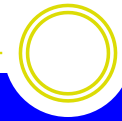


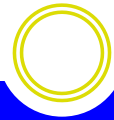
Hope and the Act of Informed Dialogue:



A DELICATE BALANCE AT END OF LIFE

**TERESA L. THOMPSON
COMMUNICATION**

Denial of death



- Common in our society, especially with modern technology
- Whereas most people used to die at much younger ages, and at home, surrounded by loved ones
- Modern medical technology now enables us to live longer, with more lingering deaths

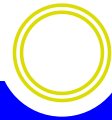
Approaches to death



- *Ars moriendi*
“A good death”

- *Ars vivendi*
“A good life”

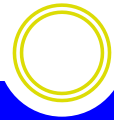
Distinction



Those who want to maximize the quality of their remaining life vs those who want to keep on fighting for life

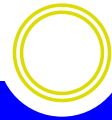
Continuing treatment typically lowers quality of life

Before we move on to the discussion of hope:



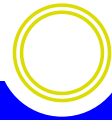
What do we know about family and
patient information preferences at
EoL?

Most research shows



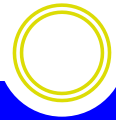
- Patients and caregivers claim they prefer honest and accurate information
- provided with empathy and understanding
- Only a minority of patients and caregivers state that they avoid detailed information to preserve hope
- The majority of patients and their caregivers report that they want the HP to be honest when discussing prognosis and EoL issues.

However,



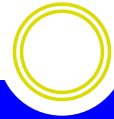
- there are different views of what constitutes an honest approach,
- with some desiring a **straightforward or direct** approach
- others desiring accurate information but **without bluntness or too much hard, factual or detailed information**
- and still others desiring a combination of **honesty and optimism**
- patients may find their situation more frightening if they sense that even their doctors cannot face the truth

It is possible for



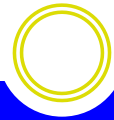
- patients to cope with their illness by wishing for a cure ('hoping for the best')
- at the same time as acknowledging the terminal nature of their illness ('preparing for the worst')
- But how?

Terminally ill cancer patients rate the following important concerns:



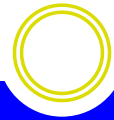
- having a sense of **hope** (99%)
- knowing what **symptoms** I might experience (95%)
- knowing my **prognosis** (93%)
- talking to my doctor **truthfully** about my prognosis (93%)

Why the concern about “hope”?



What we know about hope and
the role that it plays in health
and health care

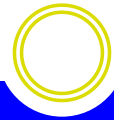
There is some evidence that



patients are less concerned than
physicians about damaged hope

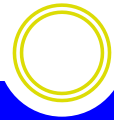
balancing hope with honesty is an
important skill for health professionals

Patients need a realistic sense of the future so



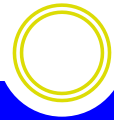
- they will do what they need to in their remaining time,
- but also need hope so they will not simply give up on life

EoL **decision-making** is facilitated by



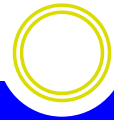
- expressing things **clearly**
- avoiding **euphemisms**
- being clear about goals and **expectations** of treatment
- using **words** such as ‘death’ and ‘dying,’
- while also helping to **maintain hope.**

Consequences of hope:



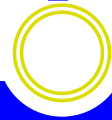
- a valuable asset in coping with illness
- hopelessness is associated with
 - depression
 - suicidal ideation
 - desire for hastened death
 - decreased physical health

Hopeful patients

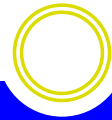


- follow treatment recommendations
- and tolerate discomfort better than patients who are not hopeful
- Are more actively involved in their self care
- And have higher levels of psychosocial adjustment

How do care providers communicate to maintain hope?

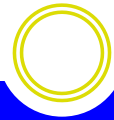


- emphasizing **outliers** (meaning patients who live longer than expected);
- encouraging patients to review aspects of their situation that move them from average to better **risk**;
- focusing on immediate **milestones** and hurdles;
- and emphasizing positive and **achievable** treatment goals.



HPs emphasize the importance of providing hope that is consistent with clinical evidence rather than raising false hopes and **reducing trust** between the doctor and patient.

But they also



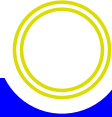
‘soften the impact’ (vaguely suggesting or recommending the discontinuation of treatment but giving the patient the choice and accommodating their decision)

Many HPs say



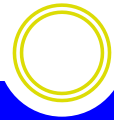
- they respect **denial** as a coping mechanism and do not compel people to hear the truth.
- you cannot **make** someone hear what they do not want to hear
- spontaneous disease remissions **do** occur rarely
- why not allow them this hope and let the patient come to terms with their limited life expectancy at **their own pace?**

Although all 56 terminally ill patients surveyed in one study:



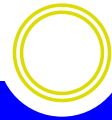
- wanted their physician to be honest,
- 91% also wanted their physician to be optimistic
- the most highly ranked factors were those that instilled a sense of being able to fight the cancer.

HPs can preserve hope more realistically



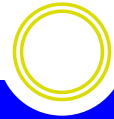
- by being honest
- acknowledging difficulties in giving prognostic estimates
- presenting information about palliative care at a rate that the patient can assimilate
- respecting alternative treatments

But these are hope-giving



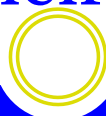
- saying that **pain** will be controlled (87%)
- appearing to **know** all there was to know about the patient's cancer (87%)
- offering to **answer** all the patient's questions (78%)
- saying that each day the patient survives new **developments** are possible (75%)
- saying that the patient's **will to live** will affect the outcome (74%).

Most patients perceive



the provision of realistic information in a supportive, collaborative environment as **more hope nurturing** than avoidant behavior

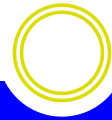
HPs see the following as a significant way to help patients to cope with their limited life expectancy



- Exploring realistic goals
- Helping patients when possible to achieve these goals

“while we are hoping that things will go well with the chemotherapy, if by some chance you didn’t get better, what would be the most important things that you would want to do while you are able to?”

Some HPs

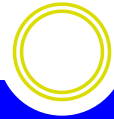


let patients fantasize even about unrealistic things if they've demonstrated that they do understand what is going on

However, some participants

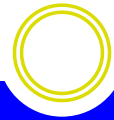
note that it **gave them hope** when the HP was honest.

Nevertheless, patients, caregivers, and HPs all
stated



- that it is important not to be too blunt
- Or not to provide a great deal of detailed information that the patient does not want to hear

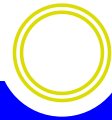
Warmth vs. coldness



influences hope

info that is communicated with more
warmth increases hope,
that communicated with more
coldness decreases hope.

Different types of hope



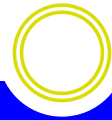
A spectrum of hope:

patients may simultaneously hope for 'cure' while acknowledging the terminal nature of their illness

Hope can be maintained by HPs 'being there'

And treating the patient as a whole person, not just as an illness

Hope is best engendered by



- a combination of **honesty and empathy**
- framing hope in a **wider** context (e.g. in relationships, beliefs and faith, having symptom control, maintaining dignity, finding inner peace, enjoying a sense of humor, and thinking about meaningful events in their lives)
- and by emphasizing **achievable** treatment goals

Types of hope



- a hope of being cured
- a hope of living as normally as possible
- a presence of confirmative relationships
- reconciliation with life and death

hope for a cure is misguided in the
context of a terminal illness

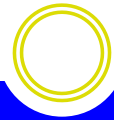
Patients have wide-ranging hopes
with some still hoping for a cure



but the majority hoping for other outcomes such as

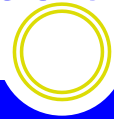
- living **longer** than expected
- making it to certain **events** or achieving goals
- everyday living
- finding **meaning** in their own life and worth
- good **pain** and symptom control
- being well cared for and **supported**
- a **peaceful** death

Other types of hope mentioned by HPs



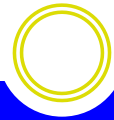
- hope in the healing of relationships
- and having special times with family and friends
- as well as finding spiritual meaning

But does the use of the word “hope” for all of these confuse things?



- While all of these are things for which one can hope, does using the same term to describe them create problems or confusion in moving from one type of hope to another?

Hope in the context of terminal illness

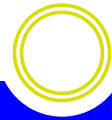


Has typically focused on hope for a cure and continued life expectancy

Instead it should be viewed as a continually changing process

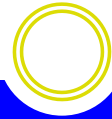
If we don't allow the patient and family to "change" these views of hope, they continue to struggle

Are these all “hope”?



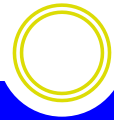
- Or are they **positivity** in some other form?
- Does conceptualizing them as hope get in the way of dealing with the positivity that is necessary?
- If we call it hope, do we limit what we allow it to do – how we allow it to function?
- If we focused on living well rather than “hope”, per se, might we handle things better and suffer less?

What we say we want is not necessarily what we want



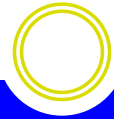
- “TRUTH”:
 - Many of those who SAID they wanted open communication did not actually want to be confronted with direct prognostic info
 - When they talk about wanting “human compassion along with the truth” they didn’t really want full truth

“COMPASSION”



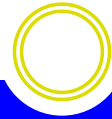
- By compassion they didn't mean compassion in the sense that I think of it – empathy, showing concern, etc.
- they meant sensitivity to knowing how much they really could hear or bear
- Compassion doesn't mean compassion in our normal sense of the word – it means something more like mind reading and the ability to try to understand what that person can handle than it really does compassion.

WORDS



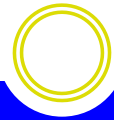
- Note the different meanings of lots of words, then, in regard to this issue
- compassion doesn't always mean compassion
- hope doesn't always mean hope (means positive affect in others ways in some circumstances)
- truth doesn't always mean truth

The fundamental bind for me as a health communication scholar



- Coping with what I knew as a health communication expert was appropriate for this situation in contrast but the rest of the family's preferences
- This situation was very different from the common problem, which is when the docs try to encourage treatment and life preservation against the family's or patient's wishes

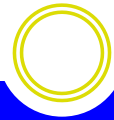
Why does the cycle of hope typically escalate?



Providers can't bring themselves to be completely frank with patients, so they make a statement implying some hope – a little bit.

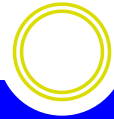
Patients pick up on only that. And every once in a while a miracle does occur. We hear of these stories and feel that we have reasons for our “hope”.

But a lot more problems caused by denial



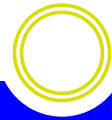
- Suffering, anguish
- Family is typically more likely to deny than are most patients

Prognosis



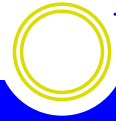
- Dramatic disagreement is often found between patients' and physicians' estimates of prognosis.
- Patients are more optimistic than their physicians, but
- physicians' estimates are more accurate

The data indicate



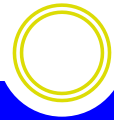
- That physicians overestimate the amount of information that they have given to patients and
- The amount of knowledge that patients have about their illness
- That surrogate decision makers tend to be low in accuracy of predictions compared to patient preferences

Among candidates for breast cancer adjuvant therapy



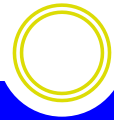
- 70% of patients overestimated their chance of cure by 20% or more compared to their physician

Among patients with cancer



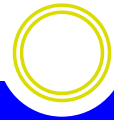
- two thirds had poor prognoses with no hope of cure,
- yet only 21% perceived they had a poor prognosis

But here's how some patients feel:



- “Knowledge {about the future} is empowering, I think the knowledge of what’s going on with you health-wise is the most empowering thing you’ve got.”
- Note how this places emphasis on the power of control over your life when you have full information

Physicians often view

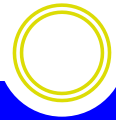


optimism about **prognosis** as the central feature of patients' hope

but there is evidence that this is not true for many patients

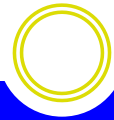
Are patients given the chance to take this power?

Key decision factor:



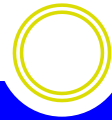
Allowing patient
preferences

Frank discussion of death



- Decreases anxiety and stigmatization in patients;
- Decreases stress in the family; and
- Improves coping in survivors.
- Shared decision making is associated with healthier families and
- Increases valuable social support, which facilitates coping and adherence

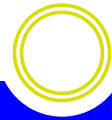
End-of-life conversations



- Should occur PRIOR to decreased cognition (including that caused by medication) or
- Decreased communicative competence/ability (including that caused by medical treatments)
- And certainly prior to unconsciousness

- These conversations should occur when the terminally ill individual is able to actively participate

These conversations

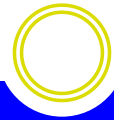


- Should occur between family and the patient, not just between care providers and the patient

We know that

- Provider-patient interactions about EoL are frequently ineffective, even when providers receive training
- Family members will frequently be making the actual decisions and must be on the same page as the patient

Final Conversations



Research indicates that:

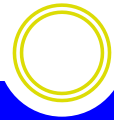
messages of love tend to create a sense of connection

messages about personal identity can affirm
individuals' positive qualities

discussing spirituality validates the importance of faith

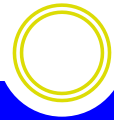
acknowledging difficult relationship issues provides an
opportunity for reconciliation

What matters is not



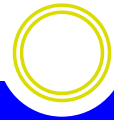
- Just talking
- But what you say when you talk – the topics you discuss and how you discuss them

More avoidance is associated with



- Less attention to face, less social support
- Less decision making efficacy and conversational satisfaction
- More distress, hurt, and burden
- **AND less** hopefulness

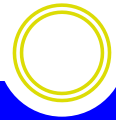
What do we have to do?



- We have to change how we look at death
- it is not a terrible thing
- it is a natural thing
- Dying well is associated with living well

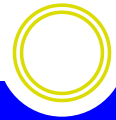
And we have to do it before
we're terminally ill

Changing the way we die



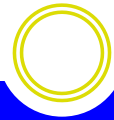
Requires changing the
way we
look at death

We are lucky



When we know and
can try to implement
someone's wishes

Generally,



- The more we talk with a loved one about terminality and their wishes in regard to end-of-life
- The more we are able to make assessments about what they'd like that are consistent with those wishes
- And the less anguish we feel about it