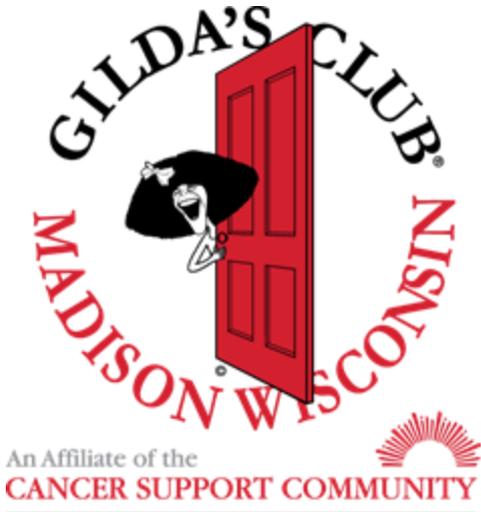


A Look into the Impact of Cancer on Family and Caregivers, and Those Who Work with Caregivers



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Wisconsin Dells, WI
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Who is a Caregiver?

caregiver (KAYR-gih-ver)

A person who gives care to people who need help taking care of themselves. Examples include children, the elderly, or patients who have chronic illnesses or are disabled. Caregivers may be health professionals, family members, friends, social workers, or members of the clergy. They may give care at home or in a hospital or other health care setting.

(National Cancer Institute Website, 2019)

Who is a Caregiver?

caregiver (KAYR-gih-ver)

Anyone who provides physical, emotional, financial, spiritual, or even logistical support to someone affected by cancer.

(Cancer Support Community, 2017)

Who is a Caregiver?

- 98% provided emotional support
- 96% went with their loved one to medical appointments
- 82% helped with decision-making
- 79% coordinated medical care
- 80% provided transportation
- 74% helped manage finances

(Cancer Support Community, et. al., 2004)



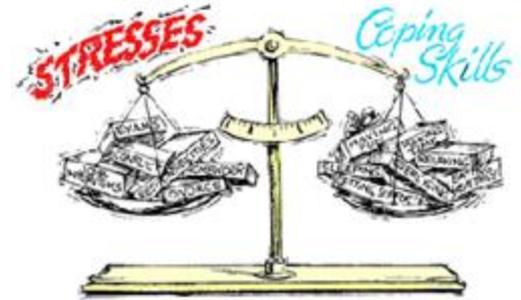
Cancer's Impact on the Family System

- Person with the diagnosis
- Partner
- Dependent Children & Adult Children
- Parents
- Siblings
- Extended Family
- Close Friend Network



Risk Factors for Families

- Cancer turns up the volume of what is already there--*Stress Pileup*
 - Mental illness/AODA
 - Additional medical issues
 - Strained relationships
 - Poor family communication
 - Socioeconomic status and access to resources
 - Financial and workplace stress
 - Support circle (single parent families, little or no family/friends/community)
 - Low self-esteem



Protective Factors for Families

- Established sense of trust and belonging
- Strong family and peer bonds
- Healthy communication
- Emotional vocabulary and expression
- Family functionality pre-cancer
- Connection to outside support
- ***Resilience***



Caregiver Specialty Registry Report, 2017

www.CancerSupportCommunity.org



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Cancer Experience Registry Index Report 2017



Specialty Registry Reports

- [Breast Cancer Specialty Registry Report](#)
- [Caregivers Specialty Registry Report](#)
- [Chronic Lymphocytic Leukemia Specialty Registry Report](#)
- [Chronic Myeloid Leukemia Specialty Registry Report](#)
- [Lung Cancer Specialty Registry Report](#)
- [Melanoma Specialty Registry Report](#)
- [Metastatic Breast Cancer Specialty Registry Report](#)
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- [Prostate Cancer Specialty Registry Report](#)
- [Stomach Cancer Specialty Registry Report](#)





QUALITY OF LIFE

42%
SAID THEIR HEALTH WAS SOMEWHAT TO MUCH WORSE THAN BEFORE THEY BEGAN THEIR CAREGIVER ROLE

36%
FATIGUE IS A CONSIDERABLE PROBLEM FOR OVER ONE-THIRD OF CAREGIVERS

47%
REPORT SUBSTANTIALLY WORSE ANXIETY THAN THE NATIONAL AVERAGE



TREATMENT DECISION-MAKING

47%
OF CAREGIVERS MADE DECISIONS TOGETHER WITH THE PATIENT

73%
OF CAREGIVERS ARE HEAVILY INVOLVED IN PATIENTS' TREATMENT DECISIONS

26%
OF CAREGIVERS REPORTED THAT PATIENTS MAKE DECISIONS AFTER CONSULTING WITH THEM



CAREGIVER ROLES

20%
OF CAREGIVERS REPORTED HAVING FORMAL TRAINING AS A CAREGIVER

19%
SPEND MORE THAN 100 HOURS PER WEEK ON CAREGIVING

44%
WISH THEY HAD MORE FORMAL TRAINING THAN THEY RECEIVED



CAREGIVER NEEDS

72%
WANT HELP WITH UNDERSTANDING THE PATIENT'S MEDICAL CONDITION AND TREATMENT

64%
WANT HELP WITH ACCESS TO FINANCIAL AND EMOTIONAL SUPPORT RESOURCES

49%
REPORT EXPERIENCING A SENSE OF LOSS OF CONTROL OVER THEIR OWN LIFE

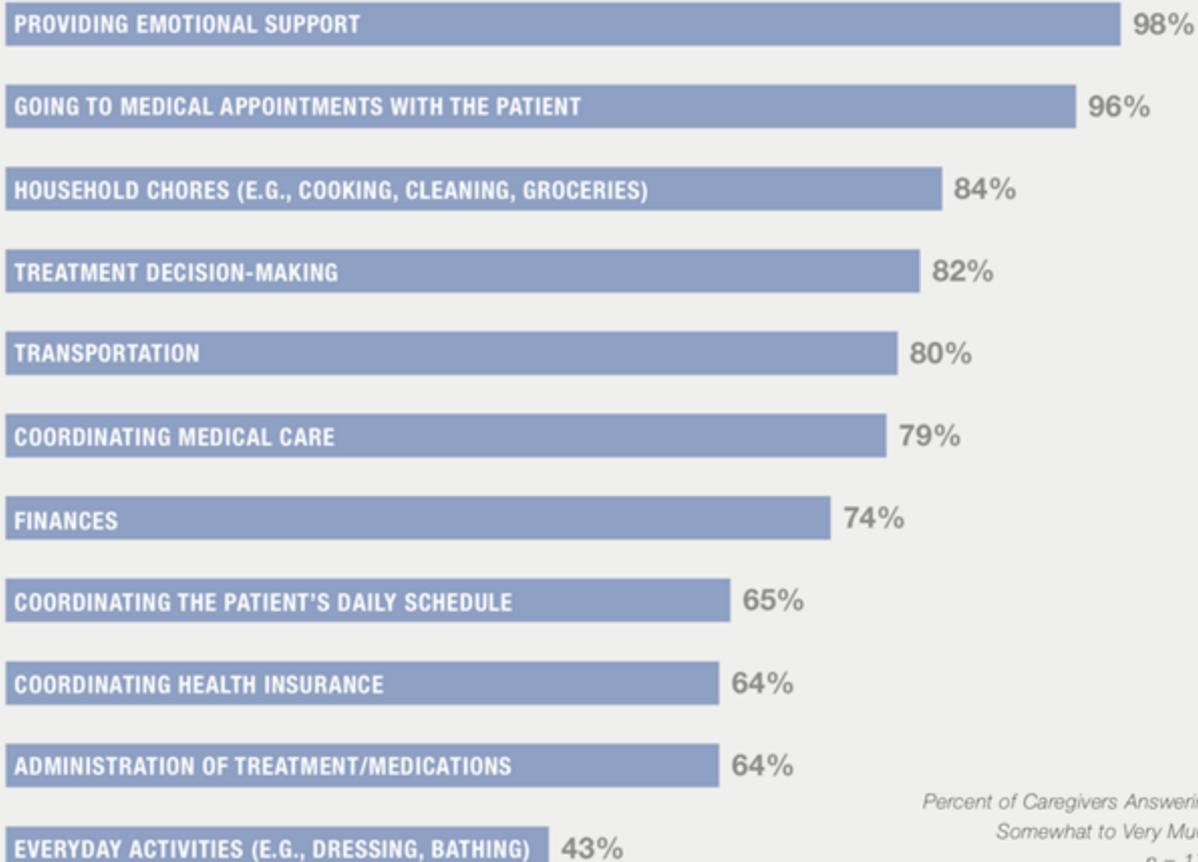
FIGURE 1 CAREGIVER REGISTRY SURVEY DEMOGRAPHICS

| | NUMBER OF PARTICIPANTS (n) | PERCENT |
|-------------------------------------|------------------------------------|-----------------|
| AGE | | |
| Mean age | (n = 220) 52.3 years, SD = 13.3 | Range: 18 to 85 |
| 18-44 | 51 | 23% |
| 45-64 | 130 | 59% |
| >=65 | 39 | 18% |
| GENDER | | |
| Male | (n = 220) 49 | 22% |
| Female | 171 | 78% |
| RACE | | |
| White | (n = 220) 187 | 85% |
| NON-HISPANIC ETHNICITY | | |
| | (n = 220) 195 | 89% |
| EDUCATION | | |
| High school or less | (n = 220) 22 | 10% |
| Associate degree or some college | 75 | 34% |
| Bachelor degree | 55 | 25% |
| Graduate degree | 64 | 29% |
| REGION | | |
| Urban | (n = 185) 37 | 20% |
| Suburban | 106 | 57% |
| Rural | 36 | 20% |
| EMPLOYMENT STATUS | | |
| Full-time | (n = 215) 112 | 52% |
| Part-time | 23 | 11% |
| Retired | 40 | 19% |
| Not employed due to disability | 7 | 3% |
| Not employed (reason not specified) | 33 | 15% |
| ANNUAL INCOME | | |
| <\$40K | (n = 212) 38 | 18% |
| \$40-59.9K | 20 | 9% |
| \$60-79.9K | 26 | 12% |
| \$80-99.9K | 21 | 10% |
| \$100K+ | 57 | 27% |
| Prefer not to share | 50 | 24% |

FIGURE 2 **CANCER STAGE, TIME SINCE DIAGNOSIS
AND CANCER STATUS OF SURVEY PARTICIPANTS**

| | <i>NUMBER OF PARTICIPANTS (n)</i> | <i>PERCENT</i> |
|---------------------------|-----------------------------------|----------------|
| STAGE AT DIAGNOSIS | (n = 175) | |
| Stage I | 3 | 2% |
| Stage II | 19 | 11% |
| Stage III | 22 | 13% |
| Stage IV | 76 | 43% |
| I don't know | 14 | 8% |
| RECURRENCE | (n = 170) | |
| | 159 | 94% |

FIGURE 3 CAREGIVERS' ROLES IN SUPPORTING PATIENTS



Percent of Caregivers Answering
Somewhat to Very Much
n = 176

FIGURE 4 **HELP NEEDED BY PATIENT WITH DAILY ACTIVITIES**

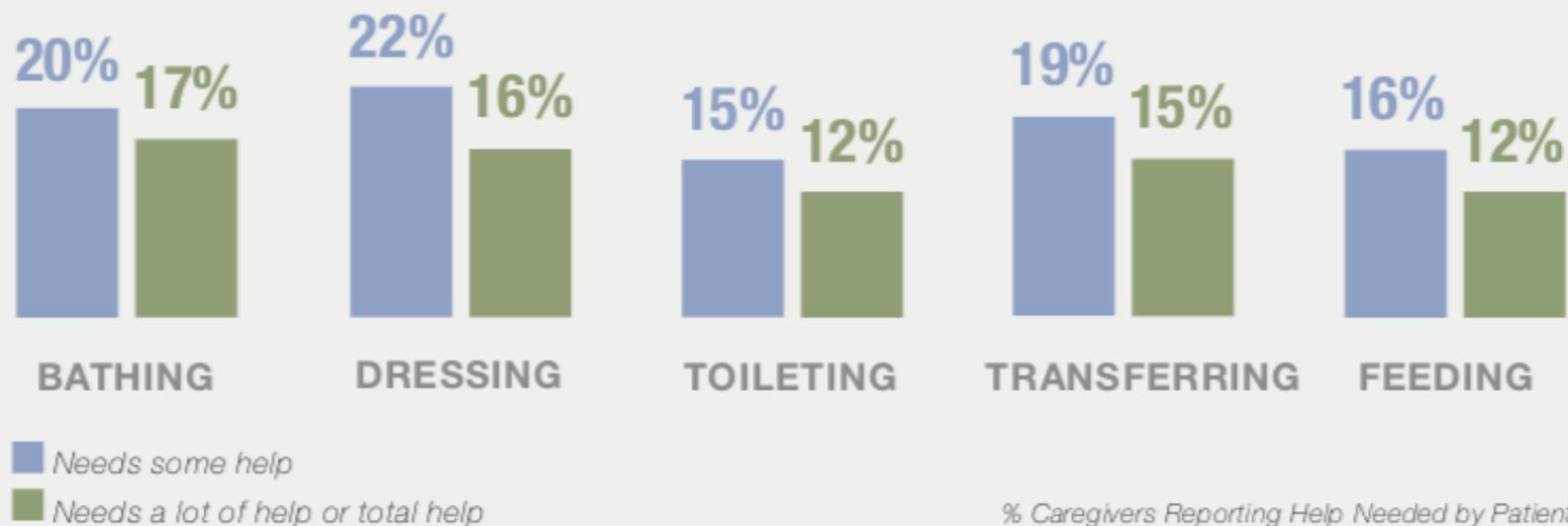
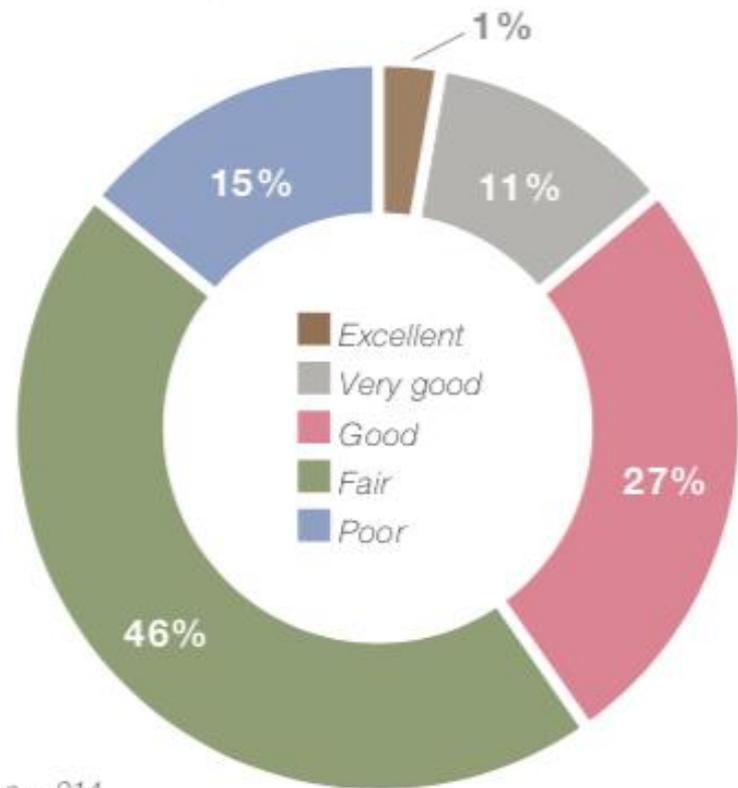


Figure 4 demonstrates caregivers' views about how much help was required by patients with basic self-care tasks (activities of daily living, or ADLs).

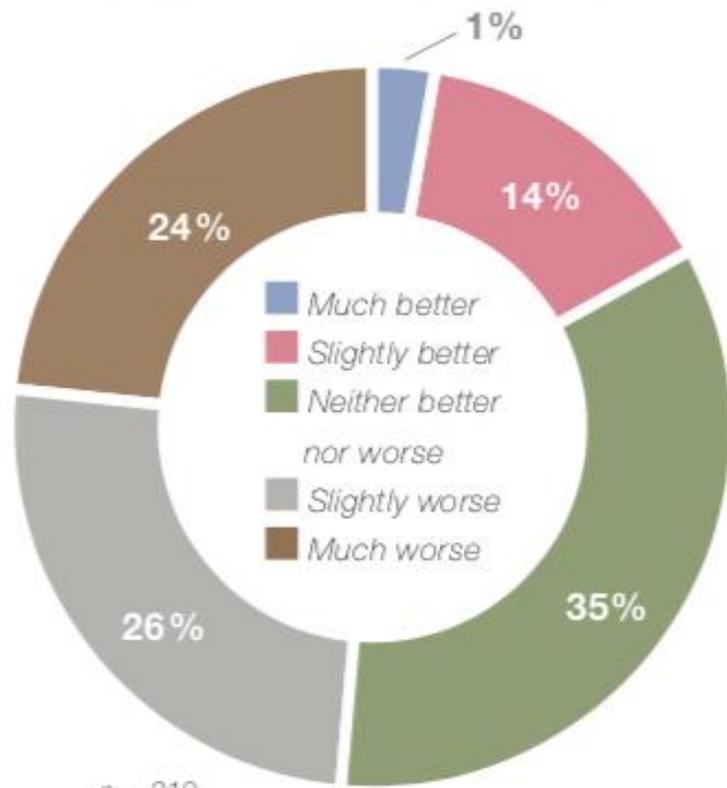
n = 172

FIGURE 5 PERCEPTIONS OF
OVERALL HEALTH



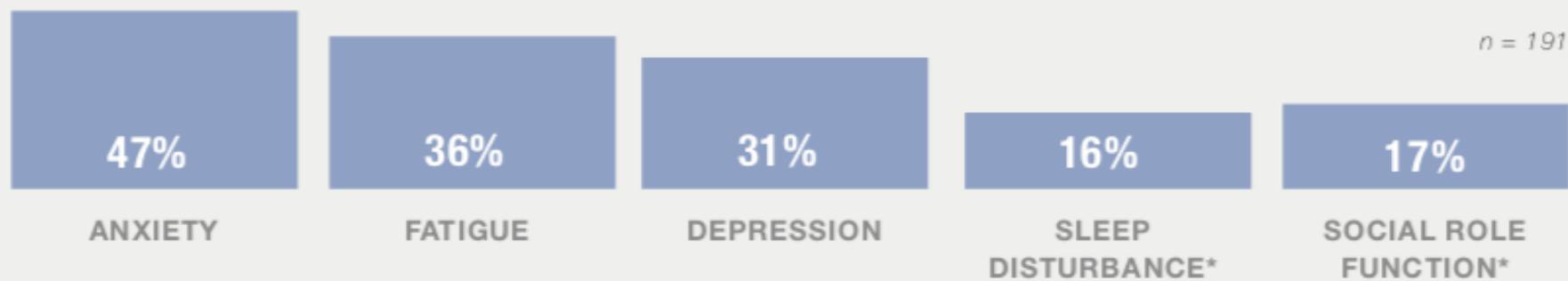
n = 214

FIGURE 6 CAREGIVER PERCEIVED HEALTH
AS COMPARED TO OTHERS



n = 213

FIGURE 7 PERCENT OF CAREGIVERS REPORTING WORSE QUALITY OF LIFE



*Note: All comparisons are vs. general U.S. population, except where * denotes comparison to U.S. population group balanced to include more people with chronic illness. Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than the respective comparison group.*

FIGURE 9 **DESIRE FOR CAREGIVING RESOURCES** *n* = 161

| 57% | 47% | 47% | 46% | 44% | 40% | 36% | 32% | 28% |
|---|--|---------------------------------|---|--|---|-------------------------|---|---|
| Caregiver support group or opportunity to talk with people in a similar situation | Online caregiving information and support groups | Education/training on self-care | Help with planning care for patient (e.g., financial benefits, long-term care planning) | Legal and financial resources (e.g., durable power of attorney, living will, trusts, legal guardian) | Education/training on how to care for the patient | Professional counseling | Community resources (e.g., meal delivery, transportation service) | Finding someone to help care for patient during the day / short-term respite facilities |
| <i>Percent responding yes</i> | | | | | | | | |

FIGURE 10 CAREGIVER BURDEN

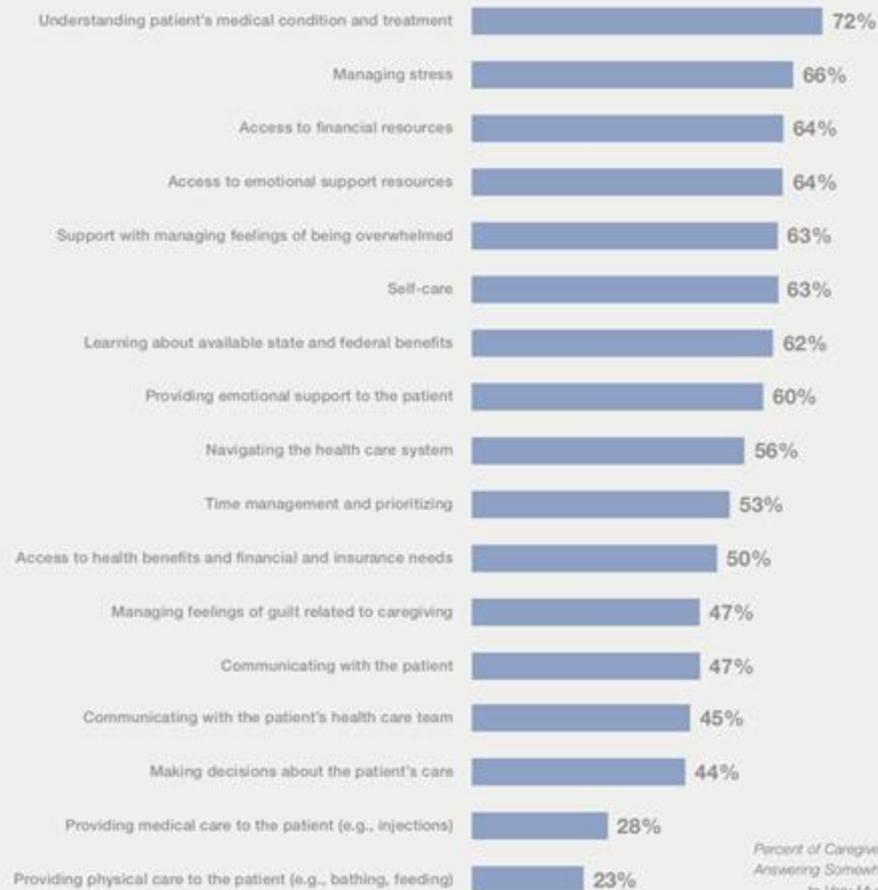


Percent of Caregivers
Answering Sometimes
to Nearly Always
n = 154

FIGURE 11 CAREGIVER MONTHLY
OUT-OF-POCKET COSTS



FIGURE 8 CAREGIVERS WANT HELP WITH...



Percent of Caregivers
Answering Somewhat
to Very Much
n = 164

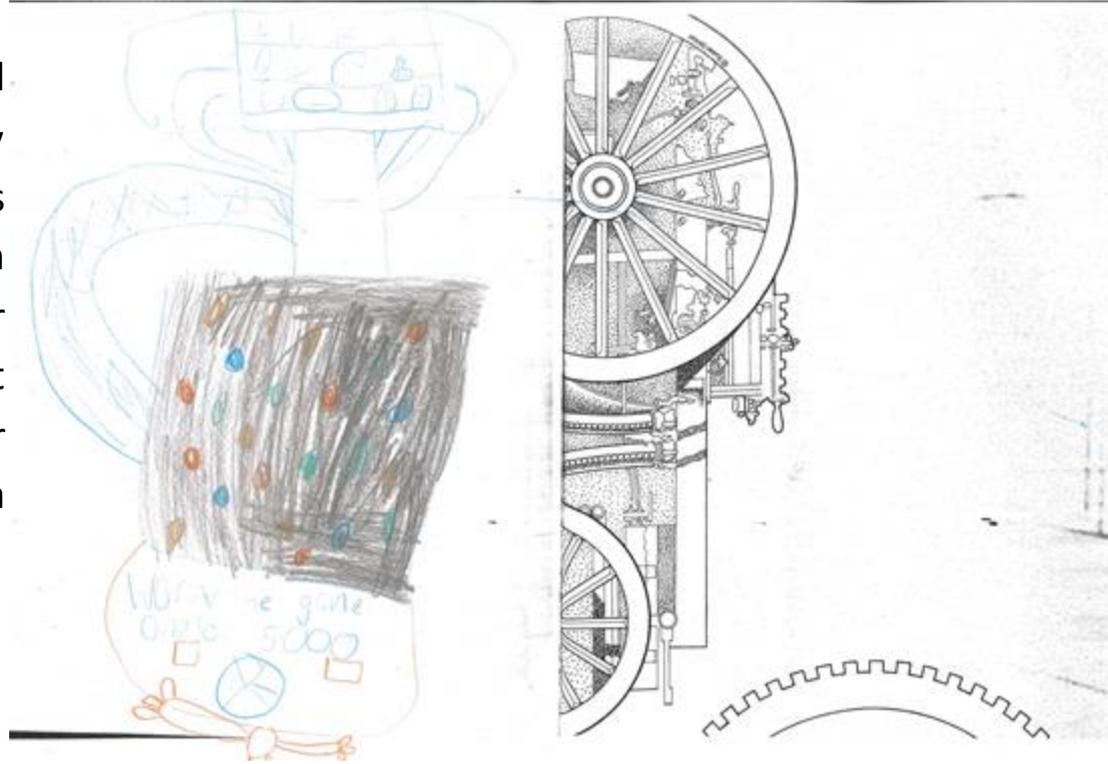
Challenges of a Parent's Cancer Diagnosis

- Approximately 1 in 5 cancer patients have dependent children
(Weaver, et al., 2010)
- 66% of parents answering a Cancer Support Community survey said that their child(ren) did not talk openly with them or share their feelings about cancer (2014)
- 25-39% of children may experience adjustment disorders for up to 5 years after a parent's diagnosis (Nelson & While, 2002)

Challenges of a Parent's Cancer Diagnosis

Strikingly, the rate of clinically elevated stress response symptoms was actually higher among the children of parents treated for cancer than among children who had experienced cancer themselves. This suggests that witnessing cancer in a family member may have a more profound impact on a child than being a cancer victim oneself.

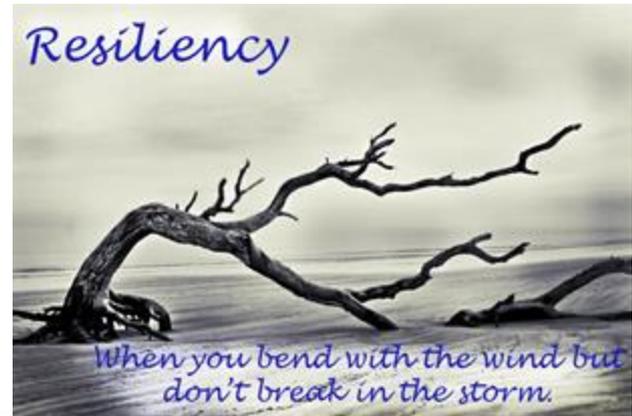
(Huizinga, et. al., 2004)



"Worry Be gone onator 5000" (GC Child)

What is Resilience?

- Ability to “Bounce Back” (“Spring Back”)
- Hardiness
- Elasticity, Flexibility
- Bend without breaking
- Capacity to endure, adapt
- Stability



What is Resilience?

- Resiliency is more than recovery
- Resilience is dynamic
- There are multiple and sometimes unexpected pathways to resilience
- Resilience is more common than we thought

(Boss, 2006; Masten, 2014 & 2015 & 2016)



“Ordinary Magic”

Resilience is common and typically arises from the operation of basic protections; the power of human and social capital (Masten, 2014).



Factors of Resilience

Belonging

Close attachment relationships, community bonds, empathy, authenticity, agreeableness

Control

Internal locus orientation, regulation, balance

Problem Solving

Flexibility, creativity, motivation to overcome challenges

Confidence

Positive self-view, mastery of skill, responsibility

Insight

Perspective, reframing

Perseverance

Realistic optimism, hope, meaning-making, belief in something bigger



Factors of Resilience

HUMOR...

...combines “optimism with a realistic look at the tragic” (Ann Graber).



Children can THRIVE in the face of a cancer diagnosis if they are:

1. Safe, loved and cared for
2. Treated with respect (honesty)
3. Connected with support and resources as needed



Silver Linings

- Maturity
- Empathy (How to be a good friend/partner/parent)
- Empowerment and Self-Confidence
- Resilience
- Life Perspective & Appreciation (Gratitude)



“The greatest gift you can give your children is not protection from change, loss, pain, or stress, but the confidence and tools to cope and grow with all that life has to offer them.”

Wendy Schlessel Harpham, MD, “When a Parent Has Cancer: A Guide to Caring for Your Children” (2004)

“Our job is to walk with our children through their difficult moments with connection and empathy, allowing them to feel, to be active participants in problem-solving, and to discover the depth of their own capacity. It’s out of our deep love for our children that we want to protect them, but their capacity will be greater if we allow that love to lead us to our own courage, so that we can feel strong enough to let them discover their own strength.”

Daniel J. Siegel, MD & Tina Payne Bryson, PhD, “The Yes Brain: How to Cultivate Courage, Curiosity, and Resilience in Your Child” (2018)

Hope

Gambling on absolute optimism or pessimism--the challenge and opportunity of HOPE

“In the short term, hoping for a return to the status quo helps maintain resilience... Unrelenting hope that is static and rigid erodes resilience and health” (Boss, 2006).



Hope

“The ability to create, resurrect, challenge, modify, and even renounce our hopes is as good as any definition of healthy as I have come across.” Steven Cooper

“Life is not fair. Life hurts. Life is good. These three seemingly incompatible expressions are really three parts of the whole of living. They are threads woven through the tapestry each one of us creates as the visible expression of our being a part of humanity. To accept these three is not to abandon hope or optimism, or to deny our real grief. To accept them is to rid ourselves of the unnecessary suffering that comes from struggling against these three truths and trying to make them something they are not.” (Coloroso, 2000).

Resources

- National Resource List
- Book list--When a Parent Has Cancer
- Bibliography

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