Partnering with Patients: A Bed’s Eye View of PFCC

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Where we’re going…

A “Hybrid Patient” Perspective

• Defining PFCC
• The 4 Guiding Principles of PFCC
• The Platinum Rule of PFE
Why the culture change?

* Pts with more access to information
* Competitive markets
* Questions about boundaries and rights
So how do we keep up with shifting expectations?

How do we improve the patient experience while attending to so many other demands?

The Institute for Patient and Family Centered Care defines Patient/Family Centered Care (PFCC) as:

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care.
“My organization is working at improving the patient experience by being more patient and family centered but not all of our staff/leaders are on board. What can we do to help them understand the importance of this effort?”

Answer:

Always start with STORY…
Diagnosed at 6 months old with the gift of cystic fibrosis

I had a relatively normal childhood
I had my first hospital stay at Age 12

I had three weeks of intravenous antibiotics and got my first taste for the need to be an advocate

This was just the beginning...

There would be countless more days spent in the hospital during my lifetime
By age 21, I was sick almost all of the time.

I was attending the North Carolina School of the Arts and I just couldn’t keep up.

I had to give up my Hollywood dreams and drop out.

I waited 4 years for my “call”

I was 95 pounds and my lung function was 25% of capacity
Facing Medical Error

**Surgical Error:**
“Wet Run” and an apology

Ripple Effect of Reactions:

In the OR
In the Transplant Protocols
In Safety Procedures Hospital Wide

I waited 1 more year for my first set of donor lungs

Now, due largely to the surgical error,
I was 87 pounds and my lung function was 18% of capacity
Patient and Family Centered Care Guiding Principle:

**Participation**

I traveled a winding road of confusion and self-doubt.

I didn’t know how I wanted to make my mark on this world.

I didn’t know how to live a life with healthy lungs.
In June of 2002, my lung function started to drop.

I was diagnosed with my second terminal illness 6 months later. I had Chronic Rejection.

Within two years, my lung function had dropped to 10% of capacity.

I was 73 pounds.

I was dying and the doctors gave me 6 more months to live.
I asked my doctors if I could have a second lung transplant.

They said no.

I reconnected with the understanding of my childhood CF was my greatest teacher and I was grateful I was at peace.
Only 4 months after I was listed, I got “the call”

My fear was overwhelming
Going into the OR, I was looking for comfort

Patient and Family Centered Care Guiding Principle:

*Dignity and Respect*
Despite my team’s concern, the recovery was easier than the first time.

Unlike after the first time, I was not confused about what to do with my life.

I felt a strong calling to reach out to others touched by illness.

I wanted to share what I had learned…
Preaching Partnership!

Patients are so different! Diversity of:

- Experience with healthcare
- Cultural/family/regional background carrying conscious or unconscious beliefs
- Motivation based on illness, prognosis etc
- Support varying from invasive to non-existent
- Socio-economic background shifting focus or worry from health to something else (including health literacy)
- Personality!
Is Partnership Possible?

Partnership is a process
Centers around Customization of Care
Several issues addressed

THE PLATINUM RULE
- Diversity respected
- Fewer missed opportunities
- Improved satisfaction

THE PLATINUM RULE

Not sure how patients and families can best be a part of the team? Just Ask!
For some questions, that may mean ask your PFAC!
Patient and Family Centered Care Guiding Principle:

Collaboration

Assess patient/family participation skills/readiness

Expert Patient and Family: Trained in SBAR

Eager Patient and Family: Track own data and medicines

One Step at a Time Patient: One simple “job” at a time
And sometimes, no matter what, people will be dissatisfied…

It’s a Ripple Effect.

Board of Directors/Trustees

Healthcare Administration

Direct Patient Care

Support Staff

Patient-Centered Care at Every Step
Thank You!

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