

Project Purpose/ Overview

The diagnosis of a life-threatening or chronic illness has the potential to affect siblings physically, emotionally, and relationally. These stressors are particularly due to disruptions in family functioning. Research demonstrates that camp experiences have led to both short- and long-term positive outcomes for this population. As a result, there is an emerging focus on how camp impacts siblings rather than focusing primarily on those living with chronic illness.

This project was conducted in collaboration with The Hole in the Wall Gang Camp, located in Ashford, CT to examine how their Hero's Journey program impacts participants' sense of self. The camp is dedicated to providing "a different kind of healing" to children and families who have been affected by chronic or life-threatening illnesses.

Literature Review

Why siblings?

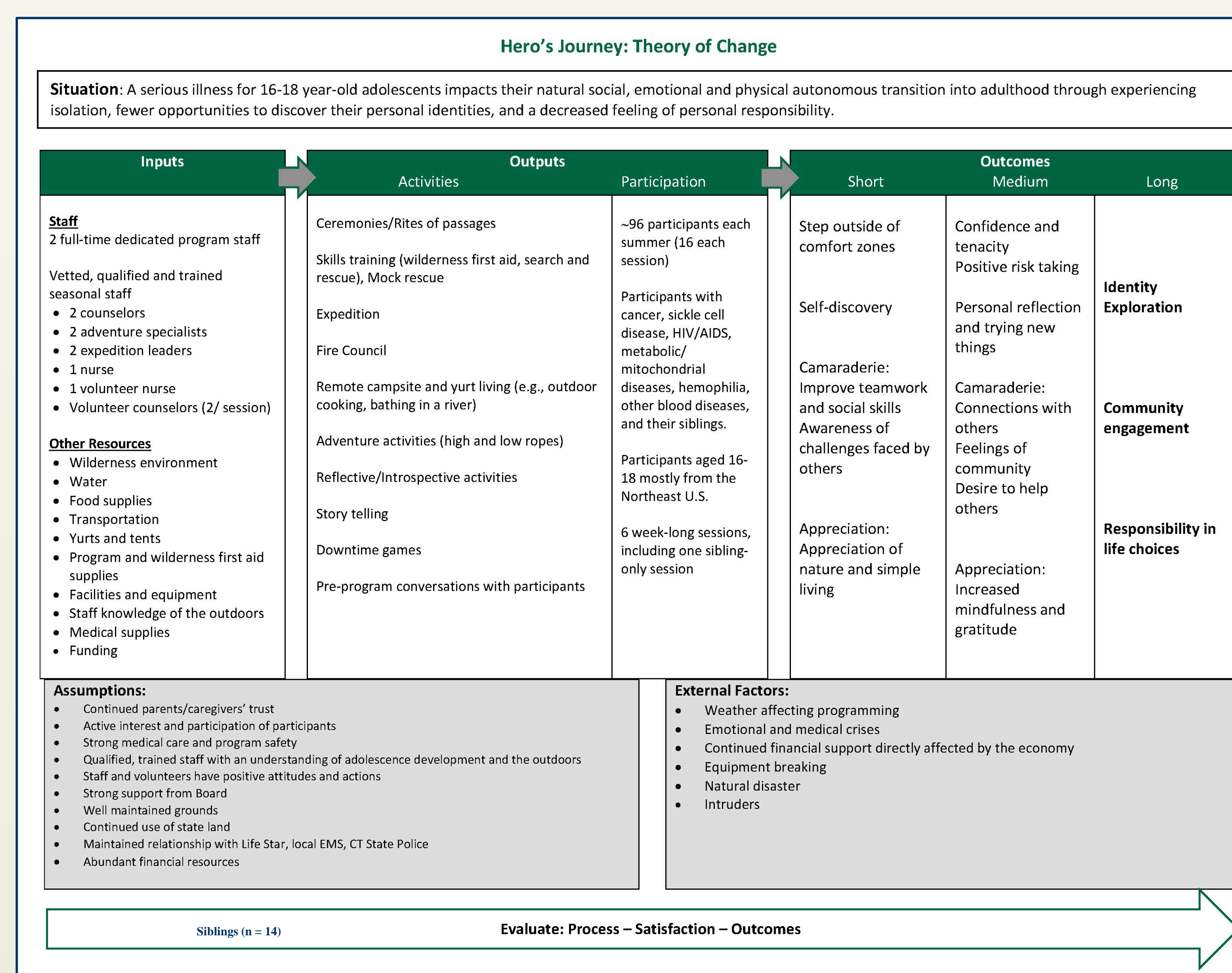
- Illness becomes a central, defining factor of family life. Siblings often grieve by themselves and ultimately assume caregiving roles to compensate for the change in the family dynamic (Chesler & Barbarin, 1987; Karampela, Hatira, & Damigos, 2010)
- Primary issues of the sibling experience include: observing their ill sibling undergo emotional and physical suffering; feelings of guilt and jealousy; lack of parental attention, isolation or decreased opportunity to engage in everyday activities (e.g., leisure and peer relationships); a perceived commitment to "take care of" other family members; and a lack of information about the nature of the disease (Barlow & Ellard, 2006; Karampela et al., 2010)
- Siblings of those with pediatric chronic illness have proven to be at increased risk more often than presenting no risk or positive outcomes (Williams et al., 2009)
- Disease severity has been associated with an increased risk of sibling maladjustment (Barlow & Ellard, 2006)
- There is a need for consistent, therapeutic social support to help siblings cope with the diagnosis and adapt to the change in one's family dynamic (O'Brien, Duffy, & Nicholl, 2008)

Why camp?

- Self-reported health-related quality of life (HRQOL) increased significantly in emotional, social, school, and psychosocial domains after attending camp (Packman et al., 2008)
- Camp allows participants to acknowledge their feelings as "normal" and gain a source of support that they did not have before (Creed, Ruffin, & Ward, 2001); improve one's social confidence and knowledge of an illness (Hancock, 2011); and perceive themselves in a more positive light (Murray, 2001)

Method

- **Staff survey.** November 2015: Two open-ended questions were administered to all Hole in the Wall Gang Camp staff members and Hospital Outreach Program managers.
 - (1) In your opinion, what is the purpose of siblings' attendance at The Hole in the Wall Gang Camp?
 - (2) What benefits do you think siblings receive from attending camp?
 Names were not recorded to ensure confidentiality. Seventeen individuals completed the survey. Results informed the camper survey.
- **Camper survey.** Summer 2016: Three open-ended questions were included in a survey administered to the campers on the last full day of the Hero's Journey program.
 - (1) What is the most important thing you have realized about yourself over the course of the Hero's Journey program this week?
 - (2) How (if at all) might the Hero's Journey experience influence the ways you interact your family when you get back home?
 - (3) How (if at all) might the Hero's Journey experience influence the ways you think about or deal with your sibling's medical issues? → Available to those in the sixth session (i.e., siblings)
 All identifying factors of the program participants (e.g., name, session number) were removed prior to obtaining the data to ensure confidentiality.
- **Data analysis.** Analysis was guided by Auerbach and Silverstein's (2003) grounded theory approach. Questions served as a primary organizing theme (Tesch, 1990). While reading camper responses, themes were identified, established as categories, named and defined. Each individual response was coded as present (1), absent (0), or missing (.)



Theme	Q1: Self-Reflection	Q2: Family Impact	Total	Percentage (%)
Self-Confidence	34	5	39	61
Communication	9	28	37	58
Mindfulness	31	N/A	31	48
Sentimentality	6	11	17	27
Positive Attitude/Expression	N/A	17	17	27
Helping	N/A	12	12	19
Leadership	5	3	8	13
Resilience	5	1	6	9

Theme	Q1: Self-Reflection	Q2: Family Impact	Q3: Influence on Medical Coping	Total	Percentage (%)
Mindfulness	7	N/A	3	10	71
Communication	1	4	3	8	57
Positive Attitude/Expression	N/A	4	2	6	43
Self-Confidence	4	1	N/A	5	36
Helping	N/A	2	3	5	36
Sentimentality	2	2	N/A	4	29
Resilience	1	0	N/A	1	7
Leadership	0	0	N/A	0	0

Themes

- **Mindfulness:** Drawing attention to both internal (e.g., thoughts, feelings) and external experiences
 - "Over the course of this week I have learned so much about myself and I've learned that I am more capable of doing things I never thought I could do."
- **Sentimentality:** Holding something/someone close to oneself; feelings of tenderness
 - "Hero's Journey will definitely impact the way I interact with my family at home because I have learned to be more thankful for the family and friends that I have. I have learned to be more grateful for the things my parents especially my mom does for me."
- **Communication:** Interactions between two or more individuals
 - "Instead of hiding my emotions and not talking about my feelings, I feel like I'm going to start sharing how I feel with my family in order to make a positive change."
- **Self-confidence:** Assurance in oneself
 - "I am not afraid to spread my wings and show people who I am."
- **Resilience:** The ability to overcome problems or adversity
 - "...that I can persist through problems and persevere despite my weaknesses."
- **Leadership:** The ability to guide others and serve as a role model
 - "I learned that I can be a leader in very stressful and tough situations. I never knew I could lead in such a good way, it was powerful to learn that about myself."
- **Helping:** Offering services to another person
 - "I will try to help more with his [my brother's] struggles."
- **Positive attitude/expression:** In regards to one's own attitude and how one acts towards others
 - "I hope to be more considerate and kind to the people around me and turn to kindness and love instead of hate and disdain."

Discussion

- Overall positive response to Hero's Journey Program based on themes that emerged
- Minimal differences between siblings and participants living with illness – i.e., exhibited similar trends in responses
- Findings are comparable to previous sibling and camp research; indicate that camp fulfills its purpose throughout the week-long experience
- Longer term impact should be examined in future research; a longitudinal study should be pursued to determine whether participants take the "lessons" they've learned home with them and the exact impact it makes over time

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