

Impact of Psychosocial Interventions on Children with Severe Physical Disabilities and their
Families: A Review of the Literature

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Introduction

The Sunshine Foundation is an organization that is dedicated to providing children with severe physical disabilities a dream-like experience to promote long-term feelings of self-confidence and optimism. A large majority of the children impacted by Sunshine currently live with conditions such as cerebral palsy (CP), muscular dystrophy (MD), and spina bifida (SB). Sunshine Foundation hopes to improve the quality of life of every child they serve in order to improve the overall mental health of this vulnerable population. There is a plethora of evidence that suggests that children with severe physical disabilities are more susceptible to develop mental health issues, however there is less research focused on determining effective methods to improve and treat the psychosocial factors of these severe physical conditions. Given the limited information available regarding the utilization of specific dream-like programs in children with severe disabilities, we broadened our scope to analyze a variety of psychosocial interventions that all share a similar goal; improving the confidence, independence, and mental wellbeing for the children and families impacted. By examining previous data assessing the efficacy of various psychosocial interventions for children with chronic conditions, this paper aims to utilize this information to determine the probable impact of Sunshine Foundation's dream program.

Disease burden on children and their families negatively impacting their physical and mental health

According to a report by the World Health Organization (WHO), currently, over 1 billion people are living with some form of disability. This corresponds to about 15% of the total world population and includes 190 million (3.8%) people aged 15 and above having significant difficulties in functioning (World Health Organization, 2021). With this number continuing to rise, the need for support through psychosocial interventions is abundant. Sunshine Foundation is serving this purpose through its work and helping young people who are living with severe physical disabilities look past the many barriers they continually face to live a fulfilling and joyful

life. Their commitment to improving the quality of life for children by supporting their dreams and taking the role of “Dream-Makers” not only benefits the children but also provides immense support to parents, caregivers, and families of these young individuals. Living with a life-threatening disability or illness comes with many challenges both physically and mentally. The effects of life-threatening disabilities/illnesses on mental health are not well-known; there should be a greater focus on positive psychosocial interventions that can drive an improvement in mental health and overall quality of life.

Some studies report that children with CP experience social withdrawal and dissocial behaviour (Weber, 2015). Additionally, behavioural, emotional, attention, and social contact problems are present in up to half CP patients (Weber, 2015). Moreover, children with MD experience a major extent of internalizing problems (Tesei, 2020). These psychological problems decrease the well-being of the children and are related to parental stress, impairment in daily activities, and patient’s level of pain (Weber, 2015). Mental health issues such as these significantly predict decreased quality of life (Weber, 2015). Therefore, interventions that assess not only the physical challenges but also the mental/behavioural challenges of living with a disability should be implemented for children living with a severe disability/illness.

Sunshine Foundation not only understands the physical and mental toll experienced by children with severe disabilities but also understands the emotional needs of parents who are responsible for the care of children that are medically fragile. This is significant because understanding the effects of a child’s chronic condition on the physical and mental health of families provides support to these caregivers, which in turn allows them to provide the best care to their child. This has been widely studied and supported by numerous papers that have examined the family functioning and burden experienced by caregivers of medically complex children. The diagnosis and treatment of childhood chronic illnesses brings a turmoil of stress and anxiety to the families of children that have severe disabilities, putting them at risk for psychosocial difficulties (Holmbeck and Devine, 2010). The high amounts of stress levels in

caregivers of children that require constant attention further causes detrimental effects on their mental health and lead to depression, extreme fatigue, poor physical health outcomes, and social seclusion (Tesei, 2020).

For instance, CP is characterized by motor, sensory, communicative, and intellectual impairments which cause limitations in daily activities like feeding, bathing, or dressing (Basaran, 2013). Hence, caregivers of disabled children are required to provide constant long-term care (Basaran, 2013). As a result, caregivers don't have time for their own social lives, leading to lower satisfaction in life and greater stress (Basaran, 2013). Stress is caused by financial burdens, time consuming treatments, and use of specific equipment (Basaran, 2013). These psychosocial stressors can negatively impact both physical and mental well-being with the progression of depression, exhaustion, and poor perception of one's own physical health (Basaran, 2013). Additionally, several studies have indicated that mothers of children with impairments experience poorer mental health than other mothers (Basaran, 2013). For example, in one study, 58% of the caregivers that had a child with impairments suffered from mild to severe depression while 71.4% had mild to severe anxiety (Basaran, 2013). Furthermore, caregivers of children with CP show significantly greater burnout (Basaran, 2013). Thus, if caregivers are not able to take care of themselves mentally, then they are also not able to adequately take care of the child. Therefore, the mental health of caregivers should be acknowledged and buffered through support interventions that will alleviate some of the stress associated with caring for a child with a severe disability/illness.

In another study, caregivers of patients with MD experience moderate to high levels of distress, feelings of guilt, and low self-esteem (Tesei, 2020). However, caregivers that receive support from external sources, have a more positive experience and less of a burden (Tesei, 2020). Hence demonstrating that interventions from external sources, such as non-profit organizations or charities like Sunshine, will create a significant positive difference in families with seriously ill children.

Another study conducted by Caicedo et al. (2014) examined the physical health, mental health, family functioning, and care burden experienced by parent caregivers of children with chronic conditions. Data was collected over a period of 5 months on 84 parents using the Pediatric Quality of Life Family Impact Module (Caicedo, 2014). Their findings showed that physically, parents experienced higher levels of fatigue that prevented them from doing regular tasks such as chores and other social activities (Caicedo, 2014). Mentally, they experienced higher levels of feelings of anxiousness, frustration, and anger as well as had increased cognitive problems (Caicedo, 2014). They were constantly worried about their child's medication, treatments, future and other aspects of life (Caicedo, 2014). Socially, they felt secluded and were not able to use their social support networks to seek comfort. With regards to care burden, a majority of parents (n = 68, 81%) reported that their work life and decisions were affected by their child's health condition (Caicedo, 2014). An average of 33 hours per week were dedicated to providing direct care to their children and an average monthly out-of-pocket expense was \$348.78 (Caicedo, 2014). The study concluded that parents' physical and mental health state were not ideal and interventions should be designed to support both parents and their children for whom they are constantly caring for (Caicedo, 2014). This makes Sunshine Foundation's work imperative as they are not only fulfilling the needs of children with severe disabilities but also including parents and other family members in the dream experience of the child so they can also see their child push past barriers and achieve goals, allowing families to build memories together and feel hopeful about the future.

Another study conducted by Tesei et al. 2020 examined various coping strategies to determine the ideal approach for a family with a child living with a chronic condition such as MD. The study found that families with adequate coping skills, higher self-esteem, and a greater sense of social support are able to hold a more optimistic outlook to help overcome their adversity (Tesei, 2020). The paper highlights the value of secondary control engagement coping, which promotes the idea of adapting to a stressor through the means of acceptance and

positive reinterpretation (Tesei, 2020). This coping style is related to positive health outcomes and increases in quality of life (Tesei, 2020). This information is relevant because through the work of Sunshine Foundation, a positive experience is provided which can help alleviate some of the stress from the families. By creating an environment that promotes optimism and hope and providing an alternative social support network, Sunshine Foundation creates a space for the families to develop positive reinterpretations so they are more likely to engage in optimal coping strategies.

Alternative Psychosocial Interventions

There is a limited amount of research directly relating to Sunshine Foundation's specific dream program for children with severe disabilities. Thus, we explored other psychosocial interventions that shared similar end-goals as Sunshine Foundation, such as increased optimism, self-confidence, and independence. A study conducted by Fee et al. (2011) examined different factors that could potentially contribute to resilience observed in children with Duchenne muscular dystrophy (DMD). Children with DMD are at an increased risk for developing emotional problems such as depression, low self-esteem, attention deficits, and lack of social skills (Fee, 2011). This is significant because the incidence of these psychosocial issues tend to be reduced in individuals with higher levels of resiliency (Fee, 2011). The study defined resiliency as the ability to positively adapt to situations and experiences that present significant adversity and it was measured in terms of "good behavioural outcomes," through the means of the child behaviour checklist (Fee, 2011). According to this study, there were many factors that contributed to resiliency seen in children with DMD, including individual, familial, and most significantly, social factors (Fee, 2011). Social support, partially characterized as involvement within the community, was a large contributor to resiliency, as it enhanced opportunities for the children to develop socially and individually by fostering confidence and independence (Fee, 2011). Thus, it can be assumed that through participation with Sunshine Foundation, children with severe disabilities would likely display improved resilience because

they are provided with an alternative support system and are put in an environment that allows them to be a part of a community.

An increasingly popular psychosocial intervention for children with physical disabilities is the enrollment in condition-specific summer camp programs. One study conducted by Zimmerman et al. (2019) evaluated the efficacy of a V.I.P. (Victory, Independence, Possibilities) summer camp focused on improving self-empowerment and independence in children with SB. Ultimately, the study found that 93% of campers reported an increase in confidence, and 86% reported a greater degree of independence following the intervention (Zimmerman, 2019). Although summer camp is a very different experience than what the Sunshine Foundation provides, the main goals of the two organizations align quite closely. According to the paper, the initial goal of VIP summer camp is to provide the children with an experience to make them feel validated, important, and confident, which is similar to the main goal of Sunshine (Zimmerman, 2019). Both of these programs are similar in the fact that they provide expense-free experiences to children with severe physical disabilities with the hopes to improve the overall well-being of the children they serve (Zimmerman, 2019). Thus, it is appropriate to make similar assumptions regarding their efficacy towards improving youth mental health in these participating populations.

Another study conducted by Holbein et al. (2013) examined a different summer camp intervention for children with SB which also focused on improving independence and social skills through the means of goal setting and interactive workshops. Many parents and children found the program to be extremely effective in increasing independence, with notable changes in perceived functional capacity of the children (Holbein, 2013). Holbein et al. (2013) suggests that it was not the actual summer camp experience that contributed to improved outcomes, but rather the therapeutic process involved with the intervention. These processes such as building connections, eliciting emotional support, and having fun are key components to the dream-like experiences that Sunshine Foundation provides (Holbein, 2013). This suggests that a positive

environment that fosters optimism and happiness allows for a change in mindset that can contribute to improvement in overall psychological well-being.

Impact of Wish-Granting Interventions and Their Effects

There have been studies conducted in the past which have aimed to elucidate the benefits of granting dream-like experiences to children living with life-threatening disabilities. In a randomized control trial by Shoshani et al. (2015), children aged 5-12 were separated into two groups: a control group who were placed onto a wait-list for a dream-like experience, and an intervention group which received a dream-like experience based on their wish. Psychiatric and health-related outcome measures were assessed prior to and following the delivery of the dream-like experience in both groups. Results indicated that children who received a dream-like experience reported significant decreases in depression, distress, and anxiety symptoms, while also having a higher quality of life and positive emotions compared to the control group. These findings corroborate with a study by Chaves et al. (2015) which also found that interventions which granted wishes significantly improved positive emotions, life satisfaction, and reduced rates of nausea in children. Subsequent improvements in the lives of children living with life-threatening disabilities following the fulfillment of dream-like experiences provide evidence for the mental and physical health benefits of granting wishes. Furthermore, findings from a study by Nereo and Hinton (2003) indicated that boys living with Duchenne muscular dystrophy (DMD) had no increased likelihood to create wishes related to improving the condition of their health. Instead, their results indicated that boys living with DMD made wishes similar to their healthy peers. These findings are important because it shows the strong desire of children to receive wishes and dream-like experiences regardless of their medical condition. Insights from literature in this field strongly indicate that Sunshine Foundation's goals of providing dream-like experiences have real impacts on the lives and well-being of their recipients.

Interestingly, the benefits of dream-like experiences are not limited to the children who receive it. Another study from Chaves et al. (2015) aimed to examine whether a positive intervention such as granting a child's wish promoted positive psychological responses in their parents. The study collected responses from parents of children who were on the waiting list to receive a wish, and children who had their wish granted. Results from the study indicated that parents whose children received a dream-like experience reported higher levels of positive emotions such as gratitude, benefit finding, and love compared to parents of children on the waiting list. These findings suggest another importance and benefit of dream-like experiences in that they also benefit the mental well-being of caregivers.

Conclusion

Overall, with this pre-existing information it can be concluded that wish-granting programs are likely to positively impact children and families living with severe physical disabilities, in regards to improvements in confidence, optimism, and independence. By extrapolating findings from alternative psychosocial interventions, there is a plethora of evidence to further support Sunshine's positive long-term impacts. Given the overwhelming evidence concerning the correlation between mental health issues in individuals with physical disabilities, the Sunshine Foundation's mission is of utmost importance, as it provides a positive way to alleviate excess stress in children with severe physical disabilities.

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