

Coping as a Caregiver for Children with Physical Disability: Mini Review

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Abstract

Background: Physical disability is a term that refers loss or impairment of part of a person's body function, resulting in a limitation of physical functioning, mobility. Arrested development of physical capacities can lead to number of problems for the sufferer as well as the caregivers/parents. **Method:** The databases PubMed, PsycINFO, Google Scholar and Scopus were searched for relevant studies published between 2000 and 2019. Data was extracted on study and participants' characteristics, independent and dependent variables. **Conclusions:** It could be concluded that this review highlights the importance of coping strategies used by caregivers.

Key Words: Children with physical disability - Coping - Caregivers

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I. Introduction

According to WHO, 2012 define children with special needs, who are children was born with a disabling health condition or impairment, most of disabilities as a result of illness, injury or poor nutrition. Children with physical special needs are those with health conditions such as cerebral palsy, spinal bifida, muscular dystrophy, traumatic spinal cord injury, Down syndrome, and children with hearing, visual, physical, communication and intellectual impairments. Some children with disabilities have a single or multiple impairment (New York State Department of Health, 2017). Physical disability is a physical condition that affects a person's mobility, physical capacity, stamina, or dexterity. This can include brain or spinal cord injuries, multiple sclerosis, cerebral palsy, respiratory disorders, epilepsy, hearing and visual impairments and more (Hampshire County Council, 2005).

According to World Health Organization (WHO,2011) Over one billion people – about 15% of the global population – live with some form of disability and this number is increasing. The latest update on the prevalence of disability in the Arab countries according to Economic and Social Commission for Western Asia (ESCWA). The highest rates of disability were in Sudan with 4.9%, and Palestine with 4.6% of the total population in the same country. Oman ranked second, with a disability rate of 3.2%. In the last rank among the top 10 Arab countries, Saudi Arabia and the UAE were included, which recorded the same percentage of disability, which is equivalent to 0.8%. (ESCWA ,2014)

Method: The databases PubMed, PsycINFO, Google Scholar and Scopus were searched for relevant studies published between 2000 and 2019. Data was extracted on study and participants' characteristics, independent and dependent variables. A review was performed to synthesize findings along the constructs social support, social networks, negative social interactions, family functioning and relationship quality.

II. Literature Review

This review covers definition of terms related to disability & physical disability, categories of disability, causes of physical disability,

Children's disabilities and distresses may burden their family members, especially their parents, who are their long term caregivers. Parents who have children with disabilities are often reported to have physical and psychological distress related to caring for their children, thus affecting their quality of life and having its impact on their coping and psychological well-being (Rethlefsen et al., 2010).

Definition of disability

According to Convention on the Rights of Persons with Disabilities (CRPD) 2006, it defines persons with a disability as including those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Definition of developmental disability

Most childhood disabilities are referred to as developmental disabilities, defined as any physical or mental condition that may impair or limit a child's ability to develop cognitively, physically, and emotionally compared to other children (Thompson, 2000). **Developmental disability** refers to a range of conditions including intellectual disability, cerebral palsy, autistic spectrum disorder, learning disability, epilepsy, etc.

Disabilities fall into one of four broad categories as following (Smart, 2000, Thompson, 2000 & Falvo, 2017): **Physical Disability**, a condition that limits one or more basic physical activity, including mobility and sensory activities. Examples include: spinal cord injuries, paraplegia, quadriplegia, amputations, cerebral palsy, seizure disorders, muscular dystrophy, arthritis, visual impairments and hearing impairments. **Intellectual Disability**, a disability originating prior to the age of 18, characterized by significant limitations in conceptual, social, and practical adaptive skills, for example, mental retardation. **Cognitive Disability**, an impairment that affects an individual's ability to access, process, or remember information, for example, learning disabilities (dyslexia, attention deficit disorder) and traumatic brain injury. **Psychiatric Disability**, a disability characterized by emotional, cognitive, and/or behavioural dysfunction, for example, autism, substance abuse, different types of mental illnesses.

A person with a physical disability is constrained by his physical ability to perform an activity independently such as walking, bathing, toileting, etc. A person can be physically disabled due to two reasons: Congenital/Hereditary – the person has physical disability since birth or the disability developed at a later stage due to genetic problems, problems with muscle cells or injury during birth. Acquired – the person acquired the physical disability through road or industrial accidents, infections such as polio or diseases and disorders such as stroke or cancer. (Handicaps Welfare Association ,2021)

Causes of Physical Disability (Perrin, 2002, Smart, 2000, Thompson, 2000), mentioned that a person can be physically disabled due to may be congenital / hereditary or acquired cause. The congenital factor, the person has physical disability since birth or the disability developed at a later stage due to genetic problems, problems with muscle cells or injury during birth. The acquired cause, the person acquired the physical disability through road or industrial accidents, infections such as polio or diseases and disorders such as stroke or cancer. Examples of childhood with physical disability refer to intrinsic biological or acquired conditions (e.g., cerebral palsy, spina bifida, traumatic brain injury, spinal cord injury, amputation) causing impairments which result in disability and limited participation in day-to-day activities (Handicaps Welfare Association, 2018).

Impact of caring children with physical disability on parents' health

Previously researchers have reported higher levels of stress among families of children with disabilities than among comparison groups of families of typically developing children (Bailey & Smith, 2000). Seventy percent of mothers of children with physical disabilities have low back pain (Tong et al., 2003). There is a higher incidence of migraine headaches, gastrointestinal ulcers, and greater overall distress (Sarafino, 2002). Parents report more anxiety, anger, guilt, frustration, sorrow, social isolation, self-deprivation, and depression (Raina et al., 2005). As well as, the consequences of impaired caregiver health include recurrent hospitalizations for their children and the decision to place their child outside of the home (Kelly, 2000).

Study done by Giulio et al., 2014, was to assess families with disabled children in different European countries; results found that, fathers of disabled children have fewer emotional exchanges, while mothers tend to suffer more in terms of social contact. Feelings of emptiness, loneliness and rejection are more typical of mothers with disabled children.

Study done by Thwala et al., (2015) was to explore the lived experiences of parents of children with disabilities in Swaziland. The findings revealed that the parents encounter challenges at work, at home, school and in the community such as emotional stress, failure to cope with the children's disability and financial challenges.

Study done by (Alkhaledi NG, 2019) was to investigate the pattern of coping among caregivers of children with physical special needs. The finding highlights the importance of coping strategies used by caregivers, most of caregivers had poor scores toward nine coping techniques. It recommends that to raise caregivers' awareness to apply and use different coping strategies.

Coping with parents having physical disabled children

Caring for a child with disability having some sort of behavioral problem is difficult for many parents and is quite taxing especially if support and resources are inadequate and parents are at risk for increased health problems and feeling of incompetence. The increased stress and poor coping with stressful situations will have a negative impact on the well-being of the caregivers. Coping with the disabled child is a Hercules task for the parents. Coping skills aim to reduce the demands of a stressful situation or to expand resources to deal with the situation (Sarafino, 2002 & Kandel & Merrick, 2003).

Study by Lazarus and Folkman (1988) , Thwala et al., (2015) discussed coping strategies can be defined as “the cognitive and behavioral efforts required to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.” Parents’ / caregivers’ coping patterns depends on a wide variety of factors, like personality, support system, education, financial situation, spousal relations, family cohesion, and the level of the child's handicap (Falvo, 2017).

"Coping Strategies" refer to conscious efforts to adopt with/solve stressful situation, they are practical active ways of responding to threatening situations". Coping strategies are divided for two major categories, (a) Problem-Focused Coping strategies which represent an attempt to do what an individual believes it might affect the circumstances that led to stressful situation, this include re-interpretation, re-evaluation and analysis of the stressful situation & (b) Emotion-Focused Coping strategies which represent efforts to regulate emotions resulted from the stressful situation, this include feelings of incompetence of changing situation, anger, anxiety, hopelessness, discomfort and stress in general (Lazarus, & Folkman, 1984 IN Glidden, & Natcher, 2009).

Study done by Bawalsah, 2016 to investigate levels of stress in parents of children with disabilities in Jordan, and coping strategies they used to handle these stresses. Results indicated the presence of high levels of stress experienced by parents of children with disabilities. These high levels of stress came as a result of parents’ incapability to provide effective efforts to handle developmental and behavioral problems in their child with disability& the negative perceptions of parents and the lack of specialized professional supporting services. Coping strategies used by parents of ^{children} with disabilities showed that engagement strategies were in general the most used ways by those parents, with preference to use problem focused engagement strategies more than emotion focused engagement coping strategies.

Parents’ / caregivers’ adjustment to the raising stresses from their children with physical disabilities depends on a wide variety of factors influencing their ability to cope such as their interpretation of the crisis event, the family’s sources of support, community resources, and family structure. As well as, the personality characteristics of the family members, their financial status; educational level; problem-solving skills, and spirituality, all influence a family’s ability to cope (Emerson, 2003 & Fazil et al., 2004 & Thwala et al., 2015). In order to avoid negative psychological, emotional, and physical consequences, researches (Ganjiwale et al., 2016 & Bailey et al., 2000) reported that when caregivers are supported, they are better able to cope with the challenges of providing care for a child with special needs. While it takes time for mothers to accept their children, as the children grow, mothers might feel pressure from society, especially on the occasions when their children exhibit unpredictable misbehavior in public, such as screaming. In order to avoid these embarrassments, mothers sometimes refrain from social activities; a wide variety of coping strategies is more helpful than having only one or two. Special parent training programs should be provided to these parents to make them effective and competent in their parenting services and to help them control the behavior difficulties of their children which will in turn decrease their stress and family burden.

Studies (Predescu & Sipos, 2013& Thwala et al., 2015)have shown that use of problem focused coping strategies results in lesser psychological distress and better mother-child interaction while use of negative emotion focused coping increases the possibility of parents experiencing depression and stress-related problems. The positive coping strategies are like acceptance, positive reinterpretation and growth, planning, seeking social support etc. which can be used by parents having children with developmental disabilities to cope with heightened stress.

Previous research (Glidden et al., 2006 & Dyson, 2010) has also shown that many families of chronically disabled children succeed in adapting and functioning well and among various factors studied, the type of disability, parental personality, the age of the child when diagnosed, demographic variables such as parental educational level, gender and socioeconomic status have been found to be associated with parental coping and adjustment.

Role of developmental disability nurse/ community nurse

Parents of children with developmental / physical disabilities are prone to facing considerable challenges, in terms of stresses relating to the nature of the child’s disabilities and limited accessibility of frequently inadequate resources (Moawad, 2012).The role disability / special needs nurse to provide different kinds of responsibilities toward parents’ based on the type and extent of special need among children, depending on the seriousness of the disability (Martínez-Montilla et al., 2017).

Because each family system is unique, each family may have different coping strategies. Nurse and parents’ are need to work together concerning their child’s level of care, as well as individual and family needs. Nurses should understand parental stressors which can lead to appropriate interventions and supports parents and their children with disabilities (Aylaz, 2017). Nurses need to establish various interventions effort to help parents reduce stress associated with raising a child with a disability. The intervention included a variety of mindfulness practices, including yoga and the use social asocial support condition can reduce parents in pain, anxiety, and depression (Pant, 2002). As well as, nurse can teach parents how work with their child’s behavioral issues is an attempt to reduce parental stress. Nurses can help parents to have also increased their mental health

and well-being through psychological interventions, which have improved the overall functioning of the entire family (King et al., 2009).

Nurses assume important roles to assess coping strategies can potentially strengthen and keep parents resources, in order to protect them from stressful situations. Nurses need to know that what coping strategies are helping each parent and identify family sources of support and promote the utilization of both formal and informal support systems. In order to accomplish this, nurses can help mothers/ caregivers realize their abilities and strengths, identify problems, develop problem-solving strategies, and identify new coping strategies (Ahmann, 2006).

Because coping in each cultural system is based on the social system such as the socioeconomic level of the family, level of education, accessibility to different services, religion, beliefs about health care, and the stigma of certain diseases. It importance that parents could develop good strategies to reduce vulnerability to such events and increase parents well-being , encourage to searching social and spiritual support to eradicating the social stigma and actively participate in parental self-help support groups (Sivberg,2002).

Nurses should inform society about disabilities and those parents with disabled children about their problems, encourage more positive and welcoming approaches to disabled children by contributing to social awareness, promoting and sharing of problems among close relatives, friends, families of other disabled children, social environment and expert people who were educated in this subject in order to reduce the anxiety experienced by parents (Kyle, 2008). Nurses can raise awareness in people about disabilities and problems of families with disabled children during home visits, in schools and when they come to healthcare institutions (Pant, 2002).

Parents of children with a disabling condition face various challenges require a range of needs associated with their children care, including specialized therapies, home modifications, adaptive equipment, medication, and educational services . Nurses advocacy to various stakeholders and able for seeking help from family members and friends, community, constitutionals, healthcare professionals, and religious groups to provide support develop an evidence-based plan (Aylaz, 2017).

Conclusions: The majority of included studies presented similar, consistent findings though highlighted different aspects of the researched experiences by using specific scopes to understand and interpret the field of knowledge around the meaning of coping strategies used by caregivers with children have a physical disability . recommended of these findings for future research and clinical practice are outlined.

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