What do patients want?

The 9th Congress of The Lebanese Urology Society
Sep.29 - Oct.1, 2016
The days of patients nodding silently as they passively receive information from their doctor are gone. Modern patients are **informed, connected and curious**. They read about their conditions online, they engage with other patients and they expect a more dynamic interaction with healthcare professionals.
There has been a lot of discussion in healthcare about patient engagement, which is defined as a partnership between patients and their family members on the one hand and clinicians and healthcare organizations on the other.

Many companies and organizations are nowadays developing ways to engage patients and families in health care.
What do patients and their families want?
To obtain patients and family caregivers input, we have invited hundred patients and caregivers to respond to four questions.

The questions were designed to elicit patient and family experiences, desired changes to health care, and the patient and family role in health care.
S U R V E Y

A. Please remember a time when you, either as a patient or as a caregiver, had a
direct care experience (for example, at a doctor’s office, hospital, clinic, or
emergency room).

1. To what extent did you feel fully engaged (treated like a partner) during
this experience? Rate the experience from 0 to 10.

|   0   |   1   |   2   |   3   |   4   |   5   |   6   |   7   |   8   |   9   |   10  |

What happened that made you feel this way?

2. Name 3 incidents that made you feel engaged.

   a. ..............................................................................................................................

   b. ..............................................................................................................................

   c. ..............................................................................................................................

3. Name 3 incidents that made you feel unengaged.

   a. ..............................................................................................................................

   b. ..............................................................................................................................

   c. ..............................................................................................................................

B. Imagine that you have the power to change anything you want to in the
healthcare system. What would you change?

..............................................................................................................................

..............................................................................................................................

..............................................................................................................................

..............................................................................................................................

..............................................................................................................................

..............................................................................................................................
Most commonly used words/concepts across responses
What makes patients and caregivers feel engaged?
A. Clear Information

ASK US
Patients & their caregivers want to know about:

- Their condition and its implications and prognosis.
- The care they were receiving / will be receiving.
- The treatment or testing options available.
- The outcomes they could expect, both benefits and potential risks.
- What role they could play in accomplishing those outcomes, including managing their care.
- Information about the costs of care.
One respondent stated:

“Educate to engage; we, patients want to know. Teach us so that we can be effective in our care management.”
Information and education should be provided in a way that is literacy appropriate and easily understood by the patient or caregiver, free of technical terms.
Said one respondent:

“I would like to see greater sharing of info without using technical words. I realize it’s easier for a doctor to use technical terms ’cause that’s how he sees it, but the patient and caregiver don’t always understand—and need it all in simple terms.”
B. More Time

MD

PLEASE DON'T WASTE THE DOCTOR'S TIME WITH QUESTIONS
C. Mutual Respect

“In any partnership, respect is the key to success. I respect my doctors’ expertise, and they respect my input as the patient.”
D. Relationship
Patient Starts Out: Engaged

I am really concerned about what I think is wrong
I am glad I looked my symptoms up on the Internet
I have my list of questions

The Medical Exam
- Physician-Driven
- Bio-medical Focus
- Same for 80 yrs.+

Patient Leaves: Disengaged

He's always so busy
He interrupted me again
I told him I don't like taking medicine
I can only ask one question!
What did he say again about that test?

A Trip To The Doctor’s Office From the Patient’s Perspective
Bottom line...
Patients want to be treated as PARTNERS...
Nothing about me without me!
People – centered and integrated services are the next evolution of healthcare...
The potential benefits?!
To patients and their caregivers

- Increased satisfaction with care and better relationships with care providers.

- Improved access and timeliness of care.

- Improved health literacy and decision-making skills that promote independence.
To patients and their caregivers - cnt’d

- Shared decision-making with professionals with increased involvement in care planning.

- Increased ability to self-manage and control long-term health conditions.

- Better coordination of care across different care settings.
To health systems

- Enables a shift in the balance of care so that resources are allocated closer to needs.

- Improved patient safety through reduced medical errors and adverse events.

- Improved job satisfaction of the healthcare professionals.
To health systems – cnt’d

- Improved workloads and reduced burnout.

- Role enhancement that expands workforce skills so they can assume a wider range of responsibilities.
Diakonia ...

Your support partner
Thank you for listening...