

Killing Yourself to Live: Unpacking the Paradox of Cancer Treatment

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Northwestern University Feinberg School of Medicine

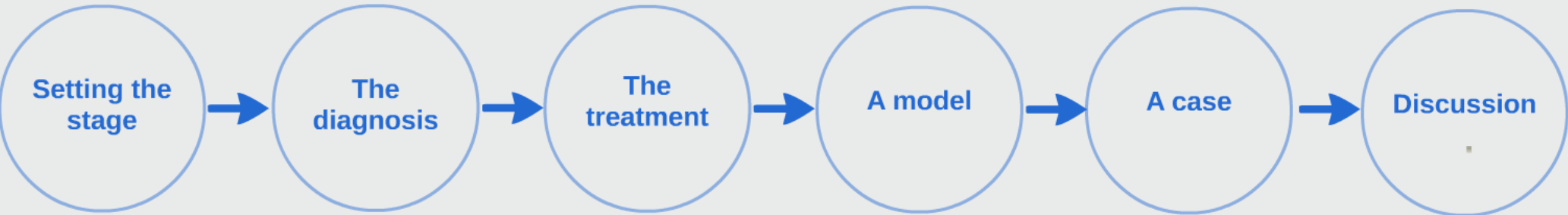
9.11.2017

Discussant

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Chief Psychologist
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Professor
Department of Psychiatry & Behavioral Sciences
Department of Pediatrics
Northwestern University Feinberg School of Medicine





**Setting the
stage**

Two defining properties of the cancer phenotype:

1) Cellular overgrowth.

2) A potential for dissemination.

Hall J. Guyton & Hall's Textbook of Medical Physiology. 13th ed. Philadelphia, PA: Elsevier, 2016.

Cellular overgrowth has probably been possible since the dawn of evolutionary history, but the potential for dissemination (and therefore damage) is more recent.

Leavitt DF, Capuzzo JM, Smolowitz RM, Miosky DL, Lancaster BA, and Reinisch CL. Hematopoietic neoplasia in *Mya arenaria*: Prevalence and indices of physiological condition. *Marine Biology*. 1990;105(2):313-321

Lichtenstein AV. On the evolutionary origin of cancer. *Cancer Cell Int*. 2005;5(1):5.

Most organisms don't live long enough for cellular overgrowth to pose a practical problem.

Humans are different.

For the vast majority of human history, cancer has been a death sentence.

Handwritten text in Arabic script, likely a manuscript page. The text is dense and appears to be a list or a collection of entries, possibly related to a historical or scientific record. The script is cursive and characteristic of the Ottoman or Mughal periods. The page contains approximately 25 lines of text, with some lines starting with large, decorative letters. The text is written in black ink on a light-colored background.

~A 3,600 year-old
document that contains
the earliest-known
description of cancer

Hajdu SI. A note from history: landmarks in history of cancer, part 1. *Cancer*. 2011;117(5):1097-102.

"Examination: If you treat a man for ball-like tumors on his chest, and you find they have spread on his chest, and if you put your hand on his chest to those tumors and you find it very cold, with no warmth in it . . . then you say about him: 'one who has ball-like tumors, an ailment.'"

"Treatment: There is nothing."

U.S. National Library of Medicine: Edwin Smith's Surgical Papyrus. cebl.nlm.nih.gov/proj/flash/smith/smith.html

This really only changed in the latter half of the twentieth century with the advent of chemotherapy:

5-year cancer survival rates:

1930s: 20%

1970s: 50%

2000s: 70%

DeVita VT, and Chu E. A history of cancer chemotherapy. *Cancer Res.* 2008;68(21):8643-53.

Based on national surveillance data from 2012 to 2014:

The average American has . . .

- Just under a 40% lifetime risk of getting a cancer diagnosis
- Just over a 20% lifetime risk of dying from cancer

National Cancer Institute Surveillance, Epidemiology and End Results Program Cancer Statistics Review, 1975-2014.
seer.cancer.gov/csr/1975_2014/results_merged/sect_01_overview.pdf. Accessed September 10, 2017.

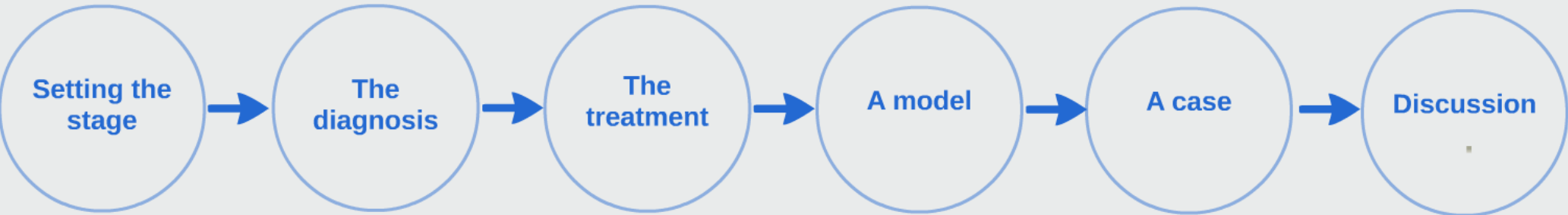
In short, since the 1970s:

- U.S. cancer rates have overall either held steady or slightly increased (and what increase exists seems attributable to changes in the relative size of age cohorts in the population).
- Cancer mortality has clearly decreased across the board.

Kort EJ, Paneth N, and Vande Woude GF. The decline in U.S. cancer mortality in people born since 1925. *Cancer Res.* 2009;69(16):6500-5.

So, at least in principle, you could say that cancer is - or should be - less of a big deal than it used to be.

And yet there's something about that diagnosis . . .





**The
diagnosis**

Questionnaire

The following questions apply to your policy about telling patients they have cancer. For the purpose of this questionnaire, assume that the diagnosis is certain and that though treatment may be possible the eventual prognosis is grave.

1. What is your usual policy about telling patients?
(check one) A. Tell.....Don't Tell.....
2. How often do you make exceptions to your rule?
(check one) A. Never.....Very Rarely.....

n = 193

Physicians (internists, ob/gyns, surgeons) at a teaching hospital (Michael Reese) in Chicago.

88% did not typically tell patients they had cancer.
12% did.

Oken D. What to tell cancer patients: a study of medical attitudes.
JAMA. 1961;175(13):1120-1128.

The attitude of the typical physician has gradually changed:

- Early 1980s: "psycho-oncology" enters the lexicon
- 2008: IOM report on "Cancer Care for the Whole Patient"

Page AE, and Adler NE. Cancer care for the whole patient: Meeting psychosocial health needs. National Academies Press; 2008.

. . . but a fear of - and discomfort with - cancer remains in the general population.

"What disease are you most afraid of?"

- 2011: USA (MetLife): 41% cancer
- 2016: UK (Aviva): 58% cancer

(Alzheimer's was a distant second in both polls)

What America thinks: MetLife Foundation Alzheimer's survey.
www.metlife.com/assets/cao/foundation/alzheimers-2011.pdf.
Accessed September 10, 2017.

Cancer most feared disease in Britain - but more than 8 million British adults take no action to reduce their risk. www.aviva.co.uk/media-centre/story/17581. Accessed September 10, 2017.

cer
(1):8643-53.

"Hundreds of publications since 1950 have suggested that the typical reaction to the diagnosis of cancer is the emotional equation in the mind of the patient that cancer = death . . . in spite of the educational effort of the medical community to make clear that 10- and 15-year relative survival rates in some cancers are as high as 90%."

Wise T, Biondi M, Costantini A. *Psycho-Oncology*. Washington, DC: APA Publishing; 2013.

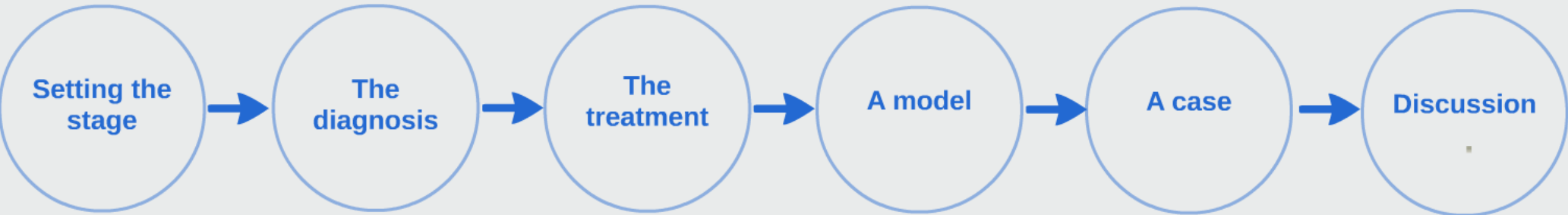
"At bottom, nobody believes in his own death . . . every one of us is convinced of his own immortality."

Freud S. Reflections on War and Death. 1915.

Breaking down the impact of a cancer diagnosis:

- 1) Existential threat of the disease
- 2) Direct social consequences
- 3) Direct physiological consequences
- 4) Treatment and its effect

Wise T, Biondi M, Costantini A. *Psycho-Oncology*. Washington, DC: APA Publishing; 2013.





**The
treatment**

Chemotherapy works
because chemotherapy is, in
a literal sense, poison.

DeVita VT, and Chu E. A history of cancer
chemotherapy. Cancer Res. 2008;68(21):8643-53.

If receiving the diagnosis is traumatic,
receiving the treatment is as well.

Short-term effects of chemotherapy:

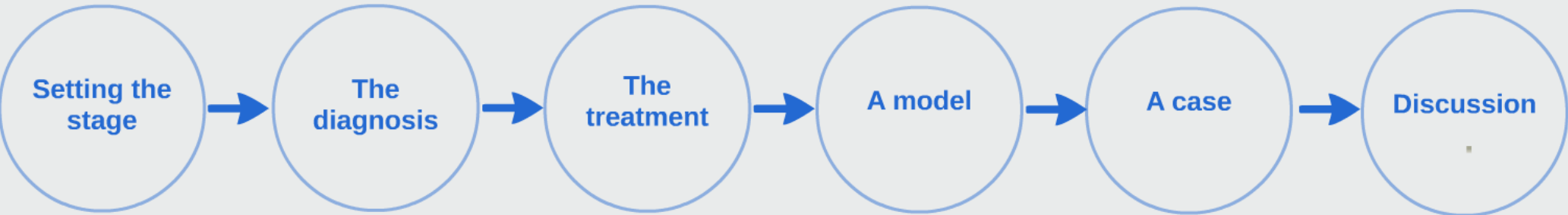
- Neurocognitive problems
- Fatigue
- Hair loss
- Taste changes

Ijpma I, Renken RJ, Gietema JA, Slart RH, Mensink MG, Lefrandt JD, Ter Horst GJ, and Reyners AK. Changes in taste and smell function, dietary intake, food preference, and body composition in testicular cancer patients treated with cisplatin-based chemotherapy. Clin Nutr. 2016.

Long-term effects of chemotherapy:

- Persistent neurocognitive problems
- Persistent fatigue
- Heart disease
- Lung disease
- Infertility
- New cancer later in life (controversial)

Ahmad SS, Reinius MA, Hatcher HM, and Ajithkumar TV.
Anticancer chemotherapy in teenagers and young adults:
managing long term side effects. BMJ. 2016:i4567.





A model

The existing literature base
re: how people cope with the
diagnosis and/or treatment
of cancer

... is somewhat less robust than one would hope.

How then to
conceptualize this?

Signal decomposition and the "cocktail party problem"

Bee MA, and Micheyl C. The cocktail party problem: what is it? How can it be solved? And why should animal behaviorists study it? J Comp Psychol. 2008;122(3):235-51.

er in life (controversial)

atcher HM, and Ajithkumar TV.
y in teenagers and young adults:
effects. BMJ. 2016;i4567.

The Cocktail Party of Cancer



Level of distress

There is an apparent correlation between level of subjective psychological distress and severity of chemotherapy-related nausea and vomiting.

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Psychiatric illness

Journal of Clinical Oncology
Volume 22, Number 12, December 15, 2004
DOI: 10.1200/JCO.2004.08.1233

Economic factors

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Coping strategy

Profiles of coping:
- "Fighting spirit"
- Hopelessness/helplessness
- Fatigue
- Anxious Preoccupation
- Cognitive avoidance

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- Pain
- Fatigue
- Neurocognitive changes

Direct physiological effects of the treatment

- Fatigue
- Pain
- Neurocognitive changes
- The so-called "ick factor"

Worthington, L. M., Dawkins, J. P., Forder, D., and Crossland, J. G. (2004). The "ick" Factor Matters: Coping Strategies Predicted Avoidance of Chemotherapy Patients. *Annals of Behavioral Medicine*, 28(3), 105-115.

Social consequences of the disease

- Embarrassment
- Fear of stigmatization

Social consequences of treatment

- Hair loss
- Disfigurement
- Change in body fat percentile

Existential threat of the cancer itself

Implications of the particular cancer diagnosis

Stephens, J. L. (2004). *The Cancer Experience*. New York: Springer.

Understanding of the disease and what it means

There is a need for a better understanding of the disease and what it means for the patient and their family. This is a key area for research and clinical practice. The aim of this research is to develop a better understanding of the disease and what it means for the patient and their family. This is a key area for research and clinical practice.

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Grassi L, Berardi MA, Ruffilli F, Meggiolaro E, Andritsch E, Sirgo A, Caruso R, Juan Linares E, Bellé M, Massarenti S, Nanni MG, and IOR-IRST Psycho-Oncology and UniFE Psychiatry Co-Authors. Role of psychosocial variables on chemotherapy-induced nausea and vomiting and health-related quality of life among cancer patients: a European study. *Psychother Psychosom.* 2015;84(6):339-47.

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Profiles of Coping

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Psychiatric illness

- Personal history of (or existing) psychiatric illness
- Family history of psychiatric illness

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- Low SES
- Limited finances
- Related problems with transportation

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- Pain
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Direct physiological effects of the treatment

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Social consequences of the disease

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Coping strategy

Profiles of coping:
- "Fighting spirit"

Profiles of coping:

- "Fighting spirit"
- Hopelessness/helplessness
- Fatalism
- Anxious Preoccupation
- Cognitive avoidance

Wastson M, Greer S, Young J et al. Development of a questionnaire measure of adjustment to cancer: the MAC scale
Psychol Med 18:203-209, 1988.

Level of distress

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Psychiatric illness

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Direct physiological effects of the cancer itself

- Pain
- Fatigue
- Neurocognitive changes

Direct physiological effects of the treatment

- Fatigue
- Pain
- Neurocognitive changes
- The so-called "ick factor"

Worsham LM, Dawicki JF, Foster D, and Crossland JG. The "ick" Factor Matters: Coping Strategies Predicts Adherence in Chemotherapy Patients. *Ann Behav Med*. 2003;25(1):105-115.

Social consequences of the disease

- Embarrassment
- Fear of stigmatization

Social consequences of treatment

- Hair loss
- Disfigurement
- Change in body fat percentile

Existential threat of the cancer itself

Implications of the particular cancer diagnosis

Journal of Clinical Oncology

Volume 23, Number 18, October 1, 2005

Implications of the Particular Cancer Diagnosis

Journal of Clinical Oncology, 23(18), 2700-2705

Understanding of the disease and what it means

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Direct physiological effects of the treatment

- Fatigue
- Pain

Neurocognitive changes

Treatment

- Fatigue
- Pain
- Neurocognitive changes
- The so-called "ick factor"

Reynolds LM, Bissett IP, Porter D, and Considine NS. The "ick" Factor Matters: Disgust Prospectively Predicts Avoidance in Chemotherapy Patients. *Ann Behav Med.* 2016;50(6):935-945.

Level of distress

There is an apparent correlation between level of subjective psychological distress and severity of chemotherapy-related nausea and vomiting.

Wong, S. M., & Chan, A. T. (2008). Correlation between subjective psychological distress and severity of chemotherapy-related nausea and vomiting. *Journal of Clinical Oncology*, 26(12), 2008-2013.

Psychiatric illness

Journal of Clinical Oncology

Volume 26, Number 12, December 15, 2008

DOI: 10.1200/JCO.2008.16.8222

Economic factors

Journal of Clinical Oncology

Volume 26, Number 12, December 15, 2008

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Coping strategy

Profiles of coping:
- "Fighting spirit"
- Hopelessness/helplessness
- Fatigue
- Anxious Preoccupation
- Cognitive avoidance

Wong, S. M., Chan, A. T., & Chan, A. T. (2008). Development of a questionnaire to measure coping strategies in cancer patients. *Journal of Clinical Oncology*, 26(12), 2008-2013.

Direct physiological effects of the cancer itself

- Pain
- Fatigue
- Neurocognitive changes

Direct physiological effects of the treatment

- Fatigue
- Pain
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Social consequences of the disease

- Embarrassment
- Fear of stigmatization

Social consequences of treatment

- Hair loss
- Disfigurement
- Change in body fat percentile

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Social consequences of the disease

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Psychiatric illness

Journal of Clinical Oncology

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Psychiatric Illness in Patients with Cancer

Journal of Clinical Oncology, 23(12), 2100-2105

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Volume 23, Number 12, December 15, 2005

Economic Factors in Cancer Care

Journal of Clinical Oncology, 23(12), 2100-2105

Coping strategy

Journal of Clinical Oncology

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Profiles of Coping in Cancer Patients

Journal of Clinical Oncology, 23(12), 2100-2105

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Direct physiological effects of the cancer itself

- Pain
- Fatigue
- Neurocognitive changes

Direct physiological effects of the treatment

- Fatigue
- Pain
- Neurocognitive changes
- The so-called "ick factor"

Wernisch LM, Dawicki JF, Finkel D, and Cozzolino SJ. The "ick" Factor Matters: Coping Strategies Predicts Adherence in Chemotherapy Patients. *Ann Behav Med*. 2003;26(1):105-115.

Social consequences of the disease

- Embarrassment
- Fear of stigmatization

Social consequences of treatment

- Hair loss
- Disfigurement
- Change in body fat percentile

Existential threat of the cancer itself

Implications of the particular cancer diagnosis

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Volume 23, Number 12, December 15, 2005

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Understanding of the disease and what it means

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Understanding of the Disease and What It Means

Journal of Clinical Oncology, 23(12), 2100-2105

Social consequences of treatment

- Hair loss
- Disfigurement
- Change in body fat percentile

LI TALKING POINTS

- Hair loss
- Disfigurement
- Change in body fat percentile

Level of distress

There is an apparent correlation between level of subjective psychological distress and severity of chemotherapy-related nausea and vomiting.

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Psychiatric illness

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Economic factors

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- Fatigue
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Worthington, L. M., Dawkins, J. P., Forder, D., and Crossland, J. G. (2011). Patient Matters: Coping Strategies Predicts Adherence in Chemotherapy Patients. *Annals of Behavioral Medicine*, 42(3), 195-205.

Social consequences of the disease

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Wortman, J. B., & Taylor, S. E. (1986). Development of a 6-item measure of coping strategies: The SBC scale. *Journal of Personality and Social Psychology*, 51(2), 220-229.

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Implications of the particular cancer diagnosis

- Stage of life
- Stage of the cancer

- Stage of life
- Stage of the cancer

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There is an apparent correlation between level of subjective psychological distress and severity of chemotherapy-related nausea and vomiting.

Wong, S. M., & Chan, A. T. (2004). Correlation between subjective psychological distress and severity of chemotherapy-related nausea and vomiting. *Journal of Clinical Oncology*, 22(12), 2281-2286.

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Understanding of the disease and what it means

"There's people that work for me, just the other day, two years old, two and a half years old, a child, a beautiful child, went to have the vaccine, and came back, and a week later got a tremendous fever, got very, very sick, now is autistic."

Miller M. The GOP's dangerous "debate" on vaccines and autism. Washington Post. www.washingtonpost.com/news/morning-mix/wp/2015/09/17/the-gops-dangerous-debate-on-vaccines-and-autism. Accessed September 10, 2017.

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Psychiatric illness

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Economic factors

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Social consequences of treatment

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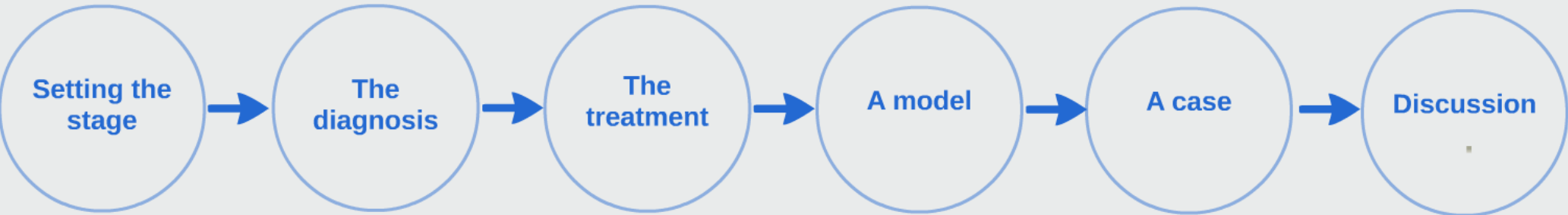
Existential threat of the cancer itself

Implications of the particular cancer diagnosis

Stephens, G. L. (2004). *The Cancer Experience*. New York: Springer.

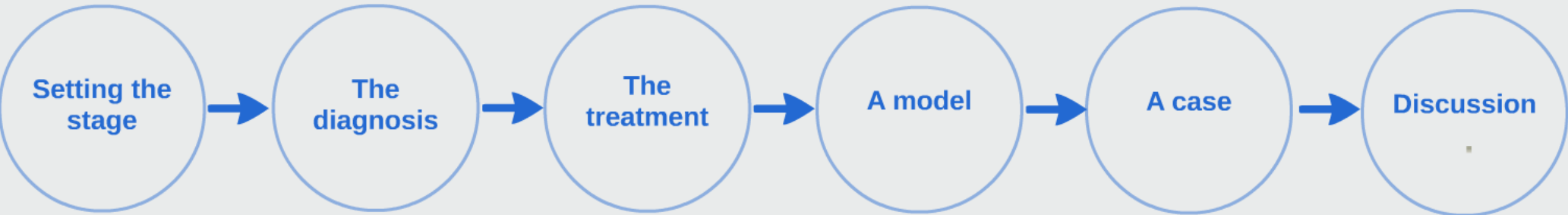
Understanding of the disease and what it means

There is a need for a better understanding of the disease and what it means. This is a key area for research and clinical practice. The aim of this research is to develop a better understanding of the disease and what it means for patients and their families.





A case





Discussion





Laura Aguiar