

Real-world holistic care for adult cancer survivors and their families: improved family dynamics and positive outlook

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Abstract

For Pete's Sake is a non-profit organization that provides adult cancer survivors and their families with complimentary holistic support. Families receive a 4–7-day respite experience. Post-respite, family members receive ongoing support (monthly newsletters, private Facebook groups, monthly gatherings, annual events). Anecdotally, families report feeling happier, closer, and recharged for battling cancer, so the purpose of this study was to assess these outcomes. This was a single group, pre-test/post-test study. Oncology professionals nominated 24–55-year-olds with physician-diagnosed cancer (any stage/site) clinically able to partake in a respite experience. Families selected destinations (e.g., Florida, Caribbean, Jersey Shore) and received materials to encourage communication and an emotionally/spiritually meaningful experience. Of the 464 families completing respites in 2014–2019, 190 families (41%) provided pre- and post-respite data, and 104 families (55%) completed the 6-month follow-up. Pre-, immediately post-, and 6-months post-respite, cancer survivors, caregivers, and children completed surveys assessing family hardiness, spousal or parent–child communication, cancer coping efficacy, and joviality. Cancer survivors experienced post-respite increases in family hardiness, caregiver and child communication, joviality, and coping efficacy. Caregivers experienced post-respite increases in survivor communication, joviality, and coping efficacy but not family hardiness. Children experienced post-respite increases in joviality, but not family hardiness or communication. At the 6-month follow-up, survivor family hardiness returned to pre-respite levels and child communication decreased, but all other outcomes were higher than pre-respite levels. All caregiver outcomes were higher than pre-respite levels; child outcomes returned to pre-respite levels. These results suggest that investing resources in families may help improve relationships and facilitate efforts to stay engaged in the cancer battle.

Keywords: *cancer, community-based care, coping, family-based care, integrative care, respite*

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1. Introduction

Cancer takes a toll on families. In the wake of a cancer diagnosis, the treatment regimen, and trying to adjust to the “new normal,” family members can be left physically, mentally, emotionally [1], and financially drained [2]. They can experience a spiritual crisis [3]. Further, family relationships are often strained, which can both impact personal mental health [4] and thwart the family's team mentality to continue the quest [5]. We align with the American Cancer Society to define a cancer survivor as anyone who has ever been diagnosed with cancer no matter where they are in the course of their disease. Interventions are emerging to help adult cancer survivors and their family members improve communication, mutual support, and confidence in coping efforts [6, 7]. Although these interventions have been helpful, respite-based family

time may provide a unique opportunity to strengthen bonds, facilitate important discussions, and bring laughter and a much-needed break from cancer. For Pete's Sake is a community-based non-profit organization that provides adult cancer survivors and their families with a complimentary 4–7-day intentional respite experience. In addition to time together engaging in fun/relaxing activities, families receive journals, games, and materials to encourage family communication and an emotionally and spiritually meaningful experience. Further, we also provide support after the respite experience to reinforce and expand holistic supportive care. Anecdotally, families report feeling happier, closer, and recharged for battling cancer. Therefore, the purpose of the current study was to evaluate program effectiveness in these areas.

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1.1. Adult cancer survivors

The words “you have cancer” can make a person’s world stand still. The stress of facing a life-threatening illness can be overwhelming. Treatment regimens become the priority for a cancer survivor’s time, energy, and finances [1]. As a result, they are less likely to be able to fulfill their usual roles both at work and within the family [8]. Spousal communication [4] and parent–child communication [9] can suffer, and cancer survivors can begin to lack confidence in their abilities to cope [10]. Adults with a current cancer diagnosis are less likely to have positive mental health compared to adults who never had cancer or previously had cancer [11]. Further, the longer someone is engaged in the cancer battle, the lower the level of their joviality/joy [12].

Although great potential exists to discourage cancer survivors in their journey, there are factors that empower and encourage them. Family hardiness refers to the internal strengths and durability of the family unit as they come together as a team to tackle challenges [13]. Higher levels of family hardiness have been associated with increased coping efficacy [14] and quality of life [15], as well as decreased fear of recurrence among cancer survivors [16]. Further, higher levels of healthy spousal communication are linked with increased coping efficacy [17].

1.2. Family caregivers

Caregivers, while facing the shock of their loved one’s cancer diagnosis, instantly need to become knowledgeable in home-based care and often need to fulfill duties their loved one is not able to do [18]. As such, caregivers’ needs often go unmet [19]. Higher levels of caregivers’ unmet needs prospectively predict lower caregiver quality of life [20] and decreased levels of caregiver happiness [21]. Interestingly, cancer survivors tend to fair better mentally than their caregivers. Mellon and colleagues [22] found that cancer survivors report significantly higher quality of life, less fear of recurrence, and more support compared to their family caregivers.

Yet open communication and family hardiness/resilience also help ease the burden of cancer on caregivers. The more open the level of communication with the cancer survivor, the better the mental quality of life for caregivers [23]. Higher levels of family resilience are associated with lower levels of caregiver burden [24]

1.3. Children

When a parent has cancer, the child loses structure and security as routines and family roles change [8]. Further, children can become distressed by the cancer’s severity and the possibility of losing their parent [9]. Amid this difficulty, open communication is beneficial to children’s mental health and adjustment [8]. Having a regular opportunity to ask questions and talk through emotions is especially helpful, as is creating new routines and maintaining connectedness and a team mentality [8].

1.4. Family resilience model

Each member of the family unit is impacted when one member is diagnosed with cancer. Therefore, logic follows that the model of care should focus on the family unit [16]. As a result of their systematic review, Qui and colleagues [16] proposed the application of Walsh and colleagues’ [25] Family Resilience Model

for family cancer care. Family resilience refers to the capacity of the family system to withstand and rebound from adversity, both strengthened and more resourceful [16, 25]. Components of the Family Resilience Model consist of communication/problem-solving processes (clarity, open emotional sharing, and collaborative problem-solving), organizational processes (flexibility, connectedness, and mobilizing social and economic resources), and shared belief systems (meaning-making, positive outlook, and transcendence/spirituality) [25].

1.5. Past family-based research on adult cancer

In reviewing the literature, we identified eleven empirical studies that have examined supportive care interventions designed to boost one or more of the components of the Family Resilience Model in families with an adult who has cancer [6, 7, 26–34]. Most focused on the cancer survivor–caregiver dyad [6, 7, 29, 31–34] or the cancer survivor–child dyad [30], with only two interventions including the whole family [27, 28]. Regarding the Family Resilience Model, all studies involved educating cancer survivors and family members on techniques to boost communication/problem-solving processes and organizational processes, whereas only three interventions targeted boosting shared belief systems [6, 7, 27]. These aspects were only a small component of these interventions, and none included meaning-making, positive outlook, and transcendence/spirituality. One study included activities to allow parents to practice learned skills with their children [30], whereas the other interventions did not include such practical application opportunities. One study included a booster session [31], whereas the other studies did not. All studies yielded improvements in mental health (e.g., decreased hopelessness, depression, anxiety, improved quality of life, etc.) or relationship satisfaction. Intervention-associated increases were also found in family hardiness/closeness and trust [27, 32, 33], communication [27, 29, 34], and coping [6, 29]. Although promising, there is room for improving family-based interventions for adult cancer by (1) including the cancer survivor, caregiver, and children, (2) including a more comprehensive representation of the Family Resilience Model, (3) including hands-on activities to reinforce healthy behaviors, and 4) including follow-up activities that continue to provide support and education.

1.6. For Pete’s Sake family respite

For Pete’s Sake is a non-profit organization providing supportive care to adult cancer survivors, their caregivers, and their children. We have adopted our model of care from Walsh and colleagues’ Family Resilience Model [25], which aligns well with a holistic framework that focuses on family, mental, emotional, physical, spiritual, and financial health. Nominated families receive a 4–7-day all-expense-paid respite experience which provides a unique opportunity to strengthen bonds, facilitate important discussions, and bring laughter and a much-needed break from cancer. See **Table 1** for a breakdown of hands-on activities and how they represent holistic care, and see **Table 2** for alignment with Walsh’s Family Resilience Model.

In addition to time together engaging in fun/relaxing activities, families receive journals, games, and materials to encourage family communication, strengthen connectedness and coping, and ensure an emotionally and spiritually meaningful experience. Further, we offer programming after the respite experience to reinforce and ex-

Table 1 • Holistic family respite care plan.

Family Health
Improve Communication, Promote Connectedness, and Boost Team Mentality
Family Time Capsule—instructions for creating a memento that includes a family picture, keepsake, and writing prompts for inspirational quotes, memorable moments, and reflections on the importance of family
Family Keystone—A family activity to create a family mission statement. Each member shares family habits and feelings/mindsets they want to cultivate to stay connected, prioritize what is important in life, and support one another. This is created into a beautiful, professionally printed keepsake.
Journal—prompts for personal reflection on feelings to encourage communication, gratitude, strength, connection, and meaning-making.
Mental Health
Laughter—age-tailored games (e.g., Old Maid, Phase-10, Apples to Apples, playing cards, puzzles), bubbles, tickets for shared experiences, Fun/Dance Spotify playlist (https://open.spotify.com/playlist/7xZwppOegp4w3rD1cbO1iR?si=WEDydbNrSS6cOoyW-O-1A&nd=1&dlsi=8f533953c8504814 , accessed on 2025 Jan 23), etc.
Unplug/Relax—bath bombs/salts, massage oil plus instructional pamphlet, essential oils with diffuser, head-scratcher, rice heat/cool pads, candles, meditation instructions, lavender lotion, fuzzy socks, Relaxation Vibes Spotify playlist (https://open.spotify.com/playlist/5t7ulBZqACFWAoguc43Ioz?si=Mt-XFvoPRTub3Fx85etlkw&nd=1&dlsi=e25f4329c89e4394 , accessed on 2025 Jan 23), etc.
Creative Expression—child/teen/adult coloring books, Play-Doh, Strength Bands (see below), etc.
Coping Inspiration
Strength Bands—A bracelet made by a previous respite traveler or a community volunteer that includes a note to remind them when they wear it to be intentional to find peace and joy and live life to the fullest. Each traveler also has the opportunity to make one for a future respite traveler.
Care Gram—A personal note written by a previous respite traveler that includes inspiration, hope, and encouragement. There are instructions and supplies so travelers can also write a note for a future traveler.
Centering Rock—on the included rock, travelers are encouraged to write a positive word (peace, love, breathe, hope) and find inspiration by holding onto the rock during uncertain times.
Emotional Health
Encourage open emotional sharing through Family Keystone, Family Time Capsule, and journal prompts.
Practice gratitude through journal prompts.
Physical Health
Encourage activity such as family walks and outdoor activities (boating, theme parks, rollerblading, etc.).
Spiritual Health
Meaning-Making—discovering the lessons that cancer has taught family members through activities such as the Family Time Capsule, Family Keystone, and journal prompts.
Embrace Faith and Hope
Angel Pin—a beautiful pin to be worn or displayed as a reminder that there is always hope for tomorrow.
Books—short stories that offer meaningful readings of hope, joy, and support. <i>Kitchen Table Wisdom: Stories That Heal</i> by Rachel Naomi Remen (for anyone regardless of faith tradition), or <i>Laughing Matters: Learning to Laugh When Life Stinks</i> by Phil Callaway (includes a Christian faith-based perspective).
Financial Health
All expenses paid, including tickets to adventures/experiences; USD 200 check to alleviate some financial stress and/or provide families with a special experience; small indulgences such as ChapStick/lip gloss, herbal tea, temporary tattoos, and mugs.

Table 2 • Breakdown of alignment with Walsh’s Family Resilience Model.

Activity	Communication/problem solving			Organizational processes			Shared belief systems		
	Clarity	Open sharing	Collaborative problem solving	Flexibility	Connect- edness	Mobilizing resources	Meaning- making	Positive out- look	Spirit- uality
Family Time Capsule	X	X	X		X		X	X	
Family Keystone	X	X	X						
Journal	X	X		X			X	X	X
Age- Tailored Games					X				
Fun/Dance Spotify Playlist					X				
Unplug Pamper Kit					X				X
Creative Expression							X	X	X
Strength Band				X		X	X	X	X
Care Gram						X	X	X	X
Centering Rock				X			X	X	X
Family Fun Activities					X				
Angel Pin								X	X
Inspirational Books				X			X	X	X

pand holistic supportive care with monthly newsletters, private Facebook groups, monthly gatherings, and annual events. There are several community-based programs that offer psycho-social support for cancer survivors and their family members. For Pete’s Sake is the only community-based program in the US that focuses on adult cancer survivors and their families. Anecdotally, families report strengthened family team mentality and communication and feeling happier and recharged for battling cancer. Therefore, the purpose of the current study was to evaluate program effectiveness in these Family Resilience Model-related areas. We made the following hypotheses:

Cancer survivors will experience pre- to post-respite increases and 6-month post-respite increases in the following:

- Family hardiness/co-oriented commitment;
- Caregiver communication;
- Communication with their children;
- Perceived efficacy in coping with having cancer;
- Joviality.

Caregivers will experience pre- to post-respite and 6-month post-respite in the following:

- Increased family hardiness/co-oriented commitment;
- Increased communication with their loved one with cancer;
- Increased perceived efficacy in coping with their loved one’s cancer;
- Increased joviality;
- Decreased difficulty working due to personal physical or emotional issues;
- A decreased number of full-time workdays lost due to providing care.

Children will experience pre- to post-respite increases in the following:

- Family hardiness/co-oriented commitment;
- Communication with their father;
- Communication with their mother;
- Joviality.

2. Materials and methods

This was a single-arm, pre-test/post-test study to evaluate respite program outcomes: family hardiness, communication, coping efficacy, and joviality. The study was conducted according to the guidelines of the Declaration of Helsinki and approved by the For Pete's Sake Ethics Committee (protocol code: 012013; approved on 2013 Aug 27).

2.1. Procedures and participants

To be eligible to receive a family respite experience from For Pete's Sake, individuals had to (a) have a physician diagnosis of cancer (any site/stage), (b) be aged 24–55, (c) be nominated by a healthcare professional member of the survivor's oncology team, and (d) have an oncology team member who believes that they have the physical well-being to be able to tolerate a 3–7-day respite experience and related travel. Due to the funding structure, preference was given to cancer survivors who reside in Pennsylvania, New Jersey, New York, Delaware, or Maryland. To date, we have had the funding to accept 100% of the cancer survivors who were nominated for a respite experience. A small number of nominees declined the respite at their discretion. Cancer survivors who accepted the respite identified their caregiver and any children to join them (note that children were required to be at least 8 years old to participate in the surveys). Between fall 2013 and spring 2020, 464 families participated in a respite experience and were mailed an invitation, consent/assent forms, and pre-respite questionnaires (survivor, caregiver, and child versions) to return in the pre-paid postage envelope.

2.2. Details of respite and follow-up support

Each family received an all-expense-paid 4–7-day respite experience, including spending money for incidentals/spontaneous fun. The For Pete's Sake team collaborated with families to select a destination (e.g., Florida, Caribbean, Jersey Shore) and activities to ensure a meaningful experience. Trained nursing professionals interviewed the cancer survivor to determine which supplemental resources would enrich the family in their cancer journey. Each family member received tailored supplemental resources in a "Take a Break Bag." The supplemental resources are described in **Table 2** (note that not all resources were included for all families, only those approved by the cancer survivor). To continue to educate, inspire, and connect families post-respite, we send monthly e-newsletters, offer support via private survivor and caregiver Facebook groups, and host monthly and annual events.

2.3. Measures

Demographic characteristics. Cancer survivors and caregivers reported their age, gender, marital status, race, education, employment, and number of children. Children provided their age, gender, and race. Cancer survivors provided cancer site and stage, and time since diagnosis.

The Family Hardiness Index (FHI) Co-Oriented Commitment Subscale [13] assessed family internal strengths, commitment to work together, and ability to count on each other. Respondents indicated the extent to which (0 = False, 3 = Totally True) eight statements described their current family situation. The summed items created a score (range 0–24), with higher scores

indicating more co-oriented family commitment (*Cronbach's α* : 0.82–0.91).

Survivor–Caregiver Communication. The ENRICH communication subscale [35] has ten items that assess comfort in sharing and receiving emotional and cognitive information (1 = Strongly Disagree, 5 = Strongly Agree). Negative items were reversed before summing (range 10–50). Higher scores indicate better communication (*Cronbach's α* : 0.85–0.89).

Parent–Adolescent Communication [36] has two subscales: Open Family Communication (10 items) and Problems in Family Communication (10 items). Parents used "my child" as the reference and children completed once for "my mother" and once for "my father" (1 = Strongly Disagree, 5 = Strongly Agree). The problem items were reversed before summing with the open items (range 20–100). Higher scores reflect better communication (*Cronbach's α* : 0.86–0.91).

The Cancer Coping Efficacy Scale was adapted from previous work [37] to reflect the extent to which individuals perceive they have adequate resources to cope with cancer. There are three positive items: "I feel empowered to handle the demands of my/my loved one's cancer," "I can cope with (my loved one) having cancer," and "I have the strength to overcome my/my loved one's cancer," and two negative items, "I am completely overwhelmed by my/my loved one's cancer," and "When I think about my/my loved one's cancer, I feel hopeless." (1 = Strongly Disagree, 5 = Strongly Agree). The negative items were reversed before averaging all items (*Cronbach's α* : 0.78–0.84).

PANAS-X Joviality [38]. The PANAS-X joviality subscale assesses the degree of positive emotional state (being happy, cheerful and festive). Respondents indicated the extent (0 = Not at all, 5 = Extremely) to which they have felt eight items over the past week, and the items were summed (range 0–32) (*Cronbach's α* : 0.92–0.97). Higher scores reflect more joviality.

Impact on Caregiver's Work. Caregivers reported the impact caregiving had on their ability to do their jobs over the past two weeks: 1) "How much of the time did your physical health or emotional problems make it difficult for you to handle the workload?" (1 = None of the Time, 5 = All of the Time); and 2) "How many full workdays did you miss to take care of the health or medical care of a family member?" (0–11+). Each item was reported individually.

We used MANOVA to compare pre- to post-respite scores except for family hardiness (non-normal distributions necessitated Wilcoxon Signed-Rank test). Before beginning the analyses, we assessed for group differences in the cancer survivor pre-respite variables based on cancer site and stage and correlation with years since diagnosis, but there were no significant findings (all *p-values* > 0.05), so we did not use these as covariates. SPSS version 27 was used and an alpha of 0.05 was used as the standard for statistical significance.

3. Results

Of the 464 families participating in the respite experience, 324 (70%) families provided written informed consent/assent and completed the pre-respite survey (survivor *N* = 324, caregiver *N* = 324, children *N* = 288). Upon their return home, participants were mailed a post-respite survey to complete and return via a pre-paid postage envelope. This immediate post-respite survey was

returned within 0–14 days of the family respite. A total of 190 (59%) of the 324 families completed the post-respite survey (survivor N = 190, caregiver N = 177, children N = 130), and 104 families completed the 6-month follow-up (survivor N = 104, caregiver N = 99, children N = 63). The average cost of a family respite was USD 3000.

Cancer survivor, caregiver, and child demographic and background information is summarized in **Table 3**. The majority of cancer sur-

vivors were White, married, college-educated females who were around 42 years old, had two children, had stage III or higher cancer, and were not working. The majority of caregivers were White, married, college-educated males who were around 44 years old, had two children, worked full time, and were the spouse of the person with cancer. The majority of the children were White and around 13 years old, with an even mix of boys and girls.

Table 3 • Demographic and background information.

Variable	Cancer survivor (N = 190)	Caregiver (N = 177)	Children (N = 130)
Mean Age (SD)	42.2 (7.8)	44.0 (11.2)	13.2 (3.5)
Gender			
Female	70%	35%	50%
Male	30%	65%	50%
Racial Background			
White	86%	83%	80%
Black	10%	7%	8%
Latinx	3%	3%	6%
Other	2%	6%	6%
Marital Status			
Married	80%	81%	
Single	14%	9%	
Divorced/Separated/Widowed	6%	9%	
Highest Education			
High School	20%	31%	
Associates	33%	18%	
Bachelors	27%	34%	
Masters/Doctorate	19%	15%	
Employment Status			
Not Working	58%	13%	
Part-Time	10%	21%	
Full-Time	32%	66%	
Mean Number of Children (SD)	1.8 (1.2)	1.9 (1.2)	
Caregiver			
Spouse	86%		
Parent	7%		
Child	3%		
Friend/Sibling	4%		
Cancer Site			
Breast	40%		
Gastro-Intestinal	21%		
Reproductive System	11%		
Other (Renal, Lymphatic System, etc.)	21%		
Cancer Stage			
I	6%		
II	17%		
III	24%		
IV	40%		
N/A	13%		
Mean Years Since Diagnosis (SD)	1.80 (2.09)		

3.1. Pre- to immediately post-respite

As shown in **Table 4**, cancer survivors experienced pre- to post-respite increases in family hardiness, communication with their caregiver and children, joviality, and coping efficacy. Caregivers experienced pre- to post-respite increases in survivor communication, joviality, and coping efficacy, a decrease in work-related issues, and no change in family hardiness. Children experienced pre- to post-respite increases in joviality, but not family hardiness, or mother or father communication.

3.2. Pre- to 6-months post-respite

As shown in **Table 5**, 6-month survivor family hardiness returned to pre-respite levels and child communication decreased, but caregiver communication, cancer coping efficacy, and joviality were higher than pre-respite levels. Caregivers experienced pre- to 6-month post-respite increases in family hardiness, survivor communication, coping efficacy, and joviality, and a decrease in difficulty handling their workload. Children experienced no change from pre- to 6-month post-respite levels in any outcomes.

4. Discussion

Ours is the first community-based family respite program to report on program efficacy in meeting objectives, although the findings should be approached with caution due to the study being a single-arm pre–post comparison. Cancer survivors experienced respite-associated improvements in family hardiness, communication with their caregiver and children, joviality, and coping efficacy. After 6 months, survivor family hardiness returned to pre-respite levels and child communication decreased, but caregiver communication, cancer coping efficacy, and joviality were higher than pre-respite levels. Caregivers experienced respite-associated increases in survivor communication, joviality, and coping efficacy, perceived decreased impacts on work, and maintained the same level of family hardiness. After 6 months, caregivers experienced increases in family hardiness, survivor communication, coping efficacy, and joviality, and a decrease in difficulty handling their workload. Children experienced higher joviality from before to after the respite and maintained the same levels of family hardiness and parental communication with both parents. After 6 months, all child outcomes returned to pre-respite levels. The results suggest

Table 4 • Pre- to immediately post-respite comparisons of cancer survivor, caregiver, and child outcomes.

Variable	Pre-respite mean (SD)	Immediate post-respite mean (SD)	Possible range of scores	Statistics
SURVIVOR Family Hardiness Index Co-Oriented Commitment	21.00 (4.00)	22.00 (4.00)	0–24	$Z = 2.80^*$
CAREGIVER Family Hardiness Index Co-Oriented Commitment	21.00 (5.00)	21.00 (4.75)	0–24	$Z = -1.09$
CHILD Family Hardiness Index Co-Oriented Commitment	20.00 (4.00)	20.00 (5.00)	0–24	$Z = 0.34$
ENRICH Survivor –Caregiver Communication	38.74 (7.81)	40.02 (7.40)	10–50	$F = 10.48^*$
ENRICH Caregiver –Survivor Communication	37.40 (7.32)	38.63 (6.46)	10–50	$F = 6.67^*$
Survivor –Child Communication	75.40 (10.83)	76.05 (10.99)	20–100	$F = 9.13^*$
Child –Mother Communication	79.29 (13.38)	79.80 (12.11)	20–100	$F = 0.28$
Child –Father Communication	74.53 (14.63)	75.82 (13.70)	20–100	$F = 1.73$
SURVIVOR Cancer Coping Efficacy	3.68(0.74)	3.95(0.71)	1–5	$F = 33.87^*$
CAREGIVER Cancer Coping Efficacy	3.63(0.65)	3.82(0.70)	1–5	$F = 12.55^*$
SURVIVOR PANAS-X Joviality	16.65(6.52)	22.04(7.10)	0–32	$F = 95.45^*$
CAREGIVER PANAS-X Joviality	17.28(6.88)	21.27(7.32)	0–32	$F = 43.62^*$
CHILD PANAS-X Joviality	22.57 (6.85)	25.32 (6.07)	0–32	$F = 20.42^*$
CAREGIVER Difficulty Handling Workload Due to Personal Physical or Emotional Health	4.16 (1.07)	3.61 (1.84)	1–5	$F = 12.57^*$
CAREGIVER Missed Full Workdays to Take Care of Family Member	1.40 (2.66)	0.92 (2.13)	0–11+	$F = 4.58^*$

Note. * $p \leq 0.05$. Family Hardiness Index Co-Oriented Commitment scores are medians (with interquartile range); we used the Wilcoxon Signed-Rank test due to non-normal distributions. Survivor N = 190, caregiver N = 177, and children N = 130.

Table 5 • Pre- to 6-month post-respite comparisons of cancer survivor, caregiver, and child outcomes.

Variable	Pre-respite mean (SD)	6-month post-respite mean (SD)	Possible range of scores	Statistics
SURVIVOR Family Hardiness Index Co-Oriented Commitment	21.00 (4.00)	21.00 (5.00)	0–24	$Z = -0.32$
CAREGIVER Family Hardiness Index Co-Oriented Commitment	21.00 (4.75)	22.00 (4.00)	0–24	$Z = -2.15^*$
CHILD Family Hardiness Index Co-Oriented Commitment	20.00 (4.00)	21.00 (6.75)	0–24	$Z = -0.83$
ENRICH Survivor –Caregiver Communication	38.67 (7.41)	39.76 (7.25)	10–50	$F = 3.65^*$
ENRICH Caregiver –Survivor Communication	36.86 (7.31)	38.26 (7.14)	10–50	$F = 4.27^*$
Survivor –Child Communication	74.64 (10.83)	69.63 (10.79)	20–100	$F = 5.42^*$
Child –Mother Communication	76.60 (12.22)	78.20 (11.45)	20–100	$F = 1.86$
Child –Father Communication	73.15 (13.16)	73.51 (12.82)	20–100	$F = 0.05$
SURVIVOR Cancer Coping Efficacy	3.71 (0.74)	3.88 (0.71)	1–5	$F = 4.86^*$
CAREGIVER Cancer Coping Efficacy	3.61(0.65)	3.79(0.75)	1–5	$F = 6.26^*$
SURVIVOR PANAS-X Joviality	16.65(6.87)	19.06(7.73)	0–32	$F = 9.63^*$
CAREGIVER PANAS-X Joviality	16.45(7.04)	18.68(8.14)	0–32	$F = 8.57^*$
CHILD PANAS-X Joviality	22.88(6.42)	23.34(6.03)	0–32	$F = 0.48$
CAREGIVER Difficulty Handling Workload Due to Personal Physical or Emotional Health	4.16 (1.03)	3.61 (1.67)	1–5	$F = 7.39^*$
CAREGIVER Missed Full Workdays to Take Care of Family Member	1.00 (2.08)	0.87(2.13)	0–11+	$F = 0.36$

Note. * $p \leq 0.05$. Family Hardiness Index Co-Oriented Commitment scores are medians (with interquartile range); we used the Wilcoxon Signed-Rank test due to non-normal distributions. Note that 86 of the 190 families who completed the immediate post-respite survey did not return the 6-month post-respite survey, so the pre-respite values are slightly (but not significantly) different (survivor $N = 104$, caregiver $N = 99$, children $N = 63$).

that investing resources in these families may help improve relationships and facilitate efforts to stay engaged in the cancer battle, especially for survivors and caregivers.

4.1. Clinical applications

Our approach to supportive cancer care differs from other family-based models used in the field in that, in addition to providing information and resources, we provide the opportunity to practice healthy behaviors in a setting that facilitates intentional connection. By providing a respite from day-to-day (especially cancer treatment) demands, families can truly take a break and have time to regroup and recharge. Further, continuing to support families with coping tips, inspirational help, and events to connect with other families going through the cancer journey also appears to be beneficial. All programming is provided at no cost to the cancer families, which is especially important given the financial burden that cancer and its treatment imposes. Many of the components of our respite program could also be included in traditional supportive cancer care. Please email the corresponding author for the instructions for the Family Time Capsule, Family Keystone, Journ-

al, Strength Bands, and Care Gram activities.

Both cancer survivors and their caregivers experienced an increase in cancer coping efficacy. This is especially meaningful because higher self-efficacy beliefs are associated with greater treatment compliance [39]. So, they likely came back with renewed efforts to engage in treatment protocols. Further, programming also appeared to enhance survivor–caregiver communication. Good communication in this dyad is necessary for both members to achieve/maintain positive mental health, and also lays the foundation for honest and supportive conversations for family life, treatment, and any end-of-life decisions.

Cancer survivors initially improved on all outcomes involving their children, suggesting that the respite offered them meaningful and bonding time from their perspective. From the child’s perspective, family hardiness and parent–child communication were not impacted by the respite (but did remain somewhat high). Regarding communication, children tend to feel left out in terms of knowing the full truth and being part of conversations that involve vulnerability on behalf of the parents [8]. Although these conversations are difficult to have, and parents often think they are protecting their

children, future work can benefit from including programming that encourages age-appropriate, truthful, honest conversations with children.

On average, cancer survivors and caregivers both felt more confident in their ability to cope with cancer/caregiving after participating in our program. Only the survivors experienced a respite-induced improvement in family hardiness, but the caregivers' increase in family hardiness did not appear until 6 months later. Of note is the fact that family hardiness is not just about unity in the battle, but also providing support to one another, and a sense of optimism in things working out because of the collective family coping effort. Caregivers' needs tend to lose precedence to those of the cancer survivor, and even the children [16]. Perhaps caregivers do not perceive support from the family as being more available to them upon their initial return to daily life, but later experience improved family support. Noteworthy is the fact that the majority of caregivers were men, so gender differences may also be influencing the results. Although individual family respites have shown promising benefits, we have recently partnered with the all-inclusive Woodloch Resort in the Poconos to build the first center exclusively dedicated to respite care for families of adult cancer survivors. Providing supportive care in this one location allows us to expand our reach, serving clients from 15 states instead of 5. Further, this expands upon the individual family respite experience with the addition of formal supportive care, which allows for the creation of deep connections with other families facing the cancer journey. Families will still experience family connection through shared activities and be pampered and recharge but can also join in panel discussion groups and other group activities with fellow survivors, caregivers, and children. The latter aspect builds support systems with co-sojourners that can endure beyond the respite. This enhanced respite program has the promise to yield even stronger effects, and we look forward to exploring this further. We welcome referrals to our expanded multi-family respite program (<https://takeabreakfromcancer.org/oncology-professional/>, accessed on 2025 Jan 23).

4.2. Strengths and limitations

One strength is that this study is a prospective assessment of the impact of a family respite program on family dynamics and their positive outlook. Further, it assesses holistic supportive care for the family unit using techniques beyond simply providing skills training or counseling. Respite experiences provide intentional opportunities to implement self-care, re-establish bonds through quality time, and process the hard things individually as well as within the family. Further, we can keep engaging with families through our newsletters, private Facebook groups, monthly gatherings, and annual events to continue support efforts.

Study limitations include a very low survey return rate, a lack of a control group, and random assignment. Families who opted out of completing the surveys could be vastly different from those who participated in the study. It is possible that the study effects could simply be due to the passage of time and/or there is something unique about people who completed the surveys at all time points or people who self-selected to participate in the respite program that would limit generalizability. Future work utilizing a randomized controlled trial would provide further insight. We assessed for group differences in the cancer survivor pre-respite variables based

on cancer site and stage and correlation with years since diagnosis. Since there were no significant findings, we did not use these as covariates. Although we assessed the need for covarying for survivor medical characteristics, we did not expand this to include the other demographics, so this is a potential limitation. Another limitation is that we have a non-working, relatively young sample (each cancer survivor was required to be no older than 55 to participate) with advanced stage breast cancer, and the caregivers were mainly males. These differences may have influenced the results. For Pete's Sake has never turned down a nominated patient/family who meets our eligibility requirements. However, some patients, because of their work or other life demands, have not been able to accept our offer of a respite. We do offer a staycation option, but have not gathered data for it yet. Future work is necessary to explore family-based respites with older cancer survivors and their likely adult female children who may be serving as their caregivers.

5. Conclusions

This is the first community-based family holistic respite program to report on efficacy in meeting objectives. These results suggest that investing resources in these families may help improve relationships and facilitate efforts to stay engaged in the cancer battle. We welcome referrals to our expanded multi-family respite programs (<https://takeabreakfromcancer.org/oncology-professional/>, accessed on 2025 Jan 23).

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Author contributions

Conceptualization, N.H., M.B.S. and E.T.; methodology, N.H., M.B.S., P.B., M.L., V.D., R.L., E.T. and R.G.K.; formal analysis, N.H., A.L., S.M. and S.L.; data extraction, P.B., M.L. and R.G.K.; writing—original draft preparation, N.H.; writing—review and editing, N.H., M.B.S. and E.T. All authors have read and agreed to the published version of the manuscript.

Conflict of interest

The authors declare no conflicts of interest.

Data availability statement

Data supporting these findings are available within the article, at <https://doi.org/10.20935/MHealthWellB7525>, or upon request.

Institutional review board statement

This study was conducted in accordance with the Declaration of Helsinki and approved by the For Pete's Sake Ethics Committee (protocol code: O12013; approved on 2013 Aug 27).

Informed consent statement

Informed consent was obtained from all subjects involved in this study.

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