



IJSRM

INTERNATIONAL JOURNAL OF SCIENCE AND RESEARCH METHODOLOGY

An Official Publication of Human Journals



Human Journals

Review Article

December 2020 Vol.:17, Issue:2

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Respite Care in Families of Children with Disabilities: A Literature Review



Susana Pizano Vega¹, Johanna G. Leichty¹, Malik D. Peterson¹, Samuel P. Abraham^{2*}

*¹Bethel University School of Nursing at Grace College
Campus, Winona Lake, Indiana, USA ^{2*}Associate
Professor of Nursing, Bethel University School of
Nursing, Mishawaka, Indiana, USA*

Submitted: 07 November 2020

Revised: 27 November 2020

Accepted: 17 December 2020



HUMAN JOURNALS

www.ijsrm.humanjournals.com

Keywords: Respite care, disabled children, parents of disabled children, caregiver burnout, effects of respite care in disabled children, and families without respite care

ABSTRACT

Background: Children with disabilities can increase stress for the entire family, including the disabled child. Stress can alter family dynamics in various ways. If left untreated, stress can lead to caregiver burnout, which ultimately affects the care the disabled child receives. One of the common ways to reduce the chance of burnout is by using respite care. **Purpose:** The purpose of this review was to examine the association between families of children with disabilities and their use of respite care. **Method:** The method used was a systematic review of the literature to collect data on the association between families of children with disabilities and their use of respite care. The patient, intervention, comparison, outcome, and time (PICOT) question was: In families of children with disabilities, what is the effect of respite care on family dynamics compared with families not using respite care? **Results:** The literature review provided evidence that respite care can reduce caregiver stress, burnout, and strengthen family dynamics. Respite care can be beneficial for the family unit and should be offered to all families who have a child or children with disabilities. **Conclusion:** Outcomes produced from respite care in disabled children have made a lasting positive impact on the health of disabled children and their families.

INTRODUCTION

Stress, burnout, and altered family dynamics are issues for families of children with disabilities [1-4]. Respite care impacts family well-being and should be offered and or used for families with disabled children [1-4]. Having a disabled child can cause negative emotional, physical, and psychological impacts and weight heavy on caregivers over time [5]. Respite care “provides parents and other caregivers with short-term childcare services that offer temporary relief, improve family stability, and reduce the risk of abuse and neglect” [6]. Respite care can be used in a variety of ways. It can be utilized daily or as needed by the caregiver when they require a break. Using respite care can reduce the stress of caregivers, promote, and strengthen family life. The importance of respite care in disabled children is high to reduce the risk of burnout in caregivers. When caregivers do not utilize respite care, they can “have a much harder time taking care of the child” [7]. With the help of respite care, caregivers can have time to spend alone with their spouse and other children, which will result in the entire family developing better relationships with each other. Overall, respite care improves caregivers and family members' mental and physical health, including disabled children. The purpose of this review was to examine the association between families of children with disabilities and their use of respite care. Utilizing the problem, intervention, comparison, outcome, and time frame (PICOT), the question developed was: “In families with children with disabilities, what is the effect of respite care on family dynamics compared with families not using respite care?”

METHOD

The EBSCOhost databases were used for this systematic review. Some of the keywords used to find studies were respite care, disabled children, parents of disabled children, caregiver burnout, effects of respite care in disabled children, and families without respite care. Published studies collected for this review were between 2017 and 2020. The data found in the reviews were qualitative and quantitative analysis, control trials, and systematic reviews. Figure 1 shows the level of evidence hierarchy used for this review. These levels were predetermined on a scale used for nursing research. Level one is the highest level of research, and level seven is the lowest. Studies in the top four levels were used when researching data on respite care services for

families of children with disabilities. No studies were found in level two and three tiers, and only one study was found in the level one tier. The 14 other studies were all in the level four tier.

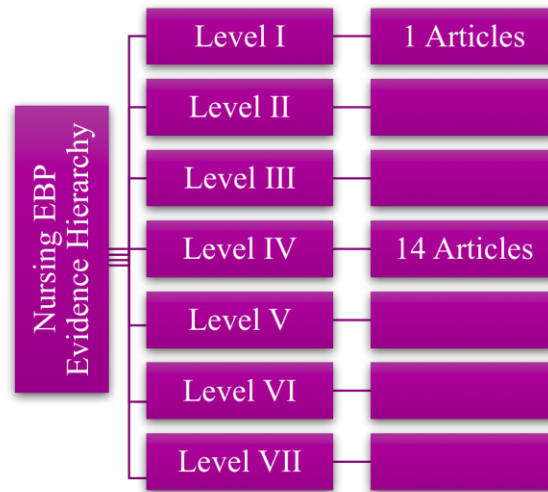


Figure No. 1: Levels of evidence for the topic of respite care in families with children with disabilities.

REVIEW OF THE LITERATURE

The purpose of this review was to identify the effects that respite care has on families of children who have disabilities. Fifteen studies about respite care and disabled children in families were evaluated. Reviewing the literature revealed many themes related to respite care and its effect on families of children with disabilities. The following themes were identified in the literature review.

Reduction of Stress for Caregivers

Stress is one of the most common adverse effects when caring for a child with a disability. Families caring for a child with disabilities are more prone to illnesses, high levels of stress and depression, and suffer from more family breakdown than those who do not have a child with a disability [4]. These families can have a significant increase in stress when they are not utilizing respite care. This added stress can lead to families developing caregiver role strain, lacking social life, and forgetting to take care of themselves. Caregivers of children with disabilities who did not utilize respite care services were in greater stress, poorer physical health, and worried about

the future than families who used respite care [8]. Respite care can be used to reduce stress in caregivers [8].

Several positive findings of reducing stress are seen when families received interventions to support caregivers [9]. Of the several interventions, respite care played a significant role. Respite care allowed families to have a mental and physical break from their daily caregiving activities.

In their study, Whitmore and Snethen [10] found that giving 22 parents with children of special healthcare needs a "community-based respite program" resulted in an appraisal of respite care. The families believed that the program allowed them to build stronger relationships with themselves and others. Through these research studies, it can be concluded that respite care plays a vital role in reducing caregivers' stress, which will further decrease the chance of burnout.

Reduction of Burnout for Caregivers

Burnout is another negative effect when caring for a child with disabilities. Barros *et al.* [1] compared caregivers of children with Down syndrome versus caregivers caring for typically developing children. The study presented the caregivers of children who had Down Syndrome with a moderate burden compared to the typically developing children. The study showed that emotional, physical, and financial burden, in addition to restrictions on social and leisure activities, can have a significantly increased risk for burnout. When families do not receive respite care, they cannot take a step back from their daily caregiving duties and take time for themselves mentally and physically. As time continues, the caregivers can develop an increased amount of stress, anxiety, and frustration that will grow into burnout. Respite care allows the caregivers to take a break for themselves and reduce some of the stress, anxiety, and frustration they may have, decreasing their likelihood of burnout [11].

A survey questionnaire was distributed in one study to assess respite care benefits for family caregivers of children with disabilities [12]. The survey was distributed to a large population that resulted in 247 responses. The questionnaires had a total of four main categorial domains. Of the four domains, two support the reduction of burnout for caregivers. The two domains are the following: 1) An increase in the sense of peace and life fulfillment among caregivers; 2) Mental health support for caregivers. Caregivers being able to feel peace and life fulfillment and mental

support by using respite care help them reduce the risks of harmful effects of caregiving that can lead to burnout [12].

Strengthening of Family Dynamics

In their study, Engwal and Hultman [13] stated the need for attention to be given to the families of children with disabilities, not just the children themselves. Parents may feel that they must focus all their time and energy on their disabled child. Because of this, parents may not have enough energy to care for their other children. The need for increased quality time with family members helps improve healthy relationships. Having respite care services allows parents to have a break from caring for their child with disabilities and focus on others' in the family, leading to a healthy family relationship [13].

Castor *et al.* [2] showed that members of the family who utilized respite care reported strengthening family life through their 15 interviews. Strengthening family dynamics involves various interventions, including respite care, that help reduce stress and burnout. Giving caregivers a break to recharge allows them to deliver a better quality of care. When respite care services are utilized, the child can learn and experience things apart from their family. Having these experiences allows the child to learn how to interact with other people outside of their family household. This allows for improved child development by experiencing new people, situations, and environments [2].

Otsuki *et al.* [12] included a domain that supports the improvement of child development. The domain shows a positive effect on child development. This domain also had several subcategories. The subcategories are the following: improvement in the social skills of the disabled child, mental growth of the child, taking care of others as an experience, increasing opportunities for new experiences for the child, and helping the child become curious. The results of this study support that respite care improves child development through the making of these subdomains [12].

Summary of Findings

The purpose of this review was to assess the effects respite care has on families of children with disabilities. Fifteen research studies were analyzed to evaluate these effects. The studies were all in the top four tiers on the levels of the evidence hierarchy. Articles discussing the use of respite care in families of children with disabilities revealed several emerging themes. Themes included 1) Reduction of stress for caregivers; 2) Reduction of burnout for caregivers; 3) Strengthening of family dynamics (see Figure 2).

The question was, “In families of children with disabilities, what is the effect of respite care on family dynamics compared with families not using respite care?” The findings reflect the positive effects respite care has on families of children with disabilities.

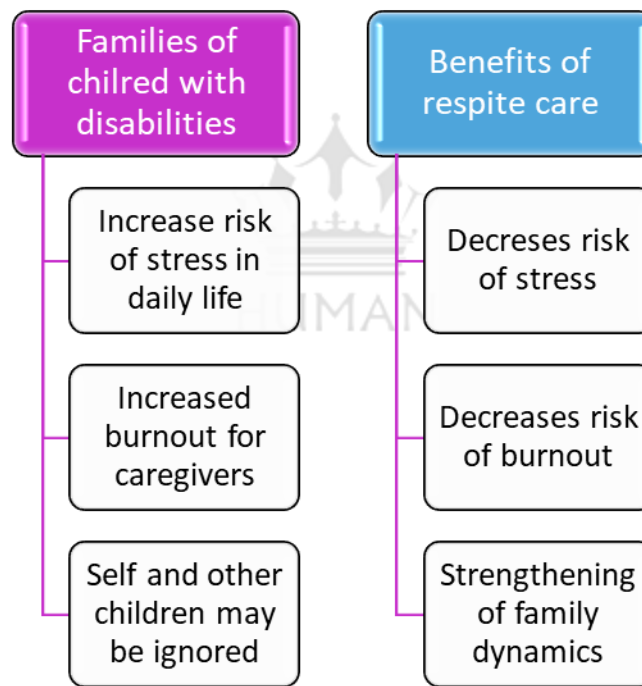


Figure No. 2: Emerging themes of respite care use for families of children with disabilities

DISCUSSION

This systematic review showed the effects respite care has on families of children with disabilities. All 15 studies revealed that families who had children with disabilities have an increased risk of stress in their daily lives. The studies pointed towards several factors of respite

care that would decrease this risk. Mazzone *et al.* [14] evaluated 68 families who had a child with autism spectrum disorder and 43 families with a typically developing child to determine how families were impacted by having a child with a disability. This study showed how much families were negatively affected when compared to how severely the child was disabled. The conclusion can be made that the more disabled a child is, the greater risk for adverse outcomes and the greater impact respite care can have on supporting the family and decreasing the negative consequences [14]. Overall, respite care positively impacts family well-being and should be offered and or utilized for families with disabled children.

Recommendations

It could be recommended that more research be done on respite care. It was not easy to find studies that focused explicitly on respite care practices in the United States. Services that are offered through respite care can vary from country to country. Focusing on respite care in the United States would provide a better understanding of the currently available services and potential needs for improvement.

While it can be easy for providers to focus only on the child's needs, the entire family's needs must also be assessed [15]. Families do not always fully understand how respite care can benefit them, and some have barriers that make it harder for them to access information on respite care [16]. Because of this, healthcare providers should assess the need for respite services at every encounter. Moerschbacher [17] shows the importance of educating communities and families on inclusive services. Educating families early on can provide faster assistance and support to decrease the chance of burnout and improve family dynamics.

Strengths and Weaknesses

The strength of this review was that there were no studies opposed to the use of respite care services. All the studies analyzed for respite care services gave positive outcomes and perspectives on the use of respite care. A weakness of the review of the literature was the lack of sufficient current studies on respite care. Out of the 15 articles, only three of them were from 2020. Most of the studies were from 2017 and 2018. Data and information are continually evolving and changing, so it is essential to have updated information on the topic. Another

weakness was that studies in level two and three tiers were difficult to find. From the 15 studies, 14 were from a level four tier, and one was from a level one tier. Having more articles from level one, two, and three tiers would provide a broader range of research to better analyze the topic.

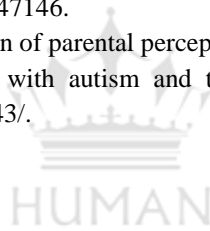
CONCLUSION



The purpose of this review was to determine the effects of respite care on families who have children with disabilities. Outcomes produced from respite care in disabled children have made a lasting positive impact on disabled children and their families' health. Family members who utilize respite services have a significantly lower risk for stress and caregiver burnout. Along with this, the child can gain new experiences that help improve their childhood development. The question, "In families of children with disabilities, what is the effect of respite care on family dynamics compared with families not using respite care?" was answered through an analysis of research articles by concluding that respite care can reduce caregiver stress and burnout and strengthen family dynamics. In conclusion, respite care can be beneficial for the family unit and should be offered to all families who have a child or children with disabilities.

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	<p>Susana Pizano Vega</p> <p><i>Bethel University School of Nursing at Grace College Campus, Winona Lake, Indiana, USA</i></p>
	<p>Johanna G. Leichty</p> <p><i>Bethel University School of Nursing at Grace College Campus, Winona Lake, Indiana, USA</i></p>
	<p>Malik D. Peterson</p> <p><i>Bethel University School of Nursing at Grace College Campus, Winona Lake, Indiana, USA</i></p>
	<p>Dr. Samuel P. Abraham – Corresponding Author</p> <p><i>Associate Professor of Nursing, Bethel University, 1001 Bethel Circle, Mishawaka, Indiana, USA.</i></p>