Adjusting to Survivorship: The New Normal

Presented by: Barb Henry, APRN-BC, MSN
Bjzh@aol.com

Melvin S. Gale MD & Associates
2135 Dana Ave, Suite 410
Cincinnati, Ohio 45207-1327
(513) 241-1811
http://www.galemd.com
Survivorship Statistics

• Latest estimate—12 million Americans—almost 4% of the total population are living with a cancer diagnosis

• 65% of adults diagnosed with cancer are alive 5 years later

• More than 1 million Americans are alive 25 years after their cancer diagnosis
Top 10 Challenges for the Cancer Survivor

• Transitioning from Active Treatment
• Fear of Recurrence
• Depression
• Fatigue
• Making/Maintaining Healthy Lifestyle Changes-nutrition, exercise, smoking cessation, sobriety, supplements
Top 10 Challenges for the Cancer Survivor

• Late Effects of Treatment
• “Chemo-brain”/Cognitive Changes
• Getting Back to Work/Retirement
• Sexuality & Relationship Changes
• Loss of Fertility, Friends, Social Connections
Book on Survivorship

After You Ring the Bell . . .
10 Challenges for the Cancer Survivor

This is a good one as are others recommended by this author and listed at the end of the slides.
Distress Management

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

 Extreme distress

 10
 9
 8
 7
 6
 5
 4
 3
 2
 1
 0

No distress

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES NO Practical Problems

- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school

YES NO Physical Problems

- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue
- Feeling Swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Tingling in hands/feet

Other Problems: _____________________________________________________________

__________________________________________________________

NCCN, 2012
Therapeutic Fly Fishing Retreats for Breast Cancer Survivors: Emotional Distress Outcomes

https://www.facebook.com/#!/CastingForRecoveryOhio?fref=ts

www.castingforrecovery.org
Fly Fishing Retreats for Breast Cancer Survivors: Emotional Distress & Quality Of Life Outcomes

Casting for Recovery
DNP Student, Northern Kentucky University, Highland Heights, KY

Barbara J. Henry, MSN, APRN-BC
Melvin Gale, MD, & Associates

Introduction

Over 200,000 women are diagnosed each year with breast cancer (American Cancer Society, (ACS), 2012). Currently there are 2.5 million breast cancer survivors (ACS, 2012). Support groups lead to better outcomes in quality of life-physical, emotional and social well-being. 70% of women who participate in Casting For Recovery (CFR) programs do not attend other support groups (CFR, n.d.). CFR meets an important need. Many support groups are segregated by cancer “stage”. CFR includes Stage I through IV breast cancer survivors; in CFR-“any age, any stage” is the motto. CFR was founded by a fly fisher and a breast reconstructive surgeon in 1996 based on these principles: • The natural world is a healing force. • Cancer survivors can benefit from one weekend free of the stresses of medical treatment, workplace, & family concerns. • Participants experience the healing power of nature in an intimate, safe and nurturing structure. • Participants learn a fun new sport that promotes increased physical activity. CFR is a 501(c)3 non-profit organization that is endorsed by medical and psychosocial experts for its innovative healing program model.

Methodology

This was a pre- and post-test research design with 42 women from 5 states. The study was approved by the University of Cincinnati Internal Review Board and determined to not cause any risk or harm to participants. Letters of introduction to the study and distress tools with postage paid return envelopes were mailed to participants 2 weeks prior to the retreat. 70 tools were mailed with 47 returned by mail; 42 of the 47 completed pre-retreat tools and signed letters of consent returned, a 67% return rate. Completed tools were assigned numbers and sent to the principal investigator without any identifiers in order to assure confidentiality of participants. The principal investigator is a psychosocial facilitator for CFR but did not participate in any retreats held in 2011 when the data was gathered.

Findings

15 of the 42 participants completed and returned the post-retreat distress tools for a return rate of 35%. The mean pre-retreat distress score was 4.02. Distress scores above 4 indicate emotional distress in need of treatment and/or referral (National Comprehensive Cancer Network, n.d.)

The mean post-retreat distress score was 2.93, a significant decrease in emotional distress. This is even more significant given 21 participants showed scores 4 or higher pre-retreat and only 3 participants had scores of 4 or higher post-retreat.

Problems were tabulated from both the pre- and post-retreat tools. The top 5 problems listed by participants were: 1) Worry, fears, and nervousness 2) Fatigue 3) Memory and concentration 4) Sadness and depression and 5) Sleep.

Clinical Implications

Quality of life and distress data from this study is valuable in planning future cancer survivorship programs. This study will be replicated with CFR participants in 2012 with the goal of obtaining information from a larger population from more states with a higher return rate.

Casting for Recovery is a valuable program to reduce and/or identify emotional distress and improve quality of life in breast cancer survivors.

The NCCN Distress tool may be better understood if it were renamed the “Emotional Distress Tool” in order to help cancer survivors and staff understand what is meant by “Distress.” Oncology nurses can use the Distress tool in clinical settings to provide cancer care for the whole person including psycho-social assessment, interventions, and referrals as recommended by the Institute of Medicine. (Adler & Page, 2008).

References


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• Debbie Hampton, CFR Ohio Coordinator, volunteer staff and participants from the CFR program
• University of Cincinnati and Northern Kentucky University Doctorate of Nursing Practice Programs
• National Comprehensive Cancer Network

Author Contact: Bjzh@aol.com
http://www.harmonyhill.org/node/26
Union, Washington (2 hours from Seattle)

- **May 28-30**
  - *(Tuesday-Thursday)*
  - General Retreat
- **June 28-30**
  - *(Friday-Saturday)*
  - General Retreat
- **July 29-31**
  - *(Monday-Wednesday)*
  - General Retreat
- **August 29-31**
  - *(Thursday-Saturday)*
  - Family Retreat*
- **September 20-22**
  - *(Friday-Sunday)*
  - General Retreat

3 day Retreats for cancer survivors are offered often and are open for up to 20 people at a time. Group sizes are kept small in order to ensure the quality of this program.

Through stress reduction skills, guided imagery, daily support groups for learning and sharing, movement and shared massage, participants facilitate their own healing and restore quality of life.

Participants stay on site in one of Harmony Hill’s fully furnished rooms. You will be treated to delicious, whole-foods meals, and opportunities for relaxation and renewal in a tranquil retreat environment of gardens, trails and spectacular views. This program (including food and lodging) is offered at no cost to participants.
More Retreats for Survivors

- **A New Beginning Cancer Retreat** holds free retreats year-round in Ellston, Iowa, for cancer survivors of all ages. Family members and friends are also welcome with a charitable contribution requested. For more information, go to [http://www.cancer-retreat.org/](http://www.cancer-retreat.org/) or call 641-772-4276.

- **Cancer as a Turning Point. 5 day residential workshops** for people dealing with cancer, and those closest to them. Madison, CT. Contact Ruth Bolletino, 212-496-9136, [rbolletino@aol.com](mailto:rbolletino@aol.com). [www.cancerasaturningpoint.org](http://www.cancerasaturningpoint.org)

- **First Descents** is a motivational kayaking camp for young adult cancer survivors in Vail, Colorado. [http://www.firstdescents.com/](http://www.firstdescents.com/)

- **Healing Odyssey** offers four weekends a year in the Malibu Mountains of California for women survivors. $125. 949-951-3930, [http://www.healingodyssey.org/](http://www.healingodyssey.org/)

- **Hilltop Retreat** – 2 day spiritual weekend of renewal sponsored by the Mayo Clinic. Contact Mary Riley at 507-288-8354, $25.

- **Kokolulu Farm and Cancer Retreat, Hawaii.** An organic farm on the healing island of Hawaii, offering $3000 week long retreats (some scholarships). [lew@kokolulu.com](mailto:lew@kokolulu.com), 808.889.9893, [http://cancer-retreats.org/](http://cancer-retreats.org/)

• **Planet Cancer** provides free weekend retreats for young adult cancer patients and survivors. The retreats are developed locally with the goal of growing a nationwide support network of young adults with cancer. For more information, call 512-481-9010 or e-mail headquarters@planetcancer.org

• **Second Wind Retreat** located 2 hours north of Atlanta, GA. Rent-free use of cottage to those in cancer treatment. Medical referral needed. 404-348-4986 or [www.secondwindretreat.org](http://www.secondwindretreat.org)

• **Smith Farm Cancer Help Program Retreat** is a week-long retreat in Comus, Maryland, for cancer survivors (spouses are welcome) held throughout the year. Scholarships are available. For more information, go to www.smithfarm.com or call 202-483-8600.

• **Stowe Weekend of Hope** – One weekend each spring, the town of Stowe, Vermont opens its 55 hotels and lodges to cancer survivors and their families at no charge. AMTRAK provides a limited number of free seats for survivors to get to Stowe from Washington, DC. 1-800-GO-STOWE, [http://www.stowehope.org](http://www.stowehope.org) 5/3-5/5


• The **Cancer Help Program** fee is $2,460 per person for the week, an all inclusive fee. The fee covers housing, meals, program, and materials. We are able to offer the Cancer Help Program at this fee only because contributions from Cancer Help Program alumni cover half the cost of the program, and enable us to offer scholarship assistance to some participants who would not otherwise be able to join us. [http://www.commonweal.org/programs/cancer-help.html](http://www.commonweal.org/programs/cancer-help.html) Bolinas CA
• **Sunstone Cancer Support Foundation** offers numerous cancer retreats in Tucson, Arizona, year-round for cancer survivors and their families. Partial scholarships are available. For more information, go to [www.sunstonehealing.net](http://www.sunstonehealing.net) or contact Nan Rubin at 520-749-1928.

• **Windriver Cancer Wellness Retreats & Programs** provides cancer survivors a tranquil place to slow down, spend time in nature, meet other survivors and learn ways to reduce stress and live happier, healthier lives. Emphasis is on emotional healing and “what’s next?”. Free of charge to survivors in treatment, recently out of treatment or dealing with a recurrence. Contact Shannon & Dave at [www.WindRiverServices.org](http://www.WindRiverServices.org) Western North Carolina

• To find the “new normal.” **Live By Living survivor retreats** offer a powerful way to help you do all this and more-$75/person, in Colorado
  
Prevalence of Mental Health Issues in People with Cancer

- _____ percent (or more) of all people diagnosed with cancer have significant psychosocial distress
- Less than 10% of these people actually are identified and referred for help.
- The suicide rate among cancer patients is ___ that among the general population.

NCCN, 2010
Managing Your Emotional Distress

• Cancer Support Community (formerly the Wellness Community):
  http://www.cancersupportcommunity.org

• Cancer Family Care
  http://www.cancerfamilycare.org

• Oncology Nursing Society-Cancer Journey & Traveling Companions
  Websites
  http://blog.thecancerjourney.org/2011/01/i-hope-you-dance/
Survivors & Staff from the Cancer Wellness Program at Tri-Health Pavilion
Cancer Wellness Program

July-August 2013
STARTS July 9th and ENDS August 29th
EXERCISE: TUESDAY and THURSDAY 6-7pm
EDUCATION: THURSDAY 7-8pm

CONTACT KAREN SIMS
(513)985-6722
(513) 985-0918 Fax Number
karenrehab_sims@trihealth.com
www.TriHealthPavilion.com

Program offered at no charge for participants due to support from the TriHealth Cancer Institute
Art Therapy-A Way to Make Sense of Cancer & Survivorship

http://www.lillyoncologyoncanvas.com/Pages/Index.aspx

This acrylic painting was done by a 75-year-old prostate cancer survivor using brush and finger painting. He explained, “The grass is my bucket list, the stems of the flowers shooting up are my projects, the blossoms are the eight samples (the two red ones were cancer), and the blue sky is like the sky out west,” one of his favorite places.
ASCO Expressions of Hope Calendar-John Kaplan, NHL Survivor
http://www.cancer.net/expressionsofhope

Even with counseling, group therapy, expressive and complementary therapies there may be depression/anxiety—might be time for some pharmacotherapy.
Common Psychiatric Medications

Antidepressants

- **SSRI’s** - citalopram (Celexa), escitalopram (Lexapro), fluoxetine (Prozac), fluvoxamine (Luvox), paroxetine (Paxil), sertraline (Zoloft), vilazodone (Viibryd)

- **SNRI’s** - desvenlafaxine (Pristiq), duloxetine (Cymbalta), venlafaxine (Effexor), atomoxetine (Strattera)

- **Others** - mirtazapine (Remeron), nefazodone (Serzone), trazodone (Oleptro), bupropion (Wellbutrin)

Epocratesonline.com, 2012
Common Psychiatric Medications (less common) **Antidepressants**

- **Tricyclics** - amitriptyline (Elavil), doxepin (Sinequan), nortriptyline (Pamelor), protriptylene (Vivactil), chlomipramine (Anafranil), imipramine (Tofranil), desipramine (Norpramin), trimipramine (Surmontil)

- **MAOI’s** - isocaboxazid (Marplan), phenezine (Nardil), seligiline (Emsam), tranylcypromine (Parnate)
Common Psychiatric Medications

Anti-Anxiety Medications

Lorazepam (Ativan)
Clonazepam (Klonopin)
Alprazolam (Xanax)
Diazepam (Valium)
Oxazepam (Serax)
Chlordiazepoxide (Librium)
Buspirone (Buspar) (*non-benzodiazepine anxiolytic*)
Common Psychiatric Medications

Sleep Aids

- Zolpidem (Ambien)
- Flurazepam (Dalmane)
- Temazepam (Restoril)
- Triazolam (Halcion)
- Eszopiclone (Lunesta)
- Ramelteon (Rozeram)
- Zaleplon (Sonata)
- Estazolam (Prosom)
- Secobarbital (Seconal)
- Chlortal Hydrate

Off label sleep agents:
- any of the medications from the anti-anxiety and antidepressant slides, as well as low dose antipsychotic medications

Epocratesonline.com, 2012
Other Psychiatric Drugs

- **Antipsychotic Medications** (brand names-Abilify, Seroquel, Zyprexa, Risperdal, etc.)

- **Mood Stabilizers** (brand names-Lithium, Depakote, Tegretol, Neurontin, Lyrica, Topamax)

- **Stimulants** (brand names-Ritalin, Adderall, Focalin, Daytrana)
Medications alone may not help, consider psychotherapy/counseling

- Research has shown that psychotherapy may improve a patient’s quality of life. It can help reduce anxiety and depression that sometimes occur in people with cancer. It can also help people cope with cancer and the changes in their lives.

- Psychotherapy can be used to help people deal with the diagnosis and treatment of cancer. It can also be useful in overcoming depression and anxiety, which are common in people with cancer.

American Cancer Society, 2012
My own Distress relief-ZUMBA!

Princeton High School 10:30 p.m. tonight!
4/27/13

“Zumba for Life” Zumba demonstration
WEB SITES

The following are some reputable organizations and their Web sites where you can find additional information about cancer survivorship.

- American Cancer Society: www.cancer.org
- CancerCare: www.cancercare.org
- Centers for Disease Control and Prevention: www.cdc.gov/cancer/survivorship
- LIVESTRONG: www.livestrong.org
- National Cancer Institute, Office of Cancer Survivorship: http://dccps.nci.nih.gov/ocs
- National Coalition for Cancer Survivorship: www.canceradvocacy.org
- Oncology Nursing Society’s “The Cancer Journey”: www.thecancerjourney.org
- Patient Advocate Foundation: www.patientadvocate.org
The following is a list of books on cancer survivorship.


Thanks for your attention😊
Survive, Thrive, & Celebrate Life!


