SITEMAN Kids
AT ST. LOUIS Children's HOSPITAL
Washington University Physicians

GOALS AND STRATEGIES FOR HAVING DIFFICULT CONVERSATIONS:

VIEWS FROM A COMMUNICATION RESEARCHER AND PEDIATRIC ONCOLOGIST

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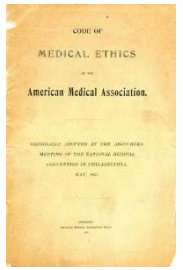
- I have no conflicts of interest related to this presentation

Overview

- Examining our history of non-disclosure



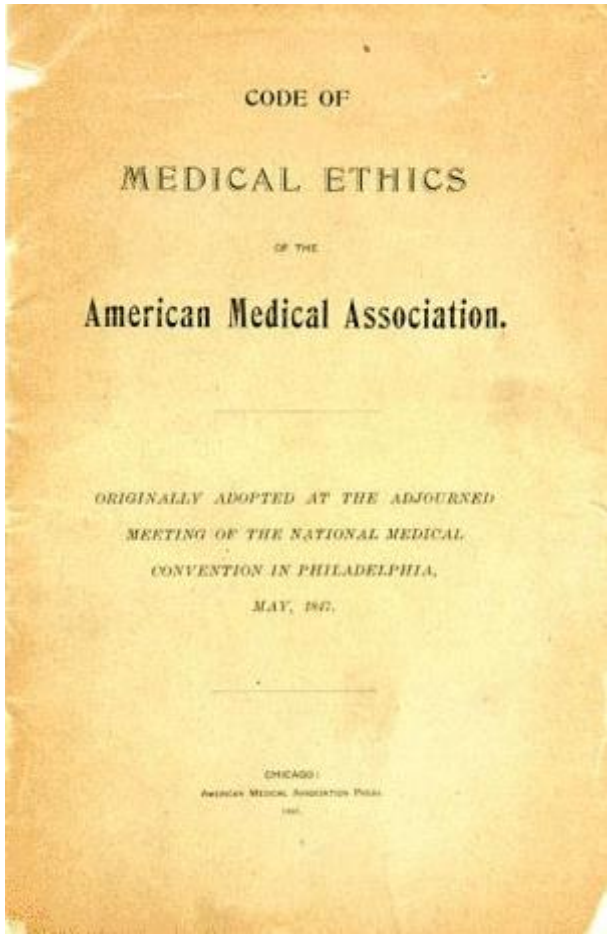
- Functional model of communication

- Practical tips for breaking bad news

Historically, physicians were encouraged to avoid sharing bad news with patients.

1847 AMA Code of Ethics – *Don't Tell the Patient*

- "A physician should not be forward to make gloomy prognostications because they savour of empiricism..."
- "But he should not fail, on proper occasions, to give to the friends of the patient timely notice of danger, when it really occurs; and even to the patient himself, if absolutely necessary."


CODE OF

MEDICAL ETHICS

OF THE

American Medical Association.

ORIGINALLY ADOPTED AT THE ADJOURNED MEETING OF THE NATIONAL MEDICAL CONVENTION IN PHILADELPHIA, MAY, 1847.

Physician were supposed to be “ministers of hope and comfort” to patients.

- “This office, however, is so peculiarly alarming when executed by [the physician], that it ought to be declined whenever it can be assigned to any other person of sufficient judgment and delicacy.”

- “For, the physician should be the ***minister of hope and comfort*** to the sick”

Physicians believed that words were physically harmful.

- "The life of a sick person **can be shortened** not only by the acts, but also by the **words** or the manner of a physician. It is, therefore, a sacred duty to guard himself carefully in this respect, and to **avoid all things** which have a tendency to discourage the patient and depress his spirits."

  -- 1847 AMA Code of Ethics

To “protect” patients, physicians were withhold difficult information.

- 1909
  - “In regard to cancer, the consensus of opinion is that **patients be kept in ignorance** of the nature and probable outcome of the disease **as long as possible**, in this way obviating the severe mental depression which invariably accompanies such knowledge.”
- 1915
  - “[I]t is not merely the danger of **‘fatal shock’** that should restrain a physician in many cases from disclosing the truth to his patient, but the almost certainty that such a **disclosure will be the greatest obstacle to a cure.**”

This protective approach persisted until recent history.

What to Tell Cancer Patients

A Study of Medical Attitudes

Donald Oken, M.D., Chicago

- 1961
  - 90% of physicians preferred not disclosing cancer diagnoses to patients

- 1966
  - When disclosure happened, often done poorly…

DISCLOSURE OF TERMINAL ILLNESS*

Barney G. Glaser†

This paper presents a descriptive process for understanding disclosure of terminal illness. This process combines both (1) the stages typically present in the response stimulated by such disclosure and (2) the characteristic forms of interaction between the patient and hospital staff at each stage of the process.

Pediatricians also historically withheld difficult news from children, such as cancer diagnosis.

1950s – 1970s

Potential inaccuracy of diagnosis	“[W]ithout an accurate diagnosis, it is cruel to arouse anxieties unnecessarily.”
Harms of truth	“Another boy, 15 years of age, who had leukemia (in remission), was being discharged from the hospital and somehow found out what his diagnosis implied. He solved the problem by leaping from his eight story hospital room.”
Kids don’t want to know	“[C]hildren observed by us rarely manifested an overt concern about death… Our suspicion is that this does not reflect an awareness but rather represents an attempt at repression psychologically of the anxiety concerning death.”
Disclosure affects the family	“We are concerned about the effect this revelation may have on relationships with parents, brothers and sisters, other relatives, and playmates and classmates.”

Some physicians openly advocated for deception as recently as the 1960s.

“We recently had a 13 year old boy with lymphosarcoma who had a frozen pelvis and a functioning colostomy. He had been told that he had a draining abscess from a ruptured appendix. As far as we could tell, we felt that he accepted this diagnosis as correct. We never intended for him to know otherwise.”

For various social, cultural, and professional reasons, physicians became more transparent in the late 1970s.

Changes in Physicians' Attitudes Toward Telling the Cancer Patient

Dennis H. Novack, MD; Robin Plumer; Raymond L. Smith;
Herbert Ochitill, MD; Gary R. Morrow, PhD; John M. Bennett, MD

• In answer to a questionnaire administered in 1961, 90% of responding physicians indicated a preference for not telling a cancer patient his diagnosis. To assess attitudinal changes, the same questionnaire was submitted to 699 university-hospital medical staff. Of 264 respondents, 97% indicated a preference for telling a cancer patient his diagnosis—a complete reversal of attitude. As in 1961, clinical experience was the major policy determinant, but the 1977 population emphasized the influence of medical school and hospital training. Our respondents indicated less likelihood that they would change their present policy or be swayed by research. Clinical experience was the determining factor in shaping two opposite policies. Physicians are still basing their policies on emotion-laden personal conviction rather than the outcome of properly designed scientific studies.

(*JAMA* 241:897-900, 1979)

Why this change?

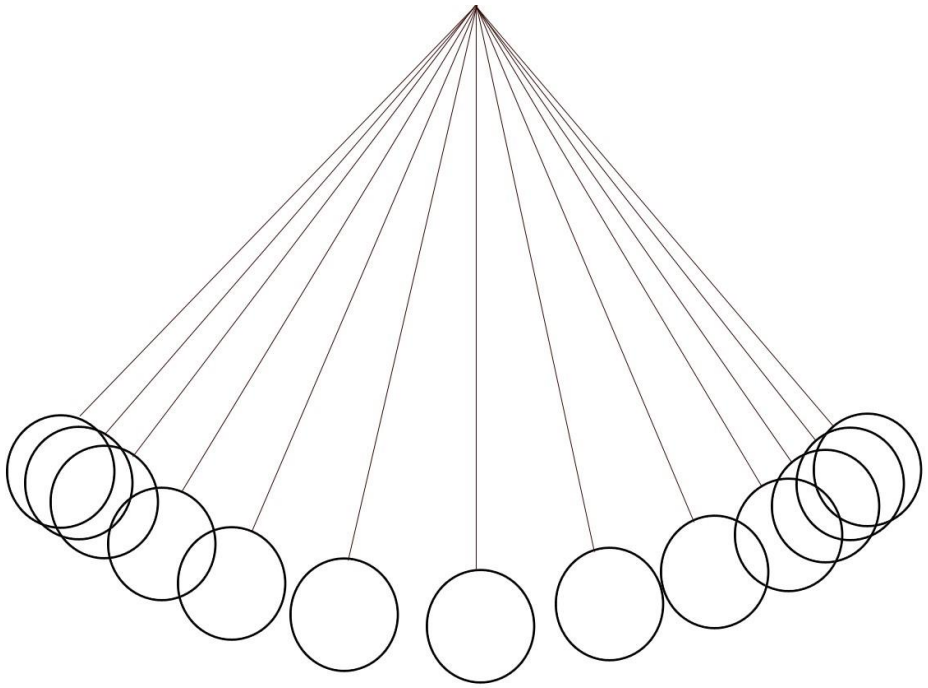
Pediatricians had additional reasons for becoming more transparent.

1960s – 1980s

Lying is hard, and the façade falls apart	“[C]hildren inevitably sense what is happening to them or in their family, even when a deliberate attempt is made to shield them from tragic, frightening or complicated affairs.”
Children actually know (or at least sense) the truth	“The fatally ill child of 6 to 10 years appears to be aware of the seriousness of his illness, even though he may not yet be capable of talking about his awareness in adult terms.”
The environment makes children fear speaking	“Is the child who does not verbalize concern really unconcerned, or only afraid to speak?”
Transparency supports children and their parents	“In order to help a child cope with the problems of serious illness, it is necessary to develop an environment in which he feels perfectly safe to ask any question, and completely confident of receiving an honest answer.”

The pendulum swung from protection to transparency (and continues to oscillate).

Never Tell



Always Tell

Disclosure involves both *what* and *how* clinicians communicate.

When I entered this field, I wanted to learn what “good communication” meant.

2016

Hopefulness

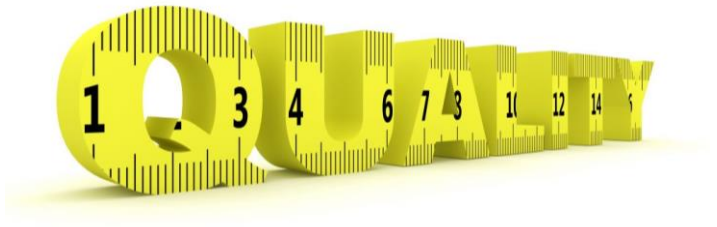
Feeling comforted

Feeling like a “good parent”

Less regret

Greater trust

Improved satisfaction

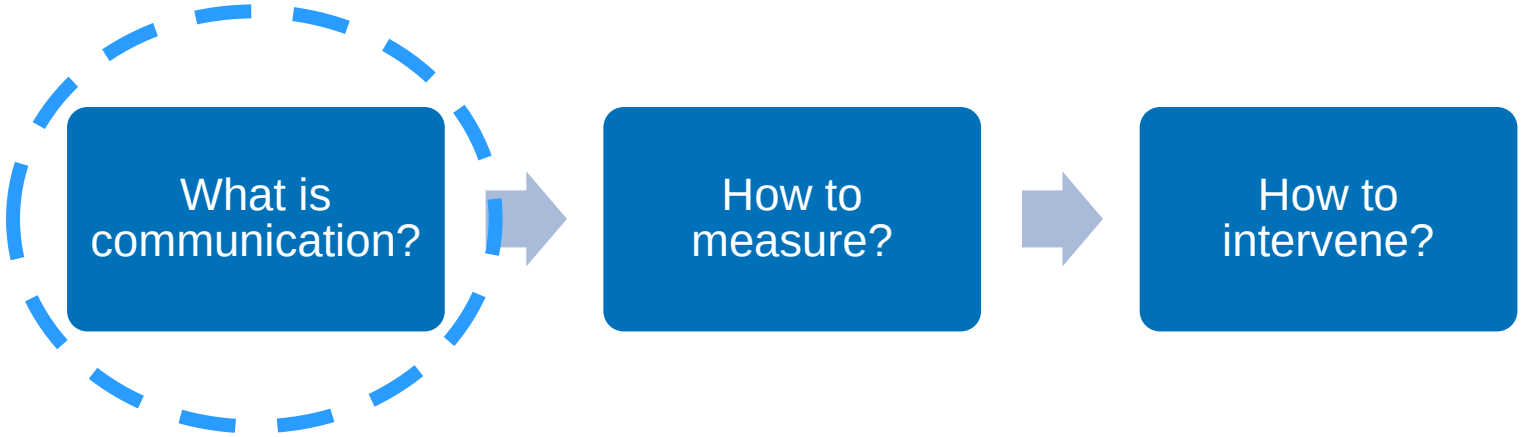


Fewer ER visits

Better self-management

Most past communication studies have focused on narrow aspects of communication, or “high-quality” communication.

We need an evidence-informed definition of communication to guide future measures and interventions.



Communication is often framed in a process model, rather than a functional model.

Process Model

To improve communication, follow specific processes.

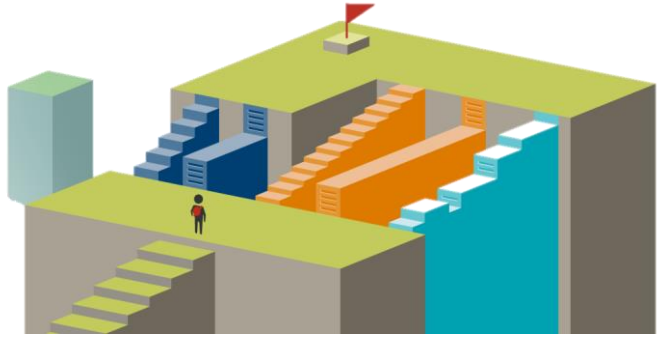
Name the patient's emotions

Ask "what if" questions

Give prognostic information to adolescents

Functional Model

To improve communication, ensure core functions are fulfilled.



Many paths, same goal

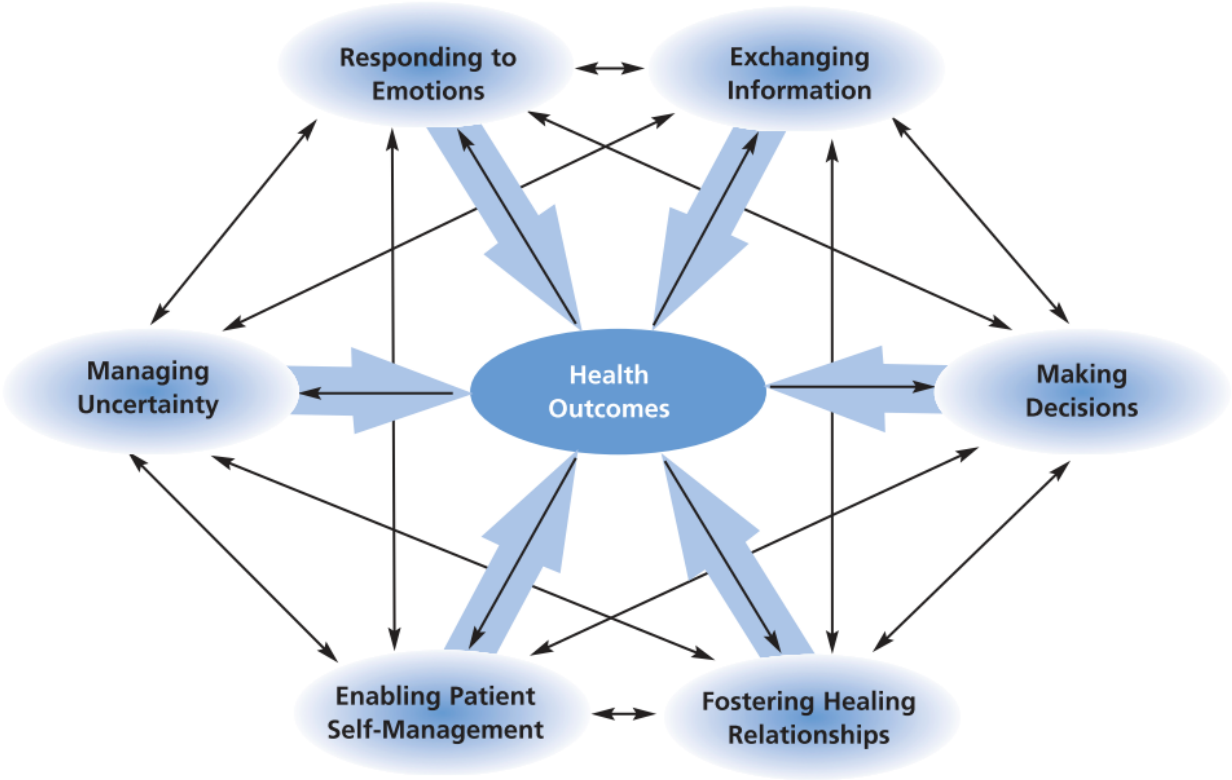
Functional communication models are adaptive to unique characteristics of clinicians and patients.

“They did the best thing they could have done… they left the room.”

- 21 year old survivor of cancer

Families know when we are insincere.

A functional model of communication was first developed in adult oncology.



… what about pediatrics?

Epstein and Street, *National Cancer Institute Monograph,* 2007

We engaged multiple stakeholders to develop a functional model of communication in pediatric oncology.

Parents
80 semi-structured interviews

Clinicians
10 focus groups 59 clinicians

AYA Patients
37 semi-structured interviews

Multi-Site Study

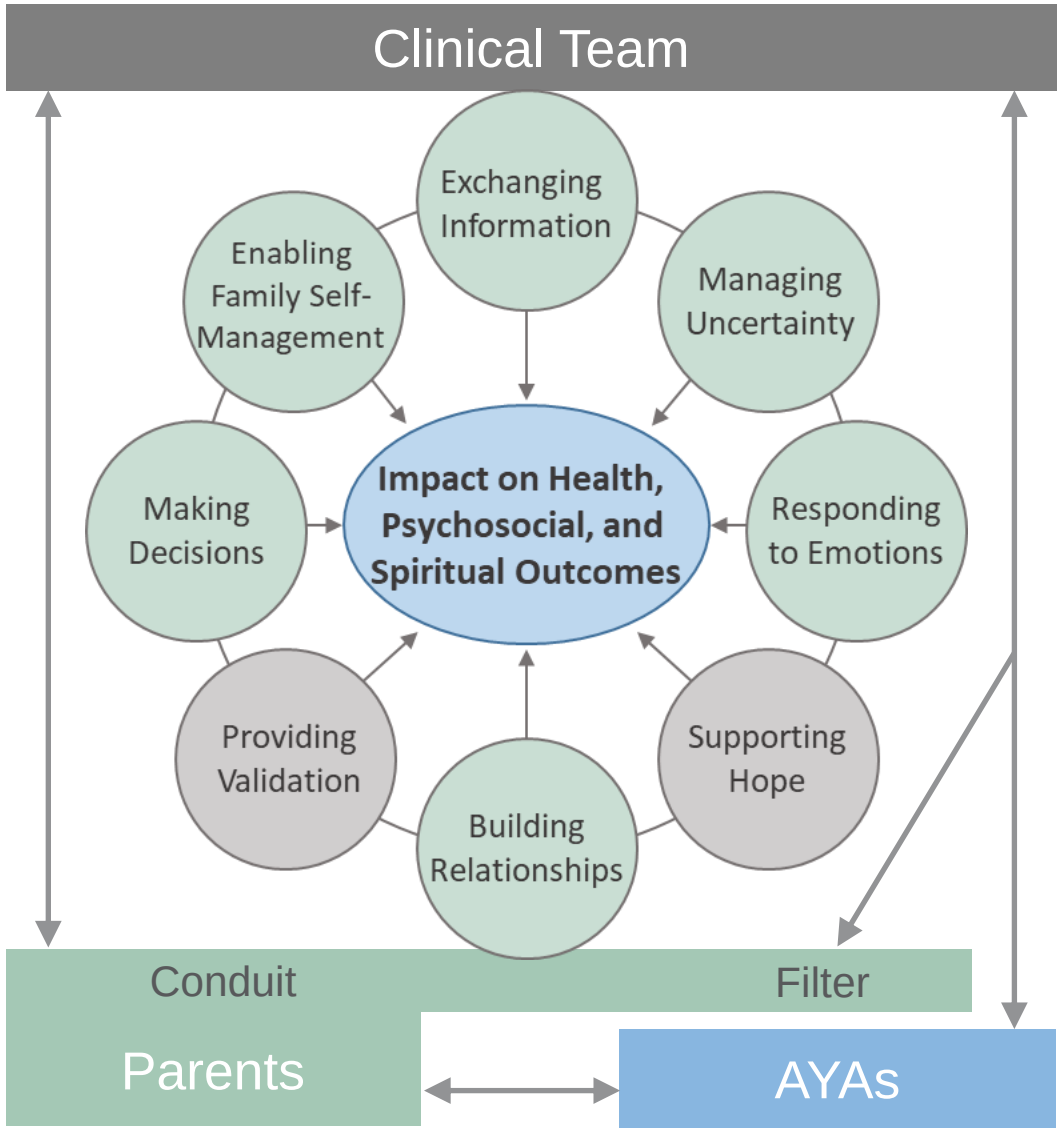
Children's HOSPITAL • ST. LOUIS
BJC HealthCare

Dana-Farber Cancer Institute

St. Jude Children's Research Hospital
ALSAC • Danny Thomas, Founder

Communication fulfills multiple functions for AYAs and parents.

Model corroborated by parents, AYAs, and clinicians



Sisk BA, et al. Pediatrics. 2020

Sisk BA, et al. Supp Care Cancer. 2021

Sisk BA, et al. J. Paliativ Med. 2021

Sisk BA, et al. Pediatr Bld Cancer. 2022

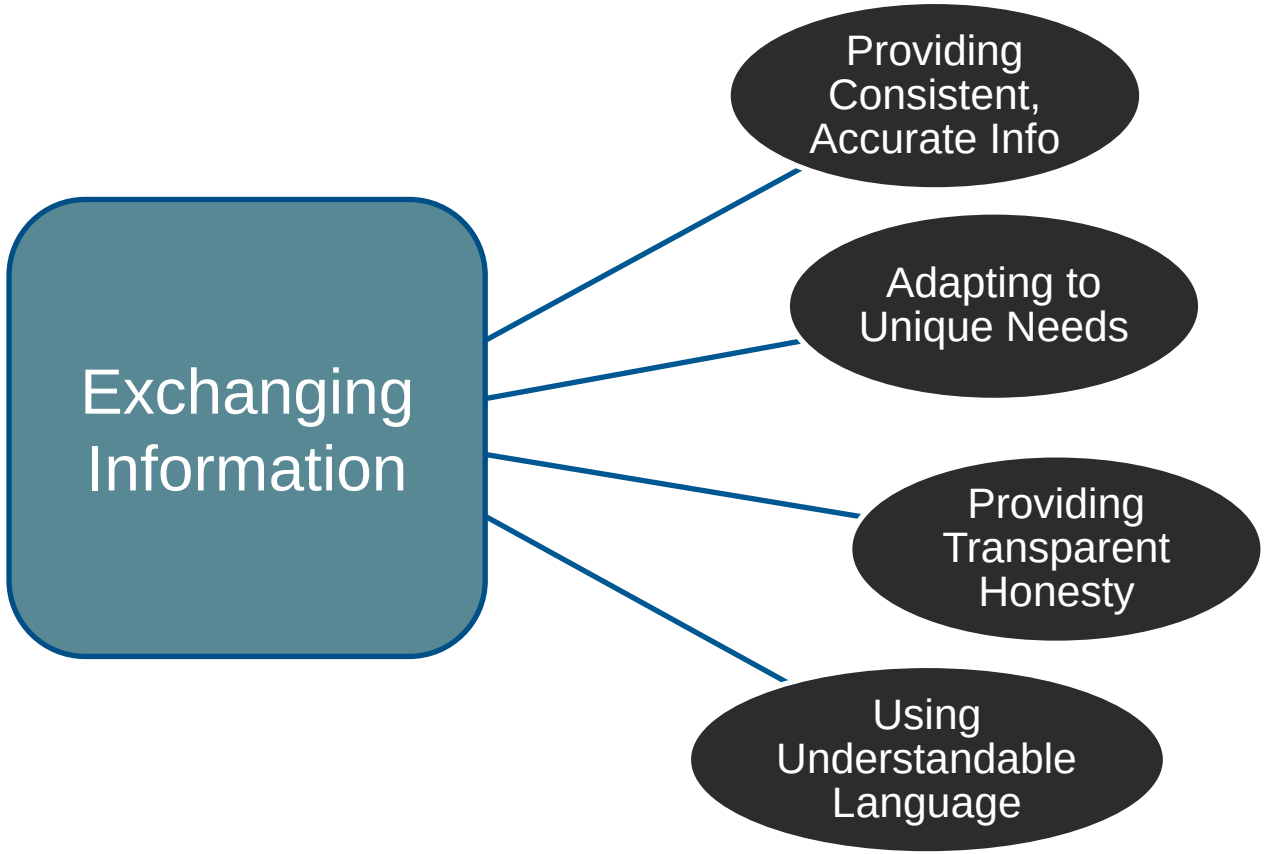
Breaking bad news involves multiple communication functions.

We will focus on 2 functions:

Exchanging Information

Responding to Emotions

Parents and patients identified multiple aspects of information exchange.



Sisk BA, et al. Pediatrics. 2020

Exchanging Information

- **<u>Parents want information</u>**
- Survey at diagnosis, 4 months, and 12 months
  - 84-87% wanted all details about prognosis
  - 91-96%: Late effects information very/extremely important
  - 83-87% wanted all possible late effects details

Sisk, B.A. et al. *Cancer*, 2017
Sisk, B.A., et al. *Pediatric Blood and Cancer*, 2018

- **<u>AYAs want information</u>**
- Survey at diagnosis, 4 months, and 12 months
  - 85-96%: Prognostic info very/extremely important
  - Higher sensitivity → Offering prognostic info before being asked

Sisk, B.A. et al. *Cancer*, 2019
Sisk, B.A. et al. *Journal of Palliative Medicine*, 2019

Families often receive insufficient information.

- Not always about diagnosis, prognosis, and treatment
- 86% of parents did not receive enough information about cancer affecting psychosocial health.

Lövgren M, et al. Pediatr Blood Cancer. 2020

How we communicate is as important as what we communicate

- Understandable
- Sensitive
- Honest
- Appropriate pacing
- Adapted to parents and child's needs and family's culture

Every family has unique needs, and we can't know unless we ask.

Numbers and percentages?

All info up front, or bits of info over time?

How much does the child want to know?

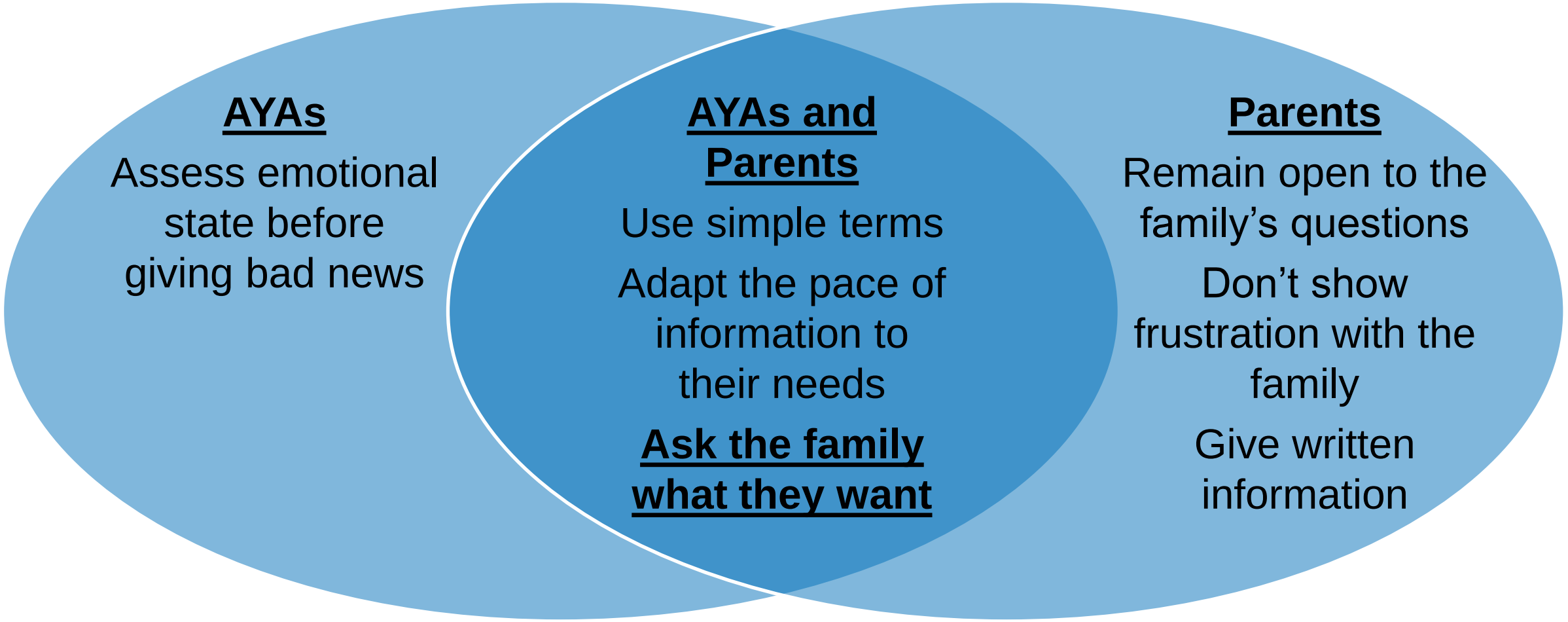
Short-term or long-term information?

Tell parent and child together or sequentially?

How much do the parents want the child to know?

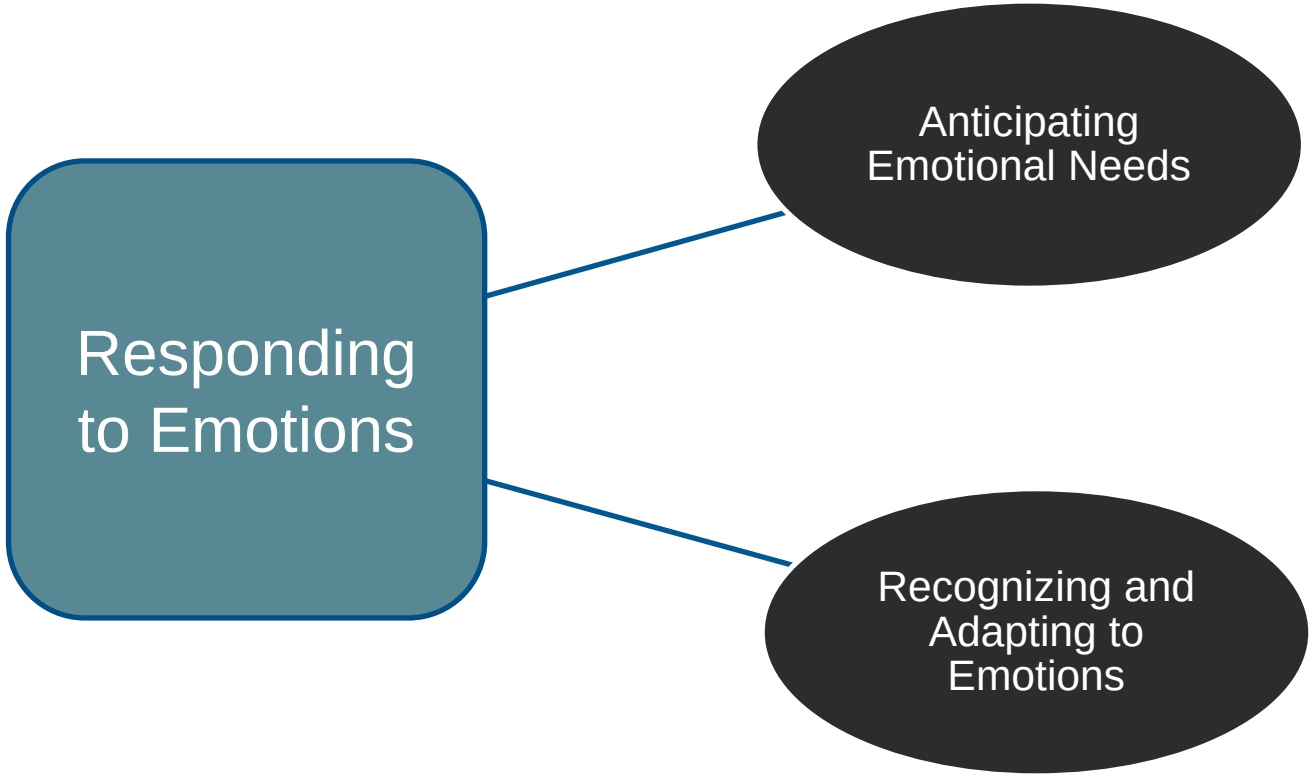
Do preferences change over time?

Advice from Parents and AYAs



Srinivas, et al. *Manuscript in Progress*

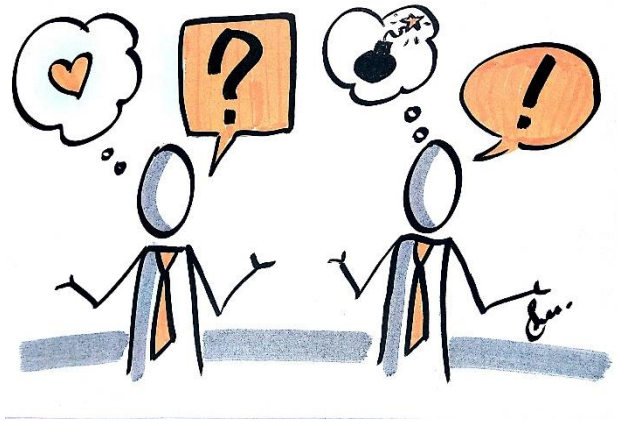
Parents and patients identified two main aspects of responding to emotions.



Sisk BA, et al. Pediatrics. 2020

Emotions are everywhere in difficult conversations

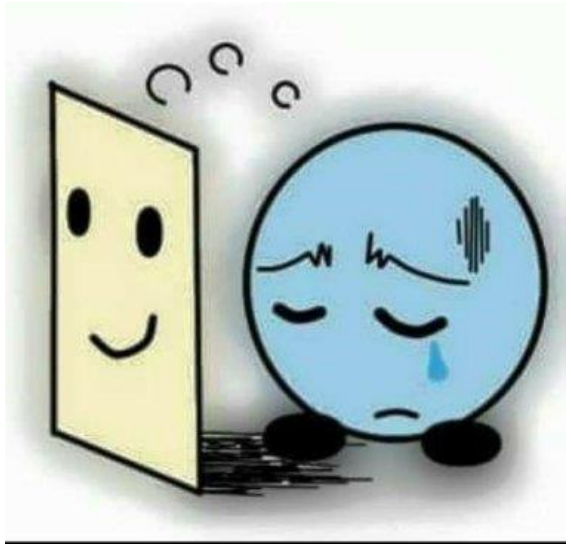
- 35 clinical encounters after relapse
- 91% contained emotional cues or subtle hints
- 40% contained explicit emotional concerns
- **<u>Children: Only 3% of cues, and NO concerns</u>**



Sisk B, et al. JPSM 2019

Emotions can be subtle.

Put on a happy face:
Positive external expression negatively correlated with self-reported affect
-Hexem, et al. 2013 JPSM



Mutual Protection:
AYAs and parents perceive mutual responsibility to be strong and protect the other's emotions.
- Sisk, et al. *Article Under Review*

Responding to emotions requires choices.

Father:
"The thought of putting her through 3 or 4 hours of surgery is…"

Technical Response:
"Well, this procedure is actually really safe, and the surgeon is very experienced."

Emotional Inquiry:
"I can see that is upsetting. What worries you about the surgery?"

Clinicians commonly respond to emotions with information

Key Takeaways - Emotions

Emotional communication is a subtle.

Parents offer hints.

Clinicians respond with information.

Children are seldom engaged.

- **N.U.R.S.E.**
- **N**ame the emotion
- **U**nderstand the core message
- **R**espect/reassurance at the right time
- **S**upport
- **E**xplore emotional content and context

- -Back et al. 2009.

Summary

Humble Curiosity

Intend to Communicate Well

Attention to Subtle Cues

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NIH National Center for Advancing Translational Sciences

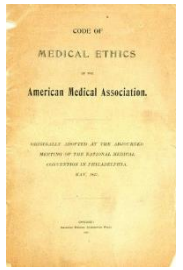
CONQUER CANCER® THE ASCO FOUNDATION

Children's Cancer Research Fund®

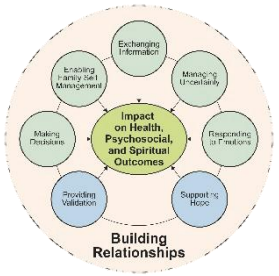
NIH Loan Repayment Programs

Questions?

- Examining our history of non-disclosure



- Functional model of communication



- Practical tips for breaking bad news

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