also have remarkable behaviors due to their disability that create the need for constant supervision and redirection.

Even with very young children, finding care for an individual with a disability is difficult. One study looked at child care needs of mothers of children with developmental disabilities. They found that mothers who worked full-time had a significantly greater level of difficulty finding care than did mothers who worked less than full-time. These mothers also encountered a greater number of problems finding child cares that could care for the complex needs of their child (Warfield & Hauser-Cram, 1996).

Half of the respite care users in one survey reported that the amount of care they received was insufficient and requested more frequent and more holiday respite care (Treneman et. al., 1997). Another study that examined 1283 families that had a disabled member found that the greatest need reported out of the group was more respite care (Herman, 1994).

These studies provide evidence that respite care is a valued commodity and parents desire more hours of this type of service. It seems likely that they are gaining something from this break from caring for their family member that is of importance to them.

Availability of Respite Care

In 1999, forty-six states provided some limited form of respite services to families (Abelson, 1999). While this seems like a high percentage, there is still a noted shortage of this service in many areas. In fact, one parent made the following comment regarding respite services: "When I needed respite care, there was a two year waiting list" (Hall, 1996). Many parents from this study expressed the need for respite care, but found they were unable to receive this type of intervention. Comments like these lead the author to draw the conclusion that respite care is becoming an unobtainable provision for families in her community (Hall, 1996). This is a common problem in many areas.

In Nebraska there is a known waiting list for families to receive government assistance for respite care. Some families on the Easter Seals list have been on this waiting list since their child was diagnosed with a disability. While respite care is available to many, to many others it is simply something that exists for people beside themselves.

Predictors of Respite Use

Because a variety of people use respite care, it is important to look at the common reasons this service is utilized. In a study conducted with the purpose of examining the use of respite by aging mothers of adults with mental retardation, 461 mothers were questioned via an interview format. Of the many findings, one area examined the reasons for using respite care services. The reasons concluded by this study included (a) poor functional skills of the disabled family member, (b) better health of this member and (c) high levels of maternal subjective care-giving burden (Freedman, Griffiths, Kruass, & Seltzer, 1999).

Cox (1997), examined 228 caregivers to determine factors associated with using and not using respite care services. Telephone interviews were conducted with each caregiver prior to their acceptance into a respite care program; follow up telephone interviews were conducted six months later, regardless of their participation in the respite program. Questions were asked regarding sociodemographic characteristics, informal support systems, need for formal support services and level of care provided to family member. Some of the results showed that caregivers of more cognitively disturbed relatives were most likely to be respite users. Caregivers who were the least anxious and experiencing the greatest amount of personal burden were also shown to be more likely to utilize the respite care service.

Patterns of Respite Care Use

Respite care is used by a variety of individuals who take care of others. Today, it is not unusual for parents to care for their disabled children at home, or for children to take their aging parents into their home to care for them. Respite care is a service that is used by both of these populations. However, it is taken advantage of by some more than others.

In one study, 308 families were sent surveys asking the caregivers for a variety of information including current respite care use, child's characteristics, parents' perceived stress level and their informal support systems. The children's disabilities were rated as to their level of dependency; low, medium or high.

Parents of the children falling into the medium and high level groups reported significantly greater levels of stress in their lives. These same parents also reported using a significant more amount of respite care (Treneman et al., 1997).

In another study that included results from over one thousand caregivers receiving a cash subsidy from the government, a survey was conducted to determine what services were most commonly utilized as a result of this money provided. Results indicated that almost half of their respondents used formal respite care services and little more than half of the families used sitters (Herman, 1994). Both are forms of respite services.

Freedman et al (1997) were particularly interested in patterns of respite use rates of aging mothers of children with mental retardation. They did a longitudinal study to see if respite use rates would change over a five-year time period. They found that in 1988, only 13% of the mothers in their study used respite care, but by 1993, 33.5% of them were utilizing this service. Respite care is quickly gaining popularity among families providing care inside the home.

Reasons for Using Respite Care

Family members report using respite care for a variety of reasons. Data from Treneman et al (1997) indicated the main reason was to simply take a break. Other reasons found from this same study include: for the child's benefit, to pursue other activities, to continue caring for the child at home, urgent relief from stress, emergency, more time with partner and more time with other children.

Reasons Against Using Respite Care

Though it has been discussed that there are often long waiting lists of families waiting to receive respite care, sometimes the individuals who do have direct access to this service fail to use it. Many reasons surround their decision. Though some families have access to respite, often times they are unaware of the services in their area that can be utilized. Lack of awareness of respite services has been rated by far as the biggest reason for not using respite care. Other reasons included not needing it, parents not trusting others to care for their child, worry of the child being unhappy in someone else's care (Treneman et al., 1997), lack of need, service not available, wary of services and inconvenience (Freedman et al., 1999). Lack of information, eligibility criteria, crisis-driven support system and inadequate and inflexible supports, administrative barriers and systemic barriers were reasons mentioned by other families (Freedman & Boyer, 2000).

Effects of Respite Care

"Respite establishes an environment where the potential exists for parents to address their own needs" (Herman & Marcenko, 1997). Although it has been stated that there is a shortage of research-based outcomes regarding respite care, there are a few articles that have provided some outcomes.

Overall results from one study in particular were very positive. Botuck and Winsberg (1991) examined the effects of a ten-day respite on mothers of schools-age and adult children with severe disabilities. Mothers reported higher levels of happiness during the respite care than prior to or after the respite. This level of happiness was determined by increased feelings of well-being according to the Bradburn Scale and less depressed mood according to the Norwich Scale. The respite also had quite an effect on the mothers' daily activities. It was found that they spent more time resting and sleeping, performing personal care on themselves, participating in more active leisure activities and interacting with others. They spent less time taking care of others and performing household maintenance. The data also indicated that the mothers felt a greater sense of well-being after respite than before.

Other studies have found that caregivers participating in a respite program experienced both increased morale and decreases in their subjective burden (Kosloski & Montgomery, 1993). Other results have found a reduction in depression, health problems and relationship strains among those caring for stable patients (Deimling, 1992).

An increase in respite care usage has also decreased the likelihood of nursing home placement (Kosloski & Montgomery, 1995). Given results like the one just stated, it is likely that findings would be similar with parents caring for a child with a disability. Increased respite care would likely lead to a decrease in out of home placement.

Caregivers receiving respite care tend to feel their load is lightened because of this assistance. Many have reported a significant decrease in their level of personal burden. Caregivers in this study also felt that their relative's behavior had improved over the six month period of receiving intermittent respite care when scores actually show the behavior of many had declined (Cox, 1997).

Quality and frequency of use of respite have also been shown to be indirectly related to depression scores in a study conducted of 71 mothers of school-aged children with developmental disabilities (Herman & Marcenko, 1997).

Satisfaction with Respite Care

It seems appropriate to assume that families who receive respite care would be satisfied with it. One investigation indicated that 85.5% of their respite recipients were satisfied with the quality of respite care they received (Treneman et al., 1997). In another study it was reported that 87% of mothers of adult children with mental retardation reported being somewhat or completely satisfied with the services they were receiving (Freedman et al, 1999). Surveys of parents receiving respite services indicate that parents perceive benefits from the services (Folden & Coffman, 1993), however, these perceived benefits were not identified.

Consequences Due to Lack of Respite Care

One researcher did a study of the economic consequences on families due to a lack of respite care. He surveyed 574 parents who had children with disabilities. Using a forced answer questionnaire, he examined three specific areas. All were related to whether the parent had lost job opportunities due to having to spend more time caring for their child. He found that 33.6% of families had reported having turned down a job offer. He also discovered that the younger the person needing care was and the more severe their disability was, the family members missed a greater number of hours of work to take care of them (Abelson, 1999).

There are other consequences due to lack of respite care other than the financial effects on the caregiver. Lack of respite care has also been shown to increase parental stress considerably (Hall, 1996).

Therefore, not only are there benefits to this respite care, but there are also consequences due to the lack of this service.

Surveys Examining Areas of Respite Care

In the process of developing this investigation, pre-existing surveys regarding various areas of respite care were located to examine content and format prior to writing the survey used in this study. These surveys covered a wide variety of topics including parental and respite care provider satisfaction with service as well questions geared toward a non-respite care user.

Two surveys were located that examined caregivers, generally parents in these cases, response to respite care that had been provided. They used similar questions, trying to grasp the parents' feelings of satisfaction with the service. Both asked questions regarding the person providing the care as well as the service in general. They had similar formats in that they were both rather short, one page only. They asked a few yes/no questions and followed them up by asking a couple of open-ended questions asking for specific feedback regarding the service (Powell & Hecimovic, 1981; Cohen & Warren, 1985).

One survey found regarding the respite care provider's satisfaction with service examined the program from their point of view. In it, questions were formatted in the yes/no question style with room for follow up dialog. There were also a few open-ended questions. They were typically geared to discover the comfort level of the respite provider and asked for suggestions to improve the process (Powell & Hecimovic, 1981).

Two surveys relating to questions for a current non-respite user were also examined. One was in a typical paper/pencil format style while the other was a series of telephone interview questions. The formats were quite different in that the paper/pencil model offered the questions in a multiple choice format where there were defined answers to select from.

The telephone format offered only one question in this format. The majority of the questions were open-ended, asking for a detailed interpretation from the non-respite caregiver. They tended to ask somewhat similar questions relating to existing problems finding a caretaker, likelihood of using a respite program and times/hours/ this program would be most desirable as well as frequency of use suspected.

The traditionally formatted survey went into a bit more depth, while also looking for more demographic information from the caregiver. It asked questions regarding the disabled member's age, gender, disability and a brief descriptor of special care needed (Cohen & Warren, 1985).

The other survey that was written for perspective respite users was even more detailed yet. It divided the survey up into many sections ranging from care of the child to family social life to expectations of the respite program. Many of the questions were open ended while a few others did simplify things down to multiple choice answer format. The survey did an excellent job of breaking down how much support the disabled member required from the family members. It even specified areas relating to who in the family did what type of care for the disabled member. Later on in the survey, questions were asked relating to the family's social life, perceived level of assistance from other areas and services. Many of these same questions were then asked to the family after they had received respite care for some period of time (Stalker, 1990).

After reviewing each of these surveys, it seemed evident that there was a lack of information questioning the benefits of respite care to the caregivers.

Summary

Respite care is an area that has been examined in many unique ways. A variety of individuals have studied respite care from different angles ranging from the need for respite care to the reasons this service is not utilized.

Some of the findings indicated that while many individuals with disabilities live with their family members for the majority of their lifetime, many of them do no utilize any formal respite care services. Reasons for this include lack of awareness and lack of availability of the service.

Results from these studies have shown some direct benefits of respite care. Respite has appeared to increase happiness levels, lower depression scores, decrease out-of-home placement and lighten the load of caregivers.

The majority of respite care users reported satisfaction with the service and have expressed the desire for more of this service to be made available to their family. If measurable effects and benefits that respite care has on caregivers can be determined, third party payers may be willing to investigate the possibility of covering some of the costs of this service.

Chapter 3

Methodology

Study Population

The experimental sample was identified from the Easter Seals Nebraska list of individuals currently receiving respite care. This list encompasses a large variety of individuals with disabilities and special needs including, but not limited to, cerebral palsy, spina bifida, quadriplegia, mental retardation, Down syndrome, autism and attention deficit hyperactivity disorder. The ages of these individuals ranges from six to eighty. The opportunity to participate in this study was made available to every individual on this list who resides at home with a family caregiver and was scheduled to attend a one-week long respite session. All of the families on this list reside in the state of Nebraska.

Instrumentation

Satisfaction with Life Scale

Diener's (1992) Satisfaction With Life Scale (SWLS) was used to compare the levels of the subject's level of life satisfaction of the respondents on a pre and post respite basis. Reliability, consistency/stability, and validity of the scale as described by Pavot and Deiner (1992) are outlined below.

Internal reliability and temporal stability.

The SWLS has been reported to have a high degree of both internal reliability and temporal stability. In a study by Diener, Emmons, Larsen, and

Griffin (1985), the scale showed a coefficient alpha of .87, and a two-month test-retest stability coefficient of .82. Since that study, a number of other investigators have reported both internal reliability and temporal stability (Alfonso & Allison, 1992; Pavot, Diener, Colvin, & Sandvik, 1991; Magnus, Diener, & Fujita, 1991).

Validity.

In at attempt to establish validity, there has been an investigation of the relationship of the SWLS to numerous self-report and external criteria (Diener et al, 1985; Pavot et al, 1991). The SWLS demonstrated good convergence with related measures, even those using a different method to measure life satisfaction. Age and gender have been fund to be unrelated to the SWLS (Pavot et al, 1991; Arrindell, Meeuswesen & Hutse, 1991; George, 1991), and Friendman (1991), found self-esteem to be highly correlated with the SWLS.

Scoring.

Scoring of the SWLS was straightforward because all the items were positively keyed; the five responses could simply be summed to arrive at a total score. A minimum score of five would indicate extremely low satisfaction with life, whereas a maximum score of 35 would be indicative of extremely high life satisfaction.

Personally Chosen Activities

Caregivers were asked questions regarding their involvement in personally chosen activities. These areas include such past times as active and passive leisure, work, personal activities of daily living, personal respite, shopping and errands, home and yard maintenance. The caregivers were asked to respond to a series of activities falling into the above categories and rate their level of participation in them by a ranking scale. On this scale, a score of one indicated no participation while a score of five indicated a frequent level of participation.

Evaluation Information

Caregivers were also asked to rate questions as to their primary purpose for sending their family member to respite care, whether it was for the benefit of the program participant or for personal respite. Other questions focused on the level of demand the caregiver felt as to physical and emotional stress when taking care of the care receiver. Lastly, it was questioned if the week of respite was anticipated to or had relieved any stress in the caregivers life.

Demographic Information

The last set of questions asked had the purpose of collecting demographic information from the respondents. Information was collected on the caregivers' gender, age, marital status, relationship to care receiver, number of other children in the household, education and annual income. Demographics were also collected on the care receivers including their gender, age and primary disability.

Data Collection Procedures

A letter of informed consent that explained the content and reason for this study was sent out to all the potential participants on the Easter Seals Nebraska list of consumers approximately three – four weeks prior to their family member's scheduled respite time. Included in this mailing was a copy of the first survey along with a stamped, addressed envelope for easy return. All of these consumers were assigned an identification number only known by the researcher written on the corner of their return envelope. Any one who chose to return the survey had provided their implied consent to participation in this research project. Those who did respond positively to this first mailing were recorded on a data sheet to track which identification numbers had returned their surveys. All returned assessments were stored, unopened, in a locked box by the researcher.

When the caregivers returned at the end of the week to pick up their family member for whom care was provided, the same questionnaire was administered again to those who's identification numbers corresponded with the numbers returned from the first round of surveys. This helped to ensure a high return of the final assessments by those participating. These forms were dropped off in a box by the participants themselves prior to their departure.

A high return rate was received by writing all information clearly and concisely. The researcher offered to share the final results of the study by asking participants to check off a box on their survey indicating they would like a copy of the results when available.

The researcher maintained confidentiality by collecting all forms personally and storing all completed instruments in a locked file cabinet. Though the first assessments were addressed to Easter Seals Nebraska, the researcher asked the rest of the office staff to not open any of the mail addressed with a confidential stamp across the bottom. They were very good at following this rule, as no envelopes or surveys were shown to be tampered with prior to the researcher picking them up. Anonymity was also maintained by assigning all participants with an identification number as noted above.

Research Design

The research design for this study was prospective in nature. It was a quasi-experimental, meaning subjects in an intact group (respite participants from Easter Seals Nebraska) were administered an independent variable (respite care).

Results from this study can be generalized to other populations because the study participants offered a wide range with a variety of types of disabilities and age groups.

Data Analysis

A one-tailed dependent t-test was run between the pre-respite and post-respite Satisfaction with Life Scale as well as the different areas of personally chosen activities. Significance levels for this were set at the .01 level.

As with any statistical analysis, there is a risk for making either a Type I or a Type II error. By setting the alpha level at .01, this researcher has decided to err on the side of caution.

Summary

The purpose of this study was to determine the measurable effects of respite care on the caregivers of relatives with disabilities. The research question posed has been: "What are the measurable effects of respite care on the caregiver?" More specifically, is there a difference in the type and intensity levels of personally chosen activities participated in by the caregiver during the respite care? Also, is there a difference in the degree of self-reported life satisfaction of the caregiver after the respite care in comparison with prior to the respite care?

This study has compared these questions among families prior to receiving respite care and upon completion of one-week of respite care. These questions were researchable and have generated some outcome-based measurements that could potentially be an asset to the field.

Chapter Four

Results

Demographics

For the purpose of this investigation, 128 surveys were sent to families on the Easter Seals Nebraska mailing list. Each of these families had a member with a disability who was registered to attend Camp Easter Seals week-long respite care program sometime over the course of the summer. Each family received the survey approximately four weeks prior to their family member attending the respite care program. Seventy-one families (55.5%) returned their survey prior to their family member attending respite care.

Upon the family's return to pick up their program participant, the follow up surveys were given to families who had responded with the first survey. Of the 71 families who returned the first survey, 55 completed the follow up one prior to taking their family member home. Thus, data from the 55 families who completed both surveys was used in this analysis, providing a 42.9% overall completion rate.

Because the return rate was less than 100%, the remaining families who chose not to participate in this study were examined. After studying their demographics, a determination was made that there were no significant differences in the demographics of those who chose not to participate with those who did participate.

The sample for this intervention consisted of families having a member with a disability who lived at home with them. Each of these individuals participated in the one-week long respite care program offered during the months of June, July and August.

Primary caregivers were found to be both male (n = 5) and female (n = 50), ages 28 to 72. While the majority of them were mothers who were married, a few were related to the care receiver by other means and nearly one third of them were single parents. A more detailed description of the caregivers can be found in Table 1.

Care receivers were also male (n = 33) and female (n = 22), ranging in age from seven to 43. Specific disability categories for the purposes of this investigation were classified by the researcher into primarily physical or cognitive in nature. Some examples of the physical disabilities noted were cerebral palsy, spina bifida, quadriplegia and paraplegia. Specific examples of cognitive disabilities include mental retardation, Down syndrome, autism and attention deficit hyperactive disorder. A detailed description of the care receiver's demographics can be found in Table 2.

When reviewing this data, it can be stated that the group represents a very accurate picture of the participants in the general Easter Seals Nebraska's week-long respite care program. Camp Easter Seals accepts individuals ranging in age from six on up with various physical and developmental disabilities. However, it

Table 1

Primary Caregiver Demographics (n = 55)

Respondent Characteristics	Respondent Categories					
Gender	**Female**	**Male**				
	50	5				
Age	**20 – 29**	**30 – 39**	**40 – 49**	**50 – 59**	**60 – 69**	**70 +**
	1	7	24	15	7	1
Marital Status	**Single**	**Married**				
	15	40				
Relationship to	**Mother**	**Father**	**Sibling**	**Other**		
Care Receiver	47	4	2	2		
Number of Other	**Zero**	**One**	**Two**	**Three +**		
Children	17	18	8	12		
Income*	**< $10,000**	**$10 – 20,000**	**$20 – 30,000**	**$30,000 +**		
	5	5	16	27		
Education	**Elementary**	**Secondary**	**College**	**Post College**		
	0	20	25	10		

*does not = 55 due to missing data

Table 2

Care Receiver Demographics (n = 55)

Respondent Characteristics	**Respondent Categories**							
Gender	**Female**	**Male**						
	22	33						
Age	**6 – 9**	**10 – 14**	**15 – 19**	**20 – 24**	**25 – 29**	**30 – 34**	**35 – 39**	**40 +**
	2	9	22	12	3	5	1	1
Primary Disability	**Physical**	**Cognitive**						
	24	31						

is also important to note that the severity of disability levels of participants enrolled in this program is very wide, ranging from mild to profound impairments. For this study, these levels were not collected by the researcher due to the difficulty in categorizing levels of impairment without bias.

The data collected reflects a wide range of ages and disability types that are generally seen in the community as a whole. Therefore, it can be concluded that it may be fairly representative of families that have a member with a disability living in the home environment.

The question was asked as to the number of hours the caregiver felt they were able to leave the care receiver alone and how many hours they felt they spent taking care of their child. Results indicated that care receivers could be left by themselves for an average of 2.3 (s.d. = 3.9) hours per day. Results also indicated that caregivers spend on average 12.3 (s.d. = 8.1) hours per day taking care of their dependent family member.

Research Objectives and Hypotheses

Research Objective 1: To examine the differences in the type and intensity levels of participation in personally chosen activities among caregivers prior to and during a one-week long respite care program.

The first research objective of this investigation was to ascertain what types and at what intensity levels do caregivers participate in on a normal daily basis and to also observe if these types and levels are impacted by participation in the respite care program. For the purpose of further analysis, the following null hypotheses has been developed for this research objective:

Hypothesis 1: There will be no difference on reported selected activities among the caregivers pre and post respite participation.

Of the 36 specific activities examined on the survey, the pre-post respite response rank order correlation for activity participation was .90. This is a relatively high correlation which signifies that personally chosen activities basically stayed consistent prior to and during the respite care intervention. Of the top 12 activities participated in prior to respite, 11 of these were again found in the top 12 post respite survey. In other words, the caregivers basically reported to be participating in the same activities with or without respite care, thus, reported pre-respite activity participation was more similar than dissimilar to post respite care activity. Based upon these interpretations, the null hypothesis is accepted. Pre and post respite activity rank order information can be found in Table 3.

Hypothesis 2: There will be no difference on reported levels of intensity of participation in reported selected activities among the caregivers pre and post respite participation.

Leisure Related Categorical Factors

In order to better understand possible overall categorical benefits for the various perceived levels of intensity of participation the statements were split into

Table 3

Pre Respite and Post Respite Activity Rank Order

Activity (Type)	Pre Rank	Post Rank
Laundry (HM)	1	4
Clean house (HM)	2	11
Grocery shopping (SE)	3	9
Run errands (SE)	4	2
Watched TV (PL)	5	10
Listened to music (PL)	6	6
Slept through the night (PR)	7	1
Spent time with other children (PR)	8	13
Read (PL)	9	7
Other shopping (SE)	10	12
Relaxed (PR)	11	3
Spent time with spouse (PR)	12	5
Went out with family (PR)	13	14
Garden work (YM)	14	18
Took a nap (PR)	15	16
Went out to dinner (PR)	16	8
Yard Work (YM)	17	20
Spent time with friends (PR)	18	15
Spiritual activities (PL)	19	17
Worked overtime (W)	20	24
Wrote letters (PL)	21	27
Went to a movie (PR)	22	21
Left work early (W)	23	33
Took vacation days (W)	24	19
Hair appointment (ADL)	25	28
Played a game (AL)	26	30
Went on vacation (PR)	27	22
Took a bubble bath (ADL)	28	29
Remodel (HM)	29	23
Aerobic Exercise (AL)	30	25
Paint (HM)	31	26
Manicure/pedicure (ADL)	32	32
Played a sport (AL)	33	31
Lifted weights (AL)	34	34
Attend fitness club (AL)	35	36
Got a massage (ADL)	36	35

Rank Order Correlation = 0.90

eight categorical areas based upon information gathered from the literature. Once the questions were categorized into benefit groups, t-tests were performed on each specific activity to see if there were any significant differences between the two self-reported intensity levels.

The categories that represent the underlying patterns of responses to reasons for participation were named as follows: Active Leisure, Passive Leisure, Work, Personal Activities of Daily Living, Personal Respite, Shopping/Errands, Home Maintenance and Yard Maintenance. Each of these areas and the activity responses are ranked on a scale of 1 – 5 with one representing no participation and five representing frequent participation. A visual breakdown of the pre and post respite activity participation analysis can be found in Table 4.

Category I: Active Leisure

For the purposes of the investigation, active leisure is a category that includes physically challenging and aerobic exercise. Specifically, the following activities were placed in the active leisure category: lifted weights, aerobic exercise, attended a fitness club, played a sport and played a game.

When reviewing the data from this category area it can be observed that while although the reported self-participation level is extremely low for all activities in the category that there was a reported higher level of participation in this category in the post test results.

Table 4

Pre and Post Respite Self Reported Activities Comparison of Means

(n = 55 except for work n= 37)

	Pre-Respite		**Post-Respite**			
	Mean	s.d.	Mean	s.d.	t-value	sig
Active Leisure						
Lifted Weights	1.18	0.67	1.42	1.06	-1.32	0.09
Aerobic Exercise	1.64	1.06	1.98	1.43	-1.64	0.05
Attend fitness club	1.16	0.60	1.29	0.87	-1.02	0.15
Played a sport	1.30	0.81	1.67	1.20	-1.86	0.03
Played a game	1.89	1.06	1.76	1.15	0.60	0.27
Passive Leisure						
Read	3.09	1.40	3.43	1.46	-1.25	0.10
Wrote letters	2.04	1.17	1.96	1.32	0.38	0.39
Spiritual Activities	2.42	1.24	2.62	1.47	-0.93	0.17
Watched TV	3.47	1.12	3.31	1.23	0.66	0.25
Listened to Music	3.27	1.22	3.45	1.26	-0.74	0.23
Work						
Worked overtime	2.13	1.46	2.10	1.54	0.08	0.47
Left Work Early	1.97	1.07	1.56	0.80	2.11	0.02
Took Vacation days	1.94	1.05	2.49	1.55	-1.90	0.03
Personal ADL						
Took a bubble bath	1.74	1.25	1.8	1.38	-0.20	0.42
Got a massage	1.14	0.62	1.31	0.92	-1.05	0.15
Manicure/pedicure	1.36	0.90	1.58	1.20	-1.08	0.14
Hair appointment	1.92	1.95	1.89	1.32	0.07	0.47
Personal Respite						
Slept through the night	3.18	1.47	4.25	1.12	-4.38	0.001
Went on vacation	1.76	1.20	2.2	1.58	-1.58	0.06
Spent time with spouse	2.64	1.42	3.51	1.45	-2.92	0.001
Spent time wit other children	3.13	1.23	3.24	1.56	-0.41	0.34
Took a nap	2.54	1.45	2.87	1.40	-1.17	0.12
Relaxed	2.67	1.14	3.58	1.16	-3.88	0.001
Spent time with friends	2.44	1.24	3.07	1.38	-2.52	0.01
Went out with family	2.62	1.27	3.11	1.41	-1.80	0.03
Went to a movie	2.04	1.28	2.25	1.60	-0.90	0.18
Went out to dinner	2.53	1.30	3.34	1.29	-3.60	0.001

	Pre-Respite		Post-Respite			
	Mean	s.d.	Mean	s.d.	t-value	sig
Shopping/Errands						
Grocery shopping	3.54	1.24	3.32	1.22	0.99	0.16
Other Shopping	2.96	1.32	3.29	1.13	-1.55	0.06
Run errands	3.51	1.36	3.69	1.14	-0.78	0.22
Home Maintenance						
Clean House	3.69	1.29	3.31	1.37	1.49	0.07
Laundry	4.13	1.15	3.58	1.26	2.41	0.01
Remodel	1.69	1.05	2.14	1.49	-2.08	0.02
Paint	1.56	1.01	1.98	1.44	-2.26	0.01
Yard Maintenance						
Garden Work	2.56	1.46	2.56	1.42	0.00	0.50
Yard Work	2.52	1.34	2.32	1.30	0.78	0.22

$P(T \leq t)$ one-tail 0.01

Category II: Passive Leisure

For the purposes of the investigation, passive leisure is a category that includes quiet, generally self-involved activities. Specifically, the following activities fell under the category of passive leisure: reading, writing letters, spiritual activities, watching television and listening to music.

When reviewing the data from this category area, it can be observed that the reported self-participation remains relatively unchanged from pre to post respite. Numbers indicate that caregivers report an occasional involvement in these activities. However, no significant changes were noted in this category from pre to post respite intervention.

Category III: Work

For the purposes of this investigation, work is a category that includes both working more and working fewer hours. Specifically, the following three activities fell under this category: worked overtime, left work early, and took vacation days.

When reviewing the data from this category area, it can be observed that some contradictory events occurred. For one, fewer working caregivers related that they left work early while their loved one was at respite care. This indicates they were working longer hours while they had respite care, however, the data also indicates that vacation days were utilized more during respite care than prior to the intervention. Thus some caregivers worked fewer hours during respite care.

Category IV: Personal Activities of Daily Living

For the purposes of this investigation, personal activities of daily living is a category that includes areas that indicate participation in self-care activities. Specifically, for this survey this area included such activities as: took a bubble bath, got a massage, manicure/pedicure and had a hair appointment.

When reviewing the data from this category area it can be observed that the reported self-participation level is relatively low for all activities in the category both pre and post respite care. There was a slightly higher level of participation in three of the four specific activities, however, none of them showed a significant level of increase.

Category V: Personal Respite

For the purposes of this investigation, personal respite is a category that includes a variety of activities that can be done alone or with others. The main focal point of this category is that all are activities that can be done to take a break from taking care of someone else. Many activity options were listed in this category. They include: slept through the night, went on vacation, spent time with spouse, spent time with other children, took a nap, relaxed, spent time with friends, went out with family, went to a movie and went out to dinner.

When reviewing the data from this category area many things can be observed. For one, though pre respite data indicates slight to occasional involvement in the ten activities, post respite data indicate an even higher level of intensity involvement in the activities. In fact, all ten areas show a higher involvement to some extent. Results further indicate that in five of the areas, there was a significant increase in participation. These significant increases were noted in slept through the night ($t = -4.38$, $p \leq 0.001$), spent time with spouse ($t = -2.92$, $p \leq 0.001$), relaxed ($t = -3.88$, $p \leq 0.001$), spent time with friends ($t = -2.52$, $p \leq 0.01$), and went out to dinner ($t = -3.60$, $p \leq 0.001$).

Category VI: Shopping and Errands

For the purpose of this investigation, shopping and errands is a category that includes specific as well as miscellaneous outings. Specifically, the category included grocery shopping, other shopping and running errands.

When reviewing the data from this category area it can be observed that there was a slight decrease in self-reported time spent grocery shopping and a slight increase in the time spent doing other shopping and running errands while the care receiver was at respite care. However, none of these relationships proved to be statistically significant.

Category VII: Home Maintenance

For the purposes of this investigation, the category home maintenance included four activities that are done in the home for upkeep purposes. The specific areas that fell into this category include: clean house, laundry, remodel and paint.

When reviewing the data from this category area it can be observed that two of the activities were reported to be participated in at a higher intensity level and two at a lower intensity level during respite care. Cleaning house and laundry were both shown to have lower intensity levels of participation during the respite care with a significant difference indicated by the data in the area of doing laundry ($t = 2.41, p \leq 0.01$). On the other hand, remodeling and painting were both indicated to be participated in at a higher intensity level during respite care with painting observed at a significant rate ($t = -2.26, p \leq 0.01$).

Category VIII: Yard Maintenance

For the purposes of this investigation, yard maintenance is a category that includes generally outdoors property upkeep. Two specific areas were listed in this category. They include garden work and yard work.

When reviewing the data from this category area it can be observed that while yard work is reported to be done at a slightly lower intensity level during respite care, no significant differences occur in either garden or yard work.

Overall Intensity of Participation

With the interest of examining overall intensity levels of activity participation, a t-test was administered to determine if any differences were noted in pre to post respite. Data indicated that self-reported post respite intensity levels were significantly higher than pre respite ($t = -5.57, p \leq 0.001$). Therefore, the null hypothesis must be rejected as a significant difference did occur. See Table 5.

Additional Self-Reported Activities

For the purpose of ascertaining what, if any, additional activities caregivers participated in regularly, an open-ended question was included requesting feedback that could be listed. This open-ended question was included to allow the respondents to specifically add additional activities participated in that may not have been included in the survey regarding personally chosen activities.

Prior to the respite week, caregivers noted things such as: take my child to the doctor, therapy, park and summer school. One mother even commented, "...I can't leave though while he (husband) is gone unless I have respite."

The surveys that were completed based on the week where the care receiver was at respite care offered a few different significant activities. Caregivers offered the following activities: uninterrupted phone time, sleeping late, extended vacations and ladies night out. One mother commented that the week was, "adult only." Another wrote, "I was able to eat hot meals with my family." Another yet commented that, "I was able to relax and put me first."

Activities listed on the pre respite survey tended to focus around the care receiver while activities listed on the post respite survey focused more on the caregiver.

Table 5

t-Test: Paired Two Sample for Reported Pre and Post Respite Activity Intensity Levels

	Pre-Respite Intensity Level	Post-Respite Intensity Level
Mean	2.38	2.61
Variance	2.02	2.36
Observations	1926.00	1926.00
Pearson Correlation	0.29	
Hypothesized Mean Difference	0.00	
df	1925.00	
t Stat	-5.57	
P(T≤t) one-tail	0.001	

Research Objective 2: To identify reported levels of life satisfaction of caregivers who participate in a structured respite care program.

The second research objective of this investigation was to establish the impact on life satisfaction on caregivers who participated in a respite care program, and see if there was any difference in their reported level of their life satisfaction pre and post respite program involvement. For the purpose of further analysis, the following null hypothesis has been developed for this research objective:

Hypothesis 2: There will be no difference on reported levels of life satisfaction for respite caregiver participants pre and post respite program participation.

The Diener Satisfaction with Life Scale was administered to all fifty-five families four weeks prior to their week of respite care and again immediately upon completion of this week of respite care. All fifty-five family members answered this five question scale completely both times. The researcher ran the data and performed a paired samples t-test and found a significant relationship between the two. Table 6 shows the results from the analysis of the self-reported pre and post respite life satisfaction survey. The post-respite data reported significantly greater scores on the satisfaction with life scale than did the pre-respite data ($t = -2.65$, $p \leq .01$). Thus, it can be observed that the care provider's life satisfaction increased significantly following their week of respite care and as a result of this analysis the null hypothesis must be rejected.

Table 6

t-Test: Paired Two Sample for Means – Diener Satisfaction with Life Scale

	Pre Total	Post Total
Mean	21.55	25.18
Variance	44.33	48.56
Observations	55.00	55.00
Pearson Correlation	-0.12	
Hypothesized Mean Difference	0.00	
df	54.00	
t Stat	-2.65	
P(T≤t) one-tail	0.01	
t Critical one-tail	1.67	

Program Impact Information

Lastly, for the purpose of evaluating the impact of the program on caregivers, six self-reporting questions were included. These questions were included to better understand the reason caregivers indicate sending their child to respite care, how demanding they feel it is to take care of their child (both physically as well as emotionally), feelings as to having sufficient time to take care of personal needs, and whether they felt the respite week was important in alleviating stress in their lives. Information gathered from these questions can be found in Table 7.

The responses indicate that caregivers agreed at a higher rate that they send their child to respite for the benefits received by the program participant than for personal respite.

Data received on 5 of the 6 questions remained steady from pre to post respite care. A significant difference was noted in one area. When caregivers were asked to rate their feelings on the amount of time they had to take care of their own personal needs, there was a significant change in the pre and post respite responses ($t = -3.42$, $p \leq 0.001$).

Satisfaction with Service

Of the fifty-five caregivers that completed the post-respite survey, forty-two completed the satisfaction with service section. Of these forty-two, forty

Table 7

Evaluation Information (n = 55)

	Pre-Respite		Post-Respite			
	Mean	s.d.	Mean	s.d.	t-value	sig
I send my child to Easter Seals for the benefits they receive	6.18	1.21	6.41	0.97	-1.26	0.10
I have enough time to take care of my own personal needs	3.98	1.67	4.81	1.77	-3.42	0.001
Taking care of my child is physically demanding	4.91	1.79	5.25	1.91	-1.08	0.14
This upcoming respite week will relieve some stress in my life	5.84	1.46	6.10	1.06	-1.36	0.09
Taking care of my child is emotionally stressful	5.16	1.84	5.07	1.74	0.28	0.38
I send my child to Easter Seals for personal respite	5.22	1.61	5.25	1.90	-0.15	0.44

(95.2%) reported that they were "extremely satisfied" with the service while two (4.8%) reported that they were "somewhat satisfied" with the respite care service.

Summary

A summary of results from these analyses indicate the effects of this week of respite care on the caregivers of family members with a disability. A significant difference was found in the degree of life satisfaction of the caregiver after the respite care had been provided in comparison with prior to the respite care. Also, caregivers reported that the week helped to relieve some stress in their lives and that they had more time to care for their own personal needs during the session of respite care.

There was an indication that caregivers tended to participate in the same types of activities whether their child was at respite care or not. However, the intensity levels varied quite extensively. Areas such as personal respite were participated in more frequently while home maintenance chores were participated in on a less frequent basis. Active leisure pastimes, while consistently rated at a low level of involvement throughout, did show an increase in participation in particular activities such as aerobic exercise and playing sports. Caregivers who work outside of the home were split between spending more time there and taking more vacation days. Overall, results indicated a significant increase in overall activity participation during the respite care time.

Chapter Five

Discussion

This study has examined two main topics concerning caregivers and the area of respite care. The first area of concern examined the potential difference in the type and intensity levels of personally chosen activities participated in by the caregiver during the respite care. The second related to levels of self-reported life satisfaction of the caregiver prior to and after the respite care. After conducting this investigation and analyzing the data, some conclusions can be formed.

Research Objective 1: To examine the differences in the type and intensity levels of participation in personally chosen activities among caregivers prior to and during a one-week long respite care program.

For the purposes of this investigation, this objective was broken down into two parts to examine in greater detail the data that the caregivers reported. First, the data was examined to see if there was a difference in the type of personally chosen activities caregivers participated in during the respite care in comparison to prior to respite. Secondly, the study called for the examination of the intensity levels of activity participation.

Pre and post respite data indicate that caregivers typically participated in the same activities whether or not they were participating prior to or during the respite care program. Of the top 12 activities that the respondents listed they participated in prior to respite, 11 of these were again in the top 12 post respite intervention. In other words, the caregivers basically reported to be participating in the same activities with or without respite care.

Some reasons that may explain why the caregivers participated in many of the same activities during respite care as they did prior to this intervention may be that the day to day routine is similar regardless of having a family member with a disability to take care of. This may be true especially for those caregivers who work. Because this intervention took place on a Sunday through a Friday, five of these days were likely spent at work, leaving little time for a change in routine with other children to take care of and just doing the regular day in, day out activities.

Another reason for the similarity in self-reported activity participation may stem from the fact that the caregivers may be unaware of other options available to them. Caregivers may have been taking care of their disabled child for so many years that their lives, including leisure activities, may have come to center around their child and what they can do with them.

Another point to consider is many of the activities that were listed in the top twelve were general everyday activities that occur in families with and without members without disabilities. Activities such as laundry, house cleaning, running errands and watching television happen regularly and have little to do with having a disabled member in the family.

For the purposes of this investigation self-selected intensity levels were also examined pre and post respite care. Results from this analysis indicated that caregivers reported a higher intensity level of participation in activities during their time with respite care. However, there also were a few activities in which they participated in at a lower level. This could be to compensate for the extra time spent on the other activities, in particular sleeping longer and taking a nap.

Active Leisure

Four out of five of the specific activities listed under the category of Active Leisure reported a higher level of participation during the respite intervention. However, pre and post respite data indicate very low levels of participation across the board in these types of activities.

If we look at the area of active leisure and what it entails, ideas can be formulated as to why participation in these types of activities are so low. Participating in active leisure, like attending a fitness club or doing aerobic exercise, is generally done outside of the home. If a caregiver is unable to find assistance for taking care of their dependent member, they are less likely to get away for the time period needed to perform this type of activity.

As mentioned earlier, caregivers report taking care of their family member on average 12.3 hours each day. Therefore, it is likely that, even if they were able to get away, they may be too tired to participate in any strenuous active leisure pastimes when time allows for it. It is likely that the caregivers use this free time to participate in more relaxing activities, with the hopes using the week to recuperate their energy. A higher level of intensity in the areas of more quiet pastimes, including passive leisure and personal respite support these claims.

As low as the involvement was, four specific areas did indicate a slight increase in intensity during the respite period. Perhaps, for some of the caregivers, because they were not taking care of an individual during this week, they were not quite as tired. This additional energy may have been used to participate in active leisure activities.

These results, mixed as they may be, appear to correspond with the results found in other research that indicated caregivers participated in more active leisure activities while their care receiver was at respite care (Botuck and Winsberg, 1991).

What may be of interest related to this area of activity participation in general, is the amount of physical energy that the caregiver uses on a daily basis taking care of their child with a disability. It may be that they are already performing some very intense physical or mental activity during their normal daily tasks with the child and thus may not be interested in further physical activity and become more interested in a more relaxed personal activity selection.

Passive Leisure

No significant differences were found when examining the data from the areas of passive leisure. This may be explained by the fact that taking care of a family member with a disability takes up a lot of time, which likely leads to caregivers with less energy. Participating in passive leisure is easier to do at home and can be done while the care receiver is not in need of any immediate attention. Perhaps caregivers of individuals with more severe disabilities have developed their lifestyles that enable them to engage in leisure activities without leaving their homes. This could be one reason why caregivers are participating in more passive than active leisure pastimes.

Work

Thirty-seven of the 55 (67%) caregivers in this study reported having a job outside of the home. Results from the category of work provided mixed findings. One result indicated that caregivers were putting in more hours at work during respite as indicated by lower levels of leaving work early. Yet, on the other hand, caregivers reported taking more vacation days from work during the respite week.

Perhaps one reason why more hours were put in at work for some caregivers is that they were not called away to take care of their family member during the week of respite care. If the caregivers were not responsible for taking care of their family member, they were able to stay at work for their full workday rather than leaving early to tend to the needs of the care receiver. This thought corresponds with data collected by Abelson (1999). Results from that study indicated parents of children having moderate to severe disabilities are prone to miss excessive numbers of work hours.

Some respondents wrote comments about having taking an extra long vacation with their family, spending the night away from home, and just getting away for a couple of days. Often times taking a family vacation with a member that has a disability can prove to be very stressful due to the care they need, the lack of self control, or the difficult accommodations that need to be made. Therefore, many caregivers do not even attempt a large vacation with their disabled loved one. That may be a reason why there was an increase in time taken off from work in vacation days. Some caregivers call months in advance to determine when their child will be attending camp in the summer so they can put in a request at their job for that same time period off. It may prove easier and more relaxing to take vacation time without the member with a disability being home.

Personal Activities of Daily Living

Respondents indicated very low intensity levels of participation in personal activities of daily living in both the pre and post respite responses. Results indicated that caregivers did not spend extra time doing special activities of daily living for themselves during the respite time.

One reason for this low occurrence is that the activities in this category were fairly specialized. For example, not many people in society ever receive a professional massage or take the time to get a manicure. It is understandable that an increase in these activities was not seen as these activities as many people simply do not have the money or the desire to pay for these services. Also, these activities take up time. Results from this study indicated that caregivers were more likely to spend their increase in free time socializing or relaxing.

Personal Respite

Results acquired from the personal respite category led to the most salient results of this investigation. Analysis indicated that all ten activities were participated in a higher intensity level, with five out of ten reporting a statistically significant higher level of intensity during the respite care intervention. These five include sleeping through the night, spending time with spouse/significant other, relaxing, spending time with friends, and going out to dinner.

This finding may be especially important to note because so many parents are hesitant to report an appreciation for the respite period for the purpose of personal respite. One mother even voiced that, "I think I've come to the conclusion that I send my child to respite more for myself than for his personal benefits. Does that make me sound like a bad mother?"

As was noted by the data, caregivers are more likely to report that they send their loved one to respite care for the benefits they receive from the program. Many are negligent about admitting that they enjoy the personal respite or that they send them to the respite program for their own personal respite.

Spending time with a spouse or significant other ranked the highest followed by time with other children and friends, then general relaxation (including areas like naps and sleeping through the night). Could this be part of the reasoning behind the respondents reporting higher levels of life satisfaction as a result of the respite? Again, findings from Botuck and Winsberg (1991) support these findings.

As a result of their analyses they found that caregivers spent more time resting and sleeping and interacting with others. It is probable that an individual who has had more rest and more time to socialize with family and friends feels that their life is more manageable.

Shopping/Errands

Shopping and running errands are activities that generally have to be done on a weekly basis no matter what may be the case, as such just because the family member with a disability is not home for the week does not mean the family does not have to do its grocery shopping. Results more than likely indicate that families with a disabled child are no different than any other family when it comes to the outside demands of daily living.

Home Maintenance

Three of the four areas in this category showed a significant difference in intensity of participation during respite care. Similar to above, these results also indicate that life must go on and home maintenance is important to keep up with. However, in this case there may be more significant levels of involvement in these activities because it could be easier to do home maintenance tasks when respite care is being provided.

Yard Maintenance

Yard maintenance participation also remained consistent. Once again, similar to shopping, running errands and home maintenance this activity is typically done on a scheduled weekly basis. Generally, a family is not going to let weeds take over their yard and garden just because they are receiving respite care.

Research Objective 2: To identify reported levels of life satisfaction of caregivers who participate in a structured respite care program.

Probably the most important finding of the investigation was the result of a significant difference in the reported degree of life satisfaction of the caregiver in the post respite care response in comparison with the response to this instrument prior to the respite care. These results correspond with the findings of Botuck and Winsberg (1991) who reported increased feelings of well being after respite as well as a decrease in depressed moods.

It is likely that the increase in life satisfaction comes from being better rested after the full week of respite care. Generally when people are more rested, they feel better about themselves and their surroundings. It could be that after a full week of respite, the caregivers may have had an enhanced level of energy, leading them to feel better about themselves and the lives they lead.

Other reasons that tie into a higher perceived level of life satisfaction include an increase of time spent socializing with family and friends. Post respite surveys indicated in increase in time spent with spouse, time spent with friends and time spent with family. Time spent with other people in an enjoyable fashion can relieve stress and increase personal feelings of well-being. This was indicated by one mother's excited response that during respite care she had a "girls night out!"

Another reason that could explain why an increase in life satisfaction was perceived by the caregivers during respite was that they were not directly responsible for every minute of care that their child needed. While the family member was at respite, their needs were being taken care of by someone else. If their child woke up in the night, the caregiver did not have to respond. At meals, the caregiver was able to eat by themselves rather than having to feed their child. They did not have to redirect, dress or transfer their child for an entire week. This decrease of time spent being on-call all of the time likely decreased their stress levels and lead them to feeling an increased level of life satisfaction.

It may be appropriate to correspond these results with the results from a personally added question that indicated that caregivers felt an increase in having enough time to take care of their own personal needs. Having this extra time may allow the caregiver to accomplish more in rest, leisure and work and thus could impact a personal perception of life satisfaction. If caregivers do not feel they have sufficient time to take care of themselves, they may have a decreased feeling of well-being. After the week of respite, response data indicated that caregivers felt more strongly that they did have enough time to take care of themselves and their own needs. This can be emphasized by the parental remark that, "I was able to put me first." The ability to put one's self first for an entire week could also have played a role in the increase felt in life satisfaction.

Limitations

There are limitations in this study that necessitate caution in its interpretation. These include the small sample size, the absence of a control group and relying on self-report from the caregivers. It is possible with these limitations that the results that occurred are biased. Biased results could be the result of a group of respondents who hold a high interest in respite care, lack of control group to compare results with, or dishonesty that could occur from relying on self-report.

To control for the possibility of a Type I error, the p-value was identified at .01. Although .05 is considered appropriate in finding significant results, it was felt with the number of t-tests performed in this study, it was safer to err on the side of caution by lowering the significance value.

Significance

This study's findings are of benefit because respite care has been promoted to be of assistance in supporting families that have a member with a disability. Respite has been recognized to be beneficial in relieving stress, which may lead to burned out caregivers. It has also been discussed as enhancing family coping, reducing risk of abuse/neglect and increasing feelings of well-being (www.respiteillinois.org, 2000). One website describes the word respite as: **R**elaxation, **E**njoyment, **S**tability, **P**reservation, **I**nvolvement, **T**ime off, **E**nrichment (www.nichcy.org, 1996). Results from this investigation provide credence to some of these alleged outcomes.

Of further significance is the availability, or lack thereof, of funding for this family support system. Currently there exists quite a deficit when it comes to state funding for the area of respite program and as a result many families are on a long waiting list to receive funding for this service. Because respite care can often be expensive, not many families are able to afford it without some type of government assistance.

Funding respite care programs, besides providing the benefits discussed, would also prove to be a cost-effective way of providing public assistance to these families. Respite care has shown to reduce the residential placement (Kosloski & Montgomery, 1995) as well as reduce hospital placement (www.respiteillinois.org, 2000). By reducing these types of placement, public funds are being saved (www.respiteillinois.org, 2000). Therefore, respite care appears to be a cost effective intervention for families with disabled members. Money spent on respite care now could potentially save even more money in the future that will be paid out to residential and hospital facilities. Third party payers may also take an interest in respite care if it can be indicated that reduced stress levels potentially provided by participation in a respite care program improve caregivers' health. Thus some of these payers future costs related to caregivers's increased illness due to the stressors of the daily around the clock demands of being a caregiver may be reduced.

Recreational Therapy Implications

Recreation therapy is a profession that provides opportunities for children with disabilities to enjoy themselves in a fun and relaxing environment. One of the roles of a recreation therapy program is to also provide opportunities for parents of these children with time off, or respite from the demands of around the clock caring for their children. There are some implications for the recreation therapy profession that can be discussed as a result of this investigation. For instance, the data from this study indicates that caregivers are participating in nearly the exact same activities prior to and during respite times. Thus, the possibility exists that caregivers may benefit from leisure education interventions.

Pre respite leisure education programming might equip caregivers with the information that could help them to branch out of their daily routine, and this education may carry over into their lives after the intervention. The data from this study indicates low levels of participation in active and passive and thus may also indicate a deficit of awareness in leisure involvement and the concomitant values of leisure participation. This lack of knowledge about what is available to them may be just what is needed to discover a world that is outside of their existing world.

Leisure education could also provide caregivers with information about leisure resources and also with more active pastimes that can be participated in with their disabled family member. Accessible vacation sites, ease in travel and fun locations for families could be some of the topics covered. Education could provide them with the materials needed to participate in a more active lifestyle with their entire family.

Recommendations for Further Research

After completion of this investigation, it is evident that there are measurable effects of respite care that caregivers find to be beneficial, however, more research could be done on this topic to get a better idea of why caregivers are requesting more respite care be available. This investigation has examined what caregivers gain from the experience from a life satisfaction and activity participation perspective, however, there still may be more benefits from this experience that we still don't know about? It would be beneficial to find out the change in life satisfaction of caregivers one week, one month and six months after the respite care intervention to determine how long these effects last.

It is also suggested that future research could examine the daily routines of caregivers when taking care of their family member and during the respite period.

Perhaps a more qualitative analysis seeking answers from caregivers to keep a leisure or personal activity journal, as a more accurate descriptor of specific levels of participation and personal feelings about the participation could be examined.

It would also prove worthwhile to examine the effects respite care has on stress levels and if stress is correlated to life satisfaction. Because decreased stress levels tend to correspond with increased health, it may be worth examining this topic to determine if respite care has any direct effects of stress levels.

Also of importance in a future analysis would be the addition of a control group consisting of caregivers who are not receiving any respite care. It could then be determined if differences exist between the two groups and what kind of an impact, if any, not participating in respite has on families.

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Appendix A

Pre Respite Care Survey

Please rate the level of your participation in the following activities over the course of this past week using the following scale.

1 = Never **3 = Occasionally** **5 = Frequently**

Active Leisure					
Lifted weights	1	2	3	4	5
Aerobic exercise	1	2	3	4	5
Attend fitness club	1	2	3	4	5
Played a sport	1	2	3	4	5
Played a game	1	2	3	4	5
Passive Leisure					
Read	1	2	3	4	5
Wrote letters	1	2	3	4	5
Spiritual activities	1	2	3	4	5
Watched TV	1	2	3	4	5
Listened to music	1	2	3	4	5
Work					
Worked overtime	1	2	3	4	5
Left work early	1	2	3	4	5
Took vacation days	1	2	3	4	5
DNA	1	2	3	4	5
Personal ADL					
Took a bubble bath	1	2	3	4	5
Got a massage	1	2	3	4	5
Manicure/pedicure	1	2	3	4	5
Hair appointment	1	2	3	4	5
Personal Respite					
Slept through night	1	2	3	4	5
Went on vacation	1	2	3	4	5
Spent time with spouse	1	2	3	4	5
Spent time with other children	1	2	3	4	5
Took a nap	1	2	3	4	5
Relaxed	1	2	3	4	5
Spent time with friends	1	2	3	4	5
Went out with family	1	2	3	4	5
Went to a movie	1	2	3	4	5
Went out to dinner	1	2	3	4	5

1 = Never **3 = Occasionally** **5 = Frequently**

Shopping/Errands					
Grocery shopping	1	2	3	4	5
Other shopping	1	2	3	4	5
Run errands	1	2	3	4	5
Home Maintenance					
Clean house	1	2	3	4	5
Laundry	1	2	3	4	5
Remodel	1	2	3	4	5
Paint	1	2	3	4	5
Yard Maintenance					
Garden work	1	2	3	4	5
Yard work	1	2	3	4	5

Please list any other activities not included above that you have participated in over the course of the past week.

NOW PLEASE GO BACK THROUGH THE LIST AND CIRCLE THE FIVE (5) ACTIVITIES YOU THINK MAY HAVE BEEN EASIER TO ACCOMPLISH HAD YOUR CHILD BEEN AT RESPITE CARE.

How many hours/day can your child be left alone? ______

How many hours/day do you spend taking care of your child? ______

PLEASE PROVIDE THE FOLLOWING DEMOGRAPHIC INFORMATION.

Primary Caregiver Information

Gender (circle one) Female Male

Age: _________

Marital Status: (circle one) Single Married

Relationship to Care Receiver (circle one)

Mother Father Sibling Other: _______________

Number of Other Children: _________

Annual Family Income Range (circle one)

<$10,000 $10-20,000 $20-30,000 $30,000 +

Highest Level of Education Completed (circle one)

Elementary School Secondary School College Graduate Degree

Care Receiver Information

Gender (circle one) Female Male

Age: _________

Please describe your child's primary disability.

Thank you for agreeing to participate in this study. I appreciate your assistance in answering the questions openly and honestly.

☐ I would like a summary of results upon completion of the study.

Below are a series of statements that you may agree or disagree with. Using the 1 – 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

7 – Strongly Agree
6 – Agree
5 – Slightly Agree
4 – Neither Agree nor Disagree
3 – Slightly Disagree
2 – Disagree
1 – Strongly Disagree

_____ In most ways my life is close to my ideal.

_____ The conditions of my life are excellent.

_____ I am satisfied with my life.

_____ So far I have gotten the important things I want in life.

_____ If I could live my life over, I would change almost nothing.

_____ I send my child to Easter Seals for the benefits they receive.

_____ I have enough time to take care of my own personal needs.

_____ Taking care of my child is physically demanding.

_____ This upcoming respite week will relieve some stress in my life.

_____ Taking care of my child is emotionally stressful.

_____ I send my child to Easter Seals for personal respite.

Appendix B

Post Respite Care Survey

Please rate the level of your participation in the following activities over the course of this past week using the following scale.

1 = Never **3 = Occasionally** **5 = Frequently**

Active Leisure					
Lifted weights	1	2	3	4	5
Aerobic exercise	1	2	3	4	5
Attend fitness club	1	2	3	4	5
Played a sport	1	2	3	4	5
Played a game	1	2	3	4	5
Passive Leisure					
Read	1	2	3	4	5
Wrote letters	1	2	3	4	5
Spiritual activities	1	2	3	4	5
Watched TV	1	2	3	4	5
Listened to music	1	2	3	4	5
Work					
Worked overtime	1	2	3	4	5
Left work early	1	2	3	4	5
Took vacation days	1	2	3	4	5
DNA	1	2	3	4	5
Personal ADL					
Took a bubble bath	1	2	3	4	5
Got a massage	1	2	3	4	5
Manicure/pedicure	1	2	3	4	5
Hair appointment	1	2	3	4	5
Personal Respite					
Slept through night	1	2	3	4	5
Went on vacation	1	2	3	4	5
Spent time with spouse	1	2	3	4	5
Spent time with other children	1	2	3	4	5
Took a nap	1	2	3	4	5
Relaxed	1	2	3	4	5
Spent time with friends	1	2	3	4	5
Went out with family	1	2	3	4	5
Went to a movie	1	2	3	4	5
Went out to dinner	1	2	3	4	5

1 = Never **3 = Occasionally** **5 = Frequently**

Shopping/Errands					
Grocery shopping	1	2	3	4	5
Other shopping	1	2	3	4	5
Run errands	1	2	3	4	5
Home Maintenance					
Clean house	1	2	3	4	5
Laundry	1	2	3	4	5
Remodel	1	2	3	4	5
Paint	1	2	3	4	5
Yard Maintenance					
Garden work	1	2	3	4	5
Yard work	1	2	3	4	5

Please list any other activities not included above that you have participated in over the course of the past week.

NOW PLEASE GO BACK THROUGH THE LIST AND CIRCLE THE 5 MOST IMPORTANT ACTIVITIES YOU FOUND EASIER TO ACCOMPLISH WHEN YOUR CHILD WAS AT RESPITE CARE.

How many hours/day can your child be left alone? ______

How many hours/day do you spend taking care of your child? ______

PLEASE PROVIDE THE FOLLOWING DEMOGRAPHIC INFORMATION.

Primary Caregiver Information

Gender (circle one) Female Male

Age: __________

Marital Status: (circle one) Single Married

Relationship to Care Receiver (circle one)

Mother Father Sibling Other: ________________

Number of Other Children: __________

Annual Family Income Range (circle one)

<$10,000 $10-20,000 $20-30,000 $30,000 +

Highest Level of Education Completed (circle one)

Elementary School Secondary School College Graduate Degree

Care Receiver Information

Gender (circle one) Female Male

Age: __________

Please describe the your child's primary disability.

Thank you for agreeing to participate in this study. I appreciate your assistance in answering the questions openly and honestly.

Below are a series of statements that you may agree or disagree with. Using the 1 – 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

7 – Strongly Agree
6 – Agree
5 – Slightly Agree
4 – Neither Agree nor Disagree
3 – Slightly Disagree
2 – Disagree
1 – Strongly Disagree

_____ In most ways my life is close to my ideal.

_____ The conditions of my life are excellent.

_____ I am satisfied with my life.

_____ So far I have gotten the important things I want in life.

_____ If I could live my life over, I would change almost nothing.

_____ I send my child to Easter Seals for the benefits they receive.

_____ I have enough time to take care of my own personal needs.

_____ Taking care of my child is physically demanding.

_____ This respite week relieved some stress in my life.

_____ Taking care of my child is emotionally stressful.

_____ I send my child to Easter Seals for personal respite.

Please circle your level of satisfaction with this respite service.

1= extremely satisfied 2= somewhat satisfied 3= not satisfied