Real Time Lessons in Medical School Patient-Student Partnerships

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“Here is Edward bear, coming down stairs now bump, bump, bump on the back of his head behind Christopher Robin. It’s as far as he knows, the only way of coming down stairs, but sometimes he feels there really is another way, if only he could stop bumping his head and think of it”
How do things change?

“As medical students we come to Dartmouth with bright dreams of caring for patients. We enter with the hope of developing meaningful relationships based on mutual trust and caring. Instead we spend up to 30 hours a week sitting in class and seeing patients at 2 week intervals.
“It seems like we are learning the nuts and bolts of medicine without having the opportunity to learn about what it is like to care for a patient, to be involved in a patient’s life, over an extended period of time”

Gary Maslow MD
DMS’04
Program is born

- 2002 initial idea and Pilot program
- 2003 patients and students recruited
- Initial sessions had physician facilitator and patient
- Formal curriculum developed
- Students prefer sharing and reflecting
Program Elements

• Voluntary elective for first year students
• Two year commitment
• Visit to child or adult with ongoing health problem
• 1-2 contacts/month
• Gathering of entire group every 6-8 weeks for story telling and reflection.
• Ending ceremony
Goals

• Understand illness in context of family and community
• Encourage being present in the moment
• Cultivate listening skills
• Value stories
• Expose and explore the vagaries of the health care system
• Support one another
Dignity and Respect

• See the patient, not the disease.
• Who is this person?
• Who is important?
• What are the favorite things?
BURDEN OF ILLNESS

• Anonymity
• Loss of Peer Relationships
• Loss to Time
• Lack of Role Models
• Loss of Autonomy
• Unknown Outcomes
Issues and Tensions

• Initial Contact difficult
• Rural Population may require lengthy travel
• Time constraints
• Unclear expectations – Illness may not be visible.
• Should all students participate?
A Student’s Perspective

Peter Bartline, DMS 2
Making Contact

- “Match Day”
- Phone
- Email
- Share thoughts and concerns
- Swap Information
- Schedule a first meeting
Max

- 12 y/o male
- Know-it-all
- Loves Discovery Channel
- Video games
- Bowler
- Skier
- Hockey player
Building a Relationship
Cystinosis

- Metabolic disorder- abnormal accumulation of the amino acid cystine
- Autosomal Recessive, rare disease
- Diagnosed between 6-18 months of age
- Affects kidneys, eyes, pancreas, muscle, brain
- Symptoms
- Treatment

http://www.cystinosisfoundation.org/brochure.html
Family

- Most important provider of care
- Specialist vs. specialist
- A mother knows
- “We’re it.”
Shaping Healthcare

- Family-centered care
- Asking the simple questions
- Quality of life
- Understanding the effect on family
Testimonials - Communication

“What does it mean to live with a disease, not just while sitting in the doctor’s office, but every hour of every day. How much will this cost? How do I arrange my life to be able to get to appointments? Every conversation gave me some new insight into the realities of medicine”

Medical Student
“I think the science is easier to learn than how to effective communicate and connect with people. Having conversations with them about their lives and daily activities helped me learn how to talk to older people and what you have to keep in mind concerning age differences and how they hear what I am saying.” – Medical student
“Doctors need to let our patients talk and listen to their opinions. We might not always know the best thing – they may know it themselves. We must take each patient as an individual and figure out individual plans to help them find the results they want.” Medical student
“I’ve gone to some of my Partner’s doctor visits and listened to his doctor and walk away and have my Partner say “What did he mean by that?” Medical student.
“I think you learn that medicine is a partnership, not a dictatorship. It is incredible that this 11 year old kid can teach this 30 year old medical student about medicine and life and struggles and how to fight.”
Testimonial - Partnership

“It offers a unique opportunity to share a piece of another person’s life and provides and avenue for medical education outside of the classroom.” – Medical student
“It helped me gain a better understanding of what its like to be on the opposite side.” Community partner
“When I agreed to be part of this program, I thought I would be contributing very much to a student. What I did not bargain for was the benefit I would receive by allowing a medical student in my life.” – Community member
“She says that we’re ‘chums’ because neither one of us looks or feels our age (not taking into consideration that there is a 63 year difference). It is usually only at the very beginning or very end of our visits that I notice how frail she is…” - Medical student
“As I struggle to find my place as a student, a doctor, a daughter, a dancer, a partner and a friend, my patient partner provides me with a shining example of how to balance many roles with grace. Some of our roles we will love, some we will struggle with, but all will contribute to who we are to be.” Medical student
“Instead of just focusing on the patient, the family members have strong feelings about things as well, and while the patient is your primary focus, you need to make sure the family is doing OK too.”

– Medical student
“The second aspect of the program is the special bond I formed among my classmates when we met each month.” Medical student
Testimonial – Dignity and Respect

“I became totally dependant on tube feeding. Alissa has been my medical partner and close friend through it all. She has been beside me in spirit on each difficult step I have faced. How I will miss her!”  -Community member
“Rebekah is compassionate and sensitive to kids like my daughter. She sees that everyone is a real human being, no matter what their disability is. When you work with kids who have disabilities, you become bigger and more inclusive in your thinking.” – Community member
“Perhaps the lesson I learned in this program is that the illness is just a part of the person – it does not define them.” – Medical student
“I learned about love, death, growing old, giving back to the community and special talents. My patient partner always wondered how she could possibly be helping me in my journey to become a doctor, but truthfully she helped me grow as a individual, which encompasses more than just becoming a good doctor.” – Medical student
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Conclusion

“Longitudinal care and the whole chaotic narrative of illness – That’s what the Patient Partnership Program is about.”

Joe O’Donnell, MD, Dean of Students, Dartmouth Medical School