Transforming experiences for patients and caregivers through empowerment

Presented by:
- Carmen Auste, Philippines
- Marnie Escaf, Canada
- David Hamilton, England
- Nora Moumjid, France
1. Maximizing Patient and Family Engagement for Better Care. **Carmen Auste**

2. The Patient Partner Program: Embedding Patients and Caregivers into Hospital Planning and Decision-Making. **Marnie Escaf**

3. Shared decision-making in the physician-patient encounter: a key factor for patient empowerment. **Nora Moumjid**

4. Challenges of involving patients in decisions in the context of the multidisciplinary team. **David Hamilton**
Maximizing Patient and Family Engagement for Better Care
Carmen Auste
Why Patients and Families Matter

The most valuable untapped resource for improving healthcare is the experiential and practical knowledge, wisdom, and energy of individuals, families, and communities who face challenging health issues in their everyday lives.

Patients and families are important stakeholders in health care, they have the most at stake. A growing body of evidence shows that their engagement leads to better health outcomes, better and more responsive care and more positive patient journeys.
Engagement is a mutual relationship. Engagement changes the FOCUS.

From taking action to improve health and healthcare for patients,

for patients,

to taking action with patients, families, their support networks
Patient and Family Centered Care

• a partnership among practitioners, patients, and their families to ensure that decisions respect patients’ wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care (Institute of Medicine, Washington, DC).
People-centred Health Care (WHO)

Rooted in universally held values and principles

Promotes culture of care and communication

Responsible, responsive, accountable services and institutions

Supportive and positive health care environments

“providing care that is respectful of, and responsive to, individual patient preferences, needs, and values; ensuring that patient values guide all clinical decisions.”
A Multidimensional Framework For Patient And Family Engagement In Health And Health Care.


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Patient and Family Engagement in Research occurs when they meaningfully and actively collaborate in:

- Governance, priority setting
- Conduct of research
- Knowledge translation (summarizing, distributing, sharing and applying the resulting knowledge)
Patients and Families influence decision making, accelerate knowledge translation and uptake of new policies and practices. Research is conducted in areas patients and families value/find meaningful. Researchers understand the value of patient and family engagement and patients and families appreciate the value of research. Researchers, health care professionals and policy makers work together with patients and families to ensure an integrated people centered approach that improves policy, practice and health outcomes.
Patient and family engagement in the national policy level includes engaging patients, families and SURVIVORS in advocacy for better access to care and improved health systems infrastructure.
What do patients, families, support networks and survivors need in order to participate effectively in their care? •

We must know it’s important (i.e. the why behind the what).

We must know it’s possible (i.e. the ways or avenues we can take that are within our ability).

We must know it’s safe (i.e. we can’t be punished, ignored, or made more fearful).

Jessie Gruman Patient, and President of the Center for Advancing Health
The Patient Partner Program:
Embedding Patients and Caregivers into Hospital Planning and Decision-Making

Marnie Escaf
Senior Vice President
Princess Margaret Cancer Centre
Toronto, Canada
University Health Network (UHN)

Vision: Achieving Global Impact

- Large academic health sciences centre, located in Toronto, Canada
- Network of 4 hospitals → 10 Clinical Programs
Presentation Objectives

1. Provide an overview of the Patient Partner Program.

2. Discuss impact and early reflections on the organization, patients & providers.
Evolution of Patient Involvement at UHN

**2014: Patient Partner Program est.**

- **Early 2000’s**
- **2016**
Patient Partner Program Structure

- Develops and executes UHN Patient Partner Strategy

**Corporate Patient Engagement Team**

**Patient Engagement Site Lead**

- Oversight and executive at site/hospital level
Building a Patient Partner Program

- Identified Need
- Recruitment
- Application & Selection
- Onboarding
- Orientation
- Engagement
- Evaluation
Identifying the Need for a Patient Partner

**Two Key Components:**

1. Spectrum of Participation
2. Staff Liaison
Team Determination of Level of Engagement

IAP2 Spectrum of Engagement for Patient Engagement

Resource: Adapted from The International Association of Public Participation (IAP2) Spectrum© http://www.iap2.org/
Staff Liaison

1. **Primary point of contact** for the Patient Partner and act as a bridge, supporting them to fully integrate and partner with the team.

2. Assess the **support needs** of both Patient Partners and the team

3. Provide administrative & communications support

4. Works and **collaborates** with the Partners in Care Team
Patient Partner Recruitment

1. Program/staff can identify candidates
2. Patient can self-select

Marketing materials:
- ✓ Posters
- ✓ Bookmarks
- ✓ Info letters
Selection Criteria to be Met

1. **Living well** with their health condition

2. **Coping well** with their hospital experience

3. Willing to **share** insights and information

4. Demonstrates a passion for **improving** health care for others

5. Ability to **listen** well, **respect** the perspectives of others

6. Respect and maintain **confidentiality** of patient and organization information

Adapted from: Agency for Healthcare Research and Quality. Guide to Patient and Family Engagement.; Institute for Patient and Family-Centered Care; UHN Partners in Care Working Committee and Working Group (2014/15)
Application Process

Application Package:
• Role overview & expectations
• Background questions
• Reference checks

Interview:
• Standard questions
• Understand care, personal skill-sets & interests
• Ensure expectations are aligned
Onboarding & Skill-Building

- Corporate values, policies & expectations

- Coaching on how to be an effective partner:
  - Listening
  - Communicating
  - Sharing
Preparing for Meaningful Engagement

1. PATIENT PARTNER MEETING
   - Collaborative preparation (“terms of engagement”)
   - Materials & information
   - Understand their role on the team

2. TEAM MEETING
   - Understand patient engagement
   - Explore thoughts on partnering with patients
   - Prepare for effective partnership
   - Review role of staff liaison
   - Review tips on communication
Patient Partners: Current Status

• UHN (corporate): 46

• Princess Margaret: 10
  • Quality Committee
  • Patient Experience Committee
  • Retreats (Goals & Objectives, Strategic Planning, CCO)
  • Caring Safely Transformation
  • Working Groups/ Project based
Evaluation Parameters...to date

• # Patient Partners recruited
• # Patient Partners participating in engagement activities

Anecdotally

I am so very thankful to be part of this program. It has given me purpose during times when I have wanted to give up on treatment.

- Patient Partner

Hearing from patient partners “made it more apparent, the divide between what we think the patients want and what they ACTUALLY value.”

- Staff member
Closing Thoughts

1. Having a **formalized program** adds credibility & value but requires dedicated resources/time

2. Patients have tremendous ‘**out-of-the-box’** insight & conversations change

3. **Culture shift**: since inception of program, more staff suggest need for patient partners in their work
Closing Thoughts

4. Setting realistic **expectations** is critical
   • Patient frustrations at **pace of change**

5. Increased need for **diversity** of individuals & perspectives
Our Next Steps

1. Enhance evaluation → quality and impact

2. Expand engagement beyond ‘traditional committees’

3. Increase diversity of partners
Shared decision-making in the physician-patient encounter: a key factor for patient empowerment

Nora Moumjid, Associate Professor, University Lyon 1, HESPER EA 7425, Léon Bérard Cancer Centre
What is Shared Decision-Making?
Definition

“The information exchange is two ways... . The defining characteristic of deliberation ... is its interactional nature” (i.e., between the physician and the patient or potential others), and “both parties work towards reaching an agreement and both parties have an investment in the ultimate decision made.” (Charles et al. 1996, 1997)

- Focus: patient-physician shared participation in every step of the decision-making process.
- Shared decision-making is relevant to the vast majority of clinical situations
Shared Decision-Making steps

1. Define problem/identify decision to be made
2. Present options
3. Discuss potential benefits/risks
4. Identify patient values/preferences
5. Explore patient ability
6. Present recommendations
7. Check understanding
8. Make/defer decision & arrange for follow-up

Makoul & Clayman 2006
Shared Decision-Making outcomes

In prevention, chronic disease treatments, primary care:
- Improve physician-patient communication
- Increase agreement between providers and patients
- Reinforce patients’ rights
- Improve patient’s knowledge
- Improve safety and quality: doing things right vs. doing the right thing

Stacey et al. 2014, Legaré & Thomson 2014
Barriers to Shared Decision-Making

- Physicians/healthcare professionals’ lack of training: to SDM/communication with patients/healthcare users
- **Time**: No and SDM helps to structure the consultation
- **Fashion**: No, and first papers have been published a long time ago (Szaz & Hollender 1950, Menzel 1959)
- **Patients are left alone**: No and Informed decision-making is not shared decision-making and physician decides after information provided to patient is not shared decision-making
- **Patients’ expectations**: paternalistic role of the physician expected by some patients and this should not be ignored
Means to overcome barriers

- **Majority of patients** want to be (i) **informed and involved** in decision-making: patients’ role/power towards physicians – **cultural paradigm shift**
- Healthcare professionals can be **trained** to shared decision-making
- **Decision aids** can be used to encourage professionals to practice shared decision-making (https://decisionaid.ohri.ca)
- Interventional and applied research in the field should be fostered to **improve**:
  - **Health outcomes**: quality and quantity of life, patient satisfaction
  - **Value of healthcare services**
- To **incite public health decision makers to fund research and pragmatic means/processes** in the field
Future issues

- SDM integrated in healthcare system policies (UK, USA etc.) and part of patients’ rights (France etc.) should now be sustained in practice: several tools/toolkits – e-health

- SDM is widely implemented in cancer: international level and in France (Kehl et al. 2015; Moumjid et al. 2007, 2011; Durif-Bruckert et al. 2014) – example to support dissemination of SDM in other medical settings

  → SDM: a key factor for patient empowerment, and going further, for person-centered care (Wait & Scrutton, 2015)
To summarize

Shared decision-making in the medical encounter: What does it mean (or it takes at least two to tango) Charles Cathy, Gafni Amiram, Whelan Tim, Social Sciences and Medicine, 1997, 44(5): 681-92

Special thought to Cathy Charles
To summarize cont’d

At the beginning, SDM was a funny little bird, with difficulties in taking flight, but is becoming a nice flying bird, friend with patient empowerment and person-centered care.
Thanks for your attention

Save the date: International Shared Decision-Making Conference – 2nd-5th July, Lyon-France

worldcancercongress.org
Challenges of involving patients in decisions in the context of the multidisciplinary team

David Hamilton
NIHR Academic Clinical Lecturer¹
Ear, Nose and Throat Speciality Registrar²

¹Institute of Health and Society, Newcastle University
²Northern Region
Multi-Disciplinary Team
Patient values should inform our decision making process
Max facs surgeon: So shall we see him together

(Silence 10 s)

ENT Surgeon: Depends how you put it to the patient isn’t it, you know!

Plastic surgeon: It’s one of these things, we’ve done this before, and you see the patient, and you have two people there, and you confuse the patient even more. I think….

Nurse: It’s horrendous, I think it is the worst thing you can do for a patient

Plastic surgeon: I agree. I think it’s a terrible thing

Nurse: Patients just don’t know, they just don’t know what to do

Max Facs Surgeon: But are we not supposed to give the patient choice?
• Members of the team often have a clear view of what they think is ‘best’
“In general head and neck there often isn’t an option; you’ve got the best treatment that there’s an evidence base for that… once you’ve decided on that option it’s not that I’m deciding on it as a non-surgical oncologist or a surgical oncologist deciding on it; that is the truth as far as we know it…that is at present universally thought to be the best treatment for the patient”

Dr Orange, Oncologist, Interview
Framing

- If one best treatment is decided by the team, this one treatment option may be delivered to the patient.
- If there is a choice, it is often ‘framed’ to ensure the ‘correct’ decision is made.
“…your skin on the outside will start getting red like it’s had a sun burn-type reaction and on the inside it starts getting red and inflamed as well. And that means that you’ll start having problems like a sore throat… So, you’ll be put on special mouth washes…. You’ll feel more poorly if you’re not keeping your strength up so we would arrange …a little tube that’s put in your tummy”

Oncologist, Observation, Clinic Appointment
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“The outside of your skin and the inside of your throat will all become quite red and hot and sore and that’s why swallowing will become very, very difficult – probably impossible. Even swallowing your own saliva will be impossible by the time you get to the end of that six weeks…….Even the strongest guys struggle, believe me and by the time they get to six weeks, life is very difficult… infection gets into your throat no problem and you’re overwhelmed….”

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Why is this a problem?

- Many treatment decisions are based on values, opinion, anecdote and current trends: there is no ‘best’
- This uncertainty and difference of opinion is seen as a something which should remain backstage
- Presenting choice is often seen as displaying uncertainty
“I really do not believe it’s fair to say to the patient, “We’re quite uncertain, we don’t know what to do, these are the options, what do you want?” I mean that is just shit because you’re the bloody expert, that’s what they’re paying you for, …. they can’t walk away thinking, “Christ, even the experts don’t know what to do.” That’s desperately wrong.”

Mr Halifax, Maxillofacial Surgeon, Interview
Group vs. individual choice

- Choice may exist at the group level, but not necessarily at the individual level.
- This causes problems when finding an individual to deliver the unbiased message from the MDT without framing.
“…we know that when these patients are presented in the clinic, they are presented in such a way, that he’ll probably go for surgery, if you’re seeing him. And if I was seeing him, I would guarantee he would have radiotherapy.”

Mr Red, ENT surgeon, observation, MDT meeting
The consequences

- A lot of the work of decision making takes place in the backstage, excluding the patient
- The patient is absent from the decision
- The team attempt to include the patient by building an ‘evidential patient’ via information
- There is no consensus about how this information should be incorporated into the decision
“You’re just making decisions based on scans and guidelines as opposed to an individual and having somebody ever having had the opportunity to explore not just their physical and psychological status, but their feelings about treatment.... it would be nice to have much more of a feel and a knowledge of the patient before it gets to that MDT”

Interview, Sally, Speech and Language Therapist
The evidential patient

- The MDT struggles to include any information other than clinical
- This impacts on any assessment of ‘best interests’
- It means the team do not know how involved the patient would like to be
Max facs surgeon: So shall we see him together

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How do patients make their decisions?
• Much of the work of decision making is not done in the clinic room, but it is done outside of it: a “distributed decision” (Rapley, 2008)

• Different pieces of evidence have different importance

• Team of individuals bring a different kind of knowledge
Discussion

- MDT working is the standard of care internationally: all cancer decisions in the UK are made in this setting
- Patient involvement is essential: many treatment decisions are value judgements
- The current structure of MDT decision making makes effective patient involvement very difficult
Acknowledgements

• National Institute of Health Research
• Patients and staff members
David Hamilton
david.hamilton@ncl.ac.uk