



What Does Evidence-based Mean at The Wellness Community?

Mitch Golant, Ph.D.
VP Research & Development
The Wellness Community National
October 19, 2005

mitch@thewellnesscommunity.org



Presentation Overview

- What Does “Evidence-based Research” Means for TWC?
- Distress and Psychosocial Oncology
- Evidence-based interventions defined
- The Link between Evidence-based Research and TWC’s Patient Active Concept
- Research on:
 - Support Groups
 - Psycho-educational programs
 - Stress-reduction exercises
 - Online Support Groups



What Does Evidence-based Research Mean For TWC?

- **Credibility**
 - With Health care professionals
 - With Patients
- **Unique Identity in the Cancer Community**
- **New Program Ideas**
- **Quality Assurance**
- **Funding**



TWC's Ten Core Principles

From *Patient Active* to *Life Active*

1. Patient Active Concept
2. Home-like Setting
3. Free
4. All Cancers
5. Adjunctive to Conventional Medical Treatment
6. Evidence-Based
7. Committed to Quality Assurance
8. Professionally-Facilitated
9. Collaborative
10. Signature Cancer Educational Programs

What is Evidence-based Research?

- A BODY of psychosocial research published in peer reviewed & practice journals.
- The “Gold Standard” in research is randomized clinical trials (RCT):
 - Treatment Group receiving the standard treatment
 - Support group
 - Treatment Group receiving the standard of care + a new treatment
 - Support group + Mindfulness-based Stress Reduction (MBSR)
 - Control Group that receives “usual care”
 - NCI pamphlet on getting support



Distress is Common

- Unpleasant emotional experiences that can impact cognitive, behavioral, social, emotional and spiritual functioning
- Distress may interfere with ability to cope effectively with cancer, its physical symptoms and treatment
- 47% of cancer patients have distress severe enough to qualify for psychiatric diagnosis
- Emotional distress is the most underreported & most common side effect of cancer



Symptoms of Distress

- Spectrum of feelings from sad, fearful, angry and unhappy to severe depression, panic and debilitating anxiety
- It is important to monitor the chronicity and severity of symptoms
- Reliable symptoms include: Persistent depressed or angry mood, lack of pleasure in activities
- Unreliable symptoms include: fatigue, insomnia, eating disturbance, decreased libido
- Symptoms decrease quality of life



What is Psychosocial Oncology?

The study of the impact of psychological reactions on physiological processes and health outcomes.

- psychological **reactions** to a cancer diagnosis
- **interventions** designed to help alleviate pain, fatigue, depression, trauma
- interventions to **improve health** behaviors



The Link between Evidence-based Research and TWC's Patient Active Concept

- TWC has designed its program interventions based upon a model of conscious change and actions leading to improved quality of life and enhanced possibility of recovery.
- All support groups, educational programs (physician lectures, stress reduction exercises, *Frankly Speaking Series*, etc.) are designed to reduce stress, improve quality of life and thereby enhance immune function through active engagement in the treatment and management of the illness.



Research Used at TWC

- Our programs include the findings from:
 - Psychosocial Oncology Research published by other scientists or academics
 - Psychosocial Oncology Research published with TWC in partnership with our academic and scientific partners.
 - Community-Initiated Research Collaborations

TWC Program Philosophy

Founded upon the *unique* Patient Active Concept

- “Patients who participate in their fight for recovery along with their healthcare team, rather than acting as hopeless, helpless, passive victims of the illness, will improve the quality of their lives and may enhance the possibility of recovery.”
- “Combining the will of the patient with the skill of the physician - A powerful combination.”

■ *Harold Benjamin, Ph.D., Founder*

TWC Program Philosophy

Founded upon the *unique* Patient Active Concept:

- “Patients who **participate** in their fight for recovery along with their **healthcare team**, rather than acting as hopeless, helpless, passive victims of the illness, will improve the quality of their lives and may enhance the possibility of recovery.”

■ *Harold Benjamin, Ph.D., Founder*

Actively Participate

- **Rooted in the “fighting spirit” research by Watson and Greer (1991) and where those who questioned their doctors and were more active in their treatment did better (improved quality of life):**
 - Watson M, Greer S, Rowden L, Gorman C, Robertson B, Bliss JM, Tunmore R. Relationships between emotional control, adjustment to cancer and depression and anxiety in breast cancer patients. *Psychological Medicine* 1991;21:51–7.
 - Watson M, Haviland JS, Greer S, Davidson J, Bliss JM., Influence of psychological response on survival in breast cancer: a population-based cohort study. *Lancet*. 1999 Oct 16;354(9187):1331-6.
 - Cordova MJ, Giese-Davis J, Golant M, Kronnenwetter C, Chang V, McFarlin S, Spiegel D., Mood disturbance in community cancer support groups. The role of emotional suppression and fighting spirit. *J Psychosomatic Research*. 2003 Nov;55(5):461-7.



TWC Program Philosophy

Founded upon the *unique* Patient Active Concept

- “Patients who participate in their fight for recovery **along with their healthcare team,** rather than acting as hopeless, helpless, passive victims of the illness, will improve the quality of their lives and may enhance the possibility of recovery.”

Along With Their Healthcare Team

- **The more positive the relationship between doctor and patient the better the treatment adherence. Patient distress negatively impacts family and doctor patient relationship.**
 - Han WT, Collie K, Koopman C, Azarow J, Classen C, Morrow GR, Michel B, Brennan-O'Neill E, Spiegel D., Breast cancer and problems with medical interactions: relationships with traumatic stress, emotional self-efficacy, and social support. *Psychooncology*. 2005 Apr;14(4):318-30.
 - Loscalzo, M.J. and J.R. Zabora, *Care of the cancer patient: response of family and staff.*, in *Topics in palliative care*, E. Bruera and R.K. Portenoy, Editors. 1998, Oxford University Press: New York. p. v. <1-4 >

Along With Their Healthcare Team

- **Psycho-educational programs lead to improved quality of life—information is support:**
 - Golant, M., Altman, T., Martin, C., *Managing Cancer Side Effects to Improve Quality of Life: A Cancer Psychoeducation Program*, Cancer Nursing, February 2003, vol.26, 1, pgs. 37-46.
 - Daugherty, C., et al., *Perceptions of cancer patients and their physicians involved in phase I trials*, *J Clin Oncol* 1995 Sep;13(9):2476]. *Journal of Clinical Oncology*, 1995. 13(5): p. 1062-72.
 - Houts, P.S., et al., *The Prepared Family Caregiver: A Problem-solving Approach to Family Caregiver Education*. *Patient Education & Counseling*, 1996. 27(1): 63-73.
 - Nezu, A.M., et al., *Relevance of problem-solving therapy to psychosocial oncology*. *Journal of Psychosocial Oncology*, 1999. 16(3-4): p. 5-26.



TWC Program Philosophy

Founded upon the *unique* Patient Active Concept

- “Patients who participate in their fight for recovery along with their healthcare team, rather than acting as hopeless, helpless, passive victims of the illness, **will improve the quality of their lives** and may enhance the possibility of recovery.”



Will improve the quality of their lives

■ Support groups benefit cancer patients

- ↓ depression, anxiety (Kassane, 2004; Goodwin, 2001; Spiegel, Bloom, Yalom, 1981)
- ↓ trauma symptoms (Classen, in press)
- ↓ pain (Goodwin, 2001; Spiegel and Bloom, 1983)
- ↑ coping responses (Spiegel, Bloom, Yalom, 1981)
- ↑ immune response (Fawzy, 1990)
- ↑ survival time (Spiegel et al., 1989)

■ Effective therapies typically encourage emotional expression within strong social support

Will improve the quality of their lives

- **We know that support groups improve the QoL of patients—especially those most distressed. These findings are based only on professionally-led groups.**
 - Goodwin PJ, Ennis M, Bordeleau LJ, Pritchard KI, Trudeau ME, Koo J, Hood N., Health-related quality of life and psychosocial status in breast cancer prognosis: analysis of multiple variables. *J Clinical Oncology*. 2004 Oct 15;22(20):4184-92
 - Kissane DW, Love A, Hatton A, Bloch S, Smith G, Clarke DM, Miach P, Ikin J, Ranieri N, Snyder, RD. Effect of cognitive-existential group therapy on survival in early-stage breast cancer. *J Clinical Oncology*. 2004 Nov 1;22(21):4255-60. Epub 2004 Sep 27.
 - Spiegel D, Giese-Davis, JE Depression and cancer: mechanisms and disease progression. *Biological Psychiatry*. 2003 Aug 1;54(3):269-82. Review.
 - Lieberman, M., Golant, M., Altman, T. *Therapeutic Norms and Patient Benefit; Cancer Patients in Professionally Directed Support Groups Group Dynamic, Theory, Research and Practice*, vol8 (4), 265-276)
 - Goodwin PJ, Ennis M, Pritchard KI, Koo J, Trudeau ME, Hood N., Diet and breast cancer: evidence that extremes in diet are associated with poor survival. *J Clin Oncol*. 2003 Jul 1;21(13):2500-7

Randomized Trials of Psychotherapy Showing No Survival Benefit

Study	Cancer	N	Psychological Outcome
Linn et al. 1982	Lung, GI	120	Less depression, more self esteem, life satisfaction
Ilnyckyj et al, 1994	Breast	127	No improvement
Cunningham et al, 1998	Metastatic Breast	66	No improvement
Edelman et al, 1999	Metastatic Breast	121	No long-term improvement
Goodwin et al, 2001	Metastatic Breast	225	Less distress, depression
Kissane et al., 2004	Primary Breast Cancer	303	Less distress, better family relat



TWC Program Philosophy

Founded upon the *unique* Patient Active Concept

- “Patients who participate in their fight for recovery **along with their healthcare team**, rather than acting as hopeless, helpless, passive victims of the illness, **will improve the quality of their lives** and **may enhance the possibility of recovery.**”



Enhance the possibility of recovery

- **These two studies set the stage for current thinking on how support groups may increase survival. Although replication studies have not shown a survival benefit, this question continues to be explored.**
 - Spiegel D, Bloom JR, Yalom I. Group support for patients with metastatic cancer: a randomized outcome study. *Arch Gen Psychiatry* 1981;38:527–33.
 - Fawzy FI, Fawzy NW, Hyun CS, et al. “Malignant melanoma: Effects of An Early Structured Psychiatric Intervention, Coping, and Affective State On Recurrence And Survival 6 Years Later.” *Archives of General Psychiatry* 1993; 50(9):681-9.

Randomized Trials of Psychotherapy Showing Longer Survival

<u>Study</u>	<u>Cancer</u>	<u>N</u>	<u>Psychological Outcome</u>
Spiegel et al 1989	Metastatic Breast	86	Less distress, pain
Richardson et al, 1990	Lymphoma, leukemia	94	Better treatment adherence
Fawzy et al, 1993	Melanoma	66	Less distress, Better coping
Ratcliffe et al, 1995 [p<.06]	Lymphomas	63	Less anxiety, nausea
Kuchler et al, 1999	GI cancers	271	Better stress management
Kissane et al, 2001	Metastatic Breast	185	Less distress

Stress Reduction Exercises

- **Stress reduction exercise—Mindfulness-based Stress Reduction, Hypnosis, & Guided Imagery consistently shows QoL benefit in reduced depression, pain & fatigue.**
 - Carlson LE, Speca M, Patel KD, Goodey E. Mindfulness-based stress reduction in relation to quality of life, mood, symptoms of stress and levels of cortisol, dehydroepiandrosterone sulfate (DHEAS) and melatonin in breast and prostate cancer outpatients. *Psychoneuroendocrinology*. 2004 May;29(4):448-74.
 - Antoni MH, Lehman JM, Kilbourn KM, Boyers AE, Culver JL, Alferi SM, Yount SE, McGregor BA, Arena PL, Harris SD, Price AA, Carver CS. Cognitive-behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. *Health Psychol* 2001;20:20– 32.
 - Spiegel, D. and J. Bloom. (1983). Group therapy and hypnosis reduce metastatic breast carcinoma pain. *Psychosomatic Medicine*, 45: 333-339.

Effectiveness of Online Support Groups

- **Findings from research on the effectiveness of online support groups are encouraging since nearly studies show reductions in depression and improved post-traumatic growth from cancer. Findings mirror similar benefits to face-to-face support groups.**
 - Lieberman, M, Golant, M., Giese-Davis, J., Winzelberg, A., Benjamin, H., Humphreys, Kronenwetter, C., Russo, S, Spiegel, D., *Electronic Support Groups for Breast Carcinoma: A Clinical Trial of Effectiveness*, Cancer, February 2003, vol. 97(4), pgs. 920-925.
 - Lieberman, M. Golant, M., Winzelberg, A. Gustafson, D., McTavish, F., *Comparisons, Professionally Directed and Self Directed Internet Groups for Women with Breast Cancer* International Journal of Self Help and Self Care June, 2004, Vol. 2, Number 3.
 - Lieberman, M., Golant, M., *Comparisons Between Internet and Face to Face Groups: the Expression of Fear and Anger in Breast Cancer Support Groups*, International Journal of Group Psychotherapy, 2004
 - Lieberman, M., Golant, M., Winzelberg, A. *Comparisons Between Internet and Face to Face Groups*, Journal Psychotherapy, 2005
 - Winzelberg, A., et al. (2003). *An evaluation of an internet support group for women with primary breast cancer*. *Cancer*, 97(5): 1164-1173.



What Do Patients Gain from TWC Support Groups?

- **Results from a randomized clinical trial with Stanford University and TWC show participants*:**
 - Develop a new *attitude* towards the illness
 - Make *changes* in their lives that they think are important
 - Better partner with their physician
 - Better access cancer information & resources

*Giese-Davis, J. Golant, M., Kronenwetter, C., Sefton, S., Spiegel D., Do Cancer Support Groups Reduce Physiological Stress? (in submission *Psychooncology*)



Take Home Messages

- Research in distress and cancer provides a resounding justification for TWC's significance
- TWC PA Concept is deeply rooted in well-established, substantive research that is as relevant today as it was in 1982 when we opened our doors.
- Every aspect of TWC program (whether groups, education, stress reduction, social events) has evidence to support its value for people affected by cancer.
- TWC uses our own research and the research of others to interpret what practices best integrate with our community-based model.



Questions and Answers