

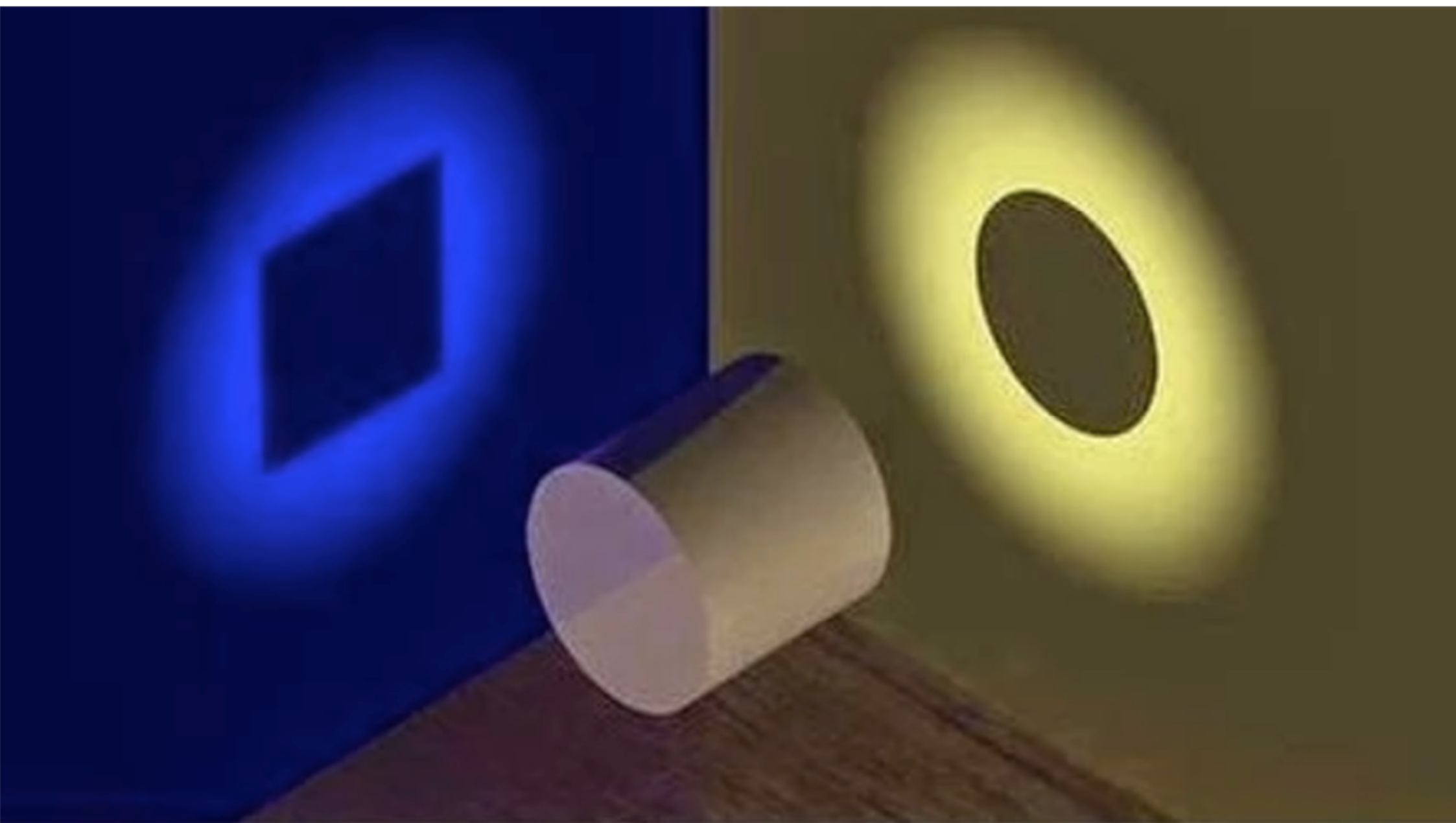


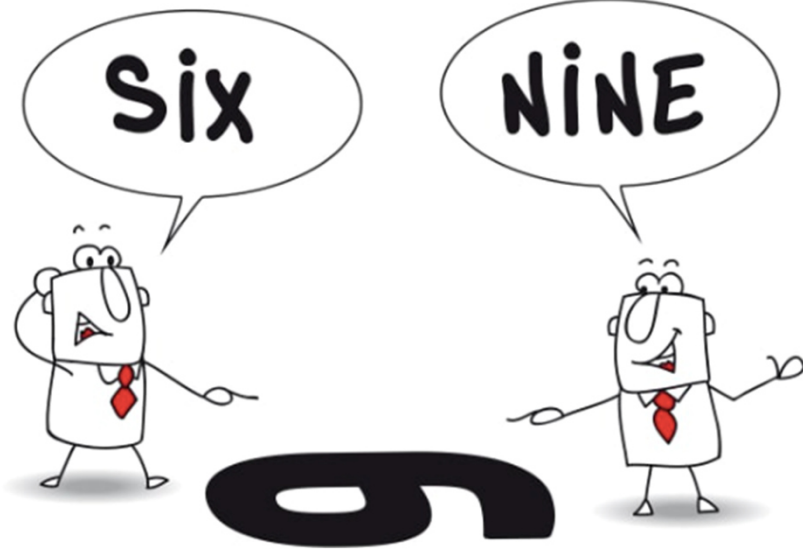
SESSION 9: BACK TO THE FUTURE: HOLISTIC APPROACH

TOXICITY MANAGEMENT: DOCTOR AND
PATIENT'S PERSPECTIVE

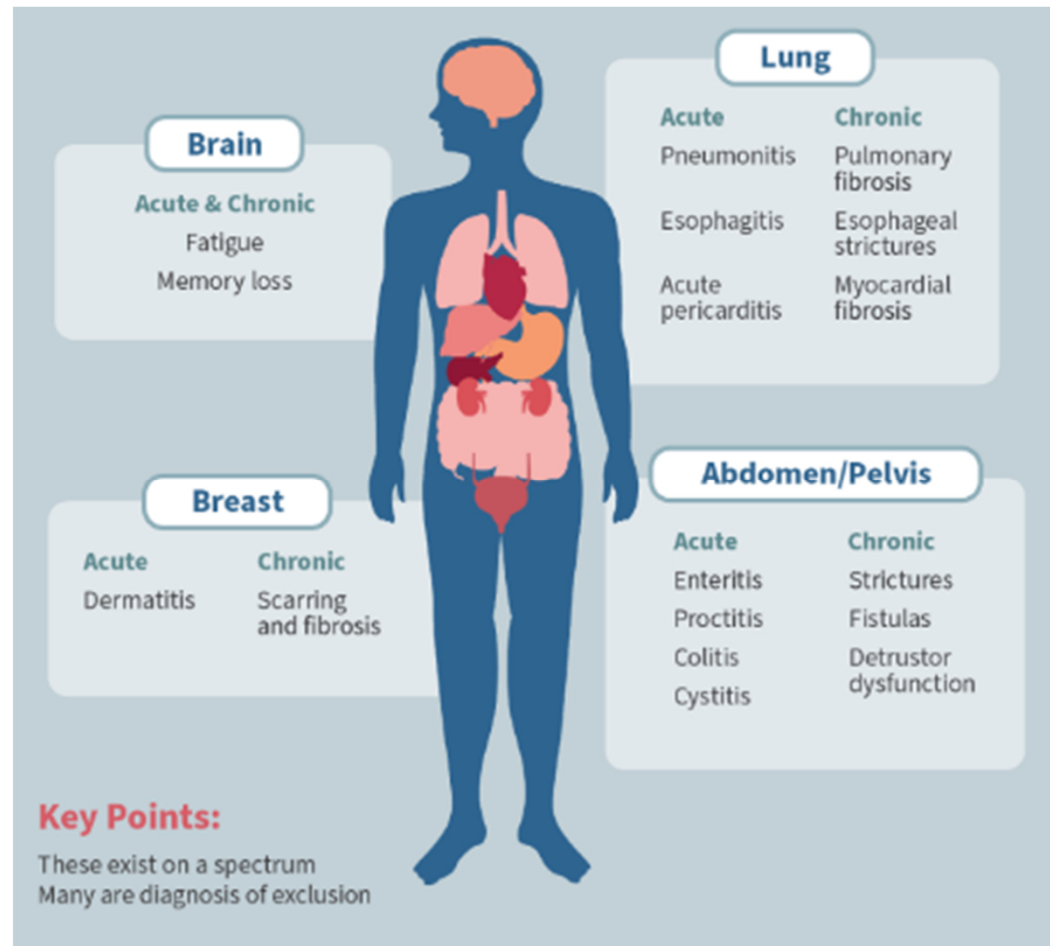
Giuseppe Colloca







Common radiation sites and side effects



Systemic effects of radiation

(1) Fatigue:

- It's by far the most common and most persistent effect of radiation.
 - It can be very mild in some, or profound and disabling in others.
 - It can last for weeks or months.

(2) Cytopenias:

Cytopenias are generally proportional to the **amount of bone marrow in the field**.

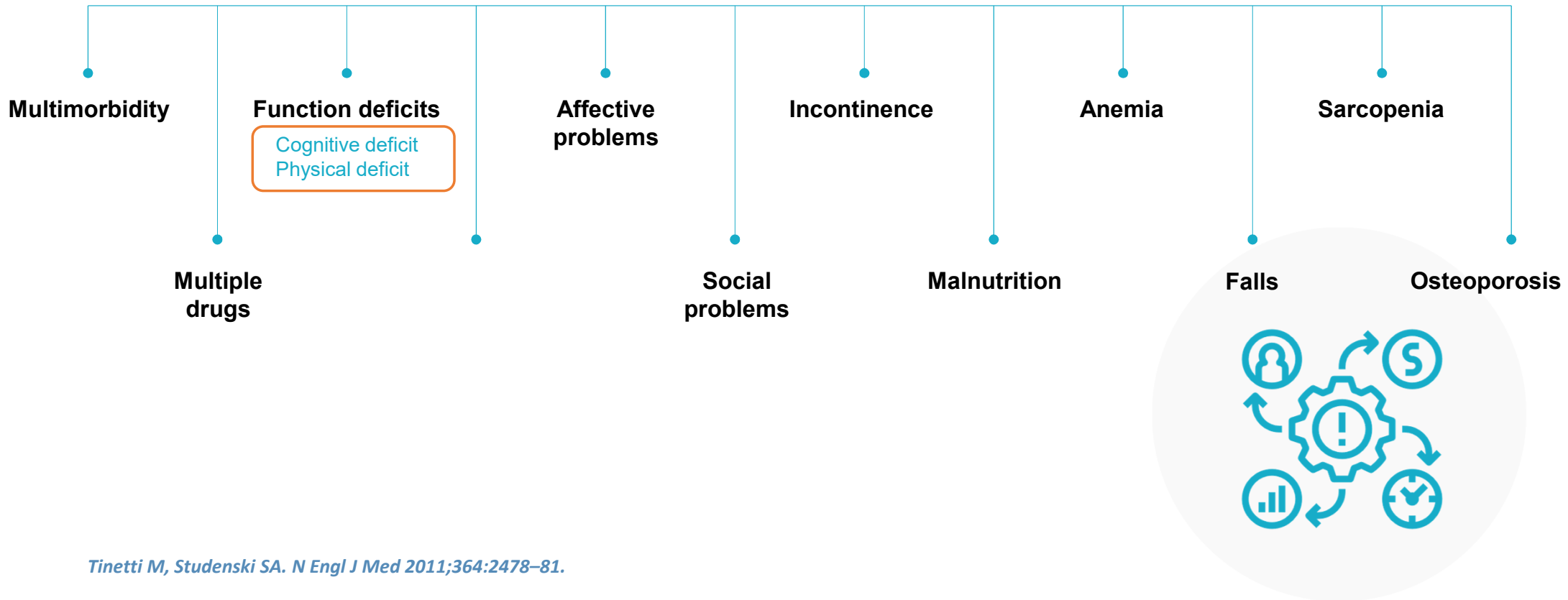
- Ex. pelvic and spinal radiation are higher-risk for cytopenias.
- However, it's much less common to see cytopenias from radiation directly, as compared to chemotherapy (or combined chemoradiotherapy).
- If radiation-associated cytopenias are present, they should only last for as long as the radiation itself.
 - If cytopenias persist after treatment with radiation alone, conduct a thorough cytopenia workup. It is unlikely to be the radiation itself.

(3) Immunosuppression: Radiation and chemotherapy combined can cause synergistic immunosuppression.

- And as with cytopenias, any immunosuppressive effect from radiation should only last as long as the radiation itself.
- Radiation can also activate the immune system through mechanisms like the "abscopal effect", in which radiation causes the immune system to attack the tumor.
 - It's rare, but a neat proof of concept: radiation's effect on the immune system is variable, and hard to predict.

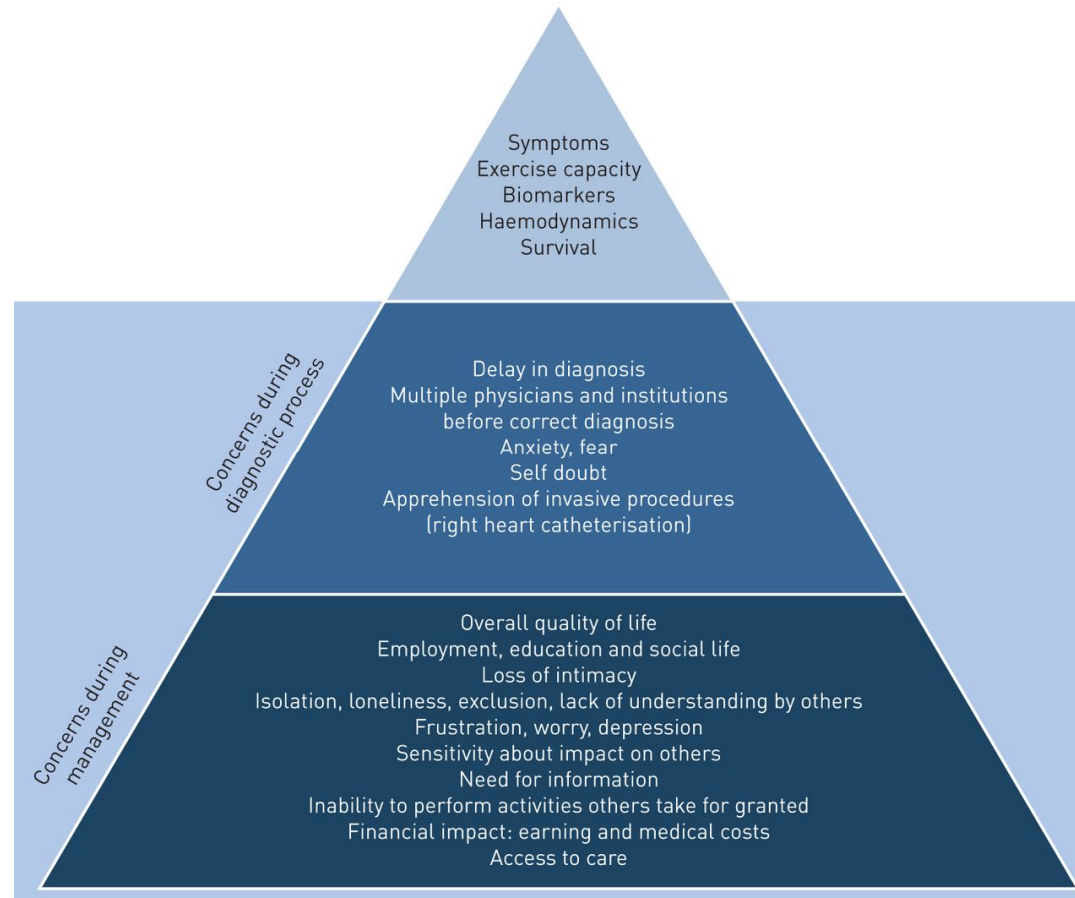
The “Complex Frail” Patient

COMPLEXITY AND FRAILITY



Tinetti M, Studenski SA. *N Engl J Med* 2011;364:2478–81.

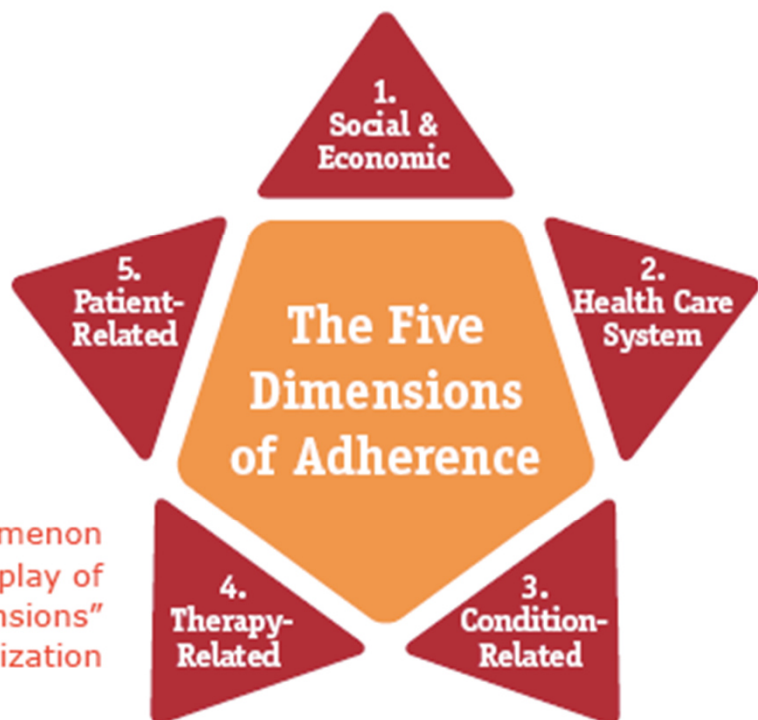
Surveys of patients and caregivers suggest that traditional parameters may be the “tip of the iceberg” when the broader range of patient concerns is considered.



“Adherence is the extent to which a person’s behavior [in] taking medication... corresponds with agreed recommendations from a health care provider”

(World Health Organization, 2003)

Adherence is a multidimensional phenomenon determined by the interplay of five sets of factors, termed “dimensions” by the World Health Organization



Different perspectives of doctor and patient in communication

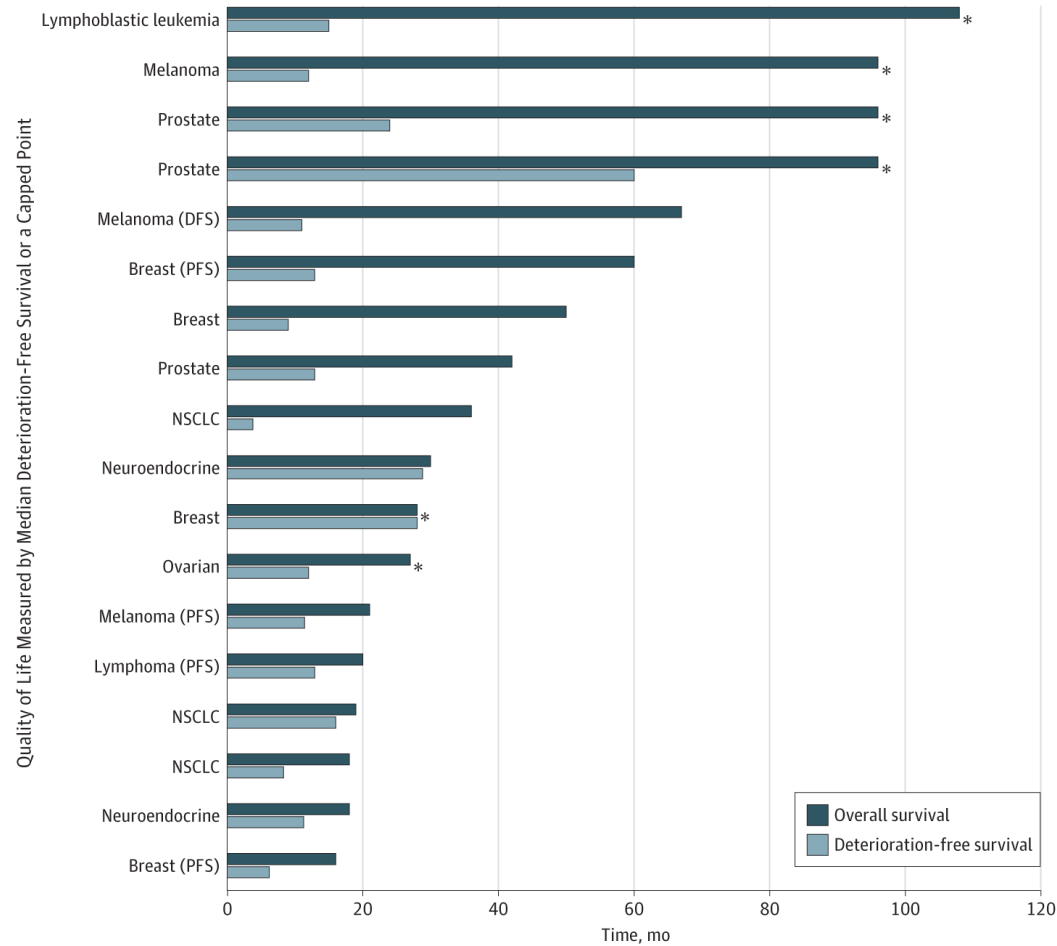
Frequencies of communication behaviors observed in 85 internal medicine visits

Communication categories	Internist	Patient
Affective		
Social conversation*	7.59	10.53
Agreements/paraphrases*	32.53	42.18
Empathy/reassurance	6.67	6.55
Instrumental		
Clarification*	9.26	2.49
Biomedical conversation ^a *	97.52	63.21
Psychosocial conversation ^{a,*}	2.81	8.76
No. of utterances*	175	139
Length of visit	14.6 min	

* Significant difference between doctor and patient (paired-samples *t*-test).

^a Biomedical and psychosocial conversation includes questions, information and advice.

Patient Experience Captured by Quality-of-Life Measurement in Oncology Clinical Trials



Known Overall Survival and Median or Capped Time of Quality-of-Life Assessment in the Intervention Arm of Studies Reporting Quality-of-Life Measures in Which Patients With Metastatic, Advanced, or Incurable Cancers Were Included and Median Overall Survival Was Not Reached. The quality-of-life assessment was capped at a set time for the items marked with an asterisk. NSCLC indicates non-small cell lung cancer; PFS, progression-free survival; RFS, relapse-free survival.

Patient Experience Captured by Quality-of-Life Measurement in Oncology Clinical Trials

Treatment	Frequency of Assessment of Quality of Life, No. (%)				
	During Treatment (n = 104) ^b	End of Treatment (n = 68)	After Follow-up (n = 81) ^c	Progression (n = 28)	Death (n = 5) ^d
Drug	87 (83.7)	50 (73.5)	46 (56.8)	25 (89.3)	1 (20.0)
Behavior	8 (7.7)	11 (16.2)	14 (17.3)	0 (0)	1 (20.0)
Radiation	2 (1.9)	3 (4.4)	10 (12.3)	2 (7.1)	2 (40.0)
Surgery	0	0	2 (2.5)	0	0
Chemotherapy combination with surgery or a drug	5 (4.8)	3 (4.4)	7 (8.6)	0	1 (20.0)
Other (procedure, device, or treatment algorithm)	2 (1.9)	1 (1.5)	2 (2.5)	1 (3.6)	0

^a Comparing global differences in whether or not quality of life was assessed for each point (eg, during treatment, end of treatment) by intervention type.

^b $P < .001$ with Fisher exact test.

^c $P = .04$.

^d Numbers were too few for statistical comparison.

Frequencies of Intervention Types for Each of the Quality-of-Life Measurements in All Included Randomized Clinical Studies (N = 149) from Lancet Oncology, Journal of Clinical Oncology, and JAMA Oncology from July 2015 Through June 2018^{aa} Comparing global differences in whether or not quality of life was assessed for each point (eg, during treatment, end of treatment) by intervention type.

^b $P < .001$ with Fisher exact test.

^c $P = .04$.

^d Numbers were too few for statistical comparison.

Association of Quality-of-Life Outcomes in Cancer Drug Trials With Survival Outcomes and Drug Class

Overall Survival and Progression-Free Survival in Trials Also Reporting Quality-of-Life Outcomes (n = 45)

Table 2. Overall Survival and Progression-Free Survival in Trials Also Reporting Quality-of-Life Outcomes (n = 45)

Outcome	Quality-of-life outcome, No. of trials		
	Improved	No difference	Worsened
Overall survival			
Improved	7	10	0
No difference	3	16	4
No data	1	2	2
Progression-free survival			
Improved	6	17	4
No difference	3	9	2
Worse	0	1	0
No data	2	1	0

Association of Quality-of-Life Outcomes in Cancer Drug Trials With Survival Outcomes and Drug Class

Distribution of Quality-of-Life Outcomes by Drug Class Among Included Trials (n = 45)

Table 3. Distribution of Quality-of-Life Outcomes by Drug Class Among Included Trials (n = 45)

Drug class	Quality-of-life outcome, No. of trials		
	Improved	No difference	Worsened
Cytotoxic	1	10	1
Targeted	3	15	3
Immunotherapy	6	1	0
Other (repurposed drugs)	1	2	2

Quality-of-life and toxicity in cancer patients treated with multiple courses of radiation therapy

QoL results reported by MRRT patients using EORTC QLQ-30 questionnaire.

Parameter		Mean (Study population)	(SD)	Mean (EORTC)	(SD)
Global health status/QoL	QL	55.8	(24.6)	61.3	(24.2)
Physical functioning	PF	72.3	(20.3)	76.7	(23.2)
Role functioning	RF	56.7*	(29.8)	70.5	(32.8)
Emotional functioning	EF	64.2	(28.0)	71.4	(24.2)
Cognitive functioning	CF	70.8	(28.5)	82.6	(21.9)
Social functioning	SF	57.5*	(35.3)	75.0	(29.1)
Fatigue	FA	51.1**	(25.3)	34.6	(27.8)
Nausea and vomiting	NV	10.8	(15.6)	9.1	(19.0)
Pain	PA	21.7	(24.2)	27.0	(29.9)
Dyspnea	DY	36.7	(35.7)	21.0	(28.4)
Insomnia	SL	36.7	(32.3)	28.9	(31.9)
Appetite loss	AP	21.7	(27.1)	21.1	(31.3)
Constipation	CO	21.7	(31.1)	17.5	(28.4)
Diarrhea	DI	8.3	(23.9)	9.0	(20.3)
Financial difficulties	FI	26.7	(25.2)	16.3	(28.1)

, MRRT patients reported significant deterioration of fatigue, social- and role functioning compared to EORTC QLQ-30 cancer patient cohort, *p = 0.05, **p = 0.006, unpaired Student's *t*-test.

DOCTOR AND PATIENT'S PERSPECTIVE

Variable	(n, %; mean± SD)
Age	63 ± 14
Sex	
F	69, 68.3%
M	31, 30.7%
Impairment ADL*	39, 38.6%
Impairment IADL [†]	54, 53.5%
Dyspnea	28, 27.7%
Depressed mood	47, 46.5%
Cancer UGI	23, 22.8%
Lung	5, 5.0%
Other cancer	19, 18.8%
Gynecological cancer (including breast)	40, 39.6%
Head-neck	12, 11.9%
Falls	7, 6.9%
Dizziness	16, 15.8%
Cough	4, 4.0%
Pain	41, 40.6%
Moderate-severe pain intensity	22, 21.8%
Anorexia	34, 33.7%
Weight loss > 5% in the last 3 months	32, 31.7%
Intravenous therapy within the last 3 days	76, 76%
Cargiver	94, 93.1%
Palliative/supportive care	66, 65.3%
Patient quality of life perceived by the doctor	52.9 ± 21.2
Quality of life perceived by the patient	55.3 ± 26.1
Fatigue	1.8 ± 1.2

* Dependence in at least one of the ADLs; [†] Dependence in one of the IADLs;

	Quality perceived by the patient < 60% (n=47)	Quality perceived by the patient > 60% (n=53)	p-value
Age mean	64.5 ± 13.3	62.5 ± 14.1	0.473
F	31	38	
M	16	15	0.536
Impairment in ADLs	22	17	0.132
ADL bathroom	27	20	0.049
ADL hygiene	19	15	0.201
ADL dressing	17	14	0.376
ADL locomotion	14	17	0.520
Dyspnea	17	11	0.087
Clinical instability	15	7	0.024
Acute patient	13	6	0.038
Perception of health status			<.001
0			
1	11	25	
2	13	21	
3	21	4	
8	2		
Need for home care	38	33	0.055
Vision problems	2	4	0.494
Depressed mood	32	15	<.001
Impairment in IADLs	32	22	0.010
IADL meals	29	19	0.010
IADL houseworks	34	24	0.012
IADL pharmacological therapy	16	10	0.084
IADL stairs	23	21	0.363
Worsening in ADLs in the last 30 days	32	18	<.001
GI Cancer	11	12	0.928
Lung Cancer	3	2	0.443
Other cancers	9	10	0.971
Gynecological cancer (including breast)	15	25	0.088
Head-neck	9	3	0.038
Falls	5	2	0.179
Dizziness	7	9	0.812
Cough	3	1	0.265
Pain	23	18	0.129
Moderate-severe pain intensity	15	7	0.024
Anorexia	19	15	0.201
Weight loss	16	16	0.680
Caregiver	44	50	0.879
Fatigue mean	2.28 ± 1.19	1.27 ± 1.50	<.001

	Quality perceived by the physician < 60% (n=47)	Quality perceived by the physician > 60% (n=53)	p-value
Age mean	66.1 ± 13.6	61.3 ± 13.5	0.086
F	32	37	
M	15	16	0.852
Impairment in ADLs	27	12	<.001
ADL bathroom	34	13	<.001
ADL hygiene	24	10	<.001
ADL dressing	21	9	0.005
ADL locomotion	20	11	0.048
Dyspnea	15	13	0.412
Clinical instability	18	4	<.001
Acute patient	17	2	<.001
Perception of health status			0.029
0	1	2	
1	11	25	
2	16	28	
3	17	8	
8	2		
Need for home care	38	33	0.055
Vision problems	2	4	0.578
Depressed mood	30	17	0.001
Impairment in IADLs	36	18	<.001
IADL meals	33	15	<.001
IADL houseworks	36	22	<.001
IADL pharmacological therapy	22	4	<.001
IADL stairs	29	16	0.002
Worsening in ADLs in the last 30 days	33	17	<.001
GI Cancer	13	10	0.297
Lung Cancer	2	3	0.748
Other cancers	9	10	0.971
Gynecological cancer (including breast)	16	24	0.252
Head-neck	6	6	0.824
Falls	3	4	0.820
Dizziness	9	7	0.391
Cough	2	2	0.902
Pain	22	19	0.266
Moderate-severe pain intensity	14	8	0.077
Anorexia	22	12	0.011
Weight loss	20	12	0.033
Caregiver	44	50	0.879
Fatigue mean	2.46 ± 1.13	1.12 ± 0.92	<.001

Impairments vs. disability

Examples of Functional Assessment

General performance

Functional Independence Measure (FIM)

Short-Form 36 (SF-36)

Karnofsky Performance Status Scale

Eastern Cooperative Oncology Group (ECOG)

National Institutes of Health Rehabilitation Medicine Department
Performance Scale (NIH-RMDPS)

Mobility/balance

Timed Up and Go (TUG) Test

6-Minute Walk Test

Tinetti Balance and Gait Assessment Tools

Pain

Visual analog scales

Brief Pain Inventory

Fatigue

Visual analog scales

Piper Fatigue Scale

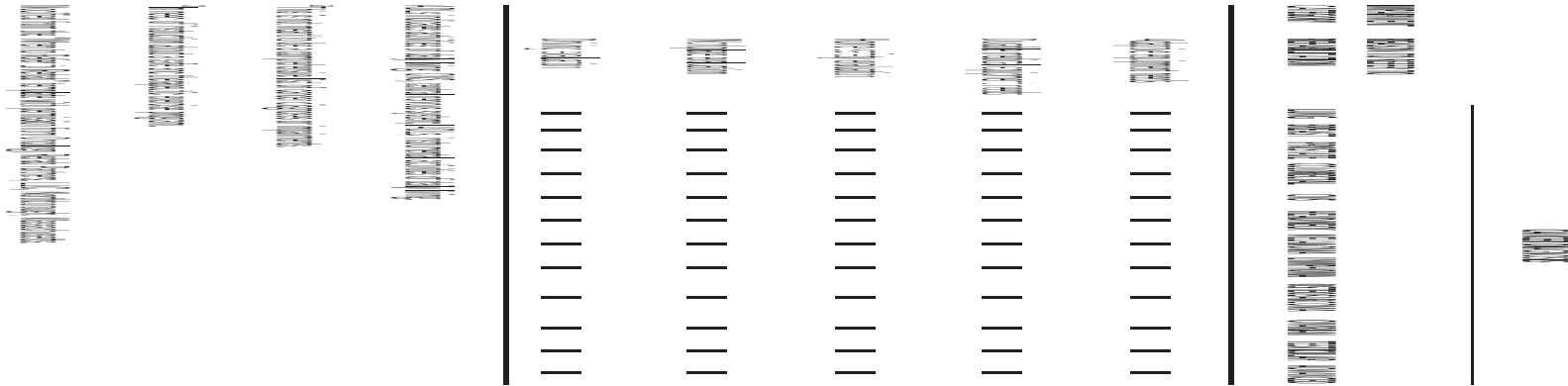
Functional Assessment of Chronic Illness Therapy-Fatigue Scale (FACIT-F)

Distress

Distress Thermometer

Hospital Anxiety and Depression Scale

Identifying Physical Impairments in Patients With Cancer



Common Impairments Treated

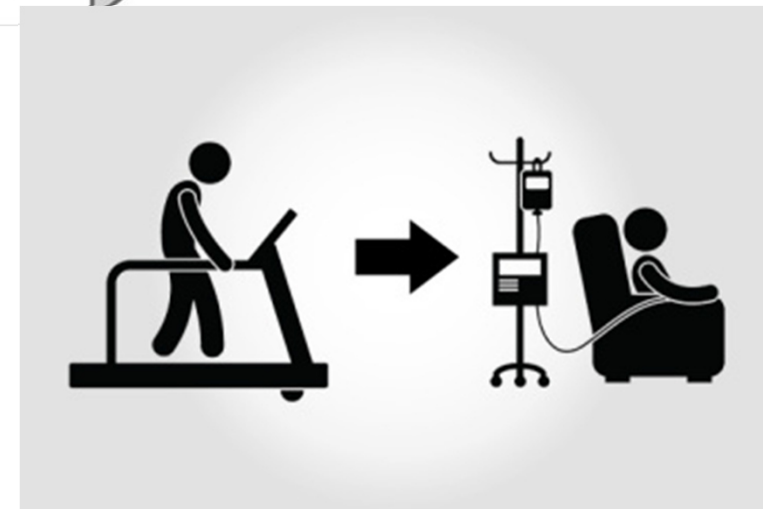
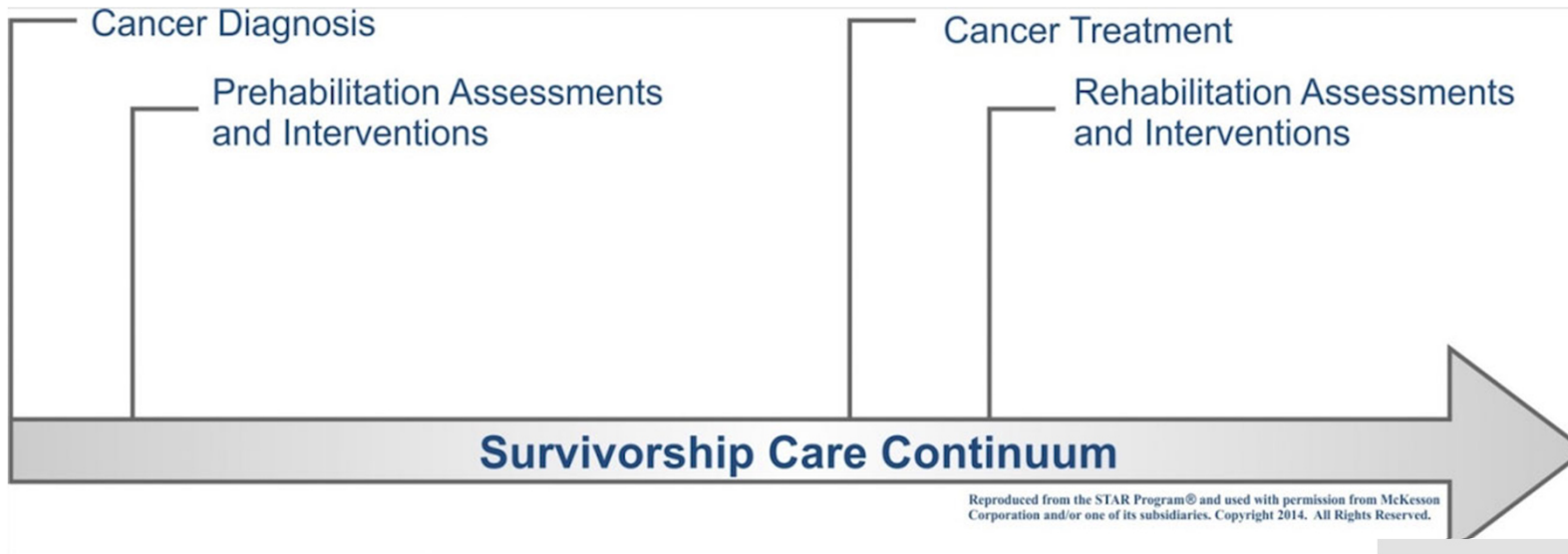
General Physical Impairments

- Difficulty returning to premorbid activities
- Joint pain, diffuse (e.g., arthralgias)
- Musculoskeletal pain (e.g., myalgias)
- Neuropathic pain
- Somatic pain
- Visceral pain
- Weakness
- Fatigue
- Deconditioning

Functional Disabilities

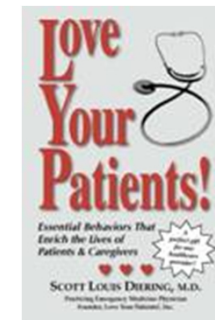
- Inability to return to work
- Difficulty caring for children/grandchildren
- Limited mobility due to safety concerns (walking, driving, etc.)
- Inability to travel and take vacations
- Difficulty with ADLs (e.g., dressing, bathing)
- Difficulty with IADLs (e.g., chores, shopping)

Cancer Rehabilitation and the Care Continuum



How can doctors help?

- Move away from your computer and look me in the eye.
- For the brief period of time we are together, make me feel that I am your only patient and my health is your only priority.
- Take a few minutes to explore my values and preferences before we develop a plan of action.
- If I am a candidate for a screening test, help me understand pros and cons, and benefits and harms, then give me time to process the information before I decide. Allow me to “sleep on” decisions, even those that might seem straightforward to you.
- Hone the skills needed to “read people”—to determine who is the information seeker, who is the emotional responder, and who is too worried to hear anything you are saying.
- Be patient when I am confused, unaware of preventive health screening, or anxious about unfamiliar symptoms or asymptomatic presentations.
- Help me understand the terminology, especially the acronyms and short forms that are familiar to you but like a foreign language to me.
- Give me the most common and important side effects of a test, treatment, or medication, but do not over-whelm me with all possible negative outcomes.
- Give me “take-aways”—printed information, summaries, or references to reputable sources of information (such as those created by the Canadian Task Force on Preventive Health Care) so I can come to the next appointment more prepared.
- Clarify the process of communicating screening or testing results; reinforce that no news is good news.
- Explain next steps: what is going to happen from this point, when I need to see you again, what I should watch for, who I should contact if I run into problems.
- Encourage me to take advantage of opportunities to prevent or improve health issues for myself and loved ones.



What can patients do?

- Go to your appointment prepared to share your values and preferences while you and your health care team develop a plan together. Reflect on what is important to you and what options you might prefer.
- Bring someone with you as a second set of ears to help with questions and to take notes for later reference.
- Come with a few general questions and later, as you process the information, record additional questions to ask at a follow-up visit; ask about screening benefits and harms.
- For testing situations, when symptoms are present, document any physical or emotional changes and their frequency and duration.
- Seek information and support from your full health care team, such as a registered dietitian who can help you learn to read nutrition labels or a pharmacist to assist you with understanding medications.
- Check with your doctor before accessing alternative treatments.
- Do not assume that action is always better than no action; based on your values and preferences, it might be better for you not to have a screening test or undergo a particular treatment. Discuss this fully with your doctor before making a decision.
- Take a proactive approach; be willing to accept and implement screening and preventive strategies to avoid more serious health issues. Be open to making lifestyle changes to prevent or improve health issues.

WHAT DO PATIENTS
REALLY WANT?



1. **Transparency:** It is acceptable if a physician does not know everything about their illness or diagnosis, but patients expect their doctors to share as much as possible.
2. **Active listening:** When your patients leave your office after an appointment, do they feel like they are leaving a speech or a conversation? This is because conversations, and not lectures, will be helpful in improving your patients' health
3. **Trust:** If a doctor is an active listener, patients will feel comfortable sharing every piece of information, including sensitive topics, assumptions, related myths and much more.
4. **Care and connection:** Patients instantly recognize the obvious signs of overtreatment, and they understand that more care is not equal to better care.
5. **Respect**
6. **Effective communication:** Illness can suffocate even the bravest of souls. Diagnosis and procedures can be complicated, and a patient often feels vulnerable and helpless in your office, irrespective of their reason for being there
7. **Time:** Accept that some patients demand more time than others.
8. **Empathy:** You can easily relate to your patient by asking about the daily schedule or eating habits.you care.
9. **Access:** If your patient is sick and wants to be seen, you must see him or her. If you are not available when they need you, what good are you to them?
10. **Clear instructions:** During an appointment, don't make the mistake of rushing through instructions at an unintelligible pace.
11. **Collaboration:** Your patients understand their body and life better than you do, and therefore you must get their consent before ordering a test or offering treatment. You must talk it through with your patients until they understand the purpose and implications of a test or treatment.

Patient perspectives

Exploring patient values and preferences

Asking not only what a patient wants or needs but also what they value results in more meaningful decision making for both preventive and responsive health care.

We are so fortunate to live in a time when there is the willingness and expertise to make this happen.



Roi Shternin



What Do Patients Want?

A Guide for Healthcare Professionals
to Understand and Empower Patients

