

**Opt-Out Mental Health Support Groups: Confronting Ethical and Financial Concerns for  
Parents Facing Childhood Cancer**

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No parent can ever be properly prepared for receiving the devastating diagnosis that their child has pediatric cancer. While it is clear this situation would be difficult for anyone, the true prevalence of mental health struggle within parents of this population has not been analyzed in the depth that it should be. The World Health Organization defines good mental health as “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” (Galderisi et al., 2015). All of these aspects are likely to be negatively affected after an unexpected pediatric cancer diagnosis.

Successful professional support groups for caregivers of children diagnosed with pediatric cancer have been shown to improve quality of life. A six week program comprised of presentations by a variety of healthcare professionals was concluded as a positive opportunity to allow caregivers to build their coping skills, understand their child’s illness better, and talk with adults in similar situations as theirs (Foreman et al., 2005). Although many current research studies separate parent needs into categories such as, “70% of respondents had moderate or high needs in the field of medical information, 55% of parents reported a moderate or high level of need for help in the psychological or emotion field, and 30% in the financial domain” (Lewandowska, 2022), caregivers with any unmet need are impacted mentally, whether they are able to self-identify it or not. This essay will identify a needed change of current advertisement of support groups with aiding information to address possible questions that may arise through various disciplines. Ultimately, all caregivers of children diagnosed with pediatric cancer should

be automatically enrolled in a guaranteed support group to prevent psychological distress, as supported with ethical and financial considerations regarding the change of approach.

### **The Necessary Change**

Professional support groups for caregivers of children with pediatric cancer are a valuable resource to encourage positive coping skills and combat the increased risk of mental health issues. With busy hospitals and multiple rotating healthcare professionals taking care of their sick child, it is unfortunately easy for communication to be lacking within the healthcare team and parental support from the hospital is likely to be lacking as well (Tan et al., 2020). With such a devastating diagnosis, it's easy for a parent to lose sight of their own life, as they put all of their efforts and attention into caring for their sick child. The stress, depression, anxiety, and self-esteem battles presented in oncology situations put parents at risk of developing mental illnesses (Norberg et al., 2012). Young caregivers often lack the coping skills needed to confront surprise pediatric cancer diagnoses, as it is not an occurrence anybody anticipates or can prepare for. Additionally, parents of children diagnosed with pediatric cancer “[use] emotion-focused coping styles such as expression of emotions and comforting cognition even less frequently than the norm population” (Hoekstra-Weebers et al., 2012), which suggests the mental health of this population of caregivers needs to be urgently addressed.

Therefore, the healthcare system can take the added pressure off of this parent population by changing the way mental health support groups are presented to them. Currently, most support groups are offered to parents as resources they can choose to participate in if they feel like they need it. However, the fault within this system is that this is not a population that will easily identify their own needs, as their focus solely surrounds their child's wellness. The solution of an opt-out frame of enrollment would automatically place caregivers into the

hospital-provided support group with the option to decline the service if they so choose, rather than the current opt-in strategies of putting the responsibility on the caregivers to seek out the service once they feel they need it. Naturally, individuals tend to fall towards the easier option open to them, which in this case would be to follow the proposed medical advice rather than going through the steps of declining support. If caregivers are counseled with facts and statistics regarding mental health of parents in their situation, this could also increase the likelihood of using these resources rather than waiting until their mental health has escalated to a more dangerous point. As evidenced in a study by Junghans (2005), participants were 12% more likely to engage in a support program if they were approached with opt-out recruitment rather than opt-in recruitment. By switching to an opt-out approach, our healthcare system will be able to reach a broader range of individuals who may need this service, yet have been reluctant to reach out.

### **Psychological Influence**

If the change of advertisement is not adjusted and the complete population of parents needing this support isn't reached, this could lead to psychological complications down the road. Natural human development of children can be shaped by parental influences and behaviors from cognitive to socioemotional growth. The significance of supporting this parent population also relies on the fact that not addressing their mental health needs could consequently reflect onto poor mental health within their child. It has been studied that "cumulative parenting stress when children are 3 to 5 years old is associated with poor child functioning at 5 years of age as well as negative parent-child relationship quality" (MacKinnon et al., 2022). Bandura's social cognitive theory states that children learn and develop by observing those around them and imitating their model (Fryling et al., 2011). Consequently, if a distressed parent that lacks adequate coping skills sits in their child's hospital room crying for the majority of the day, the child will subconsciously

develop the overwhelming urge to copy their parent's actions, as children look up to their parents for guidance and support. Furthermore, as the child continues to practice these anxious behaviors, it will negatively impact their future ability to combat stressors on their own, possibly leading them down the road towards a diagnosis of generalized anxiety or depression. Whereas, if a caregiver attending support group sessions has learned positive coping mechanisms, has an outlet to express their worries, and has gained reassuring knowledge about their child's diagnosis, their more optimistic attitude can benefit their child's healing process. Additionally, if a parent progresses to the extent of malfunctioning within daily living activities due to their impaired mental health, not only is their child's mental health in jeopardy but also their safety.

Early intervention, in terms of time from diagnosis rather than age, is an important consideration in the psychological development of mental health issues. With an opt-out approach, parents will receive mental health support early on in their child's oncology journey, instead of waiting until more severe symptoms are present to ask for help on their own. As previously mentioned, the diagnosis of pediatric cancer endures lifelong apprehension of recurrence or adverse effects, so learning how to tackle the anxiety of this diagnosis during the early stages will stop the caregiver from suffering more as their child grows up. If left unattended to, a parent's unsuccessful coping skills can progress into damaged mental health. Often times, mental illnesses are present years before they are diagnosed and could have even been prevented if proper measures were taken earlier on (Fisher, 2021). Furthermore, with an elevated risk of childhood cancer survivors developing anxiety, posttraumatic stress symptoms, and cancer-related worries during their adolescent years (McDonnell et al., 2017), caregivers need to acquire the skills to identify these symptoms and intervene effectively within themselves, can in turn better assist their child's wellbeing too.

## **Ethical Dilemmas**

### **Autonomous Rights**

Although there are support services currently in place for caregivers of children with pediatric cancer, the dynamic of their approach can be improved to reach their full potential with consideration of ethical practice. An abundance of medical jargon, treatment decisions, and sympathy is thrown at parents while sitting in their child's hospital room. The nurse may have time to hand the family a pamphlet of online support services that is available to them, if they feel they need it. Many caregivers newly adjusting to cancer diagnoses feel the need to constantly be with their child as their support system, which may prevent them from taking time for their own care. This overwhelming thought process blindsides the parents of their own personal struggling needs, and this can consequently reflect onto their child's progress. Often times, parents are reluctant and even just unaware of their needs of mental health support due to the overwhelming stress they are undergoing. However on the same note, it is impossible to force medical treatment upon anyone, despite if it is visually obvious they need it. The decision to be a participant of support needs to be a decision upheld by the individual themselves.

Compulsory enrollment of parents with children enduring childhood cancer in support groups challenges the bioethical philosophy of autonomy, "self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choices" (Varelius, 2006). Yet, the concept of autonomy becomes muddled when dealing with an individual's ability to make decisions for themselves when battling with a psychiatric disorder as cognitive and behavioral functioning are compromised (Bergamin et al., 2022). States laws uphold the right to involuntary admissions to psychiatric facilities if the patient is considered at high risk for harming oneself or other (Orlando, 2013). However, for the

purpose of this paper, the goal is not to involuntarily enroll these parents but rather allow them the autonomy to make this decision for themselves. This does not mean to infer that caregivers of children with childhood cancer do not have the ability to care for themselves, but when faced with shattering circumstances, it is much easier for caregivers to feel lost.

Therefore, the solution is to make sure caregivers have an adequate understanding to be able to make the decision regarding their mental health for themselves by shifting the way in which these services are presented to them without infringing on their autonomous rights. The caregivers always have the ability to decide to refuse the treatment of the support group recommended to them, however if they choose not to opt out, success and improvement of mental health management will be significantly enhanced (Mauder, 2012).

### **Young Parent Population**

Another ethical dilemma is why provide support to this specific population of caregivers? Why will a change in advertisement successfully appeal to the younger population of parents compared to others? There are many caregivers in need of strength and encouragement, such as parents who are caring for their own elderly parent who may be enduring cancer during their geriatric years as well. There are a few rationales why the population of parents with children who have been diagnosed with cancer are exceptionally vulnerable. Approximately two-thirds of children who survive pediatric cancer experience at least one adverse effect later in their life and about one third will experience a severe or life-threatening adverse effect (Landier & Bhatia, 2008). With pediatric cancer advancing through a child's growing body interrupting such a pivotal developmental period, it puts them at high risk to be poorly affected later in their lives. Adverse outcomes for survivors of pediatric cancer include impairment of pulmonary, auditory, cardiac, or endocrine functioning (Hudson et al., 2013). Therefore, this population of patients

along with their parents endure lifelong fear and apprehension of future medical issues compared to the older populations. As compared to other populations of caregivers, their battles may not be as prevailing if their elderly parent is naturally closer to their end of life. Along with this long lasting, unknown anticipation comes a higher risk of mental health implications. With access to support groups, caregivers will gain knowledge about these possible effects and how to mentally cope with lifelong anticipation of another stressful event. Additionally, intervening with coping skills early on is essential to a more positive mental health outcome, as discussed under the psychological influence heading.

The characteristics of a stressor can be described as “(1) the severity of the stressor, (2) its chronicity, (3) its timing, (4) how closely it affects our own lives, (5) how expected it is, and (6) how controllable it is” (Hooley et al., 2017). From a psychological standpoint, the diagnosis of pediatric cancer for a caregiver encompasses the more severe side of all of these characteristics. As malignant neoplasms hold a spot in the top three causes of death in all children, the severity of the stressor leaves no question (*Underlying Cause of Death, 1999-2020 Results Form*, n.d.). As mentioned previously, even after successful treatment, secondary health issues often arise and the possibility of a malignant relapse is possible (Hudson et al., 2013), so this disease is unfavorably continuous. Unlike some adult cancers, most childhood cancers cannot be prevented, identified through screening, and are not hereditary so the timing and expectation of diagnosis is always unexpected (World Health Organization, 2021). And from a parent’s perspective, this situation is not personally controllable as they have no direct influence on how the child’s cancer responds to treatment. Therefore, with all of these demanding characteristics, holding on to constant distress and anxiety associated with pediatric cancer puts caregivers, specifically the young parent population, at risk for developing mental health issues



even after their child is through with treatment. Naturally, the majority of caregivers of children fall within the younger age range of adults since fertility windows and pregnancy outcomes are safer in earlier adulthood. More seasoned parents have the time to develop parenting skills, coping skills with the normal barriers of life, and ultimately experience more losses as individuals in their family grow older (Menon et al., 2020). Even the stressors of being a parent in general can put individuals at a higher risk of struggling with mental health, so adding a diagnosis of pediatric cancer to their worries puts them exponentially at higher risk.

Additionally, young parents lack the financial stability of the older population of parents, as they are the sole financial providers for their child and they may not have advanced careers yet, providing them with the funds that they need (Chae et al., 2020).

### **Financial Debate**

Encouraging a change to automatic enrollment in support service for parents of children with cancer raises questions about coverage and financial eligibility. If the enrollment were to be automatic according to the opt-out style, services would have to be offered without need of insurance coverage to be able to provide for all caregivers without financial discrimination. Financial battles for any family, regardless of income status however significantly poorer for low-income families, is identified as one of the highest stressors during pediatric oncology treatment (Tan et al., 2020). Hospitalization costs of pediatric cancer are outstandingly above any other hospitalization costs for pediatric conditions, standing at an average of \$40,400 compared to \$8,100 with other conditions (Warner et al., 2015). Without even taking into consideration costs of medical oncology treatment, families battling childhood cancer also take on considerable amounts of out-of-pocket expenses during treatment. According to a study completed on financial burden of nonmedical, out-of-pocket expenditures for families of pediatric cancer

patients published by Lansky (1979), “for half the families surveyed, the total expenses plus loss of pay amounted to more than 25% of weekly family income”. Expenses such as food, which is often bought at the hospital or fast-food for all of the hours parents spend with their child in their hospital room, lodging and transportation, as families often find themselves traveling to be able to receive the best treatment for their child (Tarnasky et al., 2021), family care, as siblings need to be taken care of at home while so much of the family’s focus is on their sick child, and many more miscellaneous expenses add up quickly. Therefore, adding an additional expense for caregivers to support their mental health that is already negatively affected by financial battles would be counterproductive.

While taking into consideration the elevated costs of pediatric cancer, which is often also more expensive than adult oncology treatment (Chae et al., 2020), there are realistic ways for mental health services to be offered to caregivers without additional costs to them, and without insurance. Excluding the population of caregivers who lack personal medical insurance, would be shutting out the most vulnerable population who most needs the support. A study conducted in Oregon to measure the percent change within insurance from 1998 to 2009, showed that there was a 3.5% decrease in uninsured children, while there was a 3.5% increase in uninsured parents (DeVoe et al., 2014). So, although children are thankfully gaining access to medical insurance, the rate of adults being insured is declining, and many current mental health initiatives come with a fee. Additionally, a National Comorbidity Study concluded that 47% of its participants with an anxiety, substance-use, or mood disorder that identified their need for mental health care reported that lack of health insurance or cost as the cause of them not receiving care (Sareen et al., 2007). These statistics show the barriers to receiving mental health care solely because of financial issues, which would only increase as more parents become uninsured. If these support

groups were to focus on nonpharmacological measures, no production or distribution costs of medications would need to be factored in, allowing for more reasonable opportunity free of charge service.

When diving into current programs offering free services, the idea of how these services could be offered without charge simply changed to why not? There are currently initiatives proposed with free access support by nonprofit organizations that receive funding through donations and government grant programs. For example, the American Cancer Society invested \$295 million into patient support services, which includes support opportunities for caregivers of individuals with cancer (*American Cancer Society Fact Sheet*, n.d.). More specifically for childhood cancer families, Alex's Lemonade Stand Foundation's 2021 annual report attested to \$935,000 solely towards family service programs (*Alex's Lemonade Stand Foundation Financial Statements*, n.d.). Another slightly smaller organization, CancerCare for Kids, has a calendar filled with free community programs, such as Coping Circle Workshops that are run by licensed social workers focusing on wellness therapy, decision-making strategies, the caregiver experiences, and more (*Cancer Community Programs / New York, New Jersey, and Connecticut*, n.d.). Although this corporation resides only in New York, New Jersey, and Connecticut, it proves that free support sessions run by healthcare professionals can be provided on a smaller scale, showing hope the initiation within all hospitals rather than leaving it up to the global organizations to provide support. As shown by these successful organizations, the financial barrier to providing these programs is not the issue when considering basic support without needing interventions of pharmaceutical measures. Therefore, financial support is not a setback when looking at the change to opt-out services. The deeper dive into refuting any budgetary doubts further proved that the fault lies within the advertisement area.

### **Limitations and Future Considerations**

Even with these influential modifications to current support services standards, there are still many aspects of this topic that require further research to develop an approach to the most effective care. This paper specifically narrowed in on group support services, as they are a more manageable strategy especially related to the service's cost-free perspective. In addition, we also would have to consider parents who are uncomfortable with group settings. Is there a way they can still be offered the same services with a professional, free of charge, through personal sessions? With this consideration in mind, the benefits of a social situation compared to isolated, personal care must be weighed.

One study comparing individual versus group treatments for depression, which is one of the common mental health issues with parents of children with childhood cancer, did not conclude a significant difference of outcome between the two groups due to a lack of clinically relevant research in the area (Cuijpers et al., 2008). Similarly, there was no difference in individual versus group cognitive behavior therapy for anxiety disorder within children and adolescents (Guo et al., 2021), however these results could not support this argument since adult psychological and social responses are significant different than those of children and adolescents. Additionally, individual sessions would be more expensive to provide as more administrative costs would need to be factored in. Therefore, with support from the previously mentioned studies, if there is no evidence supporting the need for personal sessions versus group support groups, then going forward with the cheaper group initiative would be more viable.

Another consideration would be the extent of the scope of practice and treatment within professional support groups. If the services were to be provided to families without need of insurance or out-of-pocket cost, the teaching practices would fortunately fall under all

nonpharmacological measures. There are plenty of successful nonpharmacological treatments to address mental disorders such as cognitive behavior therapy, psychoanalytic therapies, or hypnotherapy for anxiety disorders (Cottraux, 2002). In general practice, nonpharmacological measures should always be taken prior to more interfering options, such as medication, as it is the patient's right to receive the least invasive form of treatment possible (Morgan & Townsend, 2020). However, if the professional running the support group were to identify a parent's need for medication intervention, that process would need to be directed outside of their support practice. A licensed medical provider is needed to prescribe any medication; if the leader of the support group were to have that certification, the question arises as to whether would caregivers have access to that? In general, the nonpharmacological measures within these specific support groups escapes the additional battle of medication costs. That debate would need to dive further into insurance measures, production costs of medications, distribution costs, and approaches to prescription. This argument stays focused on the benefits fully accessible assistance without pharmacological interventions because it is always important to provide nonpharmacological measures, as these holistic approaches can be overlooked by medicine.

There are very limited studies connecting the long-term effects of support groups on mental health for this specific parent population compared to the same parent population who were not offered support services. Although, there were many studies that provide supportive information regarding this subject matter such as the need of support services, mental health risks for caregivers, positive feedback from those who did receive care, and financial influences on the matter. Therefore, future research should focus on comparing the effectiveness of support groups for parents in childhood cancer cases compared to control groups who are not offered this support. From there, we will be able to more precisely pinpoint the aspects of group

interventions that positively benefited the caregivers whether it be the knowledge they receive from professionals or the outlet for expression that the group setting provides. With this data, eventually the best information and interventions that should be presented within these support group sessions can be identified.

### **Conclusion**

Compelling information that refutes ethical and financial concerns has supported the argument that all caregivers of children diagnosed with pediatric cancer need to be aided above the current recommendations for mental health support groups during their journey by introducing an opt-out style of advertisement. The major point of change that was identified directly challenges the ethical theory of autonomy; however, it does not infringe on medical rights. Creating an opt-out approach to these support services will help caregivers identify needs they may not be aware of in themselves due to the devastating circumstances they are facing. There would be no downside to this approach, as individuals still have the personal autonomy to refuse this treatment, yet it would be considerably less percentage of individuals.

In support of this change, financial and psychological aspects must be considered to show this is a realistic and necessary improvement. The age range of this specific cohort of caregivers puts them in a more vulnerable position, both psychologically and financially, compared to other caregivers taking care of family members with cancer. The extended time dealing with this type of diagnosis also contributes to the need to address this population of parents. With children being extremely exposed during this difficult time, if this initiative is not addressed, a caregiver lacking adequate support skills can negatively influence their child's healing journey and future psychological health as well. The increased financial burden of pediatric oncology requires a cost-free support service approach. This financial proposal makes sure to include parents of all

economic status with support from current successful nonprofit initiatives already in place that resemble the same idea. Therefore, financially this approach is supported so it falls back on the style of advertisement that is lacking in order for these services to benefit the greatest number of families. Limitations were considered to acknowledge the few faults along this approach, however considerations for future research were discussed to address the issues.

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