Patient-partnered care

Andreas Laupacis
Lead, Patient Involvement, Department of Medicine, University of Toronto
Canada Research Chair in Health Policy and Citizen Engagement
Conflict of Interest

I serve on a Data Safety Monitoring Board for a RCT funded by Novartis.
Determining patients’ research priorities

Mike Katz
Why partner with patients?

- They live with the disease
- Justice/fairness
- They may have different research and clinical priorities than clinicians
- They may have different insights into the importance of outcome measures
- They can be effective advocates for clinical and system change
“There’s a huge range in the quality of hospital care. Here’s a suggestion for quality improvement questionnaires. Don’t ask about how care was overall. I rated everything as medium. But it wasn’t really medium. I had fantastic people for whom this was obviously their life vocation, and other people who I don’t know what they were doing there. My nursing care was fantastic and it was crappy. Some of the residents were unbelievably compassionate and careful, and others were just totally oblivious.”

“The surgical residents and fellows – oh my gosh! I went back and forth between wanting to give them a slap in the side of the head and feeling sorry for them because they were so busy. My first post-surgical visit with the residents and the fellows – they came whipping in. There were about five of them. I was trying to have a pee. I had the bottle and when they came in I pulled the sheet up. They asked, ‘How it’s going?’ I said, ‘Well, I am having a little trouble peeing.’…”

http://healthydebate.ca/faces-health-care/cancer-religion-philosophy
"I think the ALS clinic has all the right puzzle pieces in place, but it needs some organization. Every time we would go there it was 'Okay, you’ll see this person for 15 minutes.' Then we’d wait an hour and a half and we’d see another person for 10 minutes. Then we’d wait… I have all the patience in the world but if I have ALS - no way. Mom literally had to not drink all day because no one could change her diaper at the hospital, which is a long drive away. That was really tough."

"WHAT I STRUGGLED WITH IS WHY THEY KEPT CALLING US BACK FOR APPOINTMENTS, BECAUSE ALL THAT WAS BEING SAID IS 'YES, THE DISEASE IS PROGRESSING.'"

"The doctor at the clinic was very interested in trials and that’s what seemed to come up more often than anything. I think they felt kind of defeated and they wanted to get a new medical trial going, so there was a lot of pressure about trials. It would come up all the time and pretty much sometimes be the focus of the appointment. And I am thinking 'I didn’t come all the way here to be asked this question. I get that trials are an important part of medicine, but…'"

NINA ON HER MOTHER’S ALS CARE
“WHENEVER SHE CAME OVER, THE NURSE SEEMED JUST AS CONCERNED ABOUT ME AND MY DAUGHTER AS ABOUT MY MOM.”

"One day she came out of my mom’s bedroom and we were sitting at my dining room table. She took 5 bottles of nail polish out of her bag and lined them up in front of me and said 'Choose a colour.' I kind of looked at her quizzically and she said 'I am going to do your nails for you. You need to take care of yourself so you can be there for your mom.' And she gave me a manicure and painted my nails. It was just phenomenal - I just couldn’t believe that.”

PAT ON BRINGING HER MOTHER HOME TO DIE
THE NEED TO BUILD “WITH” NOT ONLY “FOR” PATIENTS

PATERNALISM

- INFORM
- READ

CENTERED APPROACH

- CONSULT
- QUESTION
- STIMULATE
- REACT

PATIENT PARTNERSHIP

- CONSTRUCT TOGETHER
- SHARED LEADERSHIP

FREE AND INFORMED DECISION MAKING
RECOGNITION & MOBILISATION OF EXPERIENTIAL-BASED KNOWLEDGE
DEVELOPMENT OF SELF-CARE COMPETENCIES
MEMBER OF HIS/HER OWN CARE TEAM
MOBILIZATION OF ONE’S OWN LIFE PROJECT

MEMBER OF HIS/HER OWN CARE TEAM

FREE AND INFORMED DECISION MAKING
RECOGNITION & MOBILISATION OF EXPERIENTIAL-BASED KNOWLEDGE
DEVELOPMENT OF SELF-CARE COMPETENCIES
MEMBER OF HIS/HER OWN CARE TEAM
MOBILIZATION OF ONE’S OWN LIFE PROJECT
Stages of patient partnership

- Care partners
- Transmitting their experiences to partners (mobilizing their expertise)
- Assuming transformational leadership (maturity of expertise)
From MASS LBP – How we see the public

• Polarized, volatile, emotional, uniformed (Risk management)

• Caring, reasonable, purposeful, curious (Resource)
• Unconvincing reasons not to partner with patients

• Patients are advocates for their particular hobby horse

• Patients can’t be representative of the perspectives of all patients

• It is anti-evidence-based medicine

• We haven’t studied the impact of patient partnership sufficiently
Some other thoughts going forward

- Personality, motivation and fit is important
- Patients must realize that “their story” is important, but it isn’t the only thing – perhaps more important is, together, to improve the quality of care going forward
- Some patient stories can cause harm
- Don’t ask patients to be, or label them as, “representative”
- Training is needed for clinicians, managers and patients
- Think about the voices that often aren’t heard
- Deliberately try to make yourself a little (but not too) uncomfortable
- Just do it! If everyone is in this for the right reason, together you’ll figure out what is and what isn’t working, and improve as you go
What happens when we are ill is sometimes so unbelievably beautiful. The tenderness that happens within families at that moment of suffering. That awareness of our humanity and our mortality that we keep at a distance most of the time. The kind of intimate, beautiful, sacred conversations that happen in those moments that we would never ever be open to at other times.”

“When I was recovering from surgery one of the guys in the bed next to me grew up in a poor part of Toronto. A poor black kid. He’d become very successful in theatre and film and at the time he was working on a Hollywood action movie. Just before he left the hospital, he said he couldn’t leave until he had prayed with me. So I thought, ‘Okay, he wants me to pray for him.’ But he came around, took my hand, took my wife’s hand and then he said the most beautiful prayer. He was grateful to God that he had met my wife and I. It wasn’t so much the words, but the tactile connection of holding the hands of essentially, a stranger, and both of us having a sense of great connection through our shared vulnerability. Then he said, ‘It’s been really great to meet you,’ and off he went.”
“I know this sounds weird, but I am very lucky to be on dialysis, because if I decide that I have had enough, end of life care is really settled. We know how to stop dialysis and we know exactly how to keep somebody comfortable and for them to pass. It’s not considered committing suicide, it’s just considered discontinuing treatment. That’s something that I have held onto this whole time, knowing that if things just get too much, that I have an out.”

“I’ve had some friends who were like you know, ‘F that! What, what are you talking about?’ But most people understand. They know that I’ve really worked hard. This has not been an easy ride. I’ve come home in a walker in my 30s. I think it’s really important to understand that some of the things that we have the capability to do in medicine, we shouldn’t be doing. Just because we can doesn’t mean we should. For example, the doctors are worried the cancer will come back and they’re talking about me having a heart transplant. I am going to consider it, but just because you can give me a heart transplant doesn’t mean that it’s right for me.”

KAREN ON LIVING WITH KIDNEY DISEASE