



What do patients want to know about the future?

Paz Fernández-Ortega. PhD, MSc, RN
Chair Education SG.
mfo@iconcologia.net
Institut català d'Oncologia – Barcelona Spain

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No COI

No conflict of interest





Different generations, different way of communication

Professionals
deciding

70's

Interaction
pt -professional

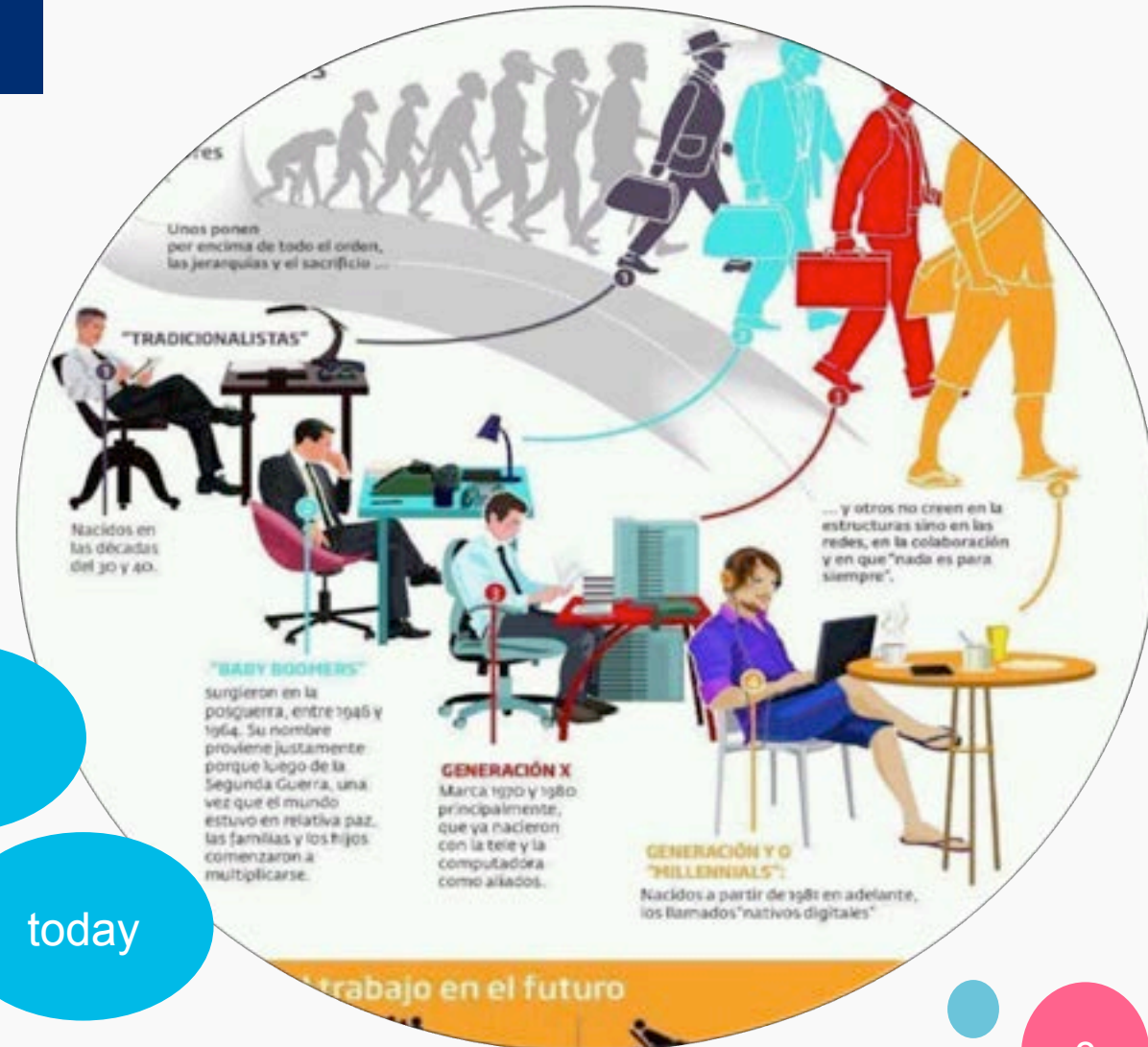
80's

Pt. expectations

90's

Increasing
participation + Quality

today



Communicating with patients:

Close your eyes and think

Which is the first thing I do in the morning?.

But for patient?..... it would all be a very different story.

.....

- 1. With patients take nothing for granted.**
- 2. Patients are usually experts on their situation** - be experts on pain, the type of wound dressing ... they know exactly how their body reacts to..., how medications....
- 3. Do not sweat the small things.** They are more worried on pressing matters, how to get relief from pain?, how to leave the child if is going to die soon” ...how much time do I have left on this earth?
- 4. To consider always the family & caregivers.**





the “silent voices” of women with advanced disease came eventually to be heard

***Misinformation
often floods the internet.....***

Musa Mayer.
Metastatic breast cancer advocacy group

Types of prognostic factors:



Performance status

- symptoms associated with cancer anorexia-cachexia syndrome (weight loss, anorexia, dysphagia, and xerostomia), dyspnea, delirium. Maltoni et al 2015



Biologic factors

- leukocytosis, lymphocytopenia, and C-reactive protein.



Psycho-emotional spiritual factors

- introversion, spiritual + existential needs, last wishes, loss of interest in others
- loss of interest, trouble concentrating, difficulty carrying activities and a “give-up” attitude versus the disease and with the process



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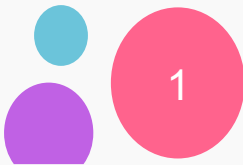


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Principles 4 - prognostication

1. Prognostication is a **process instead of an event**,
2. prognostic factors may **evolve over** the course of the disease
3. prognostic accuracy for a given **prognostic factor/ tool varies** by the definition of accuracy, the patient population, and the time frame of prediction
4. the exact **timing of death cannot be predicted** with certainty.

Hui D. **Prognostication of Survival in Patients With Advanced Cancer: Predicting the Unpredictable?** Cancer Control. 2015 Oct;22(4):489-97.





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Let's talk on Distress



Mix of anxiety and depression.
More acceptable and less stigmatizing than “ psychiatric”, “ psychosocial” or “”emotional”

NCCN 2018

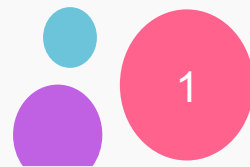


Sounds “ normal”, less embarrassing



Can de defined and measured by self-report

1/3 cancer patients experienced severe distress





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Distress NCCN 2018

**Multifactorial
unpleasant
experience
psychological**



**Cognitive,
behavioral
Emotional
Social, spiritual or
physical**

**Interfere with the
ability to cope**



**COPE:
physical symptoms
treatment side-effects**

Along continuum cancer process



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Who is at risk?-

- NCCN guidelines version 2.2018

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NCCN National Comprehensive Cancer Network®

NCCN Guidelines Version 2.2018
Distress Management

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PSYCHOSOCIAL DISTRESS PATIENT CHARACTERISTICS¹

<u>PATIENTS AT INCREASED RISK FOR DISTRESS²</u>	<u>PERIODS OF INCREASED VULNERABILITY</u>
<ul style="list-style-type: none">• History of psychiatric disorder or substance use disorder• History of depression/suicide attempt• Cognitive impairment• Communication barriers³• Severe comorbid illnesses• Social issues<ul style="list-style-type: none">▶ Family/caregiver conflicts▶ Inadequate social support▶ Living alone▶ Financial problems▶ Limited access to medical care▶ Young or dependent children▶ Younger age▶ History of abuse (physical, sexual, emotional, verbal)▶ Other stressors• Spiritual/religious concerns• Uncontrolled symptoms• Cancer type associated with risk of depression (eg, pancreatic cancer, head and neck cancer)	<ul style="list-style-type: none">• Finding a suspicious symptom• During diagnostic workup• Finding out the diagnosis• Learning about genetic/familial cancer risk• Awaiting treatment• Change in treatment modality• Significant treatment-related complication(s)• End of treatment• Admission to/discharge from hospital• Transition to survivorship• Medical follow-up and surveillance• Treatment failure• Recurrence/progression• Advanced cancer• End of life

¹For site-specific symptoms with major psychosocial consequences, see Holland, JC, Greenberg, DB, Hughes, MD, et al. Quick Reference for Oncology Clinicians: The Psychiatric and Psychological Dimensions of Cancer Symptom Management. (Based on the NCCN Guidelines for Distress Management). IPOS Press, 2006. Available at www.apos-society.org.





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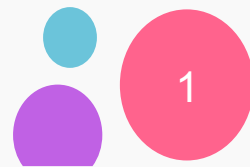
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What patients have expressed they want?



What patient's want:

An **expert & intelligent professional** but, also human sensible to others', without communication nothing is in the relationship.

But some professional

– “As a professional, do you have a “let-to-tell if not-asked” and vice versa attitude?

– **Elderly** survey on 200 hospitalized patients: Aim to determine which information they find to be most useful.

Results: most interested about treatment duration, side effects, and rate of therapy failure

- Elderly pts are most interested about **treatment duration** (79%), less for side effects (40%), and the rate of treatment failure (30%)
- Elderly would prefer 93% **verbal information** rather than written

Nikolic-Tomasevic Z. 2018. What patients want to know about disease and treatment. ASCO Journal of clinical Oncology



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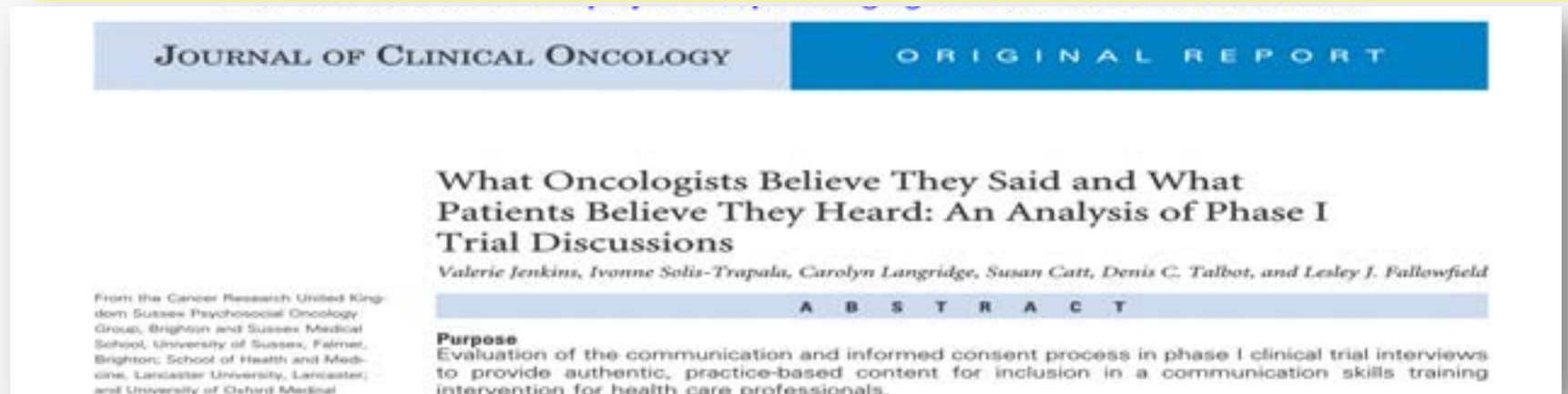
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What is needed in Phase I??

- Oncologist said and patients heard



Predisposition toward optimism. Discussion of prognosis was a frequent omission, more likely to say that oncologist did not mention it (odds, 4.8; $P < .001$).

If Clinicians were slightly ambiguous --- Pts optimistic interpretations

Example, "For me, he said they had absolutely no idea whether it would be beneficial or not, but if it's not, we haven't lost anything, and if it is, then we have gained something."



Prognosis discussions – cultural differences

Butow PN et al. Should culture affect practice? A **comparison of prognostic discussions in consultations** with immigrant versus native-born cancer patients. Patient Educ Couns. 2013

10 oncologists, 78 patients (31 Australian-born, 47 immigrants) and 115 family members participated, after diagnosis of incurable disease – audiotaped interviews

- **50% of doctors prognostic conversation was blocked by interpreters**
- Oncologists - culture did not appear to influence but less likely to convey hope to immigrants (p=0.0004) Physical issues + discussed than **emotional aspects**.
- More likely to **use medical jargon** (p=0.009) than with Australian-born pts.
- Descriptions - **expressed as weeks to months** or months to years, in 1/3 of patients with incurable disease status and a limited life span

de Graaff FM, et al. 'Palliative care': a contradiction in terms? A qualitative study of cancer patients with a Turkish or Moroccan background, their relatives and care providers. BMC Palliat Care. 2010 Sep 10;9:19

Turkish and Moroccan families in Netherlands were asked about their meaning of prognosis and palliative care.

- clear **conflict with palliative**, that include discussing diagnosis and prognosis with patient.

Families expectations: maximum treatment and curative care until the end of life,

- maintain hope or never taking away, devoted care by their families,
- avoiding shameful situations, dying with a clear mind and
- being buried in their own country





News > Reuters Health Information

Many UK Medical Students Have Negative Attitudes Toward Palliative Care

By Rita Buckley

May 08, 2018



Added to Email Alerts



REUTERS

NEW YORK (Reuters Health) - A significant proportion of U.K. medical students expect palliative care to be less satisfying than other specialties, British researchers have found.

"During their careers, all doctors will be involved in the care of the dying, and

- Is this a general feeling in other countries around the world?
- Has changed this in last years?



JOURNAL OF PALLIATIVE MEDICINE
Volume 17, Number 5, 2014
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2013.0551

Emotional Distress and Compassionate Responses in Palliative Care Decision-Making Consultations

Stewart C. Alexander, PhD,^{1,2} Susan Ladwig, MPH,³ Sally A. Norton, PhD, RN,^{3,4} David Gramling, PhD,⁵ Kelly Davis, BA,¹ Maureen Metzger, PhD, RN,⁶ Jane DeLuca, PhD, RN,⁷ and Robert Gramling, MD, DS⁸

Patients
53.6%

Loved ones
41.9%

Objective: emotional expressions or the compassionate responses providers make and how common these are in PC decision-making conversations.

- 71 audio-recorded inpatient PC decision making consultation
 - anxiety/fear emotions (48.4%)
 - sadness (35.5%)
 - anger/frustration (16.1%)

Compassionate response
75.7%

Medical
21.9%

Ignored
1.3%



40% - 30% - 30%
Alexander SC. [Support Care Cancer](#). 2011

More satisfaction

Less satisfaction

Context of a terminal prognosis, What patients want, what they understand?

*Lesley Fallowfield et al. presented research on doctor-patient communications in the context of a terminal diagnosis and **what patients understand about their treatment**, and their preferences.*

- Palliative care options are not discussed with many patients
- Oncologists **can be too optimistic** with patients, and patients **are also too optimistic about the benefits of drugs** that show little overall survival benefit.... 
- Professionals are **too negative about good supportive and palliative care.** 

Fallowfield L. ABC4 Lisbon 2017.





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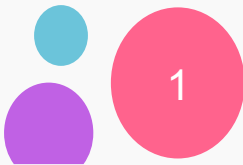
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Which tools to be used?

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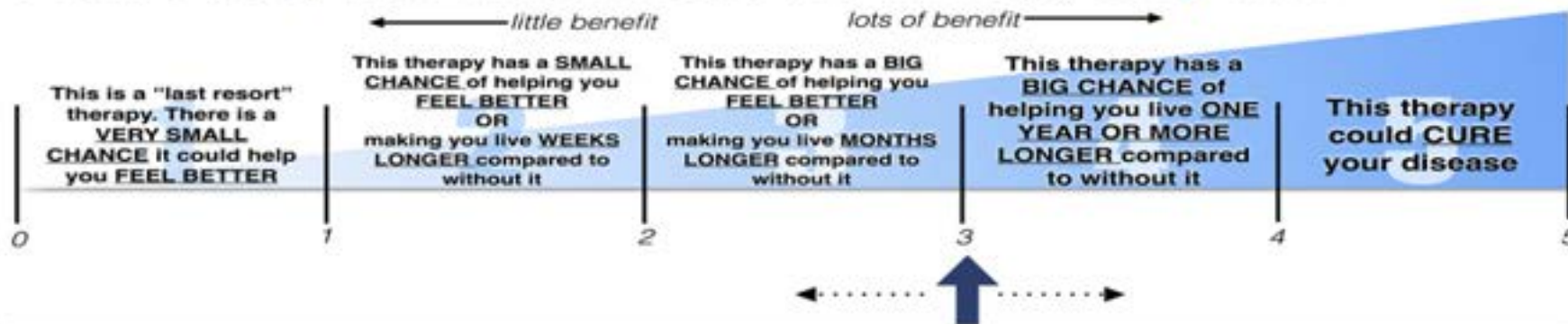


The Help-Hurt Tool (2015) *Montefiore Einstein Cancer Center*

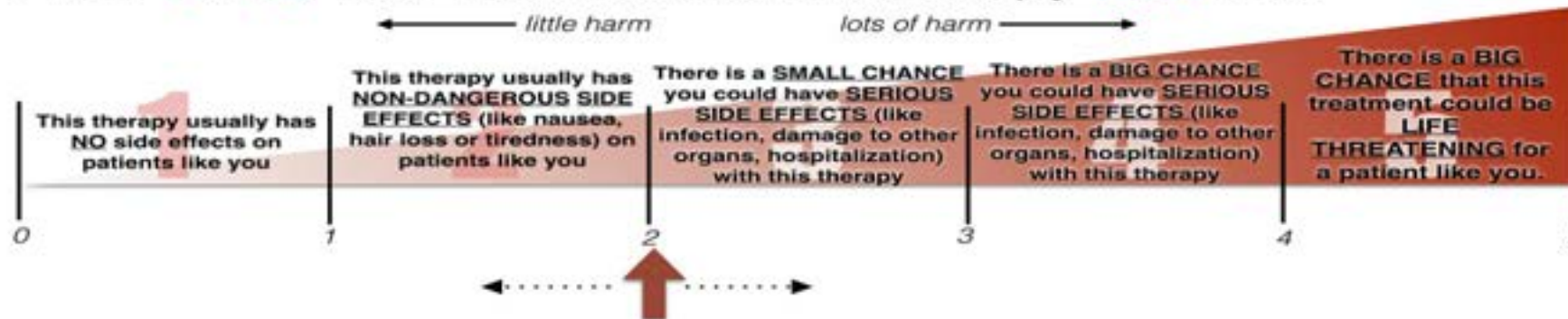
Zañartu **Help-Hurt** Tool
for Therapeutic Decision-Making*

*© Montefiore Medical Center

From **1** to **5**, how much could this therapy **help** me?



From **1** to **5**, how much could this therapy **hurt** me?



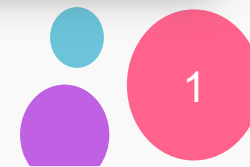
<http://www.helphurttool.com/>

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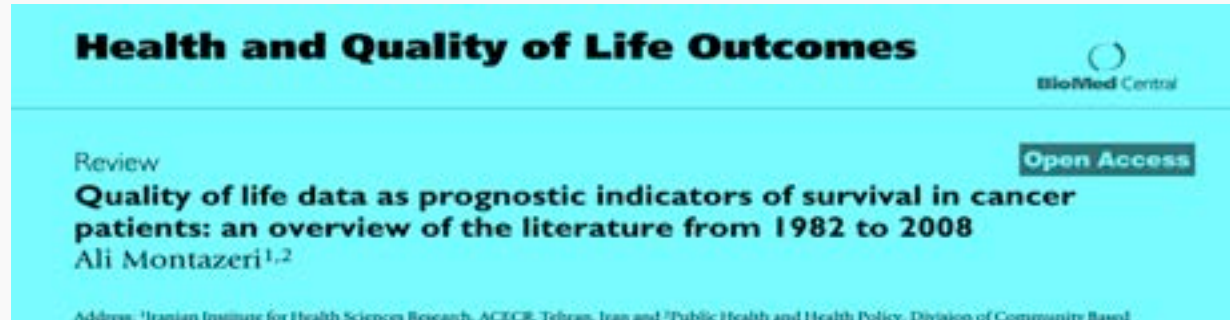
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Psycho – emotional, QoL indicators:



Review: 1982- 2008

- Mainly quality of life data measures **were significant independent predictors** of survival duration.
- QoL **59 different instruments** - EORTC QLQ-C30 + most used
- Global quality of life, **functioning domains and symptom scores** - such as appetite loss, fatigue and pain - were the most important indicators.
- Results showed a **positive relationship between QoL and survival**
- Baseline health-related QoL scores – some times predict survival



PROMs - Pt reported outcomes & prognosis

Gotay et al. The prognostic significance of patient-reported outcomes in cancer clinical trials. J Clin Oncol 2008, 26:1355-1363.

1. QoL measures **include different items** - more sensitive info than PS or toxicity
2. QoL pick up **relevant information earlier** than established clinical prognostic factors collected at baseline before disease progression
3. QoL are **markers of patients' behaviour** because they relate to diagnosis, treatment and subsequent outcomes of the disease
4. QoL - **characteristics** such **personality style and adapting** coping strategies, which **affect disease** process and the outcomes

Gordon JS. (2008) **Mind-body medicine and cancer.**

Littrell J. (2008) **The mind-body connection: not just a theory anymore**

*****Best predictor:** self-rated health as a valid prognosis Model. Survival or mortality might be explained in the context of the **body mind relationship**



Teach-Back Method: Ask-Tell-Ask

A technique based on understanding what the patient already knows before giving information. Also asking permission to go further on informing and to check several times

- Ask patient to describe what understanding of the situation. Allows to get the level of knowledge, emotional state, and degree of education and then tailor their message based on their patients' understanding.
- Examples: “asks”: “What have your doctors told you about your disease?” or “What is your understanding on the situation right now?”
- Another “ask”: permission to give additional information. Example, “Would it be okay if we talked about the results of your probes and the options for treatment?”
 - *Asking permission before telling a patient more information is a way of putting more control into the patient's hands.*

- Repeated back with your own language



An unique tool is only a
tool, not a panacea





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How patients' realize on Prognosis?

Signals from their body & from mind

Signals from professional, from family, from nurses

Bijlsma RM. 2017 Nth. DNA tests
+ be prepared for future
- Afraid for Psycho disturbances

Elderly vs young
Same needs
Different info styles
tend to lesser ask

How patient have faced adversity in the past

In Phase I CT, how they understand?

Migrants: family filtering

Elder cancer in Marocco; No questions 59% no info on diagnosis

Do patients want to know.....

Always?? Sometimes? Never?



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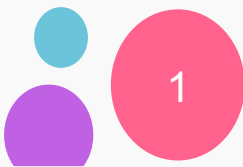
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When communicate? ...

When disease progress the psycho- social and spiritual aspects of the illness played a significant role, people sought meaning in life and relationships*

* Simon A E, Thompson MR, Flashman K, Wardle J. Disease stage and psychosocial outcomes in colorectal cancer. *Colorectal Dis.* 2009 Jan;11(1):19-25.

How patient have faced adversity in the past?



Professional behaviors of compassion care?

- Mori M, J Pain Symptom Manage. 2018;55:189-197. **Which physicians' behaviors on death pronouncement affect family-perceived physician compassion? A randomized, scripted, video-vignette study**
 - Comparing reactions to two video vignettes showing death pronouncements.
 - The vignettes involved a terminally ill man in his 70s with a chronic, incurable illness whose death had been expected, with his wife, son, and daughter at the bedside
- Ferrell B. **How to Pronounce a Patient's Death Compassionately** March 09, 2018
 1. **Waiting** until the family members calm themselves down;
 2. Explaining that physician has received a sign-out of **information about the patient's** condition;
 3. Performing an examination of the patient **respectfully**
 4. **Ascertaining time of death** with a watch - phone
 5. Reassuring families that the patient did **not experience pain**.



Spiritual issues The EORTC QLQSWB32

- **Spiritual well being** is often not discussed with patients who are facing serious or life--threatening illnesses and
- many professionals are **uncomfortable with the topic.**

QLQSWB32, **European Organization for Research and Treatment of Cancer** (EORTC) has been validated in 14 countries and 10 languages and can serve as a stand-alone measure for assessing

The tool may be useful for **quality indicators** of palliative care services.



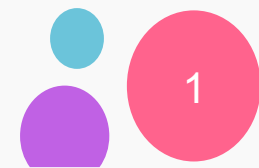
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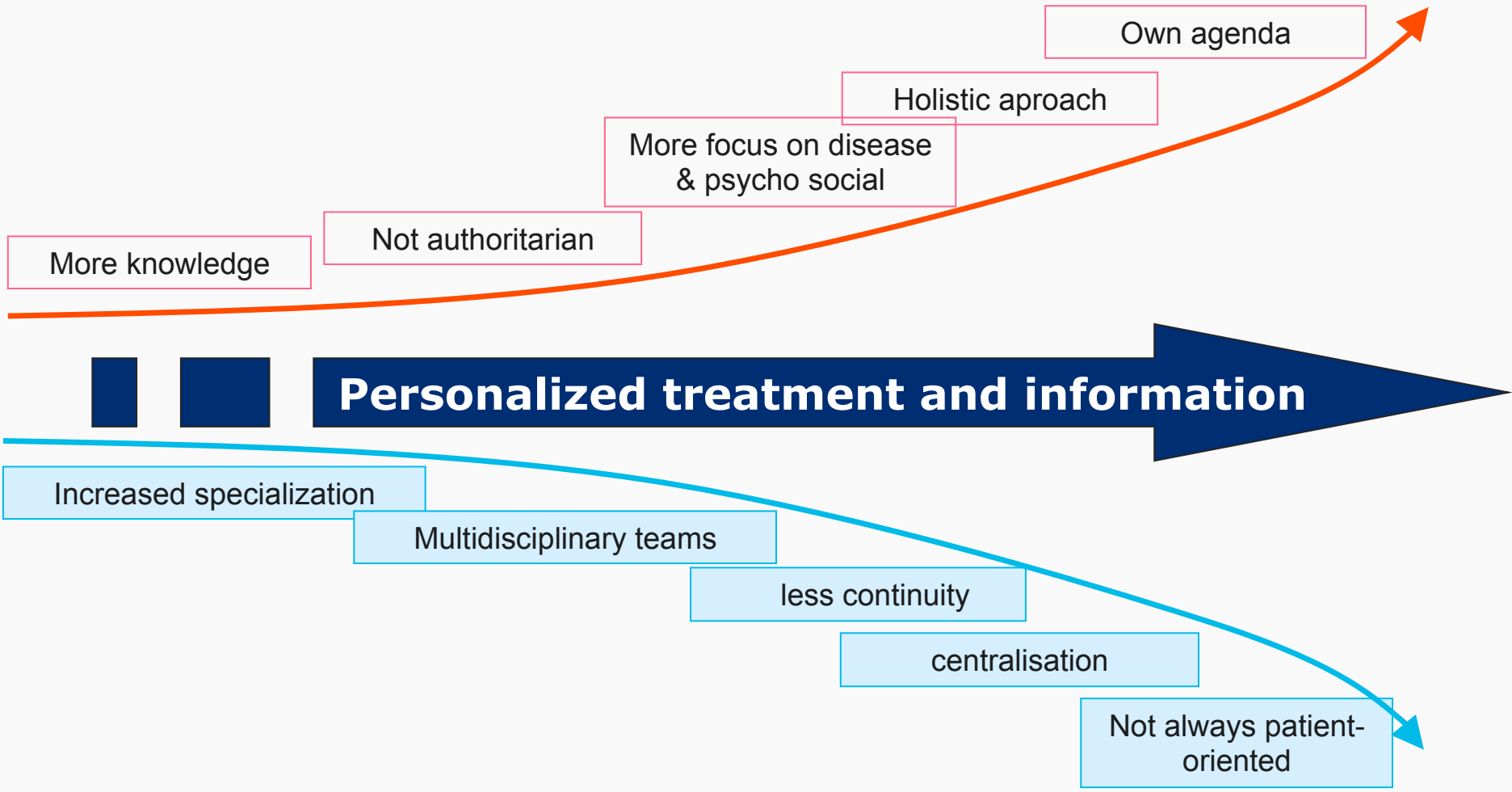
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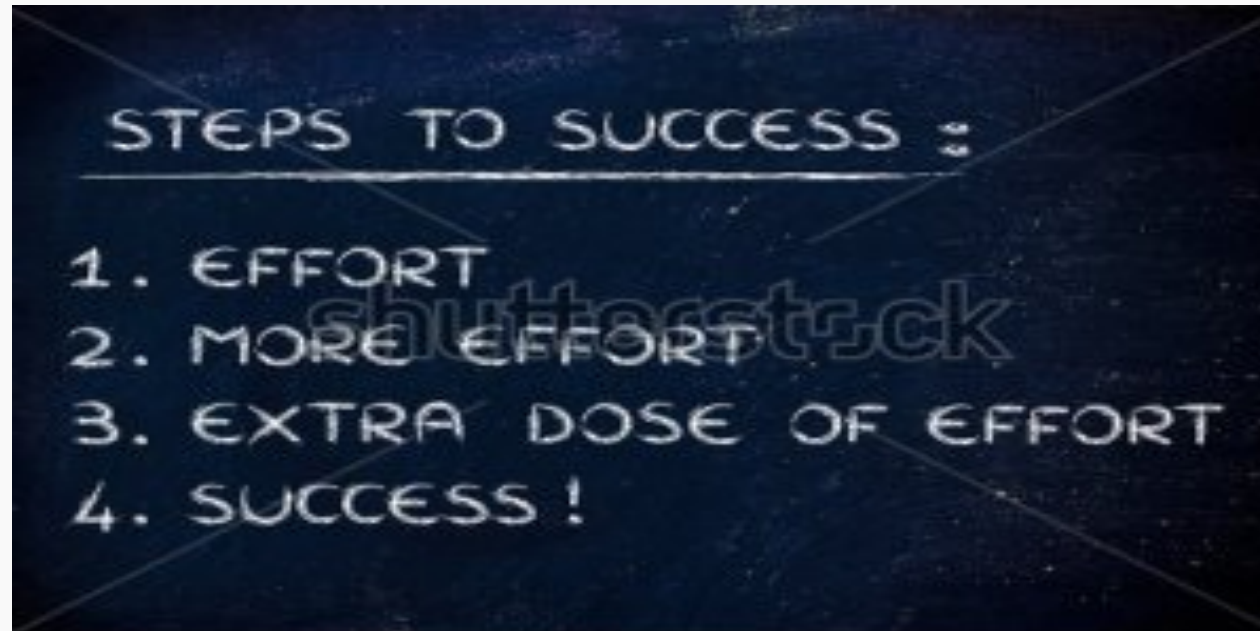
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Thanks!!



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