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Montserrat Abrego
California State University, Monterey Bay

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Heart Ambassador Newsletter

Montserrat Abrego

Jacob's Heart Children's Cancer Support Services and Alex Dami

Collaborative Health & Human Services

Department of Health Human Services and Public Policy

California State University Monterey Bay

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Author Note

Montserrat Abrego, Department of Health Human Services and Public Policy, California State University Monterey Bay. This research was supported by Jacob's Heart Children's Cancer Support Services. Correspondence concerning this report should be addressed to Montserrat Abrego, California State University Monterey Bay, 100 Campus Center, Seaside, CA, 93955. Contact: mabrego@csumb.edu.

Abstract

Jacob's Heart Children's Cancer Support Services is a non-profit organization located in Watsonville CA. It serves Children with Pediatric Cancer and their families in the counties of Monterey, Santa Cruz, San Benito, and South Santa Clara. When families are given a diagnosis of cancer, especially their child's many of them undergo high levels of stress and face financial instability. The Heart Ambassador Newsletter is a monthly newsletter that is shared with the Heart Ambassadors who have completed the training to become a Heart Ambassador for Jacob's Heart. This monthly newsletter includes information on events/community opportunities, variation of stories and op-ed pieces written by families, Heart Ambassadors or staff members and a Heart Ambassador highlight to showcase the amazing work they have done. It is recommended that Jacob's Heart considers additional staff dedicated to outreach, in this manner, other staff they can prioritize their time spent on their children with cancer and their families' needs.

Keywords: *Volunteer Engagement, Newsletter, Family Support, Outreach, Pediatric Cancer*

I. Agency Description

Jacob's Heart Children's Cancer Support Services is a non-profit organization located in Watsonville CA. It serves Children with Pediatric Cancer and their families in the counties of Monterey, Santa Cruz, San Benito, and South Santa Clara. This non-profit organization began its work in 1998 when the founder, Lori Butterworth saw the need of support in one of her close friends' son, Jacob, who was diagnosed with Leukemia. Jacob's Heart was created so that every family can feel supported during the many challenges they have to go through during the child's battle with cancer.

Jacob's Heart mission states that "Jacob's Heart Children's Cancer Support Services exists to improve the quality of life for children with cancer and support their families in the challenges they face" (Jacob's Heart, n.d.). The services provided by Jacob's Heart are support groups, therapy, case management & financial assistance. In 2018, they were able to provide \$220,886 in financial assistance to their children and families (Jacob's Heart, n.d.). They also have programs such as Heart and Wheels (Transportation), Full Hearts (Groceries), Holiday Hearts (Adopt a family). In 2018, they were able to provide 324 rides to treatment, and 3,906 grocery bags to families (Jacob's Heart, n.d.) For many families it is hard to attend doctor appointments, others don't have enough for groceries, or can't provide gifts during holidays because that money is being used differently. Through the different services provided Jacob's Heart they make a difference in families' lives.

II. Communities Served by the Agency

Jacob's Heart Children's Cancer Support Services serves the counties of Monterey, Santa Cruz, San Benito, and South Santa Clara. The populations served by the agency vary ages newborns through eighteen. Jacob's Heart serves a large population of agricultural families (Jacob's Heart, n.d.). Around forty percent of his population also suffer from house insecurity. House insecurity is that they aren't able to afford or have trouble affording for their house because the cost is more than one-third of the household's combined monthly income (Beaver, n.d.).

From the population served, about half of them qualify as high financial need (Jacob's Heart, n.d.). This means that they are having trouble with money, because medical bills and other debts that can add up when trying to focus on their child's health. Since this is an issue almost eighty percent of the population being served by Jacob's Heart is enrolled in full-scope Medi-Cal. According to DHCS (n.d.), "Full scope Medi-Cal covers more than just care when you have an emergency. It provides medical, dental, mental health, and vision (eye) care. It also covers alcohol and drug use treatment, drugs your doctor orders, and more". Another problem is that from the population being served by Jacob's Heart half of them rely on one vehicle for transportation (Jacob's Heart, n.d.). For this reason Jacob's Heart can now offer children with cancer transportation to their treatment and doctor appointments through Central Coast Alliance for Health Medical Insurance.

III. Problem Description

Too many families of children diagnosed with cancer experience high levels of stress and financial instability. Stress can be internal or external which can affect a person's physical, mental, or emotionally that causes bodily or mental tension (C. Shiel, 2018). Financial instability is when people aren't economically stable based on certain situations that they are going through and, therefore, they struggle to maintain an income.

Jacob's Heart Children's Cancer Support Services is impacted by this because they have to categorize children and their families who are being affected the most and help them understand their diagnosis, treatment and provide any other help they need through their journey with cancer. Jacob's Heart has a limited budget for how much money can be spent in their programs. This can sometimes lead to not being able to fully provide families with their needs. Jacob's Heart staff are also impacted because they get to meet each individual child and family, and they grow a connection in which they end up becoming emotionally unstable during these situations even though they are mainly providing their services.

This is a macro-level problem because many families dealing with this can't focus on providing the best for their children diagnosed with cancer. The families have to deal with the horrible news that their child has been diagnosed with cancer at such a young age which causes them to stress about other things like money, food and working a job. According to Mongelli (2018), "Life often gets turned upside down; familial roles might change and a family may lose financial security". During these hard times all of those other things can become another burden for them when they are trying to maintain their child healthy and helping them fight through

their battle with cancer. Parents always want what is best for their children and knowing that they have cancer can lead them to think the worst and cause more stress on them. Most families have to deal with financial instability because they aren't able to work full time as most parents, some have to drive far distances to get to appointments. According to a study made by Bona et al. (2014), "Studies have reported that up to 40% of CSHCN families experience financial burden secondary to their child's illness, and 25% experience work disruptions, including 13% who need to quit a job". In cases parents aren't able to provide enough food or they aren't able to invest the money they do have on things for them because their priority is their child who has been diagnosed with cancer. Families that work on agriculture generally don't have a steady income for three to four months when there is no work for them during the winter. According to All about Cancer (n.d.), "Responsibility for finances, looking after the children and many other things have to be reassessed". Families who have an income year-round still have hardships maintaining that income and have to make it last for their needs.

This problem not only affects children and families but it also makes an impact on the local community because some of these families are already considered low income families which can lead them to be less involved in their community. By being less involved they aren't able to provide much to their community in terms of economy, education and any other participation or volunteering. Families are also in search of resources that can help them with their needs. Many families depend on more than one organization that can support them through their journey with cancer. Parents can also be looking for that support to be able to push through what is happening with their child. According to the National Cancer Institute (n.d.), "Many parents benefit from the experiences and information shared by other parents". Everyone in the

family should be able to get that support through organizations or people in their own community.

Counties don't always have the resources and funding needed to support children with cancer and their families, so they are often left behind. Having more resources that can support them during the difficult times and not only be a one-time action have to be developed. Some families who are dealing with high levels of stress and financial instability are also often dealing with more than one burden. Families don't only deal with stress and financial instability, but they might also have other health problems in the family, or a recent death. This contributing factor can lead them to prioritize one and forget how to deal with the others. According to CureSearch for Children with Cancer (n.d.), "Parents of a child who has just been diagnosed with cancer are often overwhelmed by the new demands of the situation". Understanding the type of treatment, the child is going through is another contributing factor because some cancers can be more developed than others. In some cases, children have to be hospitalized for treatment which means parents have to be present and others don't. Recurrence or recurrent Cancer can also be a contributing factor to families dealing with high levels of stress and financial instability because they are aware that even though their child may be cancer free it doesn't mean that they are cured. Some cancer cells can remain in your body for many years after treatment, however if the child completes remission for more than five years or more there is a smaller possibility it won't come back (National Cancer Institute, 2019). There are cases where children get cancer again even after treatment because it is impossible to know if it will or won't come back after treating it the first time and it also depends on the type of primary cancer (Dealing With Cancer Recurrence, 2019). These contributing factors can lead to an increase of

stress and financial instability among families because these are new things that many families are experiencing and don't know how to cope with them so they turn to someone who can better support them (Macmillan Cancer Support, n.d.).

If the macro problem, too many families of children diagnosed with cancer deal with high levels of stress and financial instability isn't addressed the consequences can be very disheartening. Since many families are dealing with high levels of stress and financial instability this can cause children to not receive the proper treatment because the family might be stressed on wondering how they will get to the hospital and back when they don't have the proper transportation. According to the blog, *Overcoming Transportation Barriers to Care* (2018), "Approximately 650,000 Americans receive chemotherapy each year, yet, thousands of patients are unable to get the treatment they need due to financial toxicity, cultural differences and transportation barriers to care". Others might lose their main form of income, their jobs because they have to dedicate more time and care for their child with cancer since some depend on their parents for everyday activities like eating, making sure they are taking their medicine, or getting from place to place. Fathers are more likely to continue working but mothers on the other hand tend to cut back on hours or leave their jobs (CureSearch for Children with Cancer, n.d.). Others might get fired because the stress they are going through is affecting their job and is preventing them from completing their job deadlines. Having a child who is diagnosed with cancer can also have a consequence on the family structure because of the many visits to the hospital, preoccupation of parents, disruptions in home life, and loss of companionship for the sister or brother with cancer (CureSearch for Children with Cancer, n.d.). Siblings might not get the same attention they did before, so it can develop unwanted feelings with their sibling who has

been diagnosed with cancer or the parents. Other siblings can develop a fear of losing their sibling which can lead to isolation. It can also lead to possible arguments between parents, which can lead to divorces. These consequences will form part of the problem if not addressed. Many don't see the problem but once the consequences are described they are more likely to accept the problem and find a way to address it.

Figure 1: Problem Model

Causes/Contributing Factors	Problem statement	Consequences
Not enough services/funding	Too many families of children diagnosed with cancer deal with high levels of stress and financial instability.	Children don't receive proper treatment
Low income/high costs of treatment		Loss of income (jobs)
Low understanding of cancer treatment		Disruption of Family Structure
Recurrence or recurrent Cancer		

Project Connection with the Problem:

Not having enough services and funding for children with cancer and their families in an area is a contributing factor that will be addressed through my Jacob's Heart Newsletter. This will be addressed because the end goal of this newsletter is to increase the number of volunteers and the amount of donations/ funding for Jacob's Heart Children's Cancer Support Services. If this newsletter is a success the agency should experience an increase in volunteers and

donations which will help them continue to support more families through their programs and continue to meet the needs of their children and families.

Jacob's Heart is one of the few organizations in the area that provides support services for children with cancer. It can benefit from donations/funding and make an increase in their partnerships. This will also give them the opportunity to make new partnerships in the community that would like to support the organization and its mission. Without them many children and families would have to go through this journey alone and be unaware of what is happening to their child. Through this newsletter those who are receiving it can capture the bigger picture and understand the services being provided by Jacob's Heart Children's Cancer Support Services. Not only do they care about the children with cancer, but they are also there to care for their families during these hard times. Families also need support in order for them to be able to care properly for their child with cancer and not have to deal with it alone. For now it will continue to serve Monterey, Santa Cruz, San Benito, and South Santa Clara county children with cancer and families but in the future it will be serving more counties.

IV. Capstone Project

Project Description and Justification

Jacob's Heart Children's Cancer Support Services strives to inspire compassionate action within local communities. This Capstone project, the Heart Ambassador Newsletter was inspired by a new program that began at Jacob's Heart Children's Cancer Support Services named Heart Ambassadors. The title of the newsletter was created to be connected directly with the program. This makes it easier for those receiving it because they know what the program is and is the way that they decide to stay connected to Jacob's heart.

The Heart Ambassador Newsletter is a monthly newsletter that is shared with the Heart Ambassadors who have completed the training to become a Heart Ambassador for Jacob's Heart. The newsletter includes three main sections; Events/Community Opportunities, Story/Op-ed pieces and Volunteer Highlight.

The newsletter includes information on events/community opportunities as one way for the Heart Ambassadors to be involved in the community and make a difference in a child's life. This section includes any events that Jacob's Heart is partnered with to raise awareness and funds. It's important for the agency to make strong connections with the Heart Ambassadors to make an impact in their lives as well. The Heart Ambassadors need to feel comfortable working with staff and be able to represent Jacob's Heart in the communities served. Through the events the Heart Ambassadors get to experience how Jacob's Heart makes a difference on children with cancer and their families.

The second section in the newsletter consists of a variation of stories and op-ed pieces written by families, Heart Ambassadors or staff members. This section presents a heartfelt story or op-ed piece that showcases how different families are being supported through their fight with pediatric cancer. This story can either be a story on their fight against cancer or it can be a story that talks about how Jacob's Heart has made an impact on their lives. This will also help others in the community understand why Jacob's Heart exists and its intention to provide different services to families in need. For an example of the first draft of the Heart Ambassadors newsletter please refer to the appendix section.

The Heart Ambassador highlight in the newsletter helps every Heart Ambassador strive and stay motivated to bring awareness to pediatric cancer. The stories being shared are based on experiences that families have come across during or after their journey with pediatric cancer or from staff members who have seen families go through them. This showcases the amazing work that the Heart Ambassadors do out in the community. It gives the rest of the Heart Ambassadors a little view into what each Heart Ambassador does on behalf of Jacob's Heart and how they are creating a change. They are important leaders for Jacob's Heart and should be able to receive recognition for the amazing work they do on behalf of Jacob's Heart.

The purpose of this monthly newsletter is to continue bringing awareness of pediatric cancer into the lives of those receiving it. It catches people's attention when they receive it because it gives them a different perspective of what Jacob's Heart is doing. This newsletter helps the Heart Ambassadors stay connected to Jacob's Hearts and attracts them to be more involved with them. That being said Jacob's Heart is increasing in the number of volunteers that are transitioning into Heart Ambassadors.

This newsletter benefits Jacob's Heart because their organization's name is the minds of those receiving it. It motivates the rest of volunteers if they share it with family, friends and business partners who might be interested in supporting its cause. It's an opportunity to increase awareness and understanding of Jacob's Heart and its services. This newsletter showcases the bigger picture of Jacob's Heart Children's Cancer Support Services and motivates the rest of the Heart Ambassadors to continue taking action.

Project Implementation

The Heart Ambassador Newsletter is a marketing/awareness project. The method that was used to implement this project consisted of researching newsletters from other agencies as well as those sent out by Jacob's Heart. It was then followed by attending Developmental Committee meetings to go over the goal and expected outcomes of the Heart Ambassador newsletter.

For creating and developing this newsletter some of the other responsibilities were; talking with Staff, Heart Ambassadors in training to collect stories or op-ed pieces, worked with Sue Quijano who is the Creative Director to look at outlines used for Jacob's Heart current newsletters, presented a rough draft to Kymberly, who is the Volunteer Coordinator. These responsibilities are presented in more detail in Table 1.

Some challenges with the creation of this newsletter that set back the project was setting the name of the new program, and knowing what the organization wanted the outcome to be. Another challenge was setting dates to when the program would begin because of staff members not being present during DEVCOM meetings. Since this was a new program, it also meant that Jacob's Heart needed to gather the first Heart Ambassadors in order to distribute this newsletter.

A solution to this problem was to be strict with our Capstone deadlines, shown in table 1. Another challenge was not having enough families, staff, or heart ambassadors participating to share their story. A way to get them to participate was by getting to know them more and asking them directly how comfortable they would be with sharing their experiences. We had an option to make it anonymous, that way, they can disclose personal information without identifying themselves. Timing didn't always work with my schedule because it would interfere with theirs. Scheduling small meetings with the Heart Ambassador team that consisted of Ishtar, Haley, Kim, Leilany and I was the best decision because it allowed me to get my questions answered and allowed them to continue on with their duties after about 20-30 mins. Lastly, an assessment for the Heart Ambassador Newsletter wasn't completed due to the COVID-19 Pandemic which led to many states having to set a shelter-in-place order. This meant that many facilities, stores and other unessential jobs were closed including universities during this time. Due to this the Heart Ambassador Newsletter wasn't able to be sent out since the Heart Ambassador program had to be paused for the time being.

Table 1: Scope of Work for Jacob's Heart Newsletter project
Title: Jacob's Heart Newsletter
Project description: This newsletter will be a marketing/ awareness project with the purpose of bringing awareness of pediatric cancer into the lives of those receiving it.
Goal: Decrease the time staff members spend at events and increase volunteer connections.

Primary objective of the project: Increase knowledge about Jacob's Heart Children's Cancer Support Services			
Activities		Deliverables	Timeline/deadlines
1	Discuss capstone project ideas with mentor	Final capstone project idea approved	October 28, 2019
2	Research other Newsletters	Understanding how they work and effectiveness	November 13, 2019
3	Revising sections with Alex	Add or remove sections that might or might not work	December 3, 2019
4	Meeting with Sue	Guidance on creating outline	February 26 2020
5	Newsletter Outline	Organize into sections	February 26, 2020
6	Obtain Stories from Volunteers/Staff	Set dates/times	March 2020
7	Presenting Newsletter to Kymberly Lacrosse	Approval or Concerns	March 2020
8	Complete reporting requirements	Final agency and capstone reports	May 2020
9	Final preparation for Capstone Festival	Final presentation at Capstone Festival!!	May 2020

V. Reflection of COVID-19 Pandemic's Impact on Agency and Population Served

The agency was impacted by the COVID-19 Pandemic in several ways because the county and state ordered a shelter in place order that only allowed essential businesses to continue operating. Before the shelter in place order Jacob's Heart Children's Cancer Support Services began by limiting the amount of people going in and out of the agency, this included families and volunteers. Volunteers could no longer go into the office and work on projects like kids cards, grocery bags, etc. because it would put the families at risk of COVID-19. They were taking the extra precautions because the population they serve can be greatly affected if they came in contact with COVID-19. Soon after the agency had to close its office and staff had to begin working from home. The agency began doing weekly grocery deliveries to families instead of doing it biweekly to help their families with food assistance. However the families in south county had to remain on a biweekly grocery delivery schedule due to shortness of staff and volunteers. The agency made available home kits to the families outside their office.

The Jacob's Heart Children's Cancer Support Services families were able to get more food and financial assistance during this time which relieved some stress from families. Jacob's Heart's families were able to get weekly groceries to their front steps during this COVID-19 Pandemic which allowed them to stay at home and worry less on having to go out and be exposed to it. The children who were on maintenance phase, have had appointments cancelled to limit the amount of visits and lowering their risk of being around medical staff that is exposed to COVID-19. Children who are still in treatment were only allowed to have one parent present during their visit. Lastly, the children who are considered end of life or terminally ill

were to pass away during the pandemic only 10 people would be allowed to be present during their service or funeral.

The COVID-19 Pandemic had an impact on families of children diagnosed with cancer dealing with high levels of stress and financial instability because the numbers of those infected and deaths from COVID-19 kept increasing as the weeks went on. The pandemic made it worse causing families to deal with high levels of stress and financial instability because their children could be greatly affected by this pandemic if they came in contact with it. Families had to limit their activities or have someone else do their essential shopping to prioritize their child's health. Many families already depend on one parent for their main income so now due to the pandemic many businesses had to close and lost their main income. Not having some type of income creates worry in parents if they aren't able to provide food to their families or pay any upcoming bills. Also many parents spend a large portion of their time at hospitals with their children so their fear of them or their children testing positive for COVID-19 increases, and they now have to worry about something else besides their children's health..

The impact that COVID-19 had on Jacob's Heart Children's Cancer Support Services will have an impact on the future because of the unstable economy it created. Since Jacob's Heart is considered a non-profit agency it will affect its finances. Jacob's Heart won't be able to determine or continue to rely on the grants they have received so far or will be given to them because of this pandemic. Many businesses were affected and will need time to regain their financial stability. Other businesses have gone out of business and won't be able to give the same support to Jacob's Heart as before the pandemic. Something that they should learn as a result of this crisis for how they operate in the future is to be more precautious when it comes to

the amount of stuff being touched by volunteers and staff even if they think it can bring some happiness to them it can also cause some harm to them.

VI. Recommendations

The benefit that this project will provide for the agency is that it will give more volunteers the opportunity to work their way up to become Heart Ambassadors and be able to represent Jacob's Heart Children's Cancer Support Services. Heart Ambassadors will be able to develop new skills or apply their own among the community and have a more hands on experience. This project should be continued because it will allow the Heart Ambassadors to stay connected to Jacob's Heart and have new insight each month on the activities being done by others. It will continue to raise awareness of pediatric cancer among the Heart Ambassadors, their families and friends. Something that can be done differently is to not only share the newsletter with Heart Ambassadors but have it shared with the rest of the volunteers and families that often participate in events so they can engage more with the agency and create a bigger impact on the agency. I advise those working on this agency to continue to push for new programs like Heart Ambassadors that allow community members to engage with Jacob's Heart Children's Cancer Support Services, so they can be able to get to know the agency at a personal level.

This project relates to the broader "macro-level" social problem, " Too many families of children diagnosed with cancer deal with high levels of stress and financial instability" because through the Heart Ambassadors who receive the Heart Ambassador Newsletter the agency is able to direct events to them in the monthly newsletter which will then allow staff members to focus more on providing their services to their children with cancer and families. The results of this project will contribute to a greater understanding of how the agency addresses the social problem because staff will be able to prioritize the needs of their

children and families. They will also be able to have more time to spend time with them to relieve some emotional stress and get to know the families they are helping instead of just knowing the basics. They will also be able to dedicate more time to gathering the needs and finding ways to address them for their children with cancer and their families. Lastly, Jacob's Heart could consider adding staff dedicated to outreach, so they can prioritize their time on addressing their children with cancer and their families needs. Having more agencies nearby that serve children with pediatric cancer could help address this broader social problem because children with cancer exist everywhere and one agency can't provide for all of them.

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APPENDIX

Op-ed Piece

My name is Haley Brown and I'm originally from the east coast. With my closest family being 2,675 miles away, I used to get a bit lonely at times.

That was before Jacob's Heart came into my life.

The team, the families and the community of support that exists around Jacob's Heart has changed me entirely. Through the connections I've made, especially with the kids, I no longer feel so alone. The highlight of my workdays are when little Shane and Alice come in and beg me to play hide and seek with them. Seeing their smiles and hearing their laughter after losing their big brother just a year ago, reminds me everyday of why I am here.

I'll never be able to adequately express my gratitude for Jacob's Heart. The organization has given me more than just a job...it has given me a home.

Jacob's Heart Children's Cancer Support Services Heart Ambassador Newsletter April 2020

"Every person can make a difference, and every person should try". - John F. Kennedy

Upcoming Events

- April 15th Aptos Chamber Business Showcase at Seascapes Resort
• April 22nd Cyber Fundraiser
• April 25th First Forever Sibling Day

Ongoing Volunteer Opportunities

- Change of Heart -Change Ambassador, partners with schools to distributes jars to classrooms and collect change to provide gas cards and rides to treatment
• Full Hearts Groceries -Fresh groceries delivered on a bi-weekly schedule to families

Location: 680 W. Beach Street, Watsonville

Ambassador Highlight

"Before my first day at a Santa Cruz Warriors Game I was actually quite nervous because I did not know what to expect. Let me tell you it was so much fun. All the volunteers were energized and nice people. A volunteer and I were able to stand by the Lockerroom and high five all the players going on to the court. Then we were able to get on the court and collect all the balls which was exciting. Being able to represent Jacobs Heart during a professional basketball game was exhilarating experience. Every night I left with a good feeling in my heart because we raised money to support kids with cancer."

-Brian Castelle