

Receipt of Treatment Summaries and Care Plans among Cancer Survivors:
Data from the 2012 LIVESTRONG Survey and HINTS 2012

Stephanie Nutt, MA, MPA; Ellen Beckjord, MPH, PhD; Ruth Rechis, PhD
LIVESTRONG Foundation; University of Pittsburgh

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Overview

- Conceptual framework for analyses
- Characteristics of respondents in HINTS 2012, Cycle 2 and the 2012 **LIVESTRONG** Survey
- Comparison of receipt of treatment summary, survivorship care plan, and follow up instructions
- Associations between TS, SCP and follow up instructions on survivors' health self-efficacy (HINTS) or sense of empowerment (**LIVESTRONG**)

Diagnosis

End of treatment

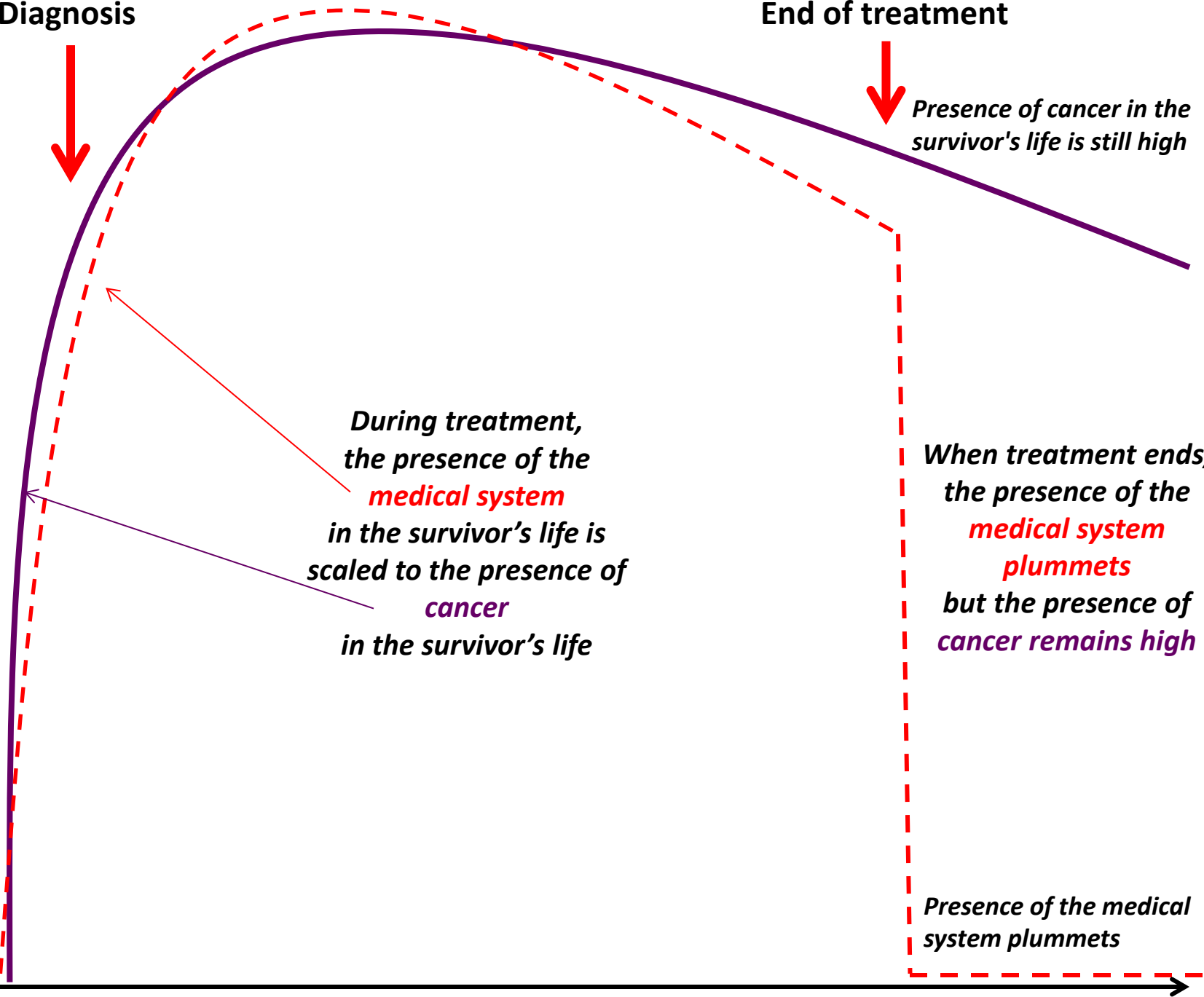
Presence of cancer in the survivor's life is still high

*During treatment, the presence of the **medical system** in the survivor's life is scaled to the presence of **cancer** in the survivor's life*

*When treatment ends, the presence of the **medical system** plummets but the presence of **cancer** remains high*

Presence of the medical system plummets

TIME



Questions asked

HINTS

- Did you ever receive a summary document from your doctor or other health care professional that listed all of the treatments you received for your cancer?
- Have you ever received instructions from a doctor or other health care professional about where you should return or who you should see for routine cancer check-ups after completing your cancer treatment?

LIVESTRONG Survey

- Did any doctor, nurse or other health professional EVER give you a summary of all cancer treatments you received?
- Have you EVER received instructions from a doctor, nurse, or other health professional about where you should return or who you should see for routine cancer check-ups after completing your treatment for cancer?
- Have you ever received a Survivorship Care Plan, a document which includes a comprehensive care summary and follow-up plan that includes critical information about your long term care?

This survivor receives a treatment summary and care plan when treatment ends.



Autonomy

Autonomy is supported by awareness of what to expect after treatment ends and having choice in options to promote health and wellness.

Competency

Competency is supported by knowing what follow-up care protocols are recommended and how to adhere to them.

Relatedness

Relatedness is supported by having a tether to the treatment team and a clear sense as to when, why, and how to reach out to them.

Better



Efficacy



&
Empowerment

Worse

Treatment ends



Autonomy is undermined by confusion about what to expect after treatment ends and lacking guidance on options to promote health and wellness.

Competency is undermined by uncertainty about what follow-up care protocols are recommended and how to adhere to them.

Relatedness is undermined by having no tether to the treatment team and no sense as to when, why, and how to reach out to them.

This survivor does not receive a treatment summary and care plan when treatment ends.



Methodology

HINTS

- Collected between October 2012 and January 2013
- Mailed questionnaire
- N = 3,630; cancer survivors who had completed treatment = 426

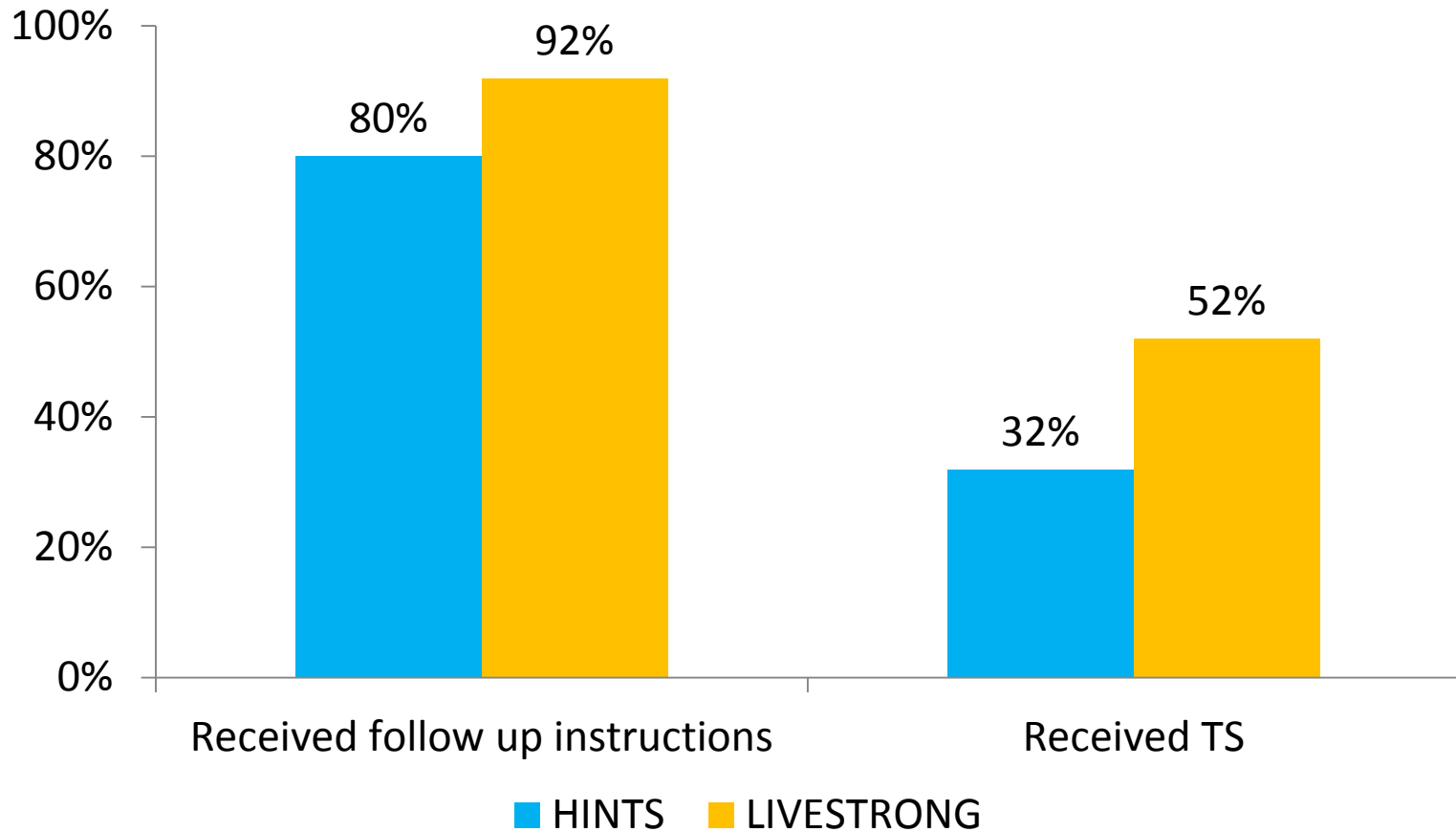
LIVESTRONG Survey

- Online survey fielded from June 2012-December 2012
- Based on Medical Expenditures Panel Survey, Cancer Survivorship Supplement
- N = 6,383; cancer survivors who had completed treatment = 5,274

Demographics compared

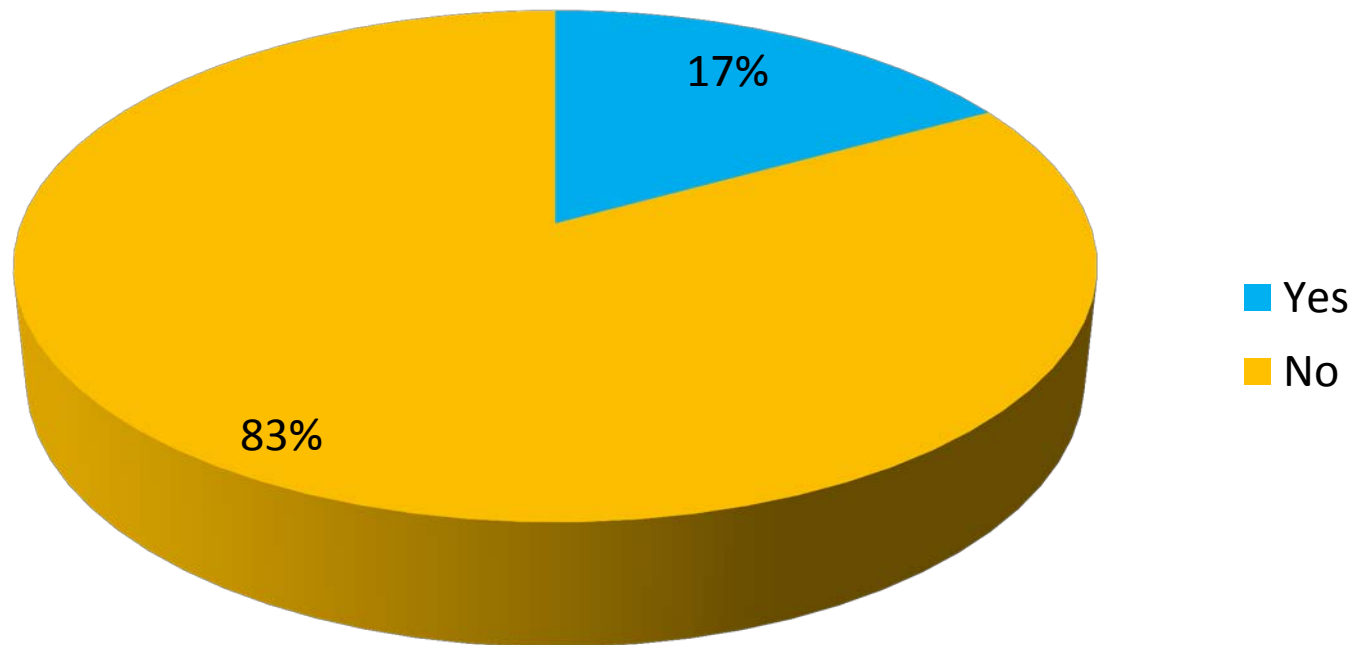
Characteristic	HINTS Percentage	LIVESTRONG Percentage
Female	55%	61%
White	80%	93%
College graduate or higher	24%	62%
Have health insurance	92%	96%
Yearly Income > \$75K	31%	40%
Time since dx	11.37 years	7.29 years

Receipt of TS and/or follow up instructions



Have you ever received a Survivorship Care Plan?

LIVESTRONG Sample only



Relationships between TS, follow-up instructions, and survivor characteristics: HINTS

- Multivariate logistic regression was used to model the odds of having received a TS or follow-up instructions
- The models included age, gender, education, race/ethnicity, income, health insurance, and time since diagnosis
- Only gender was associated with receipt of TS; women had **lower odds** of receiving a TS compared to men (OR = 0.51 (95% CI = 0.25, 1.02))
- No survivor characteristics were associated with receipt of follow-up instructions

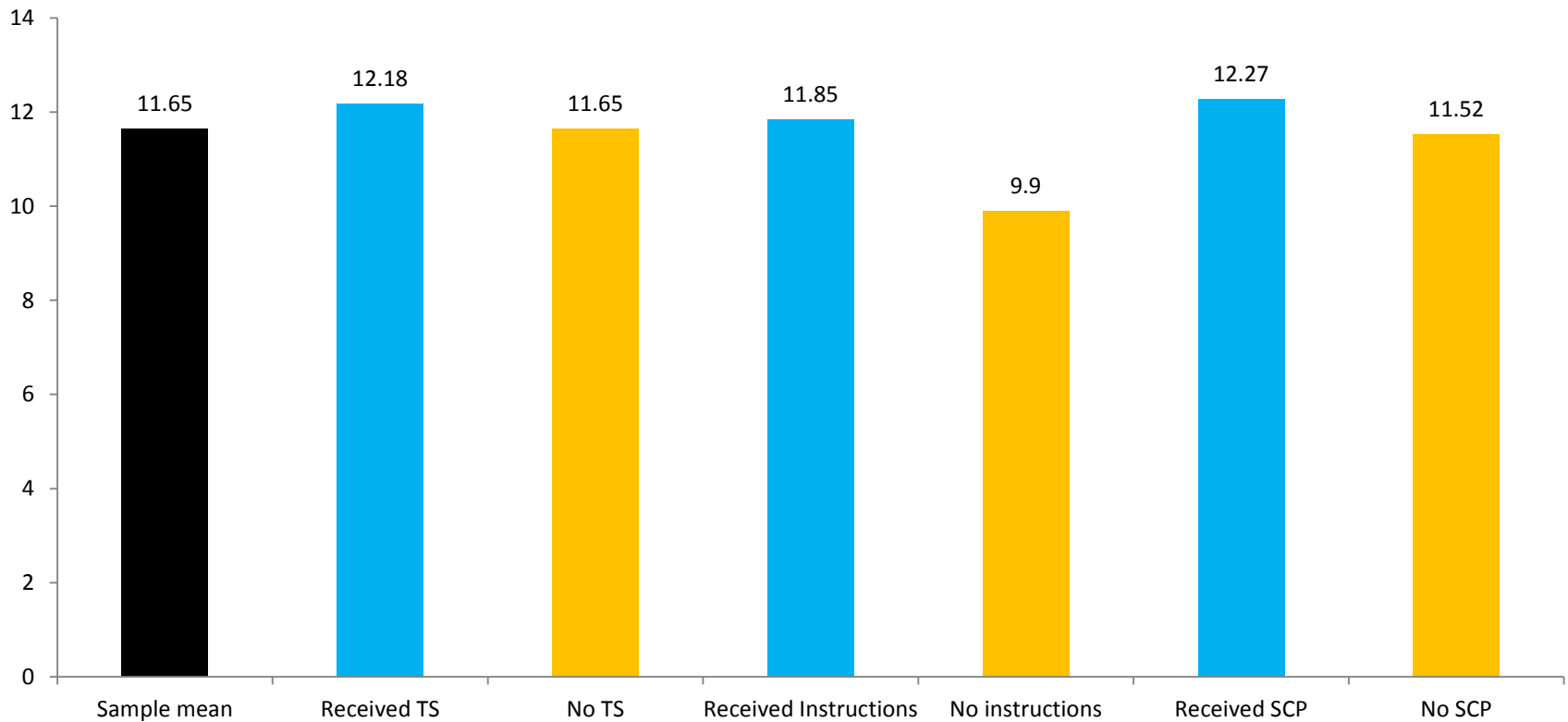
Relationships between TS, follow-up instructions, SCP, and survivor characteristics: LIVESTRONG

- Men and survivors closer to time of diagnosis had significantly **higher odds** of receiving TS, follow-up instructions, and SCP
- Non-white race/ethnicity and higher education were also associated with **higher odds** of having received a TS
- White race/ethnicity and having health insurance were also associated with **higher odds** of having received follow-up instructions or a SCP

How do TS, follow-up instructions, and SCPs relate to health-self efficacy/empowerment?

- In HINTS, survivors were asked: “How confident are you that you can take care of your health?”
- In the **LIVESTRONG** Survey, survivors were asked
 - How confident are you that you can talk to your doctor?
 - That you can make your self feel better?
 - That you can get emotional support?
 - $\alpha = 0.80$

Estimated Self-Advocacy Scores Adjusted for Sociodemographic and Medical Characteristics



What have we learned?

- Receipt of TS and care plans are not majority
- Associations with time since diagnosis – particularly in the **LIVESTRONG** data – may suggest positive changes in practice
- Continued work is needed to understand the associations observed in HINTS and **LIVESTRONG** regarding gender and receipt of TS, follow-up instructions

Questions?