Psychological and Relationship Challenges and Management

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What it's like to be an adolescent or young adult with cancer

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- *Everyone in support groups is at least 20 years older; overwhelmingly breast cancer patients.*
- *Hospital volunteers are primarily very nice people grandma’s age.*
- *Few opportunities to meet other young adults.*
- *Some of the young people you meet die.*

Overview – What do we know?

- Psychological Impact
- Relationship challenges
- Psychosocial support needs (“management”)
- Implications for practice and policy

Psychological Impact

- Psychiatric symptoms
  - Depression, anxiety, post-traumatic stress
  - Cognitive, behavioral, emotional, spiritual challenges that interfere with ability to cope with cancer, side effects, treatment
- Potentials for positive adaptation, growth, resilience

“Cancer sucks”

- *“Since being diagnosed I have not slept well, I feel depressed, scared, and constantly have a feeling of wanting to be home with my family. I was very social before and now I don’t do much.”*

- Zebrack B, Kent EE, Keegan THM, et al. *‘Cancer Sucks,’* and Other Ponderings by Adolescent and Young Adult Cancer Survivors, *Journal of Psychosocial Oncology* (In Press).

Study Aims

1. Assess prevalence and correlates of psychological distress and changes in distress over time (trajectories).

2. Track psychosocial service use/needs over time.

Longitudinal Study Design

- **Patient population**
  - Teens (14-17 yrs); “Emerging Adults” (18-25 yrs); Young Adults (26-39 yrs)
  - All invasive cancer
  - Written English or Spanish

- **Data collection procedures**
  - 4 data collection time points: (1) within 4 mos initial dx, (2) 6-months later, (3) 12-months later, (4) 24-months later
  - Serial recruitment (over 2 years)
  - $25 incentive/survey completed
  - Face-to-face; mail, telephone reminders

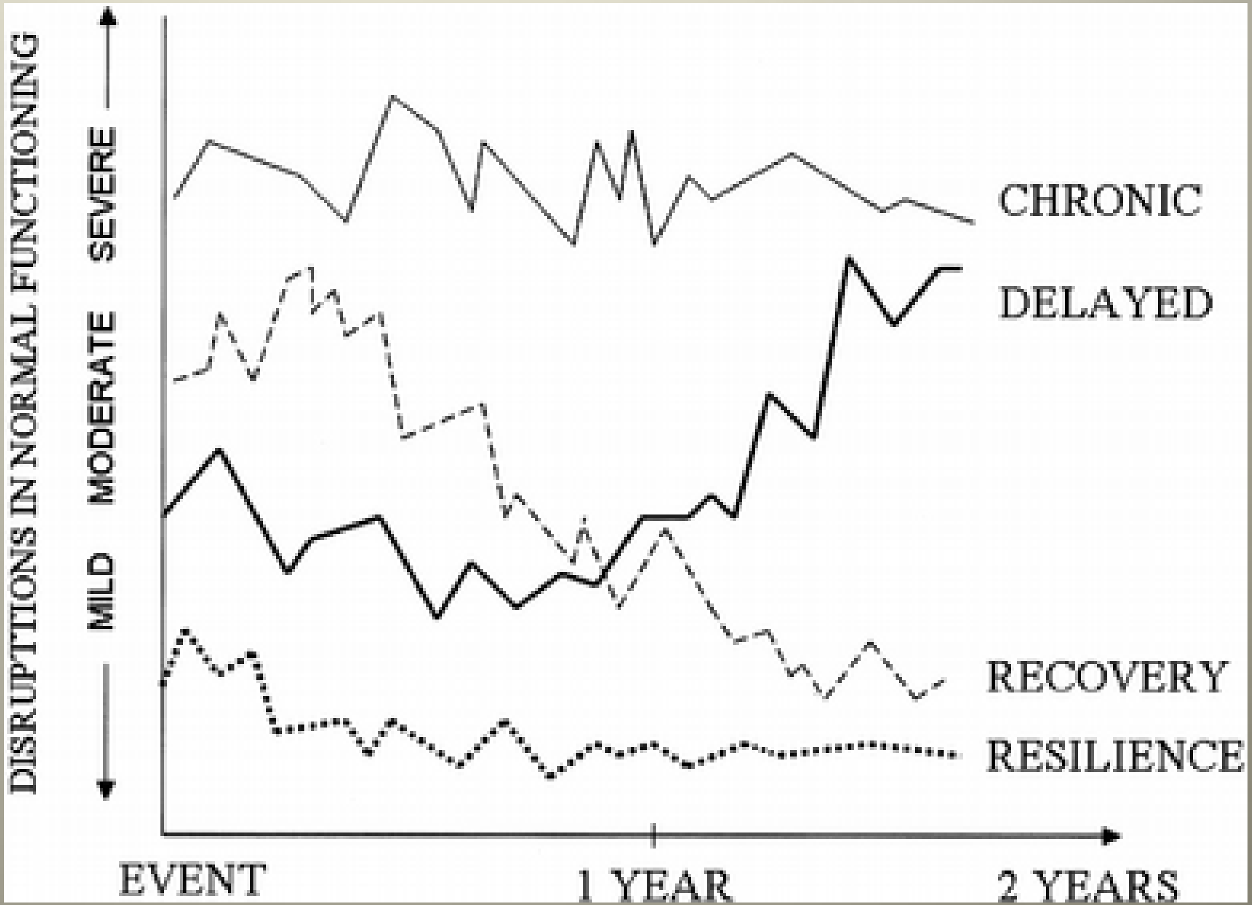
Prevalence of Distress

	Diagnosis n=215	6-month n=176	12-month n=165
"Caseness"	28%	16%	23%

35% of AYAs indicated clinically significant distress at least once during the first 12 months

- Kwak M, Zebrack B, Meeske K, Embry L, et al. *Journal of Clinical Oncology,* 2013.

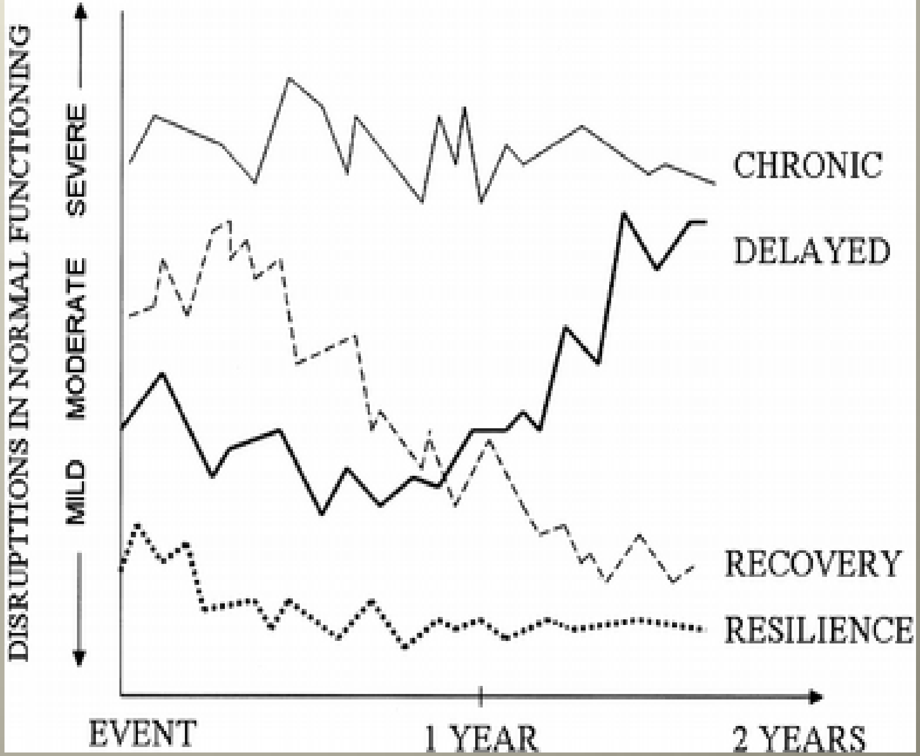
Bonanno Model of Distress Trajectories after Trauma



- Bonanno GA. Loss, trauma, and human resilience: have we underestimated the human capacity to thrive after extremely aversive events? *Am Psychol, 2004, 59(1)*:20-28.

Distress Trajectories

	Freq (%) n=152
Chronic	18 (12%)
Delayed	23 (15%)
Recovery	30 (20%)
Resilient	81 (53%)



- Zebrack B, Corbett V, Embry L, Aguilar C, et al. (Unpublished manuscript)

Potential for adaptation, resilience

- *"It was a devastating experience…[B]ut it changed my life. I became more positive, more health conscious. I exercise more. It allowed me to look at life differently. But every day I think about it and I seem very scared that it may return and I may not be strong enough to fight again!!!"*

Zebrack B, Kent EE, Keegan THM, et al. *Journal of Psychosocial Oncology* (In Press).

Relationship challenges

- Family, parents, friends and peers
- Risks for social isolation
- Dating and disclosure, sexuality and intimacy

- Zebrack, B., Hamilton, R. & Wilder-Smith, A. Psychosocial outcomes and service use among young adults with cancer. *Seminars in Oncology, 2009, 36(5),* 468-477.
- D'Agostino, NM, Penney, A, & Zebrack, B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors, *Cancer, 2011, 117(10 Supplement),* 2329-2334

Interpersonal Issues

- Parental pressures
  - Overprotection
- Social Pressures
  - Feeling different from peers
  - Wanting to feel “normal”
  - Drugs, alcohol

Dating and Disclosure

Communicating or revealing your cancer history

- **Who to tell?**
- **How much to tell?**
- **When to tell?**
- **What will happen if I tell?**
  - Fear of rejection
  - Identity: It's "who I am"
  - Discussing fertility, family

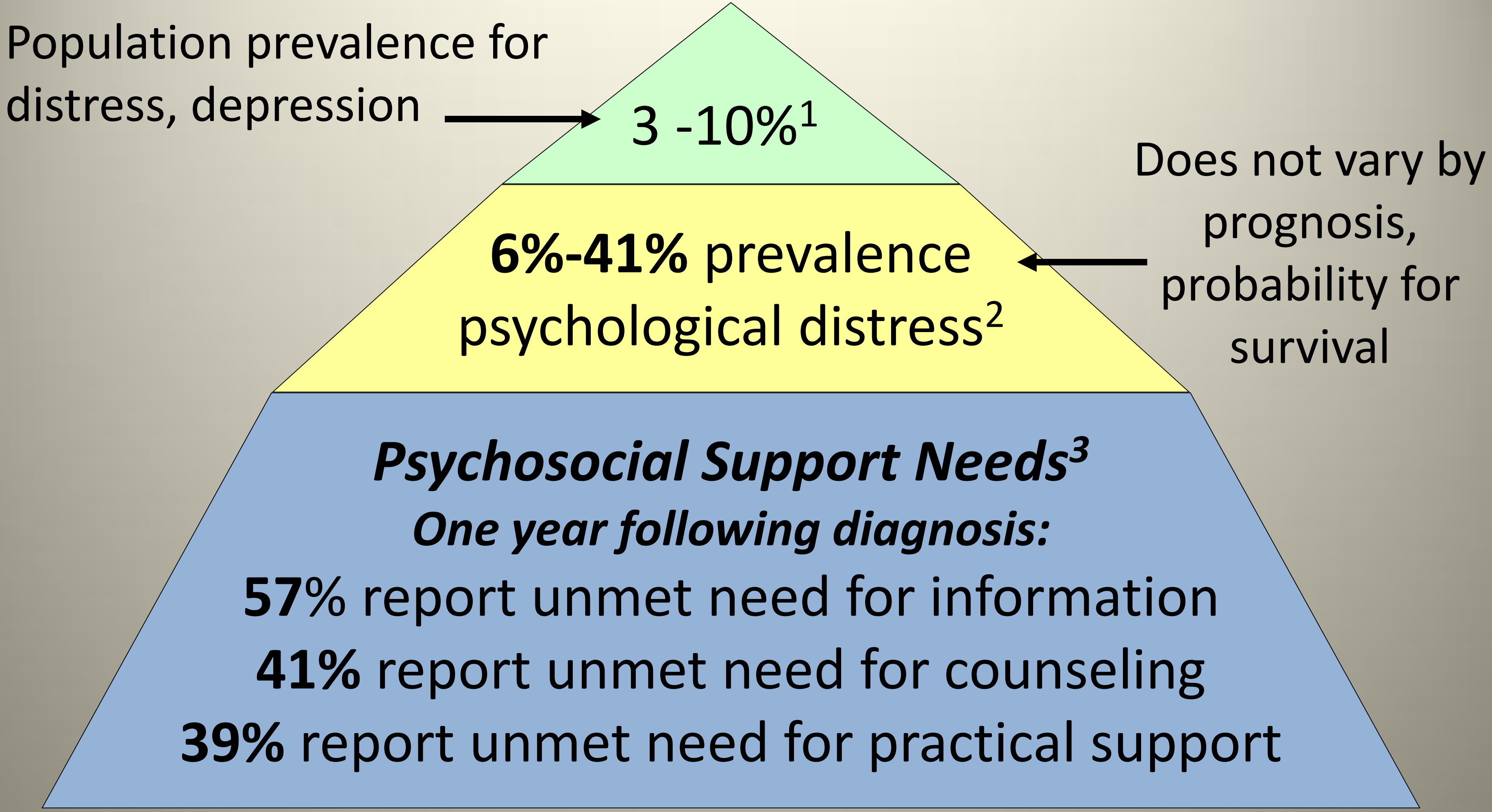
•Hamilton R. & Zebrack B. Dating and Disclosure for the Cancer Patient. In J. Mulhall (ed.) *Sexuality and Cancer*, Springer, 2011.

Relationships

- *"I lost a lot of people who were very close to me. I disappeared for a couple months and when I finally returned, everything was not the same. The people who knew my situation did not know how to approach me. I felt they had no idea who I was, and I wasn't too sure if they really cared."*

- *"My spouse did not express any interest in learning about my cancer. He was and is unwilling to talk with me about my feelings or my fears."*

  - Zebrack B, Kent EE, Keegan THM, et al. (In Press).



Population prevalence for distress, depression

3 -10%[1]

Does not vary by prognosis, probability for survival

6%-41% prevalence psychological distress[2]

Psychosocial Support Needs[3]

One year following diagnosis:

57% report unmet need for information

41% report unmet need for counseling

39% report unmet need for practical support

[1] Reeves WC, Strine TW, Pratt LA, Thompson W, et al. (2008).

[2] Kwak M, et al. (2013).

[3] Zebrack B, Corbett V, Embry L, Aguilar C, et al. (Unpublished manuscript)

Why substantial unmet need?

- AYA fear or stigma related to use of mental health services?

- AYA not wanting to be seen as different from friends and peers by identifying as a cancer patient?

- Lack of availability?

Why substantial unmet need?

Lack of knowledge or perceived unavailability of services accounts for 90% of reasons why cancer patients do not utilize psychosocial support services with demonstrated benefit.

- Data from 2010 National Health Interview Survey (NHIS), n=1,177 survivors of adult-onset cancer

•Forsythe LP, Kent EE, Weaver KE, Buchanan N, Hawkins NA, et al. Receipt of psychosocial care among cancer survivors in the United States. *Journal of Clinical Oncology, 2013, 31*(16), 1961-1969

- Independent studies and systematic reviews emphasize that psychologically-distressing problems created or exacerbated by cancer can be effectively addressed by psychosocial and peer support interventions

- Faller, H., Schuler, M., Richard, M., Heckl, U., Weis, J., & Kuffner, R. (2013). Effects of psycho-oncologic interventions on emotional distress and quality of life in adult patients with cancer: Systematic review and meta-analysis. *Journal of Clinical Oncology, 31*(6), 782-793.
- Jacobsen, P. B. (2008). Psychosocial interventions for anxiety and depression in adult cancer patients: achievements and challenges. *CA: A Cancer Journal for Clinicians, 58*, 214.
- Gottlieb, B. H., & Wachala, E. D. (2007). Cancer support groups: a critical review of empirical studies. *Psycho-Oncology, 16*, 379-400.

Implications for practice and policy

Psychosocial Challenges

- Emotional functioning, psychiatric symptomatology
- Life disruptions
- Relationship challenges
- Coping deficiencies

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Proximal Outcomes

- Adherence to treatment
- Completion of therapy
- Satisfaction with care
- Use of scarce resources (clinician time, clinic flow)

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Distal Outcomes

- Survival
- Quality of Survival
- Institutional Efficiencies
- Clinic Operations

Recommendations

- Promote peer relations
  - Social networking, social media
- Survivorship care plans
  - Patient-centered
- Need for further research
  - Who will benefit from what, and when?

Acknowledgements

Project Funded by HopeLab Foundation, Redwood City, CA

- Rebecca Block
- Brandon Hayes-Lattin
- Leanne Embry
- Christine Aguilar
- Kathleen Meeske
- Yun Li
- Steve Cole
- Melissa Butler
- Minyoung Kwak
- David Zeman
- Rachel Hamilton
- Laurel Couture