



American Brain Tumor Association®

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A New Reality: Brain Tumor Survivorship

Mary P. Lovely, PhD, RN, CNRN

American Brain Tumor Association

mlovely@abta.org

2013 Patient and Family Conference
Living with a Brain Tumor: A Holistic Approach

www.abta.org

1-800-886-ABTA (2282)

abtacares@abta.org

Study Collaborators

C. Amidei, PhD, RN, CNRN, FAAN

M. Page, RN, MS,

K. Mogensen, MSN, APN-C,

J. Arzbaecher, RN, MS, CNRN,

K. Lupica, MSN, CNP,

M. Maher, RN, MSN, CNP



Background

- Medical advances have improved mortality for some patients with malignant glioma
- Survivorship issues are increasingly important
 - Fox (2007) – fatigue, sleep disorders, cognitive changes
 - Steinbach (2006) – all survivors had neurological symptoms
- Few researchers have listened to survivors' experiences



Purpose of this study

Explore the experience of survivors who have lived with highly malignant brain tumors at least three years from diagnosis



Interview Questions

1. What was life like for you before you had the brain tumor?
2. What happened when you were diagnosed with the brain tumor? What was this like?
3. What was it like after the brain tumor and what is it like now?
4. Anything else you would like to offer about your experiences?

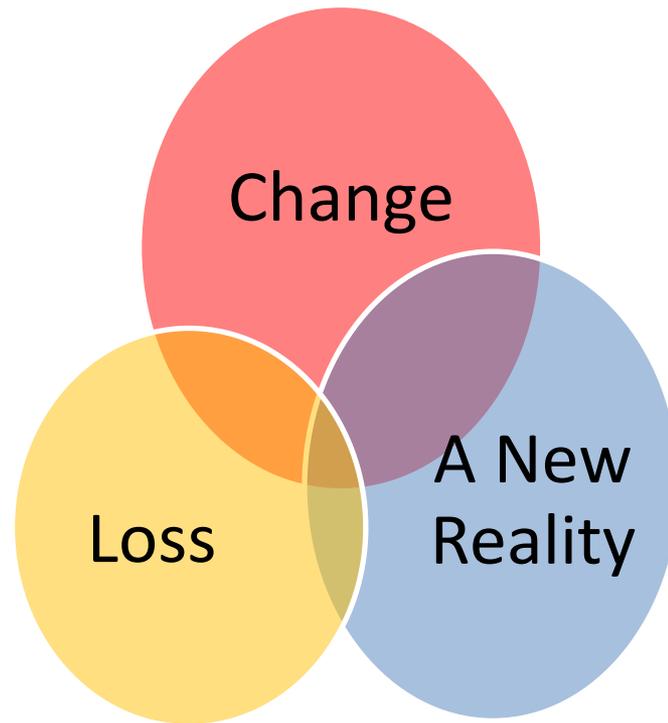


Sample Demographics

	Survivors n = 35	Caregivers n = 35
Gender	Female = 13 Male = 22	Female = 22 Male = 13
Age	51 yrs. (30 to 65 yrs.)	52 yrs. (43 to 77 yrs.)
Race	Caucasian 94%	Caucasian 88%
Education: Highest in number of years	16 (12 to 22 yrs.)	15 (12 to 22 yrs.)
Patient/caregiver relationship		Spouse or partner = 34 Mother = 1
Survival time from diagnosis	6 yrs. Mean (3 to 15 yrs.)	
Tumor type	GBM = 25 (71%) AA/high grade oligo = 10 (29%)	



Key themes



Stability

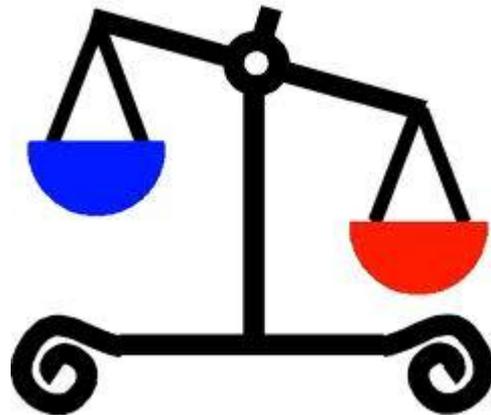
Being involved with family, being employed and having social relationships

“My life was my work, my family, and my friends. My life was grounded, and it was great. But the tumor changed all of that for me.”



Life Changed after Diagnosis

- Life direction changed
- Changes were persistent
- Participants struggled to perceive balance



Reasons for Life Altering Changes

- Physical and cognitive symptoms
- Psychological change – depression, trouble thinking, challenges in work or remembering things
- Difficulty processing and being distracted



Cognitive Changes

Survivors had losses that other people couldn't see but were expected to perform as they had prior to the brain tumor.

“ I have a lot of invisible deficits that people don't see unless they know me. People don't understand that I am the same person but different, and that makes me sad.”



Energy Changes

- Fatigue
- Lack of Motivation
- Difficulty trying to compensate

“ I have to think, think, think, all day long and it wears me down.”



Physical Symptoms

- Headaches
- Weakness
- Lack of coordination
- Language deficits
- Vision
- May worsen in spite of tumor stability



Seizures

- May start at the diagnosis or begin after many years
- Frequency and intensity varied for individuals
- Medications compounded symptoms such as fatigue and trouble thinking



Survivors Adopted Avoidance Techniques

- Avoided social situations to camouflage symptoms
- Limit activities to avoid falls
- Caregivers supported avoidance as a protective measure
- Caregivers needed to be vigilant for unsafe situations

“ I could no longer take part in my gardening, my passion. This is worse than the tumor diagnosis or treatment.”



Behavior Changes

- Frustration
- Depression/Anxiety
- Caregiver noticed behavior changes more than patients: moodiness, impulsiveness and intolerance



Loss

- Experienced from the beginning of diagnosis
- Continued through the course of the disease
- Exacerbated by worsening symptoms



Loss of Hope

- Message at diagnosis
- “Make the most of your time.”
- “Get your affairs in order.”
- Guilt related to living too long.

“I am living beyond my expiration date.”



Loss of Roles and Relationships



- Roles reversed with or assumed by caregiver
- Survivors not entrusted with responsibilities
- Relationship changes may include intimacy
- Loss of parenting, being overruled or left out
- Children became premature caregivers



Loss of Employment Status

- Consistent experience
- May need to downgrade or work part time
- Noise intolerance, easy distractibility

“I used to be the breadwinner, and now I don't make enough money to buy a loaf of bread. My wife has to do that.”



Loss of Independence and Spontaneity

- Loss of a drivers license
- Getting lost
- Caregivers incurred significant burden
- Activities planned carefully or abandoned

“I miss being able to go off and do things by myself.”



Loss of Sense of Self

- Decreased self esteem
- Decreased confidence
- Some felt incompetent when they felt they had “arrived” in their stage in life

“I became the person with the brain tumor and was no longer me.”



A New Reality

- Becoming a survivor
 - Acknowledging they are a survivor
 - Life has value, even though it is different
- Identify reason to live
 - Examining past lives
 - Put current situation in perspective
- Tenacity and endurance



A New Reality: Taking Back Control

- Set new priorities
- Slow down
- Change expectations
- Take one day at a time
- Make healthy choices
 - Food
 - Exercise
 - Sleep



A New Reality: Taking Back Control

- Have information and knowledge about the disease and treatment
- Sought resources beyond healthcare professionals
- Used internet sites



Coping

- Internal Resources
 - Maintain a positive attitude
 - Be hopeful for the future
 - Appreciate family life
 - Faith, a spiritual perspective, having a place with God



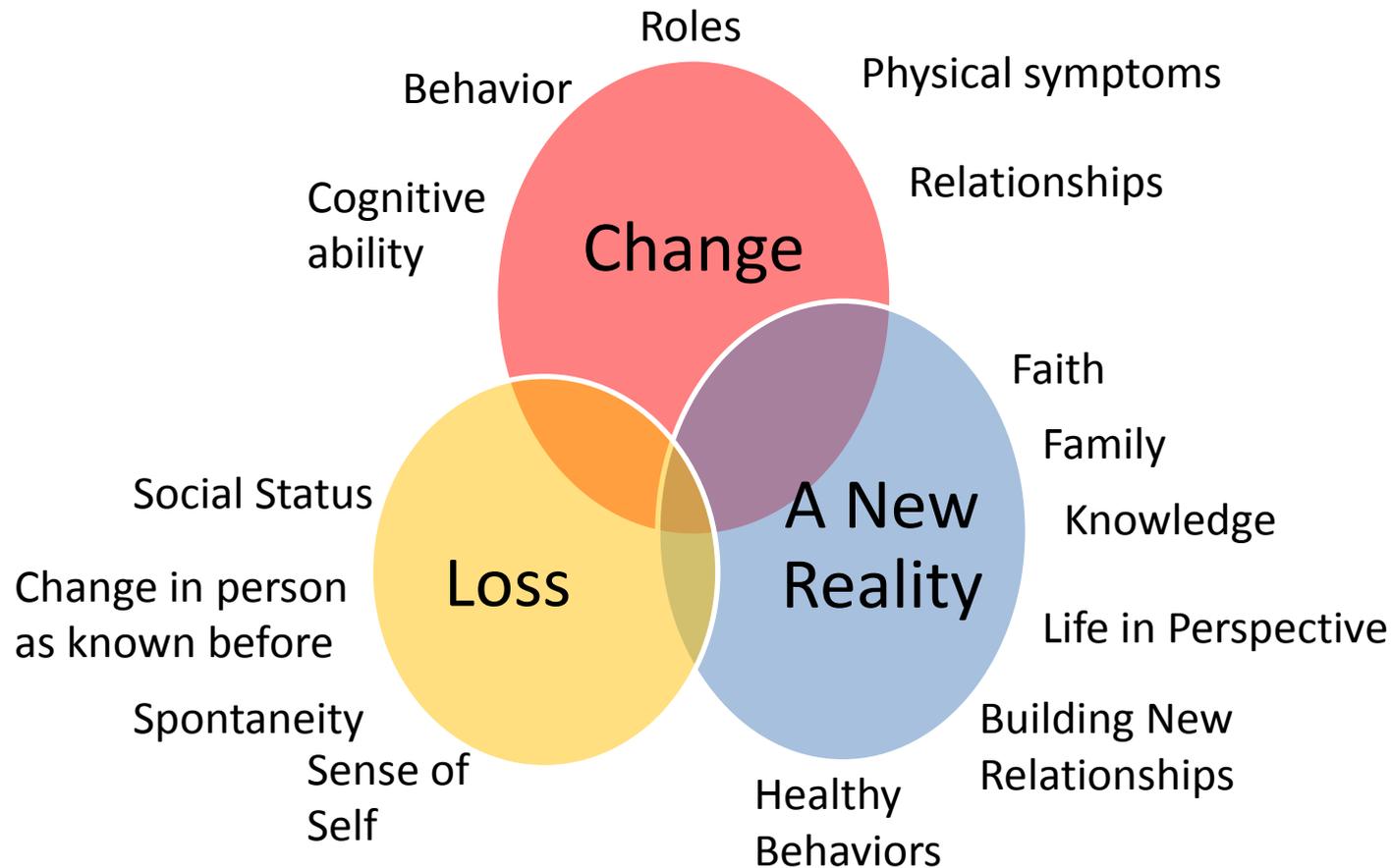
Coping

- External Resources
 - Family, pets
 - New friends made through diagnosis and support groups
 - Church activities
 - Reaching out and helping others
 - Finding activities to stay engaged

“My world became a much smaller place, but it was one I could manage.”



Themes identified by survivors and caregivers





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THANK YOU

Any Questions?

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