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Parental Perceptions of Perceived Emotional QOL of Children with Cerebral Palsy In the Presence of a Family Dog

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Abstract

The environment plays a critical role in supporting quality of life for children living with Cerebral Palsy (CP). Animals may be part of the environment of children with CP and may influence their emotional quality of life. The naturally occurring environmental role of animals, specifically a family dog, and the quality of life of children with CP has yet to be fully explored. Exploring this role will help to begin to identify benefits of a family dog for the quality of life for children living with CP. Phase 1 of this pilot survey study explored the epigenetic influences on emotional quality of life for children living with CP. Eighty-nine parents of children with CP who live with a family dog completed survey questions about the

child's involvement and interaction with the family dog, and the PedsQL (Peds Quality of Life) 4.0, emotional quality of life parent-proxy sub-scale. Involvement with the family dog was reported by 88%. Overall, those who reported the child living with CP being involved with the family dog had higher mean scores on the PedsQL 4.0 than those who did not report family dog interaction. Types of interaction, including physical presence, verbal cues, or petting/ holding the family dog did not show significant differences in perceived emotional quality of life. While further study is needed it is promising to see that for children whose environment includes a family dog, the emotional quality of life may be positively influenced for those who interact with the family dog.

Keywords: cerebral palsy, emotional quality of life, family dog

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Introduction

Cerebral palsy (CP) is a complex genetic diagnosis that affects varying degrees of fine motor, gross motor, and language skills. There is great intensity of care required by family and typically a deep desire to put into place all interventions that may benefit the child and improve their quality of life.

Regardless of the actual cause that results in a child having CP, from either birth trauma or inherited genetic factors (genetic material passed from parents to their offspring), this is a devastating diagnosis. It is also a very complex diagnosis as there are varying effects on the fine motor, gross motor, cognitive and language skills, all of which impact quality of life. While environmental factors that affect DNA cannot yet be altered post-nataly, the environment of the child plays a critical role in supporting growth and development, family systems and quality of life for the child and caregivers. Caregivers are impacted by this diagnosis and may carry a burden of guilt related to the child's challenges.

Finding ways to support caregivers to enhance the quality of life of children living with CP is essential to the health of all involved in the 24 x 7 care of these children with CP. Children with CP can benefit from assistance animals, this has been established with animal assisted interventions with canines (Tuncay Elmaci & Cervizci, 2015; O'Haire, 2010; Schuck, Emmerson, Fine & Lakes, 2013; Sobo, Eng & Kassity-Krich, 2006), and with equine therapy (Frank, McClosey & Dole, 2011; Angsupaisal, et al, 2015; Charry-Sanchez, Pradilla & Talero-Gutierrez, 2018), While the role of assistance animals is established, the naturally occurring environmental role of animals, specifically a family dog, and this association with quality of life for children with CP has yet to be fully explored. Exploring this role will help to begin to identify benefits of a family dog for the quality of life for children living with CP. Phase 1 of this exploratory pilot survey study explored the epigenetic influences on emotional quality of life for children living with CP. The outcomes of this study may add to our ongoing understanding of the role of canines assisting in human health.

Review of Literature/ Background

Quality of life has multiple components. Health-related quality of life (HRQOL) typically focuses on the physical, emotional, psychosocial, and role functioning components. Tools have been developed to quantify and categorize all of these components and may also allow the focus on and assessment of a single aspect of HRQOL The Peds QL 4.0 (Varni et al., 2006) has been used to assess HRQOL in children with various conditions, such as, migraine headaches, cancer, hematologic conditions and sickle cell (Powers, SW, Patton, SR, Hommel KA& Hershey, AD, 2003; Chaudhry, Z& Siddiqui,S, 2012; Strullu, M et al, 2013; Panepinto, JA et al, 2008). The overall tool consists of a Likert subscale with a focus on emotional functioning as perceived by the parent proxy. The subscales consist of five questions: "feeling afraid or scared, feeling sad or blue, feeling angry, trouble sleeping and worrying about what will happen to him/her" (Varni et al., 2006). The emotional quality of life for children was ascertained with the Peds QL 4.0 subscale parent proxy-scale (Varni et al, 2006). The three PedsQL scales yield a total score. Internal consistency reliability for the total score (0.90 parent report) and validity was demonstrated using known group method (Varni et al. 2006). In this study the exploration of the emotional aspect was of interest in this population. In consultation with the developer of the PedsQL 4.0 tool approval was given for the single use of the Peds QL 4.0, emotional quality of life parent proxy-subscale.

Canines and Human Health

Overall, canines assist humans in multiple areas of activities of daily living formally as service dogs for physical and/or mental disabilities, guide dogs for vision, and hearing, or, through animal assisted interventions to support different types of therapy by encouraging motivation and bringing comfort. Informally humans can benefit from dogs who provide companionship, exercise, interaction, comfort, and purpose. Regardless of their role, dogs can help build trusting relationships with others, improve social skills, decrease negative behaviors, increase self-esteem, encourage routine behaviors, and encourage a safe environment. The characteristics dogs can bring to human interaction have been identified as beneficial to occupational and rehabilitation therapy setting. rehabilitation (Tuncay-Elmaci, & Cevizci, 2015; Gadomski, et al. 2015; Hawkins, & Williams, 2017; Niewiadomska, & Markis, M 2015).

Canines Assisting Children with CP

There are various studies that explore how children with CP and other mobility and health conditions are positively supported through animal assisted interventions (Tuncary- Elmaci, & Cevizci. 2015; Min, & Zaw, 2016; Niewiadomska, & Makris. 2015; Schuck, Emmerson, Fine & Lakes, 2013; Sobo, Eng & Kassity-Krich, 2006; Tuncay-Elmaci & Cervizci, 2015). The role of assistance animals specifically for children with mobility challenges, as well as specifically with CP has been identified with canines and animal assisted interventions (Tepfer et al. 2017; Charry-Sanchez et al.2018). For example, Min & Zaw (2016), identified the positive role assistance animals, specifically canines play when incorporated into pediatric occupational therapy.

They explored preschool aged children with limited mobility without CP and found that dogs improved happiness and increased interests in activities. The children involved with dogs were more talkative, less likely to be annoyed, had improved task outcomes, and they were more enthusiastic about what they had to do. The presence of a dog redirected emotions, improved motivations, and improved outcomes. While Tuncay-Elmaci & Cevizci (2015), evaluated three children with cerebral palsy.to assess quality of life and daily outcomes with interviewing and direct observations. The results were positive and consistent across all three children with cerebral palsy. All three patients were noted to have improved motor function and improved emotional stability. Tuncay-Elmaci & Cevizci (2015), found that including dogs in treatment with patients who have cerebral palsy resulted in the disappearance in

temper tantrums, and improvements in selection ability (able to decide what they want), focus during games, independence, overall awareness, communicating desires, happiness, and improved behavior/mood.

Canines as the Family Dog/ Companion Dog

Studies reveal that emotional and physical changes happen when a family dog is present. The concepts of empathy (Hawkins & Williams, 2017) & (Niewiadomska, & Makris, 2015), emotional quality of life (Tuncay-Elmaci& Cevizci., 2015) and the physiologic reactions of an increase in serotonin levels as well as decrease levels of cortisol in children with a family dog (Peterson, et al. 2017; Hawkins & Williams, 2017) found that children who have an attachment with their pets have exhibited caring behaviors, friendships, compassion, and improved attitudes. Children can be attached to multiple types of animals, and of all animals, dogs are most likely to understand and read their owners emotions. Children build the strongest relationships with dogs compared to any other animal. Niewiadomska & Makris, 2017, found dogs provoked empathy in children as young as at the preschool age.

The literature also supports the value of a family dog in quality of life (Tepfer, et al. 2017; Purewal, et al. 2017). Interestingly, Tepfer, et. al, (2017), studied the family dog in assisting with the physical therapy of a 10-year-old patient with Cerebral Palsy. The focus of the study was on formally incorporating the family dog into the patient's daily and rehab routine. After 8 weeks there were improvements in motor abilities. The researchers also assessed the patients QOL and found that it improved in multiple domains. Based on the patient self-report there was: 17% improvement in sociability, 13% in overall functionality, 19% in physical health, 5% in emotional health and no change in pain reporting. These results demonstrate improvements in motor abilities, and an increased human-animal bond. This study found that formally engaging a family dog as opposed to a trained service dog is feasible and decreased the wait time associated with receiving a service dog. A family dog is also beneficial in patient's time management; there is no need to make formal appointments for physical or occupational therapy to work with a therapy dog, as the dog is readily available as needed by the owner. It is also suggested that utilizing a bond that already exists (already owned and loved animal), is more therapeutic for the child, and may increase long-term therapy participation.

In a systematic review assessing children without any known disabilities, Purewal et Al., (2017) found companion animals to be beneficial to child and adolescent emotional, cognitive, behavioral, educational, and social development. In the Purewal, et al. study (2017) the

children's results varied based on age group. For children aged 4-10 (sample size 643), dogs were proven to decrease anxiety in components such as panic, social anxiety, and separation anxiety. Six months after implementing a companion dog for children aged 8-12 (sample size 56), the children exhibit increased overall confidence (Purewal et al, 2017). In addition, there was decreased crying/weeping noted throughout the children after 12 months of owning the dog. In a sample size of 22 children between the ages of 10-12 years old, it was noted that the children enjoyed owning a dog for the companionship and emotional dimensions that dogs provide (Purewal et al, 2017). Overall, dogs can assist in human health in a variety of ways, formally as a service, through animal assisted interventions, or, as a family/companion dog.

Methods

Phase 1 of this pilot survey study explored the emotional quality of life for children living with CP with a family dog. The survey included children with the diagnosis of CP that have a family dog. Demographic data included age and gender of child. The survey included items to help define the relationship the child with CP has with the family dog (interactive vs non-interactive, verbally, and physically). Pace University's Institutional Review Board approved this pilot study, which was conducted in accordance with the Institutional Review Board's ethical standards.

Quality of life and emotional functioning scores as measured by the PedsQL 4.0 parent proxysubscale were analyzed to assess the degree of quality of life and emotional functioning reported in children with CP who have a family dog. The PedsQL 4.0 tool scales can be used individually with permission which was obtained for this study (Dr. Varni, personal communication). The PedsQL 4.0 emotional quality of life scale has five items that are inversely scored, with the maximum per item score of 100, and maximum scale score of 500. The higher the score the better the emotional quality of life.

Participants were recruited from a partnership with Qualtrics Research Services. The survey and targeted population were discussed with the Qualtrics team. The survey was deployed, and 89 subjects responded and were recruited. The survey was conducted from November 2019 through December 2019.

Results

Independent Samples Mann-Whitney U tests were run to assess between group differences in the emotional functioning subscale summary mean and predictor variables with 2 categories. Additionally, Independent Samples Kruskal-Wallis tests were run when predictor variables had 3 or more categories. These tests are non-parametric and were chosen due to the small sample of the population and the reduced likelihood of Type I Error.

There was a total of 89 (N=89) participants in the sample with data being provided by a parent on the self-report measures. The age of the children ranged from 2 to 18 years, with 28% (n=25) being female and 72% (n=64) being male. The overall mean score on the Peds 4.0 was 267 (SD 85). While female children had a slightly higher mean score on the PedsQL 4.0 emotional functioning subscale parent proxy-report (M=292, SD= 88), than male children (M=258, SD=82), this was not statistically significant (p = 0.09).

Additionally, the vast majority of participants in the sample 88% (n=78) reported that their child was close with the family dog and spent time with the dog. Conversely, 12% (n=11), reported that the child did not pay attention to the dog during interactions. The Peds QL 4.0 summary score for children who were close to and paid attention to the family dog were higher (M=329, SD=108) than those who did not pay attention to the dog (M=287, SD=92) than for those; however, this difference what not statistically significant (p=0.62).

Nearly half the sample (47%, n = 41) reported that their children interacted with the dog with a combination of physical presence, verbal cues (i.e., speaking to the dog), and petting/holding the dog. About a third of the sample (32%, n = 28) only pet or held the dog, where 9% (n = 8) only spoke to the dog, and 13% (n = 11) only interacted with the dog through physical presence. Across the different methods of interaction those children who pet/held the dog had the highest mean score on the Peds QL 4.0 emotional functioning subscale (M=276, SD =105), as compared to a combination of methods (273, SD=67), verbal (M= 246, SD=79), and presence (M=247, SD=89). There was no statistical difference between the method by which children interacted with the dog and their parent-proxy report score on the PedsQL 4.0 emotional functioning subscale (p=0.33).

Limitations

The major limitation of this study was the sample size which may have inhibited the ability to assess for statistically significant differences. It is noteworthy that all the participants were able to financially provide for a family dog. Socioeconomic status was not obtained and may have impacted the diversity of the data.

Discussion

This pilot study observed gender prevalence in the results of males with higher incidence of CP in males than females which is consistent with that of the general population. This is key in understanding the population demographic of children with CP. It has also demonstrated, by parent's self-report, that those children living with CP who are identified as being close with the family dog have a higher PedsQL 4.0 score than those who are not. Although this difference did not meet statistical significance, most likely due to sample size, this remains an important finding and suggests that the association with the family dog may improve quality of life for children living with CP. This is a clinically significant finding that needs to be explored further due to the potential impact in developing an intervention to help children with CP and their emotional quality of life.

In reporting types of interaction with the family dog, no differences were found with the types of interactions and PedsQL 4.0 scores. While 88% reported their child being close with the family dog, 46% of those reported types of interactions. This may be due to limited emotional interaction capacity of the children. This finding is important to note as overall regardless of the ability to interact in the ways assessed, being close with the family dog was found to be beneficial to the child's emotional quality of life. Being in the presence of the family dog, may, in and of itself, be beneficial to emotional quality of life for these children. (Freund, McCune, Esposito, Gee & McCardle, 2016). If this can be replicated in future studies this can support the value for children with CP being close with the family dog to increase the child's emotional quality of life. The experiences children have during their growth and development is known to shape future behaviors. If there is data that supports an increase in emotional quality of life during this period, it is important to explore.

Conclusions/ Implications- Education, Practice and Research

Education

In understanding the importance of children with CP and their healthcare needs, emotional quality of life must be included. In the care of a child with CP healthcare providers have specific guidelines for the assessment, treatment, and ongoing management of this population (Liptak, G.S & Murphy, N.A. 2001). However, care for the emotional quality of life for children living with CP and their family/ caregivers is not as well formulated and disseminated. Educating healthcare providers about how canines can assist in the emotional health of a child is vital to providing the support that may be understood anecdotally by parents/caregivers who have a family dog, as well as for those who based on the information from this study may wish to consider this to support their child's emotional quality of life. The pilot data provide a starting point for understanding the connection with children with CP and their family dog and its therapeutic support of their emotional quality of this. This information has moved from anecdotal to clinical significance.

Practice

Sometimes the support needed from providers is to simply acknowledge the value of the environment parents/caregivers create for the child with CP. It is very common that the environment may include a family dog, and this is something that can be include in the patient history. The ability for providers to dialogue with parents/caregivers about their child's environment offers a space to explore the ways the child can benefit from involvement with the family dog. It also offers the provider the opportunity to acknowledge that the parents/caregivers willingness to have a family dog may help to support their child's emotional quality of life. This type of acknowledgement can help parents/caregivers to see another way in which they support their child who is living with CP.

Encouraging this communication and support is part of caring for the child and family. Providers can include these conversations in their discussion of anticipatory guidance and screenings during the child's health maintenance visits. In the future, we may consider having the family bring their dog with them as part of the visit.

If the family does not have a dog, providers may explore the possibilities with the family and child. Keeping in mind that having a family dog involves willingness, time, and financial support, providers need to consider this in the context of family when making the recommendations. Another aspect would be understanding the culture of a family. Many

families may not have had any experiences with having a dog to care for growing up. The notion of having a family dog may be foreign to them and intimidating. However, providing education, resources, and support may help the family consider having a family dog.

Research

Additional researcher is needed to increase the sample size to better understand emotional quality of life for children living with CP in the presence of a family dog. Phase 2, of this project will explore quality of life for children living without disabilities in the presence of a family dog. This will then lead to Phase 3 of this project which will compare the Phase 1 and Phase 2 study outcomes. Comparing the groups and increased numbers of participants will offer greater understanding of the emotional quality of life of children living with and without CP in the presence of a family dog.

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