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Rest for the Heart: Respite Care Training for Interns

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## Rest for the Heart: Respite Care Training for Interns

## Abstract

Jacob's Heart Children Cancer Support Services is a local nonprofit agency that provides support for families of children that have been diagnosed with cancer. Due to the complicated treatment processes and their effects, families of children with cancer experience high levels of psychological distress. To support these families, Jacob's Heart intends on providing a respite care program. However, interns at Jacob's Heart are unprepared to provide respite care to families experiencing a cancer diagnosis. An educational intervention was utilized to prepare interns to confidently provide quality, compassionate respite care to families of children with cancer. The training curriculum developed has four main foci: cultural humility, compassion and empathy, listening, and speaking. As expected, the curriculum was approved by staff for future implementation. Alternative recommendations to address psychological distress among families include developing a base of long-term volunteers to provide consistent respite care.

*Key words:* children, cancer diagnosis, psychological distress, respite care, curriculum

### **Agency and Community Served**

Jacob's Heart Children Cancer Support Services is a local nonprofit agency that comes alongside families of children that have been diagnosed with cancer and other life-threatening illnesses so that they do not have to go through a major battle alone. The mission of Jacob's Heart is to "improve the quality of life for children with cancer and support their families in the challenges they face" (Jacob's Heart, 2018a, para 1). They "envision a community where every child with a serious or life-threatening condition has a strong, supported, and informed family empowered to fully participate in their care" (Jacob's Heart, 2018a, para 2).

Jacob's Heart provides services based on Abraham Maslow's hierarchy of needs, starting with the basic, physiological needs and moving up through emotional needs to self-actualization. Practical support provided includes financial assistance with rent, utilities, phone, and other expenses. Jacob's Heart also provides transportation to and from treatment, most of which is to Lucille Packard Children's Hospital at Stanford. There are also many groups and events put on by Jacob's Heart that aim to make families feel love and a sense of belonging, both of which are so important while going through all that accompanies a pediatric cancer diagnosis. To improve the emotional well-being of families, Jacob's Heart also provides expressive therapies, individual and group counseling, hospital and home visits, and a variety of grief-specific services (Jacob's Heart, 2018b).

Jacob's Heart provides these services to families that have a child diagnosed with cancer in Monterey, Santa Cruz, San Benito, and South Santa Clara counties. Families are referred to Jacob's Heart by staff at either Lucile Packard Children's Hospital or the University of California at San Francisco Benioff Children's Hospital. Jacob's Heart also offers certain

services to families of children with life-threatening illnesses other than cancer (Jacob's Heart, 2018b).

There are several community organizations and businesses that partner with Jacob's Heart and support their mission to improve the lives of families of children with cancer. The list of partners is too long to include them all, but some examples are Second Harvest, Lucille Packard Children's Hospital, Granite Rock Construction, and Lakeside Organics (Jacob's Heart 2017).

### **Problem Description**

Due to the complicated treatment processes and their effects, families of children with cancer experience high levels of psychological distress (Choi et al., 2016). While studies support social support as a protective factor for psychological distress, interns at Jacob's Heart are unprepared to provide respite care to families experiencing a cancer diagnosis (Williams et al., 2014). The psychological distress families face is exactly why Jacob's Heart was founded in the first place. The type of stressors that families face, demand a close-knit network of support, which Jacob's Heart aims to create. In order to add a depth to the support services Jacob's Heart already provides, they are planning to add respite care to the list. This type of social support, even if only perceived, has been found to act as a protective factor to psychological distress (Lakkis et al., 2016). Additionally, the availability of support for things like assistance with daily tasks helps parents develop healthy coping strategies (Lakkis et al., 2016). At the current moment Jacob's Heart does not have the staff to provide respite care to their families. Interns are going to be utilized, but they are severely unprepared to step into such a role. The project's purpose was to give interns some level of confidence and competence before they enter the home of a Jacob's Heart family.

## Causes and Consequences

The causes of psychological distress among parents of children with cancer stem from the huge caregiver burden they must manage (Choi, et al.,2016). These parents have a wide array of demands for example hospital trips, making sure children take their medicine, managing side effects of treatment, and communicating with the healthcare team not to mention their extended families and friends. These duties coupled with financial stressors and uncertainty create an overwhelming amount of stress. In fact, most parents “experience sustained distress and adaption difficulties even after the child’s completion of active treatment” (Choi et al., 2016, p. 544). Parents experiencing psychological distress will suffer from symptoms of depression and anxiety “which often coexist with other somatic complaints, chronic conditions, and medically unexplained syndromes” (Arvidsdotter, Marklund, Kylene, Taft, & Ekman, 2016, p. 687). All these symptoms can lead to strain in relationships, even within a family, and also make giving support to a child battling cancer and their siblings even more difficult. To intervene, Jacob’s Heart would like to implement a respite care program to alleviate some of the psychological distress and caregiver burden parents face. Because there is currently no staff for that an intern base must be utilized, however these interns are also not trained to provide care and are unprepared to interact with a child’s cancer diagnosis. There isn’t part of a budget allocated specifically for a respite care program Jacob’s Heart at this time. The consequences of having unprepared interns providing respite care is that families are not receiving the competent, quality care that they need and deserve. The interns will lack confidence when interacting with family and also run the risk of not displaying verbal and behavioral professionalism. The largest consequence of unprepared interns is that Jacob’s Heart may damage relationships with their

families and lose some trust and rapport that they have been so dedicated to building. One alternative to preparing interns would be to hire paid staff to take professional level respite provider care trainings. While this alternative is costly, the care may be a much higher caliber and not run the same risk of possibly damaging relationships. Another alternative would be to encourage volunteers and the community to lobby the local government to increase the availability of respite care services to families experiencing a child's cancer diagnosis. With Jacob's Heart having a beautiful history of impacting palliative care legislation regarding children with cancer, they are definitely capable of such work.

### **Implementation Process**

#### **Project Description**

The project was an educational intervention that involved creating, developing, and refining a training curriculum for Jacob's Heart interns as they prepared to join the respite care internship. The curriculum was composed of four modules, the themes of which are as follows: Family Experience & Cultural Humility, Compassion & Empathy, Listening, and Speaking. The training, along with an orientation and supervised visits with the families, was intended to prepare the intern to confidently provide quality, compassionate respite care to families of children with cancer.

#### **Project Justification**

The primary goal of this project was to develop a curriculum to train interns regarding how to provide respite care for a family of a child with cancer. Jacob's Heart will soon be introducing respite care to the list of programs and services they already offer to their families, and as an internship opportunity for potential college students. Interns will be trained to be of

service to families during treatment and up to six months removed from treatment. This service could be spending time in the home, running errands for the family, or spending time with the other children in the family. Parents battling a child's cancer diagnosis are stretched thin from hospital visits, home treatments, financial burdens, while trying to keep up with everyday life like errands and chores. According to Lakkis, Khoury, Mahmassani, Ramia, & Hamadeh (2016), psychological distress is very common among parents of children with cancer. Through means of education for the purpose of providing respite care, the project addresses this problem of psychological distress in families of children with cancer. It also aligns perfectly with the vision of Jacob's Heart which is that families will be informed and supported so that they can fully participate in their child's treatment. With respite care available, parents will have some extra time to catch up on household tasks, spend time with their ill child, or take a moment for themselves.

### **Implementation Plan**

The implementation methods that were utilized to develop this training curriculum for interns included collaboration with Jacob's Heart staff, conducting research to identify best practices and current knowledge on the subject matter, creating engaging presentations and accompanying activities, and compiling a detailed reference list/resource guide for interns and staff to reference. During the month of February, the intern researched information for the four training modules. During the month of March, the intern designed four PowerPoint presentations and accompanying activities to aid learning. On April 4<sup>th</sup>, 2019 the curriculum was presented to staff and approved for future implementation.

Participants in the project were the intern who created the curriculum, Alex Dami, Director of External Programs and Adriana Moody, Director of Family Support Services. The

staff members mentioned above held the responsibility of approving the training curriculum and providing feedback to the intern for improvements or additions. Resources used during the implementation of the project were research materials, previous Jacob's Heart training material, PowerPoint, computer with projector, and office space to present to staff.

### **Challenges**

One massive challenge was the complete change of projects that happened in late January. A meeting with the Executive Director and Director of External Programs led to the shift of the project from writing a program plan to creating a training curriculum. This required a completely new description, problem model, scope of work, etc. Also, it cut the time for both implementation and assessment back to only two months. In order to address this huge challenge, an in-depth discussion between the intern and mentor happened to discuss exactly what was needed from the training curriculum. Also, there was an agreement made that all office hours of the intern would be solely dedicated to creating these trainings.

### **Final Project Assessment Plan**

#### **Expected Outcomes**

As a result of this project, the main outcome expected was that the training curriculum would be approved by Jacob's Heart staff and integrated into the training process of their upcoming Respite Care Internship. The long-term outcome that the intern will not be around to evaluate is that the training curriculum adequately prepares interns to provide respite care in the future.

#### **Measuring Success and Impact**

In order to know if the expected outcomes were achieved, the curriculum was presented to the staff at Jacob's Heart in a meeting. The staff then decided if it was something they could

implement or not. The intern conducted an in-person interview with staff members to gain feedback on the curriculum's relevance and ability to train interns. The staff found the curriculum and all its components suitable; therefore, the main outcome was achieved.

### **Results of Assessment Process**

#### **Assessment Results**

As a result of creating the training curriculum and presenting it to staff, Jacob's Heart now has the base training for interns to learn about providing respite care. Changes can be made as needed when the respite care program actually starts up. The project addressed the immediate need at Jacob's Heart, namely that they had no training for a respite care program. With this training in place, they are one step closer to being able to start running a program. In order to tell if the training is effective at preparing interns to provide respite care, it must be evaluated at a future date when the program is existent. The completion of this training also made an effort towards addressing the larger societal problem of parents of children with cancer experiencing symptoms of psychological distress. Through adequately training interns, these families will receive quality, compassionate care, which has been shown to reduce the effects of psychological distress.

#### **Strengths**

One major success of the project was the amount of new resources that Jacob's Heart received. While conducting research for each of the modules, a wealth of resources was discovered regarding respite care. Even if the resource wasn't used directly in the modules, all pertinent information was passed onto Alex Dami in the form of an annotated bibliography that described each resource. The bibliography may also prove to be a great launching pad for a

future intern to conduct even more research on the topic. A main strength of the project was the fact that the intern creating the training had previously provided respite-like care for a Jacob's Heart family. The intern provided the service with no training and so had a good idea of what an intern might need or want to know.

### **Limitations and Challenges**

The project largest limitation was the short time frame. This meant that a limited amount of time could be spent researching each module and then also planning the activities. Another limitation was that the content of the training was already decided before any work was done researching or creating the training. This ended up being extremely restrictive. There were many other areas outside of the initial content that may eventually need more focus as the program starts and interns provide feedback. Additionally, one challenge faced was that the creator of the training was not going to be giving the training, so notes and teaching suggestions had to be given in great detail so that someone new to the curriculum could understand key objectives. Spending a great deal of time explaining the curriculum took away already limited time from researching and diversifying the types of accompanying activities and resources.

### **Recommendations**

#### **For Jacob's Heart**

As aforementioned, the completion of this training curriculum puts a fully functioning respite care program within closer reach of Jacob's Heart. During the presentation to staff for approval, very important conversations were sparked between staff members regarding the logistics of running a such a program. Perhaps these ideas and questions were not on the radar of the staff before the creation of the training.

As the respite care program eventually takes off and continues, one recommendation would be to expand their care providers to volunteers. While interns are great asset because of their passion and concurrent schooling, they have limited time frames due to school schedules. For example, at the end of the semester they may travel back home from university. To a family already experiencing a huge change, this sort of abandonment would not be ideal. This is why local and dedicated volunteers may be a better alternative long term. Another recommendation is that the volunteers that go onto become respite care providers have the requirement of already volunteering consistently with Jacob's Heart for at least 6 months, and on top of that commit to another year. These time commitments will hopefully address any concern of inconsistencies in service to families.

### **Broader Social Significance**

As already mentioned the completion of this training made effort towards addressing the larger societal problem of parents of children with cancer experiencing symptoms of psychological distress. Through adequately training interns, these families will receive quality, compassionate care, which has been shown to reduce the effects of psychological distress. Uncovering research on the topic of psychological distress made it all the more clear that Jacob's Heart has the right idea with the other types of services they currently provide. Things like grocery deliveries, social gatherings, and counseling services all work towards lowering the effect of psychological distress in caregivers of children with cancer.

### **Personal Reflection**

Hiking happens to be one of my favorite pastimes, not only for the beauty of the outdoors, but for the very grounding reminder each time I go that as steep as those mountains

seem from the bottom looking up, the view from the top is always more than worth the effort. This was very much the case with my field placement and capstone experience. Some of the most important lessons learned, I would not have initially chosen. It was the difficult and trying times that stretched me personally and professionally. For example, having the focus of my project entirely changed with two and half months to finish, was indeed daunting at first glance. But, in the end, knowing that I succeeded against all odds gave me a real appreciation for determination and newfound confidence in myself as a future professional. Also, I took away two very important lessons from that challenge. First of all, you can never communicate enough, especially when working on a large project. Secondly, if I am to ever work in the nonprofit sector, I must become accustomed to having plans changed seemingly on a whim. Most organizations have everchanging funders, staff, and initiatives from their board. Being flexible will be an absolutely necessary skill.

The aspect of my field placement that pushed me out of my comfort zone the most was providing respite care to a family that just received news that doctors could do nothing to help their 11-year-old son. The family also had two younger children and were right in the midst of bracing themselves for the worst, while desperately hoping for a miracle. I entered this home completely unprepared for what I would experience. The vulnerability of a young boy shown to a complete stranger humbles me to this day. I am forever grateful to him for re-instilling in me a sense of purpose that I thought I had lost through years of struggle of my own. In those precious moments with him and his family, I learned firsthand what it means to remain a professional without leaving your heart at the door. While not an easy skill, it's one that I realized I had deep inside of me and that no one could necessarily teach me. My emotional strength through an incredibly painful time for that family, provided both parents and grandparents an outlet to

express things to me that they could not express to one another. The memories shared with this incredible family I will cherish all of my life.

For future CHHS interns about to embark on this senior capstone I have a few pieces of advice. First, I would recommend being open to what the experience will teach you. As with all of life, it's often things we didn't plan for that are the most rewarding, even when they are difficult. Another piece of advice I would give to future interns is to advocate for yourself, and if at first you don't know how, ask for help from your field advisor. Your mentors and other agency staff are there to help you, but they are not mind readers. Learning to be respectfully assertive will be your greatest ally.

My last piece of advice is something that I believe will help you in all your life, not just your capstone: remember to keep perspective. When you first start at your agency you may be overwhelmed and scared to make a mistake. Keep perspective; you are brand new and mistakes are a part of learning. No one is expecting you to do a seamless, perfect job. When that tough part of your capstone project presents itself and you're wondering why you even chose this major, keep perspective. Even if the project they asked you to do is not what you want, you are really providing a service that will not only help the staff, but ultimately help that target population that you initially felt called to. When you are exhausted and don't know how you will get it all done, remember, each and every day is a gift and we are never promised tomorrow. I was reminded of that by an incredibly wise and loving 11-year-old boy who didn't live to see his 12<sup>th</sup> birthday. Cherish every moment, even the hard ones. They make the great ones all the more sweet.

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## Appendix A

### Scope of Work

	<b>Activities</b>	<b>Deliverables</b>	<b>Timeline/deadlines</b>
<b>1</b>	Discussed refocus of capstone project	Defined problem and solution	January 31, 2019
<b>2</b>	Researched and gathered resources for Module 1 (Family Experience/Cultural Humility)	Provided evidence basis for PowerPoint.	February 3, 2019
<b>3</b>	Researched and gathered resources for Module 2 (Compassion and Empathy)	Provided evidence basis for PowerPoint.	February 10, 2019
<b>4</b>	Researched and gathered resources for Module 3 (Listening)	Provided evidence basis for PowerPoint.	February 17, 2019
<b>5</b>	Researched and gathered resources for Module 4 (Speaking)	Provided evidence basis for PowerPoint.	February 24, 2019
<b>7</b>	Presented research/literature for review	Analyzed progress/prepare for formatting into training modules	February 28, 2019
<b>9</b>	Created training for Module 1 – including activities	Made trainings relevant and engaging for future interns	March 7, 2019
<b>10</b>	Created training for Module 2	Made trainings relevant and engaging for future interns	March 10, 2019
<b>11</b>	Created training for Module 3	Made trainings relevant and engaging for future interns	March 17, 2019
<b>12</b>	Created training for Module 4	Made trainings relevant and engaging for future interns	March 24, 2019
<b>13</b>	Presented final training program to staff	Evaluated success of project	April 4, 2019
<b>14</b>	Reflected on experiences	Developed capstone reports	April 19, 2019
<b>15</b>	Completed report requirements	Final agency and capstone reports	May 3, 2019
<b>16</b>	Prepared capstone presentation in selected format	Presented at Dress Rehearsal for grading	May 8-10, 2019
<b>17</b>	Final preparation for Capstone Festival	Final presentation at Capstone Festival!!	May 16, 2019

**Appendix B**  
**Problem Model**

<b>CAUSES/RISK FACTORS TO BROADER HEALTH PROBLEM</b>	<b>BROADER “MACRO-LEVEL” HEALTH/SOCIAL PROBLEM</b>	<b>CONSEQUENCES TO SOCIETY</b>
<ul style="list-style-type: none"> <li>• Wide range of duties</li> <li>• Caregiver burden</li> <li>• Lack of social support</li> <li>• Financial stressors</li> <li>• Uncertainty</li> </ul>	<p>Rates of psychological distress are too high among families of children with cancer.</p>	<ul style="list-style-type: none"> <li>• High prevalence of psychological distress among families of children with cancer</li> <li>• Relational strain</li> <li>• Compromised quality of care for children with cancer from family</li> </ul>
<b>CAUSES TO AGENCY PROBLEM</b>	<b>AGENCY-SPECIFIC “MICRO-LEVEL” PROBLEM ADDRESSED BY PROJECT</b>	<b>CONSEQUENCES TO AGENCY</b>
<ul style="list-style-type: none"> <li>• Lack of budget</li> <li>• Lack of staff</li> <li>• Insufficient trainings</li> </ul>	<p>Jacob’s Heart interns are unprepared to provide respite care.</p>	<ul style="list-style-type: none"> <li>• Interns lack confidence and professionalism</li> <li>• Lack of trust among families towards Jacob’s Heart</li> <li>• Families aren’t receiving quality respite care they deserve and need</li> </ul>