

Therapy for Advanced Stage Cancer: What Do Patients Want and Expect?

*Assessing and Improving Value in Cancer Care
A National Cancer Policy Forum Workshop*

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Marti Nelson Cancer Foundation
www.CancerActionNow.org

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Patients undergoing treatment for advanced cancer WANT TO LIVE

Is it really that simple?

- *Quantity versus Quality*

How do expectations change when treatments succeed or fail?

- *For whom does one live?*

*For of all sad words of tongue or pen
The saddest are these: 'it might have been!'*

John Greenleaf Whittier



One person's experience—sometimes called an anecdote

“I’m relatively young and healthy. I’m looking for survival. I would always measure the success, or value, of a treatment by survival. Quality of life is important, but I’m less concerned with side effects as long as I can still do things I could do before.”

G.C, January 2009, treated with bevacizumab for the past 5 years



Hope versus False Hope

What constitutes realistic hope?

What drives false hope?

- *Misguided enthusiasm*
- *Incomplete information*
- *Fraud*

“Hope is independent of the apparatus of logic.”

Norman Cousins



Hope and Misguided Optimism

“A drug is that substance which, when injected into a rat, will produce a scientific report.”

Author Unknown

“Judah is going to cure cancer in two years.”

James D. Watson

New York times - 1998

“If I can just hang on for five years, I know they’ll have something better for me then.”

Cancer patient

now deceased - 1987



Distinguishing Hope from False Hope

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Diagnosed With Cancer?

**If You or a Loved One Has Been
Diagnosed With Cancer,
Here Are 11 Effective, Natural Strategies,
Alternative Cancer Treatments
to Defeat This Deadly Disease**

If you are reading this information for the first time
it's probably because you or someone dear to you
is about to embark on the fight of their life...



Distinguishing Hope from False Hope

**You are just moments away from
discovering how to beat cancer and
rid your body of this disease
permanently.**

Click below NOW to access this crucial information

As seen in
Healthy Living
Magazine



Jayne Harvey, England

In "***Crack the Cancer Code***" Jayne reveals
how she 'cracked her code' and cured her
cancer *without* chemotherapy or
radiotherapy.



Life Beyond the “Standard of Care”

- **Most cancer drugs benefit a minority of patients.**
- **Most cancer drugs harm everyone who uses them.**
- **Evidence varies in quality and utility.**
- **How are statistics used by individuals?**

“There is no treatment that will help you. Come back when you need morphine.”

A California oncologist in 1994 to a patient with metastatic prostate cancer who died in 2006



Realistic Hope for Value

A positive outcome has value.

- *Value increases with verifiable life-extension*
- *Value increases through avoidance of other costs*

An opportunity for a positive outcome has value.

- *Failure does not cancel the value of the possibility*
- *Failure limits costs*

Is there value in rapid elimination of possibilities?



Lessons and Questions From BRiTE

Are double-blind, randomized clinical trials an over-rated gold standard?

**Value of registries and observational studies—
how do people really make treatment decisions?**

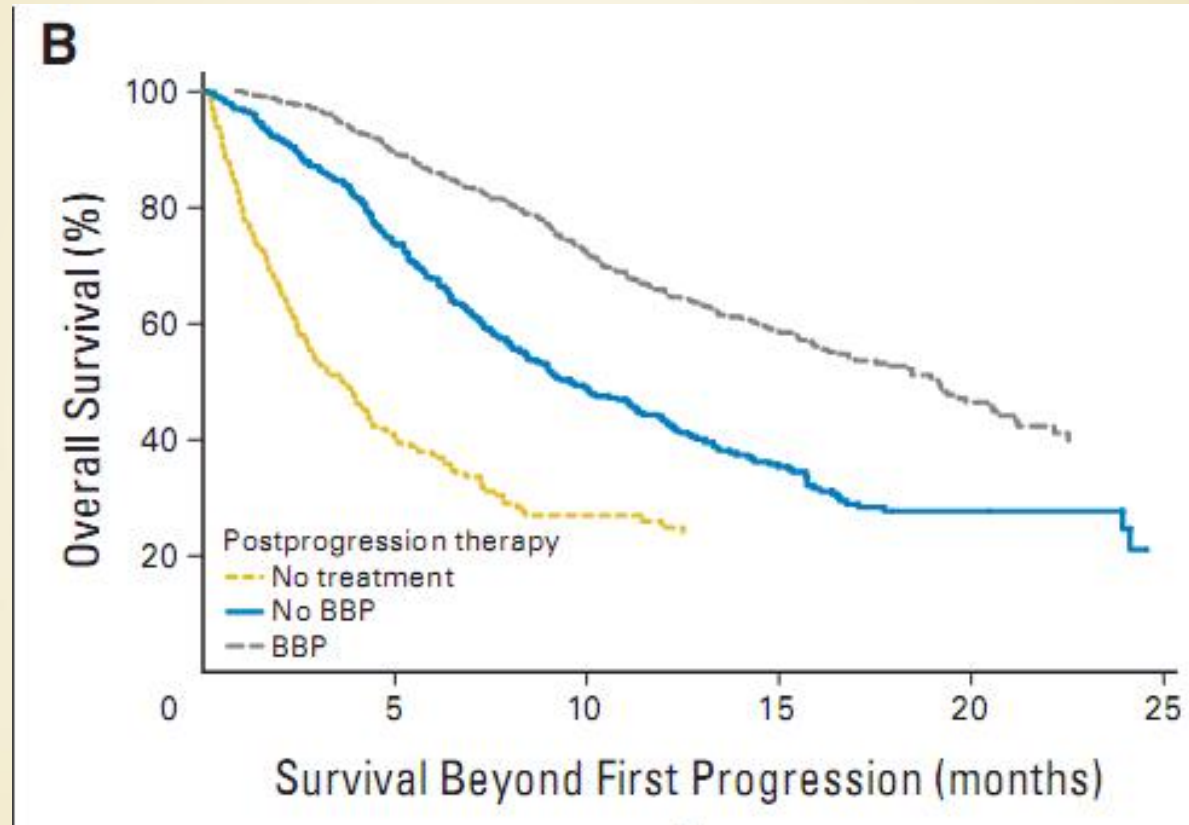
The pessimist sees difficulty in every opportunity. The optimist sees the opportunity in every difficulty

Winston Churchill



What is the Value of Opportunity?

Grothey et al. *J. Clin. Oncol.* 28, 2008



Insights into What Patients Want: What Do They Do?

Influence on Research and Treatment

- ***Experimental Drugs***
 - ***Compassionate Access / Expanded Access***
 - ***Clinical Trials as Therapeutic Options***
 - ***Off-Label Use of Drugs***
- ***Reimbursement & Insurance***

Accelerated Drug Approval Processes

- ***Efficacy & Safety Endpoints, Standards & Timelines***



Value is More Than Cost or Price

- **Price to efficacy relationships**
- **Comparative clinical effectiveness vs. Cost effectiveness**
- **Value of response vs. opportunity for response**
- **Pay for performance**
- **If the patient were the payer?**



Cultural Factors & Perception of Value

- **The power of words**
 - War – Fight – Battle – Arsenal
 - Win – Survivor – Victory
- **Other words**
 - Peace – Acceptance – Preparation

“The difference between curing and healing is important and frequently misunderstood.”

A cancer patient



Value Beyond Treatment Failure

- **Life and death with dignity**
- **Referral to hospice—should not be incompatible with ongoing treatment**
- **Empowerment, Compassion, & Understanding**
- **Financial considerations**

“In reality, hope is the worst of all evils, because it prolongs man’s torments.”

Friedrich Nietzsche



The Value of What is Often Missing In Cancer Care

- **Truth**
- **Discussions of death**
- **Discussions of love**

“Life is not lost by dying; life is lost minute by minute, day by dragging day, in all the thousand small uncaring ways.”

Stephen Vincent Benét



Therapy for Advanced Stage Cancer: What Do Patients Want and Expect?

- **Return to health and normal life.**
- **A few more years, or months. . . And hope.**
- **Good quality in the time remaining.**
- **The truth.**
- **Dignity and absence of pain.**
- **A “good death.”**

*“While I thought that I was learning how to live,
I have been learning how to die.”*

Leonardo Da Vinci



Two Final Observations

“The value of a drug is based on scientific value judgments, including a clinical evaluation and an economic evaluation, and social judgments, including considerations of efficiency and effectiveness.”

National Institute for Clinical Excellence

“People who want to limit treatment options because of the cost to society are not the people doing the dying—at least not yet”

A cancer patient



Two Final Observations

“ Fair market value is defined as the cash or cash-equivalent price at which property would change hands between a willing buyer and a willing seller, both being informed of the relevant facts and neither being compelled to buy or sell.”

American Society of Appraisers

“We had to try anything that might have helped. Otherwise, the guilt would be unbearable—but maybe that’s a mistake in the end.”

Spouse of a deceased cancer patient



Thank you
for your interest in this important topic!

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