

Ella Baars

Dr. Maisano

Mental Health Communication

4/25/2024

Resource (Brochure)



Problem Identification

I plan on creating a resource for older teens and adolescents, as well as their support systems, that are struggling with their type one diabetes diagnoses. I personally have experience with this issue. In December of 2021, I was diagnosed with type 1, a curiously "late" diagnosis- most people develop T1D in early childhood or preteen years. I felt alone because of the nature of my diagnosis- my younger brother was diagnosed when he was 9 years old, and I felt guilty

that I had time to prepare in a way that he did not. I felt freakish and “wrong” after my doctors told me that I was somewhat of an anomaly due to my age. I was very lucky to have knowledge about the disease, as well as a support system that was so familiar with it, but the effects of the diagnosis on my mental health were immense. In the following months after my diagnosis, I struggled very much with depression and suicidal thoughts, but had trouble communicating this with the people around me. As time went on, I became more accepting of my new reality and more open to expressing my feelings to those around me. I wish that from the beginning, I had been more willing to communicate and reach out for help, as I believe this would have lessened my suffering. Additionally, I feel that because I was older, my lifestyle change was more drastic- it was not easy for me, as a 17-year-old, to accept this huge new part of my life. It was not something I had grown up with and I was not gently given the news or babied as most younger patients would have been. My target audience is a reflection of myself at that time, as I can acknowledge now that I very much could have used a resource to help me discover or relearn coping mechanisms and communication strategies. That is my reason for wanting to help those who are going through the same process I did. The specific need I plan on addressing is grief after a diagnosis, with an emphasis on open communication- “letting people in” rather than isolating. As previously mentioned, I was very afraid and hesitant to open up to even the closest individuals in my life, and felt that I was a burden when I did talk about how I was feeling. Looking back, this was unhealthy behavior- I am still trying to unlearn the shame and the inferiority that I felt in those few months. My goal is to give recommendations that are realistic, but still helpful for my audience. Hopefully, this would destigmatize talking about mental health- specifically grief and depression. I want people to use my resource to give them ways to cope

and generally feel better, emphasizing communicating about poor mental health. (This has been shifted for the end result)

Format

I wholeheartedly believe that although it may not be the most engaging format, that a brochure would be the most practical output for my problem identification. Since I plan to work with parents or caregivers of children experiencing a diagnosis and grieving the loss of normality, I feel that it would be the most effective to have my information be portrayed through a brochure, since it could be a helpful resource either given directly by providers or, more generally, found in the healthcare setting. This is the main format, in my experience, that is used to communicate in places like hospitals and doctor's offices, which is the ideal location that information pertaining to health (as my project will be) is found. I feel that especially since the information will appeal to both parents and other support systems going through a child's diagnosis, a healthcare provider can aid them by giving them a brochure such as this one as an additional form of support. While social media may be able to reach a much wider audience, I feel that an issue this specific needs to be conveyed in a more controlled environment. Those who do not have the experience to comment on the situation do not need to be involved. I also believe that something physical, like a brochure, is not only more accessible to those in the situations that I am catering to, but easier to revisit as needed. Social media posts are so ephemeral, and often are scrolled past without thought. However, in this situation, a physical piece of paper would be very helpful for caregivers to be able to cope with a life-changing event. Additionally, something as emotional and deep as identity, grief, and disease, is often criticized in online spaces. My ideal goal is to show people that they are supported no matter what, and the internet does not always provide that kindness.

Recommendations

The issue that I have decided to make a resource based around is grief after a lifelong disease diagnosis and how family and friends can make a positive impact on that person. The focus has shifted slightly, with my audience now being parents and caregivers of someone dealing with a diagnosis (now general as opposed to children with diabetes). This is due to the resources and academic journal articles I was able to find, which focused overwhelmingly on the caregiving perspectives.

Grief and loss are experiences very common for those going through a life-changing diagnosis, but the same effects can be found on the diagnosee's caregivers or parents in many cases. Parents of children with diseases or disabilities are at much higher risks for chronic grief (Ghesquiere et. al., 2011), and the trauma associated with this often goes unresolved (Pianta et. al. 1996, Sher-Censor et. al. 2020). Recommendations that I am considering making a part of my resource include the following, which I have found ample support for in academic literature and studies. To begin, finding a network of support can be hugely beneficial for parents who not only want to learn about the disease their child has been diagnosed with, but to find common ground and bonds with people going through similar experiences (Miller et. al. 2009). Secondly, practicing mindfulness or meditation to avoid constantly feeling stress, fear, and anxiety. Additionally, reaching out to family and friends to express sadness and grief as opposed to the child (Stuntz & Linehan 2021). It is important to recognize here that although the caregiver's feelings and grief are valid, the child is not responsible for fixing these issues. Speaking to other adults is a much healthier way of expressing oneself while also allowing the child to cope with their own diagnosis. To continue, realizing that emotions are human and that going through the grief process is normal in an awful time like this is essential (Stuntz & Linehan 2021). This, of

course, ties into nurturing personal relationships and speaking with other adults. Allowing oneself to feel, to cry, etc, is a great way to move towards acceptance in the grief process naturally. Finally, another suggestion I plan on including is prioritization. It can be extremely difficult to get out of bed in the morning when one is grieving, according to Coughlin & Sethares (2017), but putting together something like a motivation/mood/inspiration board and including the things that are important could make a large difference in perspective (Akard et. al., 2021).

Self-Evaluation

Looking back on this process as a whole, I feel that not only have I learned a lot about dealing with grief as a parent of a child going through a diagnosis, which has made me reflect on my own parents' experiences, but I have learned many applicable coping mechanisms for struggles in everyday life. The project has gone through many changes from the beginning, but as it has evolved from something personal to me into something truly meant to help others, I have been able to reflect on my own experiences as well as loved ones. This project has ended up being very special to me, and I have been inspired to genuinely attempt to make differences in the lives of those who struggle with my topic. It was already close to my heart, but this experience has helped me think about, and hopefully help, others.

Works Cited

- Coughlin, M. B., & Sethares, K. A. (2017). Chronic sorrow in parents of children with a chronic illness or disability: An integrative literature review. *Journal of Pediatric Nursing*, 37, 108–116. <https://doi.org/10.1016/j.pedn.2017.06.011>
- Ghesquiere, A., Martí Haidar, Y., & Shear, M. K. (2011). Risks for complicated grief in family caregivers. *Journal of Social Work in End-of-Life & Palliative Care*, 7(2/3), 216–240. <https://doi.org/10.1080/15524256.2011.593158>
- Miller, A. R., Condin, C. J., McKellin, W. H., Shaw, N., Klassen, A. F., & Sheps, S. (2009). Continuity of care for children with complex chronic health conditions: Parents' perspectives. *BMC Health Services Research*, 9, 242. <https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,uid&db=edsgao&AN=edsgcl.216368873&site=eds-live&scope=site>
- Pianta, R. C., Marvin, R. S., Britner, P. A., & Borowitz, K. C. (1996). Mothers' resolution of their children's diagnosis: Organized patterns of caregiving representations. *Infant Mental Health Journal*, 17(3), 239–256. [https://doi.org/10.1002/\(SICI\)1097-0355\(199623\)17:3<239::AID-IMHJ4>3.0.CO;2-J](https://doi.org/10.1002/(SICI)1097-0355(199623)17:3<239::AID-IMHJ4>3.0.CO;2-J)
- Sher-Censor, E., Dan Ram-On, T., Rudstein-Sabbag, L., Watemberg, M., & Oppenheim, D. (2020). The reaction to diagnosis questionnaire: a preliminary validation of a new self-report measure to assess parents' resolution of their child's diagnosis. *Attachment & Human Development*, 22(4), 409–424. <https://doi.org/10.1080/14616734.2019.1628081>
- Elizabeth Cohn Stuntz, & Marsha M. Linehan. (2021). *Coping with Cancer : DBT Skills to Manage Your Emotions--and Balance Uncertainty with Hope*. The Guilford Press.

Akard, T. F., Dietrich, M. S., Friedman, D. L., Wray, S., Gerhardt, C. A., Given, B.,
Hendricks-Ferguson, V. L., Hinds, P. S., Eunji Cho, & Gilmer, M. J. (2021). Effects of a
web-based pediatric oncology legacy intervention on parental coping. *Oncology Nursing
Forum*, 48(3), 309–316. <https://doi.org/10.1188/21.ONF.309-316>