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Tangible Needs Assessment for Teenage Cancer Patients and Their Siblings

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Abstract

Jacob's Heart Children's Cancer Support Services works to improve the quality of life for children with cancer and support their families in the challenges they face. Jacob's Heart serves families in Santa Cruz, Monterey, San Benito, and South Santa Clara Counties who have a child diagnosed with cancer under the age of 18. Unfortunately, too many teens with cancer and their families experience emotional instability and lack of self awareness. To address the social problem, a tangible needs assessment was created with the support of the department of Family Support Specialist. The assessment will help Jacob's Heart teens achieve tangible needs and post-traumatic growth. By asking questions that push teens to be as specific as possible in their likes and dislikes, teens will obtain a sense of control resulting in self awareness. It is recommended that the agency begins implementing the assessment.

Keywords: Teens with Cancer, post-traumatic growth, tangible needs, self-awareness, emotional instability

I. Agency Description

Jacob's Heart Children's Cancer Support Services began in 1998 by current executive director, Lori Butterworth. She started the non-profit organization when her friends' son Jacob was diagnosed with leukemia. "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" (Jacobs Heart, 2019). Jacob's Heart serves families in Monterey, Santa Cruz, San Benito, and South Santa Clara counties who have a child experiencing pediatric cancer.

According to the National Cancer Institute, pediatric cancer is defined as cancer diagnosed from birth to the age of 15, yet Jacob's Heart serves children from the age of birth to 18 who have been diagnosed with cancer. If a child is diagnosed a month before their 18th birthday they are still eligible for the agency's services.

Jacob's Heart receives their families on a referral system. The agency has partnerships with The University of California San Francisco Medical and Lucile Packard Children's Hospital Stanford. When local children are diagnosed with cancer they are sent to one of the mentioned hospitals to receive treatment. Once the child and family meet with their social worker, they are referred to Jacob's Heart. Depending on the child's diagnosis and age they are referred to a Family Support Specialist. From there, the Family Support Specialist will schedule a hospital or home visit to explain more about the agency and what they are there for.

The services provided by the non-profit agency are based on three evidence and scientifically-based systems: Maslow's Hierarchy of Human Needs, Standards of Practice for Pediatric Palliative Care and Hospice, National Hospice and Palliative Care Organizations (2009), and Standards for the Psychosocial Care of Children with Cancer and Their Families (Wiener, L., Kazak, A.E., Noll, R. B., Patenaude, A.F., & Kupst, M.J., 2015). Most programs and services offered by Jacob's Heart fall into a category within Maslow's Hierarchy of Human Needs. To help meet physiological needs, the agency offers direct financial assistance, resources, referrals, direct transportation as well as pre-paid gas cards. Safety and security is met with individualized care plans unique to each child and family served. This is achievable with the help of staff and volunteers. "Love and belonging" are met with quarterly art events where families are invited to the office to interact with other families. Other services that help meet this need and family support and counseling sessions as well as peer-to-peer support. All events that help meet love and belonging are designed to ensure Jacob's Heart families make connections to staff and other families. Family Support groups which include teen groups, grief support, and emotional support groups help meet Jacob's Heart family's emotional needs. The last need of Maslow's Hierarchy is self-actualization which is met with hope and healing within.

II.Communities Served by the Agency

Jacob's Heart Children's Cancer Support Services serves children between the age of birth to 17th who have been diagnosed with cancer and reside in Santa Cruz, Monterey, San Benito, or South Santa Clara counties. Between 2011 to 2015 Jacob's Heart had 1,800 cases. A large portion of the families Jacob's Heart serves are agriculture families. 79% are enrolled in full-scope Medi-Cal. Of all the families served 45% qualify as high-financial need. According to Jacob's Heart 50% rely on one vehicle transportation, meaning they will often benefit from transportation services from Jacob's Heart. 37% of Jacob's Heart families experience housing insecurities. Jacob's Heart helps families with housing insecurities with Direct Financial Assistance (DFA). DFA can be used for rent, mortgage or any bills. The services Jacob's Heart offers are developed for the benefit of what the family is struggling with.

III. Problem Description

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. When a child is diagnosed with cancer many difficulties arise. During treatment and post treatment too many teens with cancer and their families will experience emotional instability and lack of self-awareness. Emotional instability refers to rapid, often exaggerated changes in mood where strong emotions and feelings are very present (Merriam-Webster Dictionary. 2019). Lack of self-awareness is defined as the inability to better understand ourselves as unique and separate

individuals (Merriam-Webster Dictionary. 2019). With lack of self-awareness it is possible that an individual often compares themselves to others and wishes to be like others. The emotional instability and lack of self-awareness can create even more difficulty with finances, the need to work extra hours or even the turnout Jacob's Heart has for events.

Jacob's Heart provides family-centered care that addresses emotional, practical, and financial struggles. (Jacob's Heart Children's Cancer Support Services, 2019). Jacob's Heart serves families in the tri-county, which include Monterey County, Santa Cruz County, San Benito County and South Santa Clara County where many are one income or low-income families. Due to the counties served many of the families work in agriculture, meaning they only have a consistent income during the season. Seasonal employment can cause financial hardships due to the low wages especially for families living in these counties where living cost is exceptionally high (MagnifyMoney, 2016). After a child is diagnosed with cancer it is very likely that one of the parents will stop working to ensure their child has reliable transportation. "Twenty five percent of families report losing more than 40% of their annual income" (The National Children's Cancer Society, 2018). Deciding to stop working can be a difficult decision because many of the time it is unpaid, yet it is quietly taken because the priority is to ensure the child will be able to attend their appointments.

With financial hardships comes the cost of treatment. According to the National Childhood Cancer Society the average cost associated with childhood cancer starts at \$833,000. The cost for treatment stated does not reflect the possible insurance coverage. The families or

child's insurance will determine how much of each stay is covered. According to the American Childhood Cancer Organization each private insurance will determine what parts of treatment are covered, how much and in some situations, there will be a need for advanced authorization to obtain coverage. When there is a need for advanced authorization paperwork can be daunting and hard to understand (National Childhood Cancer Society). The fear of whether your insurance will cover can cause emotional instability. In many cases for families with pre-teens or teens with cancer the emotional instability can be dwelling on them as well (National Childhood Cancer Society).

Not only is financial instability directly associated with treatment but there is a high number of out of pocket expenses such as gas/transportation, extra childcare and in some cases hotels. Jacob's Heart families have to travel to Lucille's Packard Children's Hospital or UCSF for treatment. The drive to both of these hospitals is at least an hour in a half one way not taking in consideration possible traffic. For families who have other children in school it is likely that one parent will stay home and will do weekly weekend visits, so the rest of the children do not miss school. Depending on family support and work flexibility there might be a need for child care which becomes another out of pocket expense. Organizations such as Jacob's Heart offer monthly gas assistance as well as Direct Financial Assistance that can be utilized for any bills the family wishes.

Emotional instability and lack of self-awareness are a result of cost of treatments, low wages, financial hardships, and lack of adequate support services. Jacob's Heart Children's

Cancer Support Services does a great job addressing emotional, practical, and financial struggles. Emotional support is given with the help of family support specialists as well as support groups and interactive activities, yet turnout can be low due to factors such as transportation and lack of personalized activities, particularly for teens. When a child is diagnosed with cancer the family's main focus is the child's well-being, limiting other family members to focus on themselves.

Figure 1: Problem Model

Figure 1 presents the problem model discussed in this section.

Causes/Contributing Factors	Problem statement	Consequences
Financial Hardships		Effect on marriage
Low Wages		Effect on children
No Services	Too many teens with cancer and their families experience emotional instability and lack-of-self	Low turnouts for events
Lack of knowledge of diversity in age group of population served	awareness.	
Need to work more hours		

Project Connection with the Problem:

By developing a needs assessment that was given to teens with cancer, Jacob's Heart Children's Cancer Support Services will be able to provide more services that are adaptable towards each teen and for the benefit of the teens they serve. During the process of obtaining this information, Jacob's Heart teens will have the ability to define what will benefit them. The personalized list

created by the teens themselves will help support them thrive during their treatment as well as post treatment.

IV. Capstone Project Description and Justification

This capstone project consisted of developing a needs assessment that will help Jacob's Heart meet the tangible needs of teens with cancer. The data collection component of the project uses an assessment added to the intake packet which is initially filled out by Family Support Specialists during the first meeting with the children and their families. Currently the intake packet includes forms of consent such as media, form of communication and much more. During the intake, Family Support Specialist, discuss the programs and services Jacob's Heart offers while also having the opportunity to get to know each family member and their interest which is then followed by referrals. The creation of a tangible need assessment will help direct Family Support Specialists in a specific path. Not only will the assessment help Family Support Specialists, but the children and their families will be able to determine what type of support would benefit them. The assessment included questions about the teens personal interest which can include sports, colors, hobbies, and brands they love. The goal of the assessment is to determine what will help the teens thrive during their treatment. The information obtained from the assessment will result in developing personalized care packages as well as gifts for adopt-a-family, Teen Day events and possible future incentives.

Catering to the interest of the teens themselves will help build trust and a connection with their Family Support Specialist. With the assessment, teens will also have the direct ability to

state what they like and dislike, giving them a sense of control and ultimately help get Jacob

Heart teens to reach post traumatic growth. The data analysis retrieved from the filled assessment
will be presented to both donors and the Jacob's Heart's grant writer to allow purchase of items
requested.

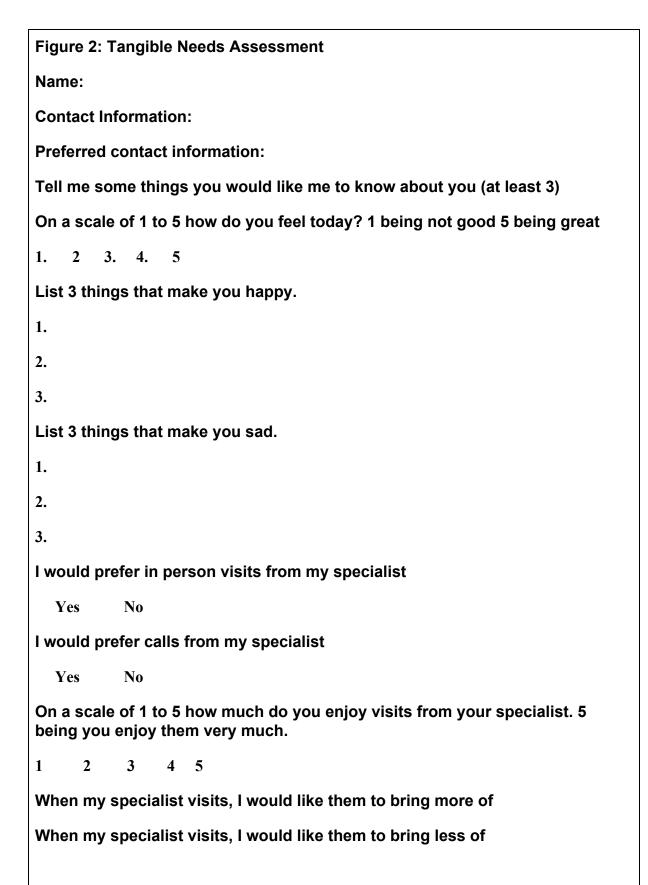
Jacob's Heart Children's Cancer Support Services serves children 18 and younger who have been diagnosed with cancer, yet donations and many support services such as mailing of Kids Cards and other activities tend to be catered towards the younger kids often leaving teens with events and gifts that don't seem to be fit for them. Jacob's Hearts has Teen Days that are catered towards teens only, but can better be personalized towards their interest. The assessment will help determine what are the interests of the teens and guide Jacob's Heart to obtain resources that will meet the interest of the teens. The goal is to determine what tangible needs Jacob's Heart can help meet to ensure the teens are thriving during their treatment.

With the help of this capstone, Jacob's Heart Children's Cancer Support Services will have an additional source to their intake package. The assessment currently included in the intake package is more associated with physiological needs and as stated by the teen family support specialist it is a form that can be of greater use for the Psychologist at Jacob's Heart not necessarily the Family Support Specialist. The assessment will allow the Family Support Specialist to better cater to the tangible needs of the children they serve, especially the teens.

V. Project Implementation

The tangible needs assessment was created with reference to the current Individual Counseling assessment included in the current intake packet. The questions were catered towards teens with the guidance of Teen Family Support Specialist, Mariela Medina and resources from authors such as Jane McGonigal, Rose Offner, MFA & Sherri Brisson, MA. Once the assessment was created it was added to the intake packet. The assessment included questions about favorite clothing stores, favorite shoe stores, type of expressive arts teen enjoys, as well as various questions to be answered on a scale. Information was to be provided to the grant writer as well as the events coordinator to advocate for specific items that are catered towards Jacob's Heart teens.

To complete the assessment, participants would have included newly diagnosed teens as well as teens who have been with Jacob's Heart and are currently in treatment. Due to Coronavirus, COVID-19, an order of Shelter in Place was effective on March 16th for Santa Cruz County causing a difficulty for the assessment to be implemented. Implementation was going to be through home and hospital visits. Due to the shelter-in-place there was a great change at Jacob's Heart. Staff began working from home and were no longer allowed to complete home or hospital visits. The assessment will be available to Jacob's Heart Children's Cancer Support Services for future use. Figure 2 presents the teens' assessment instrument



How frequently would you want your specialist to visit?							
Once a mon	th t	wice a	month	every two	months	I will call/to	ext
If I had a clothing shopping spree, I would go to							
Forever21	H&N	M	Zumiez	Tillys	Other		
If I had a shoe shopping spree, I would go to							
Nike	Adidas	S	Vans	Other			
List 3 gifts	you wo	uld be	excited to	receive fro	om Jacob's	s Heart	
1.							
2.							
3.							
I like to express myself through							
Painting	Drawin	ng	Puzzles	I'm not a fa	an of art	Other	
On a scale of 1 to 5 how interested in Teen Days are you. 5 being very interested.							
1 2	3 4	1 5					
I would be more interested in Teen Days if they were on:							
Monday 7	Tuesday	We	dnesday	Thursday	Friday	Saturday	Sunday
I would be more interested in Teen Days if:							
-							
-							
-							
On a scale of 1 to 5 do you think this assessment will help me get to know you better.							
1 2	3 4	1 5					

On a 1 to 5 scale did you enjoy this assessment.

1 2 3 4 5

Is there anything you wish this assessment would have asked? If yes, explain.

The assessment presented in figure 2 consists of personal questions and well as questions that can measure tangible needs. The first 7 questions, including name and contact information, are general questions created to obtain an idea of how teen completing assessment currently feels as well as likes and dislikes. Questions 8 through 13 are designed to adapt Family Support Specialist visits to the request of the teen. Allowing teens to manage how they want their visits to go, gives them a sense of independence which will ultimately support their post-traumatic growth. Question 14 through 17 are directly related to helping meet the teens tangible needs. These questions were created to get an insight of the type of gifts they would enjoy. The original intake packet has an area to discuss the interests of the teens, but these questions are more precise to ensure broad answers are not given. Question 18, 19, and 20 were included to help teen day participation. Teen Day is a monthly event where teens with cancer or siblings get together and hang out with hopes of developing relationships with those experiencing a similar health situation as them. The last two questions are an opportunity for teens to reflect their thoughts on the assessment itself. Not only does this assessment give teens the ability to create their own ideal visit, teen day or care package, but the use of scales allows the information

obtained to be used for grants. Table 1 presents the project's scope of work and implementation timeline

Table 1. Draft Scope of Work Template

Project description: Create an assessment that will help Jacob's Heart teens achieve tangible needs and post-traumatic growth.

Primary objective of the project: To help teens achieve post-traumatic growth

Activities		Deliverables	Timeline/deadlines
1	Discuss capstone project ideas with mentor	Final capstone project idea approved	October 2019
2	Research the importance of tangible needs	Read and analyze the books "Digging Deep" and "SuperBetter: The Power of Living Gamefully"	October – November 2019
3	Develop assessment	Create tangible needs assessment	December 2019
4	Identify individuals who will be completing assessment	1 2 3	January/February 2020
5	Complete capstone report	Complete capstone report by discussing issues due to COVID-19	March/April 2020
7	Prepare capstone presentation	Instructor approval	May 2020
8	Final Preparation for Capstone Festival	Final Presentation at Capstone Festival	May 2020

Implementation challenges

The expected outcome would have been achieved with the analysis of the information obtained as well as continuous use of the assessment by Jacob's Heart Children's Cancer Support Services. Due to COVID-19, implementation was not possible. On March 16th, Santa Cruz County placed a Shelter-in-Place Order causing the agency to close its doors to volunteers, a crucial part of the agency, and have employees work from home. Home and hospital visits would no longer take place, which was essential to being able to implement the assessment. Although Jacob's Heart became vulnerable due to no volunteers available they continued to provide support to families. From home, Family Support Specialists make weekly check in calls to all families. These calls would normally occure bi-monthly, but due to the situation it is important to support families in every way possible. To ensure the safety and well being of Jacob's Heart Families bi-monthly grocery deliveries turned into weekly deliveries. Grocery bags, Full Hearts, were packages with the help of volunteers, due to COVID-19 groceries would be packaged by staff only. On Thursdays of every week, staff meets at the office, packages food and delivers. The first week of Full Hearts with staff only was very overwhelming to the agency causing them to seek help from interns. On Thursday March 26th, staff and interns completed Full Hearts much sooner than originally expected. With COVID-19, Full Hearts not only has changed its frequency, but the items provided. During Full Hearts deliveries care packages are also delivered, which are usually delivered during home visits. Care packages contain hand sanitizer, diapers, baby wipes, anti-bacterial wipes, water bottles and extra food if needed. Each care package is customized to the needs and requests of the family. In addition to Full Hearts, families who do not usually obtain grocery deliveries are welcomed to request canned goods. Full Hearts

had become the direct support for families to try and help them avoid the need to go to grocery stores. Jacob's Heart ensures the safety of families by wearing gloves, changing them every hour, and use of masks when packaging food. A mask and gloves are also used when delivering bags of groceries. With the need to ensure safety with constant use of gloves and masks, a lack of resources may arise due to difficulty in finding such items, but the agency will continue to supply weekly groceries to families. COVID-19 has caused great difficulty in the completion of the assessment and the overall wellbeing of the agency.

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

Impact of COVID-19 Pandemic on Agency:

As a result of the COVID-19 Pandemic, Jacob's Heart Children's Cancer Support

Services changed how they operated. The agency was closed to volunteers, a crucial part of the success of many programs. Volunteers would no longer be able to help package fresh produce and canned goods for families nor make kids cards which are sent monthly to Jacobs Heart kids and their siblings. Without the help of volunteers, the agency was pushed to creativity. As of the 2nd week of Shelter in Place, take home kid card kits were available for volunteers. These kits are placed outside the agency, to limit entry to the office. During the same week, take home kits were available, the agency's office location was closed to families. If families need assistance with food, diapers, clothing, etc. they are to call the office and request a care package be made

for them. These care packages are delivered or can be picked up by the family outside the office, they are not allowed to enter as a safety precaution. Jacob's Heart continues to provide most services and has increased Full hearts grocery deliveries. An increase in deliveries is possible due to staff and interns. For the safety of families and employees, the agency does not allow home or hospital visits which once again resulted in a push for creativity from the agencies part. Normally, during a child's birthday their Family Support Specialist makes a visit with gifts and a cake. Since this interaction is not possible, recently Jacob's Heart Teen Family Support Specialist, Mariela Medina, conducted a social distancing celebration. Medina and the rest of the Family Support Specialist visited the teen at his home and sang Happy Birthday from outside his window.

Impact of COVID-19 on agency clients:

Although the Jacob's Heart office is closed, families continue to receive most services with additional support. South Monterey County families now receive fresh produce and canned goods bi-monthly instead of the usual once a month. Families in Santa Cruz, San Benito, Monterey, and South Santa Clara County are receiving Full Heart deliveries weekly. These deliveries are possible due to staff and interns. With an increase in Full Heart deliveries, care packages have also increased. Both groceries and care packages are delivered on every Thursday of the week. Families no longer receive home or hospital visits from Family Support Specialists, but constant phone calls and check-in continue. In addition to phone calls from Family Support Specialists, counselors continue to be available for phone or virtual sessions to offer emotional support.

Jacob's Heart received a stipend which allowed an additional \$500 in financial assistance per family. This stipend is crucial since the agency does serve families who are undocumented or of "mixed status" and will not be reciving the federal stimulus check. Children who are in the maintenance phase, also referred to as maintenance chemotherapy, have had appointments cancelled. Maintenance phase is the third phase of chemotherapy and usually lasts from 18 to 24 months (UCSF Health, 2020). Both Lucile Packard Children's Hospital and UCSF Medical are only attending patients who are currently on chemotherapy and are only allowing one parent to be present. Families who have not had appointments cancelled continue to receive gas cards to help with transportation. During the COVID-19 Pandemic there is the possibility of Jacob's Heart kids passing away. If this were to occur, families will receive support with funeral expenses and flowers which is normally done.

Impact of COVID-19 on social problem:

COVID-19 will negatively impact teens and their families emotional instability and lack of self awareness. With the unknown of how long COVID-19 will last anxiety and various emotions will be present in many teens with cancer and their families. Only one parent or guardian is allowed to be with their child during treatment. Although nursing personnel is available, nothing compares to the support of a spouse or family member. It is common for parents to both be present or rotate to ensure someone is with the child at all times. Without the ability to do so extreme exhaustion can occur causing an increase in emotional instability. For parents, having a child who is considered terminal or end-stage emotional instability is expected. If their child were to pass away grief would be extra difficult. Due to COVID-19 funeral services

would only allow 10 individuals tobe present. Support from family, friends, Jacob's Heart Family Support Specialist or Oncology Social Worker would not be physically present.

Restrictions on what someone with cancer can participate in are already high without COVID-19 present. With the pandemic, the need for sanitation has increased. This fear of having or being a child who is part of a compromised population can increase anxiety. Daily walks or outings are no longer an option. Staying home is all that can be done. Without the ability to venture and discover, lack of self awareness can increase.

Impact of COVID-19 on the agency's future:

With the COVID-19 Pandemic many homes will be hit with financial struggles. With this in mind the agency will have to develop a budget for next year ensuring the areas with most need are met. As many non-profits, Jacob's Heart Children's Cancer Support Services relies heavily on grants and community donors. D'La Colmena, Lakeside Organics, Martinelli's, Sumano's Bakery, Second Harvest Food Bank, and many other local companies are crucial in the success of agency programs such as Full Hearts. These companies donate their goods to help our families get the groceries. If COVID-19 were to impact these companies financially it is unknown if the number of donations and contributions would continue.

Holiday Hearts is a program that distributes gifts to families during the holiday season through adopt-a-family and organization funds. Community members adopt-a-family and shop for their gift list. In some instances company employees around the counties served, get together and adopt various families. With the inability to know how many people will be financially impacted, there is the possibility of less families being adopted. If less families are adopted, Jacob's Heart will have to utilize more of their budget to purchase additional gifts for families.

Overall, funding is unknown for the next year(s). There is an unknown of how many current grants will be available next year or if there will be a monetary decrease in grants. There is an unknown on future in-kind donations, community support, and volunteer frequency.

VII. Recommendations

Recommendations for the agency

The tangible needs assessment will help Jacob's Heart better support teens reach post-traumatic growth. The assessment will be added to the intake process completed by Teen Family Support Specialist, Mariela Medina. The assessment will focus on specific tangible needs as well as interest in services to better assist teens. Obtaining specific information on interest versus the current generic information provided, will allow the agency to cater more independently to each teen on their route to reaching post-traumatic growth. Unfortunately, due to COVID-19 the assessment was not implemented. It is my recommendation that Jacob's Heart begins implementing the assessment. When completing the assessment, it is recommended to encourage teens to be as specific in their answer as possible.

Broader social significance

By providing a tangible needs assessment for teens with cancer and their siblings that focuses on their individual preferences, teens and their siblings will be able to develop self awareness which will ultimately lead to post-traumatic growth. With traumatic life situations such as fighting cancer, whether directly or indirectly, emotions vary day by day. As teens, it is

already difficult to understand one's own character, feelings, motives, and desires; fighting cancer makes it much more difficult. Jacob's Heart Children's Cancer Support Services utilized Maslow's Hierarchy of Needs to determine the importance of their programs and ensure their mission statement is being met. With the tangible needs assessment, the agency will be able to help meet three of the needs; love & belonging, esteem, and self-actualization. Self-actualization is the growth need also referred to as self-fulfillment need, which is crucial for the accomplishment of post-traumatic growth.

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