Is there something wrong with my body? Symptom vigilance and health uncertainty in pediatric pain

Lauren Heathcote, PhD

Associate Professor of Health Psychology King's College London

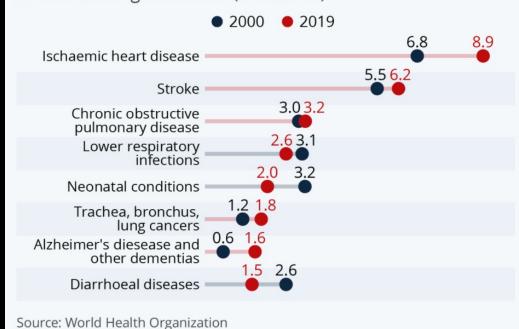






The World's Leading Causes Of Death

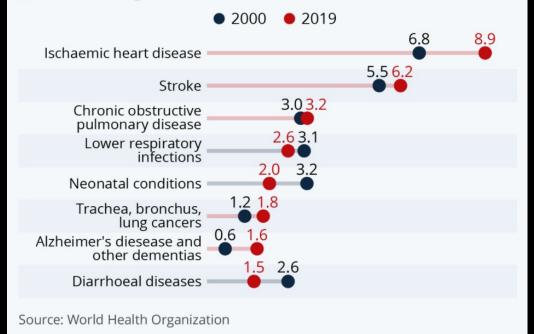
Total number of people who died from the following conditions (in millions)



https://www.weforum.org/agenda/2021/02/top-10-global-causes-death/

The World's Leading Causes Of Death

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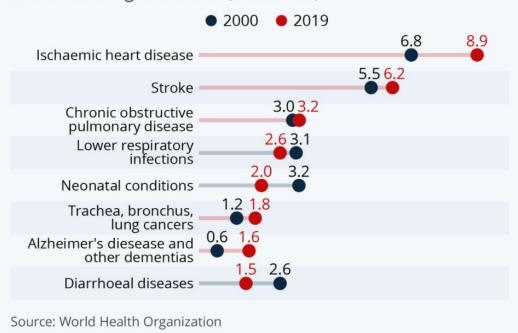


Relapsing-remitting conditions (IBD, cancer)

Chronic conditions (somatic symptom disorders)

The World's Leading Causes Of Death

Total number of people who died from the following conditions (in millions)



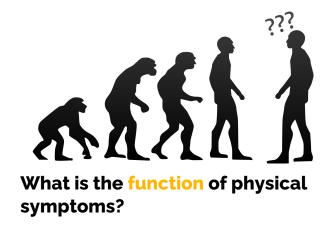
Relapsing-remitting conditions (IBD, cancer)

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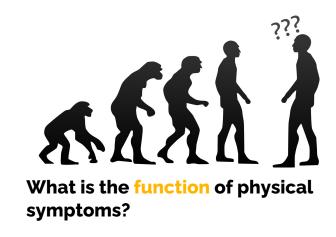
physical symptoms are a primary (but often ambiguous, non-specific) source of information with high motivational value in situations of health-related uncertainty

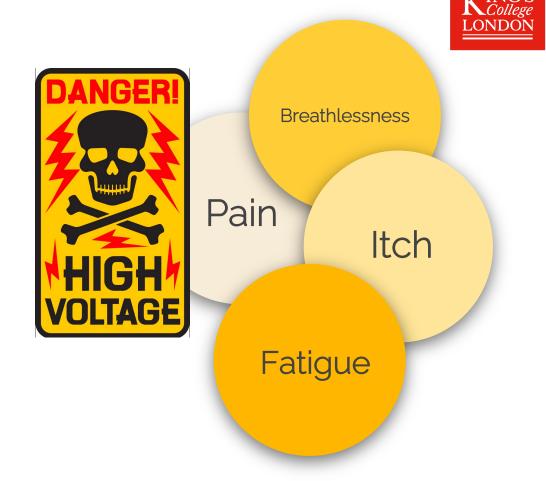
https://www.weforum.org/agenda/2021/02/top-10-global-causes-death/





















Uncertainty in pediatric chronic pain





Article

Something Else Going On? Diagnostic Uncertainty in Children with Chronic Pain and Their Parents

Vivek Tanna ¹, Lauren C. Heathcote ¹, Marissa S. Heirich ¹, Gillian Rush ¹, Alexandra Neville ^{2,3}, Melanie Noel ^{2,3,4}, Joshua W. Pate ⁵ and Laura E. Simons ^{1,*}

Table 1. Three-item measure of perceived diagnostic uncertainty.

Item	Answer
1. I have been given a clear label/diagnosis for my (my child's) chronic pain.	Yes/No
a. What label/diagnosis have you been given?	(open)
b. Generally speaking, I agree with this label/diagnosis.*	Yes/No
2. I have been given a clear explanation about why I have (my child has) chronic pain.	Yes/No
a. Generally speaking, I agree with this explanation.	Yes/No
3. I think there is something else happening with my (my child's) chronic pain which the doctors have not found out about yet.	Yes/No
a. What do you think is going on that the doctors have not found out about yet?	(open)



ORIGINAL ARTICLE



How does pain work? A qualitative analysis of how young adults with chronic pain conceptualize the biology of pain

Hayley B. Leake^{1,2} ○ | G. Lorimer Moseley¹ ○ | Lexa K. Murphy³ ○ | Caitlin B. Murray^{4,5} | Tonya M. Palermo^{4,5} ○ | Lauren C. Heathcote⁶ ○



FIGURE 1 The relationship between the themes describing how young adults conceptualize the biology of pain.

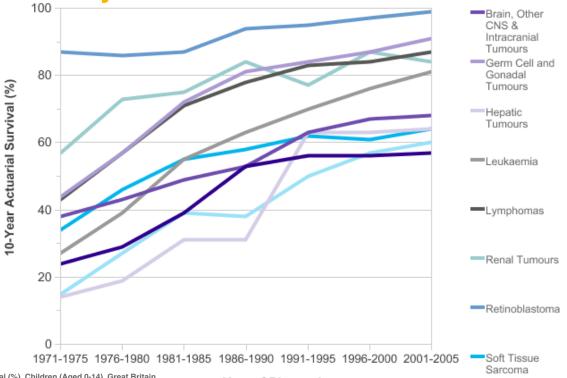


Bone Sarcoma

Childhood Cancer Survivors

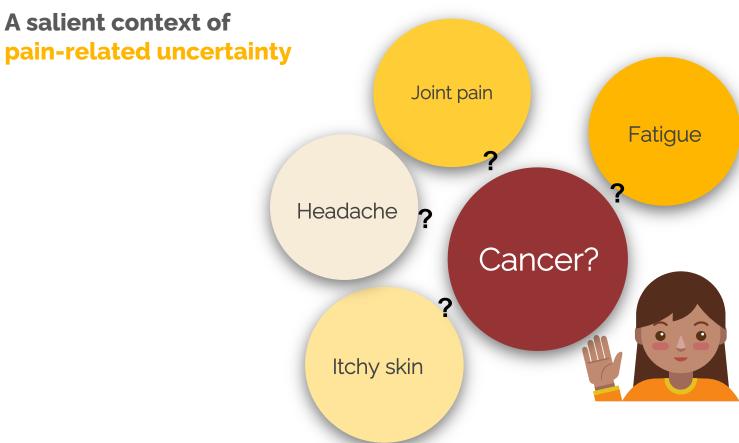
A salient context of

pain-related uncertainty





Childhood Cancer Survivors





Pain is a common sign of cancer - informs diagnosis





Clinical instruction to be vigilant

Personal View The Lancet Oncology

Advancing shared decision making for symptom monitoring (in people living beyond cancer



Lauren C Heathcote, Daniel S Goldberg, Christopher Eccleston, Sheri L Spunt, Laura E Simons, Louise Sharpe, Brian D Earp



Topical Review

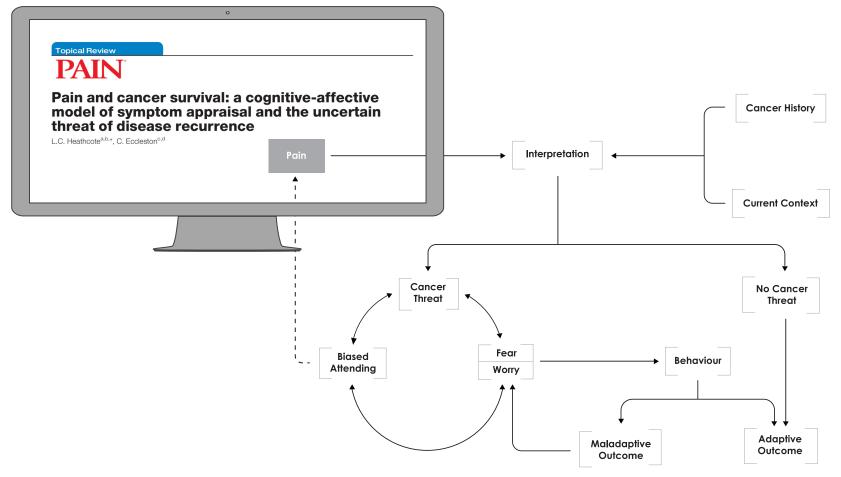


Pain and cancer survival: a cognitive-affective model of symptom appraisal and the uncertain threat of disease recurrence

L.C. Heathcote^{a,b,*}, C. Eccleston^{c,d}







Cancer Threat Interpretation (CTI) Model



Capturing lived experience of pain-related uncertainty



Childhood cancer survivorship is laden with uncertainty about symptoms



PSYCHOLOGY & HEALTH 2021, VOI. 36, NO. 10, 1182-1199 https://doi.org/10.1080/08870446.2020.1836180



Symptom appraisal in uncertainty: a theory-driven thematic analysis with survivors of childhood cancer

Lauren C. Heathcote^{a*} , Nele Loecher^{a*}, Pamela Simon^b, Sher Abbie Jordan^d, Perri R. Tutelman^e, Sarah Cunningham^a, Lidia Scl Laura E. Simons^a

^aDepartment of Anesthesiology, Perioperative, and Pain Medicine, Stanford Univ-Medicine, Stanford, CA, USA; Department of Pediatric Hematology-Oncology, Lu Children's Hospital Stanford, Palo Alto, CA, USA; 'Department of Pediatrics, Stant childhood cancer School of Medicine, Stanford, CA, USA: dDepartment of Psychology & Centre for University of Bath, Bath, UK: eDepartment of Pediatrics, Dalhousie University, Hal CA, USA

Objective: Somatic symptoms capture attention, demand interpretation, and promote health behaviors. Symptom appraisal is particularly impactful within uncertain health contexts such as cancer survivorship. Yet, little is known about how individuals make sense of somatic symptoms within uncertain health contexts, nor how this process guides health behaviors.

Design: 25 adolescent and young adult survivors of childhood cancer completed semi-structured interviews regarding how they appraise and respond to changing somatic sensations within the uncertain context of survivorship.

Main Outcome Measures: Interviews were transcribed verbatim and subjected to a hybrid deductive-inductive thematic analysis. guided by the Cancer Threat Interpretation model.

Results: We constructed three themes. Symptoms as signals of bodily threat (theme 1) captured that participants described commonly interpreting and worrying about everyday sensations as indicating cancer recurrence or new illness. Playing detective with bodily signals (theme 2) captured participants' felt need to employ cognitive and behavioral strategies to determine whether somatic sensations indicated a credible health threat. These two themes are qualified by the final theme, Living with symptom-related uncertainty (theme 3), which captured participants' recognition that post-cancer symptoms are wily and influenced by psychological factors such as anxiety.

Conclusions: These data highlight that making sense of everday somatic sensations can be particularly challenging following an experience of cancer. There is a need for novel symptom management approaches that target how somatic sensations are appraised and responded to as signals of bodily threat.

WILEY

When "a headache is not just a headache": A qualitative examination of parent and child experiences of pain after

Canada; Department of Medical Oncology, Stanford University School of Medicin Conrad V. Fernandez^{5,6} O | Lauren C. Heathcote⁷ O | Melanie Noel^{8,9} O | Annette Flanders⁶ | Gregory M.T. Guilcher^{10,11} | Fiona Schulte^{11,12} | Jennifer N. Stinson^{13,14} IJulia MacLeod¹⁵ Maya Stern¹⁶

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> 5 Department of Pediatrics, Dalhousie University, Halifax, Nova Scotia, Canada ⁶ Division of Pediatric Hematology-Oncology, IWK Health Centre, Halifax, Nova Scotia,

⁷ Department of Anesthesiology Perioperative and Pain Medicine. Stanford University Medical School, Stanford, California, USA ⁸ Department of Psychology University of Caleary Caleary Alberta Canada 9 Alberta Children's Hospital Research Institute University of Calgary, Calgary, Alberta, Canada 10 Departments of Paediatrics and Oncology University of Calgary, Calgary, Alberta, Canada 11 Haematology, Oncology and Transplant

Program, Alberta Children's Hospital, Calgary, Alberta, Canada 12 Department of Oncology, University of Calgary, Calgary, Alberta, Canada

13 Child Health Evaluative Sciences. The Hospital for Sick Children, Toronto, Ontario ¹⁴Lawrence S Bloomberg Faculty of Nursing. University of Toronto, Toronto, Ontario,

15 Patient Partner, Halifax, Nova Scotia, Canada ¹⁶ Patient Partner Toronto Ontario Canada

Abstract

Objective: Today, more than 80% of children diagnosed with cancer are expected to survive. Despite the high prevalence of pain associated with the diagnosis and treatment of childhood cancer, there is a limited understanding of how having cancer shapes children's experience and meaning of pain after treatment has ended. This study addresses this gap by exploring childhood cancer survivors' (CCS') experiences of pain from their perspective and the perspective of their parents

Methods: Twenty semi-structured interviews were completed with CCS (50% female: mean age = 13.20 v. range = 8-17 v) and their parents (90% mothers). Data were analyzed using interpretive phenomenological analysis.

Results: Analyses revealed three superordinate themes present in the data: (a) pain is a changed experience after childhood cancer; (b) new or ambiguous pains may be interpreted by CCS and parents as a threat of disease recurrence, late effects, or a secondary cancer: and (c) pain interpretation occurs within the broader context of how CCS and parents appraise their cancer experience. Parents generally appraised their child's cancer and pain as more threatening and were influential in guiding their child's interpretations

Conclusions: The cancer experience played an important role in shaping CCS' and their parents' experience and interpretation of pain in survivorship. This study provides novel data to inform the development and refinement of new and existing conceptual models of pain and symptom perception after cancer. The results also point to key areas for future investigation and clinical intervention to address the issue of pain in cancer survivorship.

cancer, cancer pain, childhood cancer survivors, interpretive phenomenological analysis, oncology nediatric pain qualitative research

Psycho-Oncology, 2019:1-9.

wilevonlinelibrary.com/journal/pon

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Symptom appraisal in uncertainty: a theory-driven thematic analysis with survivors of childhood cancer

Lauren C. Heathcote^{a*} , Nele Loecher^{a*}, Pamela Simon^b, Sheri L. Spunt^c, Abbie Jordan^d, Perri R. Tutelman^e, Sarah Cunningham^a, Lidia Schapira^f and Laura E. Simons^a

In-depth, semi-structured interviews with 25 AYA cancer survivors and their parents









Cancer Type

- Leukemia (44%)
- Osteosarcoma (24%)
- Ewing Sarcoma (12%)
- Lymphoma (12%)
- Wilms Tumor (4%)
- Germinoma (4%)





What is uncertain about pain after cancer?

"I have a headache! Does that mean my tumor's back or does that just mean I have a headache?"

"there is that precarious line that we all walk, not wanting to be a paranoid mess on one side and being vigilant on the other"

"it doesn't matter how much you tell yourself you are being irrational and the pain is probably nothing, the mind eventually wins over reason"

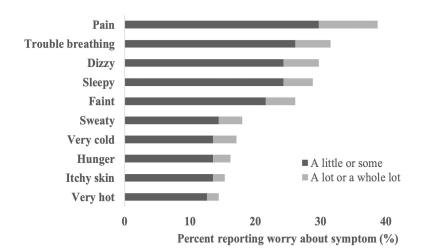


Quantifying pain-related uncertainty



Worry about somatic symptoms as a sign of cancer recurrence: prevalence and associations with fear of recurrence and quality of life in survivors of childhood cancer

Sarah J. Cunningham¹ | Michaela Patton² | Fiona Schulte^{2,3,4} | Patricia A. Richardson^{5,6} | Lauren C. Heathcote¹









Unique associations of pain frequency and painrelated worry with health-related quality of life in survivors of childhood cancer

Lauren C. Heathcote^{a,b}, Sarah J. Cunningham^b, Michaela Patton^c, Fiona Schulte^{c,d,e}

Table 2	
Hierarchical linear regression models for physical and emotional h	ealth-related quality of life.
Physical HROol	Emotional HROol

	Physical HRQoL			Emotional HRQoL		
	В	R²	F	β	R²	F
Step 1	11111111111	0.19	7.62***		0.18	6.56***
Time off treatment	-0.08			0.12		
Age at diagnosis	-0.29**			-0.07		
Sex	-0.35***			-0.36***		
Step 2		0.40	15.38***		0.22	6.52***
Time off treatment	0.03			0.17		
Age at diagnosis	-0.12			0.01		
Sex	-0.24**			-0.31**		
Pain frequency	-0.49***			-0.23*		
Step 3		0.46	15.23***		0.26	6.45***
Time off treatment	0.04			0.18		
Age at diagnosis	-0.10			0.03		
Sex	-0.22**			-0.29**		
Pain frequency	-0.37***			-0.13		
Pain worry	-0.27**			-0.23*		

 $^{^*}P$ < 0.05, **P < 0.01, $^{***}P$ < 0.001. HRQoL, health-related quality of life.

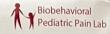


Can we reduce symptom uncertainty?





International Survey of Pediatric Oncologists' Beliefs, Attitudes, and Communication Practices Regarding Symptom Self-Monitoring for Childhood Cancer Survivors



Background

their cancer may return.

nicians

practices.

knowing how to monitor and interpret physical symptoms while living with the uncertainty that

The child's oncologist plays a central role in

guiding the patient's symptom self-monitoring

Little is known about how pediatric oncologists

communicate about symptom self-monitoring, and

n be a source of distress for their off-therapy

Methods

all sampling recruitment technique dents were asked 22 items regarding symptom

This study aims to ..

patients

hether they believe that symptom self-monitoring

nitoring for off-therapy survivors of childhood

nderstand pediatric oncologists' attitudes,

99% of

clinicians

encourage self-

monitoring with

off-therapy

patients at some

point

2% discuss which

symptoms could

indicate a

recurrence and

3% discuss which

were unlikely to

indicate a

recurrence

, and communication styles regarding

m self-monitoring for their off-therapy

Sarah N. Webster, Sarah J. Cunningham, Sheri L. Spunt, Claire Wakefield, Stephanie Smith, Nicole M. Alberts, Oxana Palesh, Laura Simons, Lauren C. Heathcote Childhood cancer survivors face a lifetime of physical and mental health challenges, including

Department of Anesthesiology, Perioperative and Pain Medicine, Stanford University

tend to proactively stress much more the xiety that goes with finishing therapy and mptoms that may arise that are not going to be recurrence than belabouring the symptoms in detail. This arises from my programmed of having a few logs.



I try to tailor my conversations based on patient/parent level of ty. Sometimes it is difficult to the balance of keeping them rmed without causing more

"ALL of my patients experience a high level of anxiety about their cancer Female Leuk/Lymph

returning, even after more than 10 years"

· Caregivers and management an of pediatric SCA . This qualitative s

perceived discrin potential solution discrimination am

Participants

· Adult caregivers of

from two SCA clinic

Hydroxyurea/Penici · Providers were recn aligible if they were

Participants

- •196 international cohort of pediatric oncologists
- ·Mean age: 47 •78% White, 11% Black, 1.5% Asian •64% Female
- *40% had practiced medicine for over 15 years
- *52% General Hem/Oncology *30% Solid Tumor
- *18% Lymphoma/Leukemia



Results

Disease Specialization...

Leuk/Lymph oncologists feel more confident informing patients about which symptoms they should be concerned about (F.(2,193)=.319, p=.05) compared to Gen Hem/Oncologists

Gen Hem/Oncologists are more likely to encourage self-monitoring for signs of treatment late effects (F,(2,193)=2.974, p=.053) compared to oncologists who focus on solid tumors

Gen Hem/Oncologists are more likely to only encourage symptom monitoring for patients who have a high risk for cancer recurrence or late effects of treatment (F.(2,193)=3.84, p=.024) compared to Leuk/Lymph oncologists

Over 15 years of experience...

More likely to endorse that their offtherapy patients worry unnecessarily about symptoms of late effects of treatment (t=.2.53, p=.012)

More likely to discuss which symptoms are likely (t=-2.48, p=.011) and unlikely (t= -2.31, p=.022,) a sign of late effects

More likely to worry that encouraging symptom monitoring will lead to additional clinic visits or inquiries (t=2.38, p=.018)

Perceived Stress and Worry...

to reduce anxiety

Almost one third of pediatric oncologists worry that encouraging symptom self-monitoring would cause their patients to experience unnecessary stress.

These oncologists encourage selfmonitoring significantly less often for symptoms of cancer recurrence (t=4.47, p<.001) and treatment late effects (t=2.82 p=.005)

More likely to directly ask patients if they ever worry that symptoms are a sign of late effects of treatment (t=2.45,

I would use a brief screening tool to and how much my off-



· 28 English-speaking

interviews exploring (

 11 female and majori 30-minute interviews system in outpatient I

Data Analysis

· Data were transcribed respondent type and a Sneigrove, 2019).

Data collection continue

tological Association

Webster et al



. High disease

· Childhood expe

nonadherence

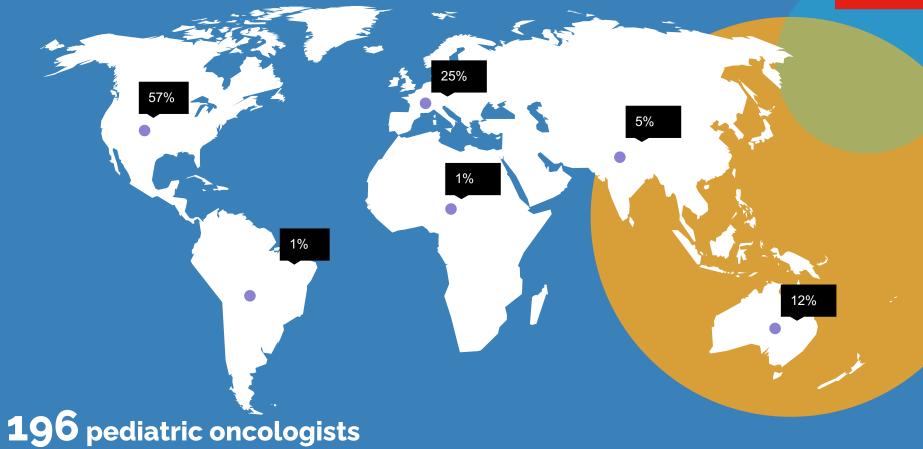
Rfespan (Burne

. To date, few stu

conceptualized.

to disease- and Sickle Cell Ane



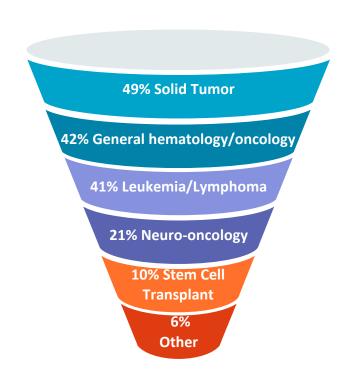


Webster et al (2023), JCO Oncology Practice



77.6% spend more than 50% of their time in direct patient care

Sample







Symptom self-monitoring is perceived as important and can be encouraged

Most clinicians believed that **it is important** for their off-therapy patients to...

self-monitor for symptoms of cancer recurrence 90% self-monitor for symptoms of treatment late effects 94%

Results

Although some acknowledged that these are typically detected by routine surveillance **before symptoms appear**...

cancer recurrence 30% treatment late effects 55%

Almost all clinicians reported...

encouraging symptom self- monitoring with their offtherapy patients at some point 99%





Large heterogeneity in perception of unnecessary worry and communication practices

Do off-therapy patients worry unnecessarily about symptoms of cancer recurrence?

Yes 31% No 31% Neutral 38%

Results

Do off-therapy patients worry unnecessarily about symptoms of late effects?

Yes 14% No 50% Neutral 36%

62% discussed which symptoms could indicate recurrence

43% discussed which symptoms were *unlikely* to indicate recurrence

Information is Power



\$

I try to **empower the patients** with knowledge about their disease and the risks of recurrence so that they have some control. I therefore think it is an important part of follow-up appointments with this age. *-Female, Solid Tumors*

Important to **empower patients** about self-care and symptom awareness. *-Female, General Hem/Onc*





A Fine Balance Between Informed & Worried

Sometimes it is **difficult to find the balance** of keeping them informed without causing more stress. *-Female, General Hem/Onc*

I try to tailor my conversations based on patient/parent level of anxiety. Sometimes it is **difficult to find the balance** of keeping them informed without causing more stress. *-Female, General Hem/Onc*



ŧ

The Patient Doctor

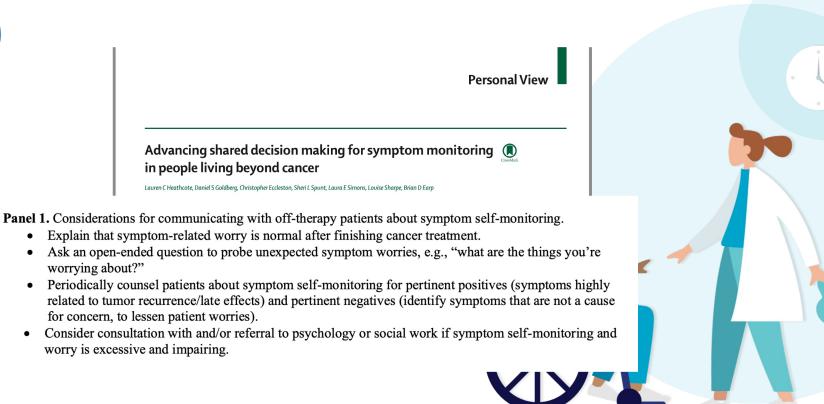
I tend to proactively stress much more the **anxiety** that goes with finishing therapy and symptoms that may arise that are **not going to be recurrence** than belabouring the symptoms in detail.

This arises from my **personal experience** of having a Ewing sarcoma during fellowship and spending the first 10 years freaking out whenever I got a new symptom:)

-Female, Solid Tumors

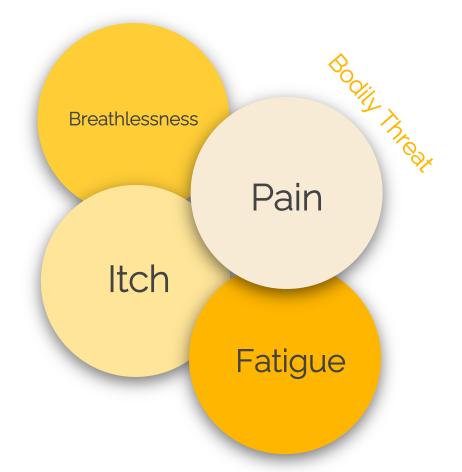


Communication training for oncologists to de-threaten symptoms?



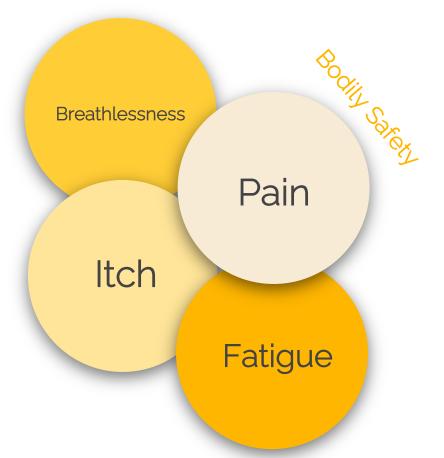






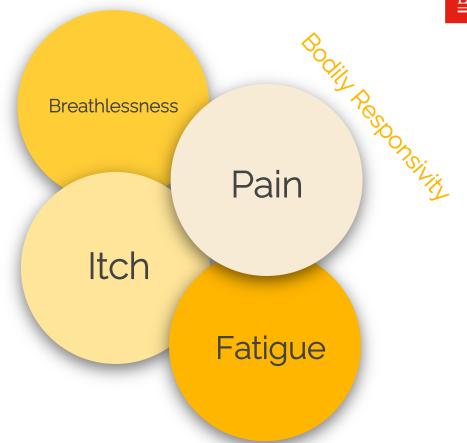






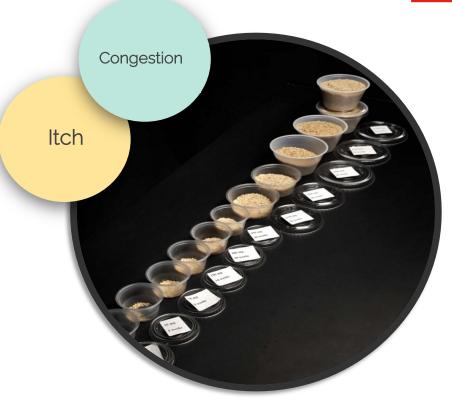




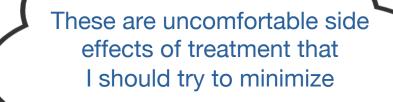




Oral immunotherapy treatment for food allergies in children

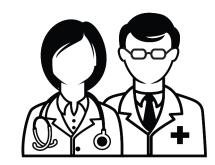




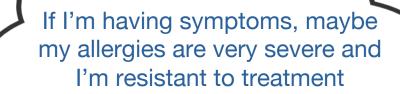


I'm sorry you're not feeling well!
Symptoms are just an
unfortunate part of treatment.







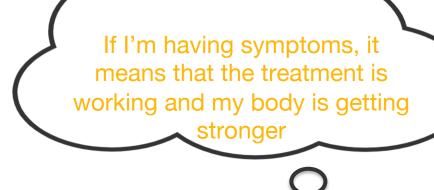


I'm sorry you're not feeling well!
Symptoms are just an
unfortunate part of treatment.









I'm sorry you're not feeling well, but symptoms mean the treatment is working!



Symptoms as Positive Signals Mindset

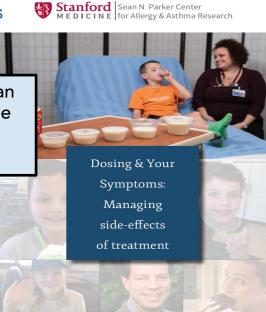


Harnessing mindsets about symptoms as

positive signals

"Symptoms as Side Effects" (24 patients) ymptoms are ar

Symptoms are an unfortunate side effect of the treatment



"Symptoms as Positive Signals" (26 patients)

Symptoms are a signal that the body is strengthening and treatment is working





Managing Discomfort

There are a few things you can do to minimize the discomfort of your symptoms during the dosing process:

- · Take your dose on a full stomach
- · Drink some water after taking your dose

"The hardest part of the study was feeling sick after taking my daily dose. I dreaded taking it! But by drinking more water every day I was able to feel less sick and get through to the end of the study.

I'm glad I stuck with it." – Leslie, age 14



"It's really scary to start feeding your child the food they've been avoiding their whole life, especially when you see your child having symptoms and are worried you're putting her at risk. To help minimize her discomfort, I always made sure she took her doses on a full stomach, and in the end our peace of mind has been completely worth it."

— Caroline, Leslie's mom





Lucile Packard Children's Hospital Stanford



Help Your Body Build Strength

When your muscles are sore from running, you rest, hydrate, and stretch. There are also things you can do to be more comfortable while your symptoms work with your body to build up tolerance during the dosing process.

- · Take your dose on a full stomach
- · Drink some water after taking your dose

"The hardest part of the study was feeling sick after taking my daily dose. But I know that meant that my body was getting stronger and more able to handle peanuts! I'm glad I stuck with it." — Leslie, age 14



"It's really scary to start feeding your child the food they've been avoiding their whole life, especially when you see your child having symptoms and are worried you're putting her at risk. I had to keep reminding myself that the symptoms are actually a sign that the treatment is working, and in the end our peace of mind has been completely worth it."

— Caroline, Leslie's mom



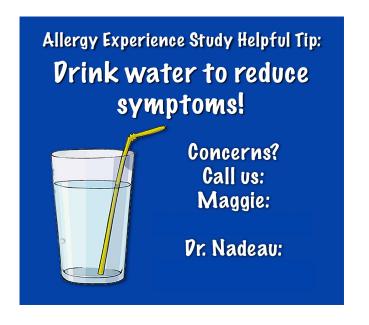


Lucile Packard Children's Hospital Stanford

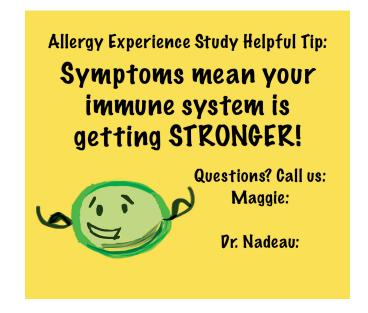


Reminders in frequented locations (e.g. fridge magnets!)

"Symptoms as Side Effects"

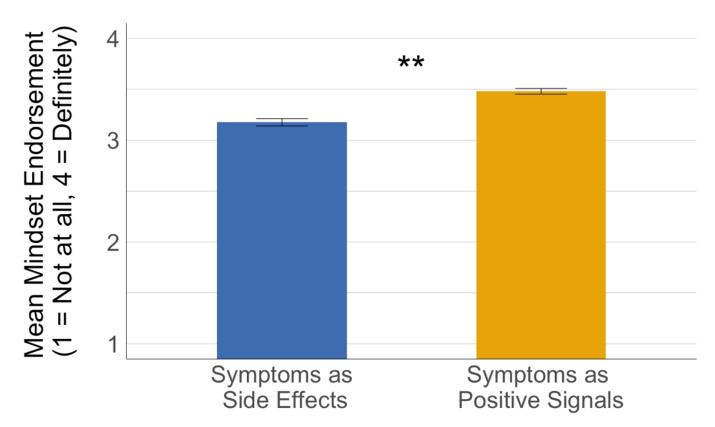


"Symptoms as Positive Signals"



Mindset about Symptoms

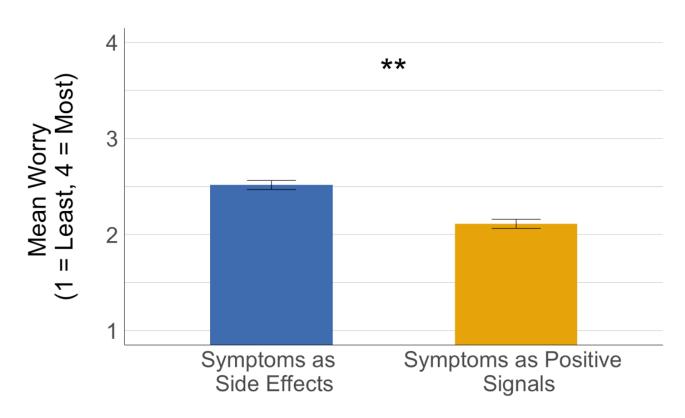




t(68.15) = 2.88, p = .005

↓ Anxiety

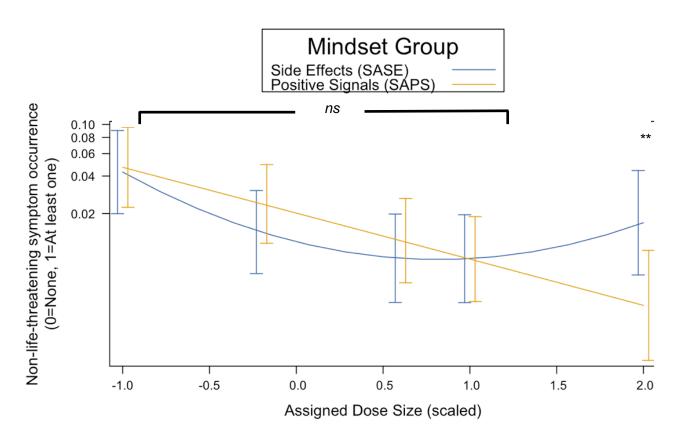




 $t_{\text{Main Effect of Group}}$ (69.61) = -2.94, p = .005

↓ Symptoms







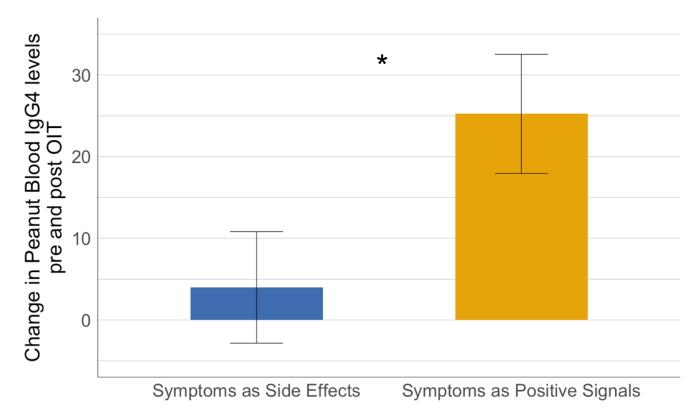
↓ Patient contact re: symptoms

Contact with treatment staff related to symptoms	
Symptoms as Side Effects	17.5 % (27/154)
Symptoms as Positive Signals	9.4% (15/159)

 $\chi^2(1) = 4.42, p = .036$

↑ Treatment Efficacy













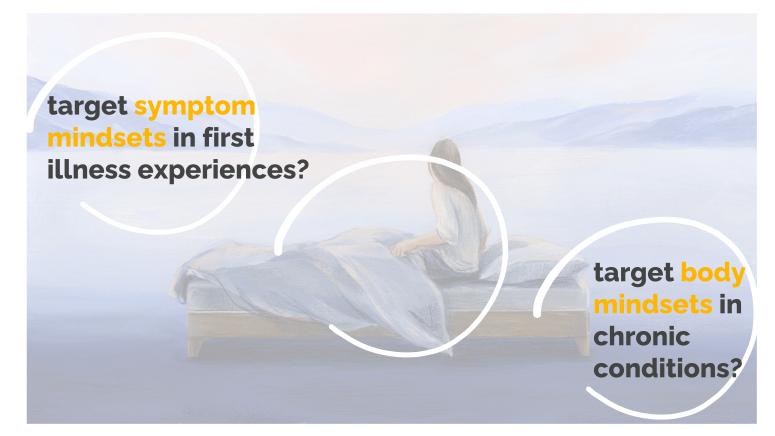
"Symptoms as Positive Signals"



Harness adaptive mindsets throughout the illness journey







target body mindsets in chronic conditions?

66

While finishing cancer treatment is something to celebrate, it can also bring new challenges for the child and their family. It is vital that we can offer evidencebased support and treatment programmes for young survivors to help them manage ongoing pain after cancer.

)Dr Lauren Heathcote



Over 50%

of childhood cancer survivors report ongoing pain symptoms

Alleviating pain in childhood cancer survivors Dr Lauren Heathcote, King's College London

Pain treatment in cancer currently focuses on alleviating the pain during active cancer, but there's almost no tailored treatment approaches to alleviate **post-cancer pain** in children and adolescents.

Using this funding, **Dr Heathcote** and her team will develop and test one of the first behavioural interventions to alleviate the impact of pain and improve wellbeing in childhood cancer survivors.

Medical ResearchFoundation



 Children experience uncertainty about pain and other somatic symptoms as a normal part of medical illness

 Uncertainty about symptoms is a social phenomenon that is shaped within clinical encounters

 Language is powerful. Doctor-patient communication can shape patients' symptom-related uncertainty in for the worse and for the better



