

Candlelighters Pediatric Cancer Parent Peer Support Group



Background/Introduction

A Community of Hope for Families with Childhood Cancer

There is an unmet need of social-emotional support for parents and caregivers of children facing pediatric cancer throughout Oregon and SW Washington. We hear frequently from hospital care teams that parents/caregivers with newly diagnosed children are desperate for connection and ask help to meet other parents who have experienced a similar diagnosis. Due to HIPAA regulations, the hospital care teams struggle with this request and are not able to facilitate direct parent-to-parent connection.

Candlelighters for Children with Cancer seeks to pilot a parent peer support program to help meet the need for social-emotional support of parents whose child has recently been diagnosed with cancer.

Currently, 15-20% of the families we serve identify as Latinx. This project will include Latinx mentors to match with Latinx mentees to address language and cultural barriers Latinx families experience throughout a pediatric cancer journey. Additionally, nearly 60% of the families served report making less than \$100,000 in combined annual income, and our partner hospitals report that approximately 50% of families in the target population qualify for Medicaid. We seek to provide inclusivity and accessibility to all families we serve.

Goals and Objectives

Goal:

Assess effectiveness and feasibility of a 1:1 matched parent mentoring program. Match at least 10 mentees to 20 mentors by the end of the grant period.

Objectives:

- 1) At least 10 mentors are recruited and paired with 1-2 mentees each.
- 2) A minimum of 20 mentees will be matched with a peer mentor throughout the duration of the pilot peer support program.
- 3) Mentees will be contacted at least once every 2 weeks during the duration of the mentorship relationship by the end of the grant period.
- 4) A minimum of 75% will report positive impact from the program by the end of the grant period.

Key Partners







Methods/Project Design

Target Population

Parents and caregivers of children with cancer. Children with Cancer Mentors Provider care teams Candlelighters staff and board

Project Design with Activities/Efforts/Initiatives

1. Recruitment of mentors and mentees

- 1. Mentor/Mentee application development.
- 2. Development of printed marketing materials for hospital distribution.
- Partner with hospital psycho-social team to recruit mentors and mentees.

2. Screening

- 1. Application review.
- 2. Interview.

3. Training

- Mentor is provided with a workbook to complete prior to orientation.
- Mentor attends mentor training session to learn program logistics and mentor guidelines.

4. Matching and Initiating

- Mentee completes form detailing preference in mentor (ex. child's diagnosis, treatment plan, age, gender, etc.).
- Program Manager matches mentee to mentor.
- Program Manager meets with mentor and mentee over zoom for introductory call.

5. Monitoring and Support

- 1. Mentor checks in every 2 weeks and documents encounters.
- Program Manager checks in with mentor once a month.

6. Closure

- Program Manager completes end of program closing procedures.
- Distribution of end of pilot program surveys to mentees.
- Program Manager distributes qualitative surveys to mentors, hospital psychosocial team, and program staff.

Project and Evaluation Timeline for: Parent Peer Support Pilot Program

	Month											
Project and Evaluation Activities	1	2	3	4	5	6	7	8	9	10	11	12
Finalize pilot program structure	X	X										
Develop training		Х	Х									
Develop/adapt survey tool		X	X	X								\Box
Conduct educational meetings with hospital social workers in preparation of pilot program launch.			Х	X	X							
Social workers conduct outreach to parent/caregivers				X	X	X						
Screening/Matching/Initiation of Matching process begins				X	X	X	X					
Mentees are matched to mentors and engage in mentoring relationship				X	X	X	X	X	X	X		
Complete closing process with matches completing 6-month relationship									X	X		
Distribute surveys to matches completing 6-month relationship									X	X		
Analysis of surveys and results										X	X	X
Report Summary											X	X

Evaluation Plan

Assessing Effectiveness

Likert scale surveys to mentees in English and in Spanish, modeled after St. Jude's study or a pilot parent mentorship program (Berry-Carter et al., 2021):

Parent	mentor	program	survey	(n =	38
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On a scale of 1–5, please indicate your level of agreement with the following statement	1	2	3	4	5	
	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree	
My mentor helped me through difficult times	8%	5%	13%	32%	42%	
I could trust my mentor to share appropriate information about my child/family with authorized staff	5%	10%	13%	26%	46%	
My mentor offered me additional support options when I needed them	16%	5%	18%	24%	37%	
My mentoring relationship met my expectations	8%	8%	11%	39%	34%	
I felt better able to handle my St. Jude journey because of the mentoring relationship	11%	3%	24%	21%	42%	
Having a mentor helped me to feel less isolated	13%	3%	12%	13%	50%	
Having a mentor helped me feel less anxious	13%	3%	24%	24%	37%	
My mentor responded to my questions/needs in a timely manner	3%	3%	18%	24%	53%	
Having a mentor who had been through a similar experience helped me feel understood	8%	8%	18%	13%	53%	
My mentor was sensitive to my needs and feelings	5%	5%	11%	24%	55%	
I had things in common with my mentor other than having a child with cancer	8%	8%	32%	21%	32%	
I would recommend the mentor program to other St. Jude parents	3%	0%	18%	21%	58%	

Note. The image was created from the Journal of Pediatric Nursing Publication. From "Development of a structured peer mentoring program for support of parents and caregivers of children with cancer" by Berry-Carter, K., Barnett, B., Canavera, K., Baker, J. N., & Mandrell, B. N., Journal of Pediatric Nursing, 59, 131-136

Assessing Feasibility

- Qualitative questionnaires/interviews to mentors, hospital psychosocial team, and program staff.
- Analysis of quantitative data including:
 - Outreach and interest compared to mentors recruited.
 - Encounters initiated by mentors compared to mentee responses.
 - Surveys distributed compared to response rate.
- Cost/benefit analysis.

Acknowledgements

- Funding for this project was provided in part by the OHSU Knight Cancer Institute Community Partnership Program, a grant program that supports communities across Oregon in addressing local cancer-related needs.
- The healthcare staff at Randall Children's Hospital and at Doernbecher Children's Hospital provided input on this project and is helping recruit mentors and mentees for this pilot program.

References

Berry-Carter, K., Barnett, B., Canavera, K., Baker, J. N., & Mandrell, B. N. (2021). Development of a structured peer mentoring program for support of parents and caregivers of children with cancer. *Journal of Pediatric Nursing*, 59, 131-136.