

Seeing the Whole Person: What Students Learn When Patients Become Mentors

with Mandy Young, Lelainia Lloyd and Pooja Kadakia

[Intro Theme Music]

Dr. Barbara Lee

00:05

Hello, everybody! Welcome to season two of *The Knowledge Exchange, a Partnership-in-Action podcast*. I'm your host, Dr. Barbara Lee, Assistant Professor at the University of British Columbia School of Social Work, Co-Director of the Center for the Study of Services to Children and Families, and Knowledge Exchange and Mobilization Scholar.

This episode features Mandy Young, parent of a medically and behaviorally complex child and a long-time partner with University of British Columbia's Patient and Community Partnership for Education (PCPE). Mandy has volunteered for over a decade in the Interprofessional Health Mentors Program, both as a Health Mentor for health care students and as a Community Engagement Coordinator. Joining her is Lelainia Lloyd, a rare disease and disability advocate with 13 years of experience as a Health Mentor. Also with us is Pooja Kadakia, now a first-year internal medicine resident in Winnipeg, who joined the program as a student mentee three years ago. Together, they reflect on how the Health Mentors Program fosters interprofessional learning, reshapes students' professional perspectives, and improves the way that healthcare providers can interact in the system with their patients and with their colleagues.

Mandy Young

01:21

Okay, so I think I'll just introduce the Health Mentor Program. Our health mentor program's been running for 15 years. It brings together a health mentor who we've also brought here today, and students from four different disciplines. And we connect with community partners to support recruitment of our mentors and a lot of word of mouth amongst our mentors who also know folks that live with a chronic condition. And they've accessed the healthcare system at many different entry points throughout their lifetime. That's how you'd explain it too?

Lelainia Lloyd

02:08

Yeah, I think so. And it just gives an opportunity for students to be able to ask questions in a safe environment and to learn a little bit about some of the challenges and successes that we have as patients working with our care providers.

Mandy Young

02:25

Yeah. And the program runs for nine months. So it starts in September and runs right through until May. And the students are in a group of four and they meet with their mentor over that course of time. So they have seven meetings for two hours, and they really get to create this environment where they really learn about the patient in an exploratory way. Pooja, do you wanna add a little bit from your perspective about the program?



Pooja Kadakia**03:02**

The program has been very well summarized. I would add that in addition to safe spaces for Questions, it's a safe space for challenges and for reflection. It challenges a lot of our stereotypes and, our thoughts on the way healthcare works, the way the world works and a significant portion of health mentors is devoted to reflection. Students not only have to write reflections after they have met with their mentor, but the symposium at the very end is a reflection of all that we have learned throughout the year. And so by having an active space, not only for discussion, but also for those challenges and for reflection. It really creates a forum for change and for improving the way a healthcare provider can interact in the system with their patients and with their colleagues.

Mandy Young**03:54**

Do we wanna just take a couple minutes to each introduce ourselves?

Lelainia Lloyd**03:59**

I'm Lelainia Lloyd. I've been a health mentor with the program for, this is going into my 13th year. I joke that I'm the moldy, oldie. There's just a handful of us that have been there pretty much from the beginning, but I keep coming back year after year because I very strongly believe in this program and what it can accomplish. It's also really wonderful to have the opportunity to play a part in someone's professional development. And I'm somebody who's chronically in the healthcare system, so it really matters to me, not just for myself, but for other patients to be able to influence. How healthcare is delivered in this province. I'm a rare disease patient. I have a disease called neuromyelitis optica, which is my immune system attacking my optic nerve and my spinal cord. I'm also hearing impaired. I have arthritis and I'm a wheelchair user because I have complex chronic pain as well as damage to my spinal cord. That sort of gives you an idea. Some of the health mentors are people caring for people with chronic illness or disability as well. So we have some parent child teams and some caregiver teams like for example people with Parkinson's or dementia who have a care partner that. They also participate in the program, so you're getting a really well-rounded wealth of experience within the program thanks to all the health mentors.

Mandy Young**05:38**

I'm Mandy Young. I have been with patient and Community Partnership for education for a year and a half now. In the role of community Engagement Coordinator, I have been connected to this unit for many more years than that. I was originally a health mentor myself and had the privilege of mentoring 11 groups of students over the years. I just kept coming back year after year because it is such a rewarding experience for me as the mentor and just learning through the students and being part of education and that excitement was what kind of kept me in this work year after year. And I come in as a caregiver. Lelainia said we do have caregivers. I am the caregiver to my 14-year-old who was born with a rare disease. So we've accessed the healthcare system since birth, and we continue to access it today. And we have seen how this health mentor program has changed healthcare providers because we have accessed the healthcare system for 14 years. We've seen the curriculum change

throughout. These years that I've mentored for the last 11 years and have really been able to see that come in the healthcare system, it hasn't come quite as quickly as the education has increased for the students around person-centered care and multidisciplinary care, but it's getting there. Pooja, do you wanna share how it is for you?

Pooja Kadakia

07:27

Hi, my name is Pooja. I'm a first-year internal medicine resident physician in Winnipeg. The Health Mentors program is one that definitely changed my life for the better. As you two have so eloquently put it in the way that it's impacted healthcare providers, I had the privilege of not only participating in my first year of medicine but also participating in the fourth year of medical school. It was a promise I made to myself to be able to not only set the tone for how my medical school journey would go, but then to reflect on the lessons I had learned as a budding physician with the experience I'd had with providers and patients alike, especially in my third and fourth year. The Health Mentors Program has been one that has really allowed me to provide perspective and to be open to new perspectives in patient journeys and to prioritize patient first and family first care, especially when it's a busy season and there's many other people to see, and it can get quite hectic. It's one of these programs that has really changed my life and allowed me to put it first, regardless of other competing interests.

Mandy Young

08:35

So Lelainia, you've been with the program right from the beginning and you have more than one role. You are a health mentor yourself, but you also do the interviews for our up-and-coming health mentors.

Lelainia Lloyd

08:50

I do.

Mandy Young

08:51

Can you tell us a bit about that?

Lelainia Lloyd

08:52

Yeah, so I think it's been six or seven years that I've been doing this now. Towards the end of July and August every year we conduct interviews of potential health mentors and usually I'm paired with a student, sometimes the same student, sometimes a new one. And we have a list of questions that we ask that's really, an opportunity for us to get to know the person who's applying to see, are they able to handle a group of students? Are they open and welcoming and a safe person in terms of a safe space? Because we do have a very wide range of students and we wanna make sure that they're getting education from somebody who is accepting and because if there's not a safe space with them, then it really impedes the ability to learn from them. I'm always pleased with the wealth of knowledge that everyone brings to the table. And I get a taste of that in the interviews. But I'm also like so impressed with how spoiled for choice we are every year. We make our recommendations after the interview and we submit those and I'm always like, thank God I don't have to make

the choice because there are a limited amount of spaces available for mentors and when you have such great people, that's a good problem to have. And I just feel really privileged to be able to have some influence on the type of people that are gonna be coming into the program to serve students. It's also a great way for me to get to know the newer people and I'm a friendly face that comes to orientation, so they don't feel like they're walking into a room full of strangers when that that happens when we have that. I just really love doing it and I learn a lot every time I do it. Just what perspectives they have and a little bit of their own journey. And it's always good to feel like, oh yeah, that's familiar to me. And I think those students will be really like whoever they get will be really engaged with them.

Mandy Young

11:19

Yeah, it's really important to have patient and community partnership in education that those interviews aren't done by us staff. We really want those interviews done by a health mentor who's doing the work, right? They are the educators in these small groups. And then we always bring in a student because we wanna make sure that the student is being able to see a teacher. In that person that we're interviewing and right and that this work is really meant to enhance student learning. So if by chance a student said, I don't think that's the right fit for this role, we would really take that to heart and probably wouldn't bring in that mentor as they might be quite ready to do the health mentor work. We do have other opportunities that person could get involved in, and maybe they need a bit of trying a few different activities before they get into this larger commitment of being a health mentor. And so for Pooja, for you, was that quality of health mentor for you? You had two different mentors, so you have a bit of perspective on the differences of how they were.

Pooja Kadakia

12:38

It's so hard to put that into a tangible thought. I very much want to cop out and say it's just an overall presence of wisdom and maturity. But I think that the things I was looking for in a mentor that I definitely found in both of mine were that they were reflective on their own life experiences. I think that it's very easy for individuals to swing one way or the other and to have quite extreme viewpoints of their past experiences, but to be able to have a holistic perspective of what they had gone through, what the pros were, what the cons were, what the context was, and to have empathy for themselves, their family, and also the people who might have engaged in challenges with them and provided obstacles. That type of empathy and reflection was something I was looking for because it meant I was going to be able to learn a balanced perspective rather than joining somebody's crusade. Something else that I was looking for is somebody who was kind and who asked a lot of questions because it's easy to sit there and listen to someone speak, but to have somebody then ask you questions, really listen to your perspective, as I was mentioning earlier, provide those challenges. I think that is the makings of a really good mentor because you can see how they're very gently, but lovingly push you to be a better version of yourself. And so by doing so in a very balanced way with a lot of kindness and compassion, that I think is the makings for a mentor who really can share their story and leave a positive impact on their students.

Mandy Young

14:22



Just to talk a little bit about that. That screening or that gathering of new mentors. Every year we try to bring in a few new folks for fresh perspectives. And so we do that interview process. Every mentor, regardless of if it's their very first year or their 15th year or 11th year like myself, you have to apply for the program again. And it's a way for the mentors to really realize that like they're coming with their full self again, they're coming into this work fresh and new. You have to attend orientation every year. I've attended 11 orientations and I love them all. It's a really great opportunity to just refresh the program. We have a time where the mentors come together and the seasoned mentors share a bit about how that experience has been for some of our new mentors. And it's a really a great way to do some community building amongst our mentors. And then you get into that larger room with all the students and it's a really vibrant, lively event. We generally take 150 students and about 50 mentors every year. So the program runs around 200 folks. And they represent a wide range of mentors and experience.

Lelainia Lloyd

16:00

I always call orientation Christmas day because you get to meet your students for the first time and find out what disciplines they're coming from. Because we have about 10. There's Medicine, Nursing, PT, OT, Speech and Language Pathology, Community Health, Pharmacy, Social Work, Kinesiology, Dentistry, Genetics, and Dietetics. Yeah. And you only get one student from each discipline out of the four. So you won't have two nurses or two doctors. but you'll usually have a nurse and a doctor because they have to do it. And I believe PT is the other discipline that requires it.

Mandy Young

16:42

Occupational therapy.

Lelainia Lloyd

16:45

Yeah. And then the rest are it's a voluntary thing, so you do get a mix. And also you never know if you're gonna get a group of all women or a mix of women in men's. It changes the dynamic every time, which kind of keeps it fresh if you're doing it year after year. But also the personalities of the people that you're working with are always different, and it's always so exciting to get to know one another that first night.

Mandy Young

17:13

Yeah. We also have our program coordinator who takes such care in matching the mentors with students that might benefit from their condition. So matching disciplines to the condition. So for example, I generally get a dietetic student and a genetic counselor, and then one of the other therapies like OT or PT, and then maybe a nursing or a medical student. And so there's such care in the matches and the mentors often have first choices of which disciplines they'd like to have in their group. And so it's a really great way of, making sure that the dynamics of the groups are really a good fit. This next set of questions is just around what has the Health Mentor program done for you or changed the way you're thinking or how it has changed how you've accessed the healthcare system.

Pooja Kadakia**18:24**

There're so many things I want to say. I think the biggest thing that I really got at the Health Mentors program was perspective. I think that as a physician, it's very easy to live in a world where, future colleagues and people alike are a sound chamber for your own thoughts and beliefs, and it's very easy to form ideas and perspectives on people and what they've gone through. We learned so many complex medical cases and we shove so much information in our heads. And we see people at very vulnerable points in their lives. But a lot of what we do is devoted to looking at lab values, looking at physical examinations, imaging findings to figure out what we think is going on with people and provide support in that way that it's really easy to forget that they are. People with lives who have been distanced from their family and their friends, especially if they're hospitalized. I think it's very easy to lose perspective on the impact it has on people both in the short term and long term. And it can be especially frustrating when you meet patients who don't fit your cookie cutter mold of a textbook diagnosis, or the person who is going to say yes to everything that you suggest. People who provide questions and pushback or any negative emotion in any way can be deemed and have been deemed as difficult patients or people that normally we don't wanna work with. And I think that the reason I value the health mentors' program so much, just because being able to sit there and listen to someone tell their stories and their experiences of how medicine has been there for them and how medicine has not been there for them all the time. They experienced hardship and challenges and had to navigate the confusing medical system and what it meant not to be listened to or not to be believed has really put it into perspective, because now when I meet patients who are upset with me or who challenge me or who have questions. I view that as a good thing, as someone who is willing to share those emotions with me and potentially build a space of trust. Someone who is a human being with real emotions, who does not have to say yes to everything that I say, and it's about partnership. And so it's actually been a very humbling process to be encountered with all sorts of people from all sorts of walks of life. And remember that I'm not there as a person to fix them. I'm their partner to help empower them to make health choices that benefit their goals. I think I have so much more I want to say, but I could spend hours talking about why I love the program. I definitely want to make sure I take this space to say thank you to Lelainia, because your story is the reason I went back in my fourth year. Listening to your experiences and your interactions with healthcare left a lasting impression with me on how I view patients. Both of whom have rare diseases and who have common ones about the way they've had to navigate the healthcare system. I will not forget the lessons that you taught me, and it's something I take with me into medicine even today. And I often think about the things and the critiques that you made towards medicine and really work to be a better doctor because of your experiences. So I really wanna say thank you to that because it made me a better doctor.

Lelainia Lloyd**21:54**

Tearing up here. It was my privilege to be your mentor and just hearing you talk now in this interview it's evident that, you learned a lot from the program, not just from me. I just wanted to touch on a couple of things that you said, and one was that pushback. I think the days of doctors being the be all and end all. The all-knowing days are on their way out and patients



really wanna be partners in their own care. And part of that is understanding what they value and what their goals for treatment are. And it sounds to me like you've really, given a lot of thought to that. And you pay attention to that now. And I think that's like amazing. That's proof positive that this program is making an impact. And I also feel when we have, when we're sickest is when we have to advocate the hardest for ourselves, and so when you recognize that as a care provider, that scary, vulnerable time so much less frightening. So I'm really amazed hearing you speak and I'm so impressed. And to think that I had a small part of that is very humbling. So, thank you for that.

Mandy Young**23:19**

And what's really unique about Pooja's experiences, she did it in year one of medical school and the program is voluntary and she chose to do it in year one, and then she had the maturity and the reflection to know that she wanted to do it again in year four, just before she was finishing and going out into her residency and that commitment to the program and to her learning is going to take her ahead of her fellow colleagues. And it's just really wonderful to see, and again, heartwarming to me to hear you speak of the program that way as well.

Pooja Kadakia**24:03**

I appreciate that, by the way. I really do. I think that it's because you guys have set up such an incredible program, and as you've both eloquently mentioned, the way you go about lovingly choosing mentors who are going to really embody what the program stands for and the compassion you take for the mentors and then in choosing the groups, I think it's a no-brainer and I don't know why more people don't do it more than once. Just saying. But I'm biased.

Mandy Young**24:33**

Yeah. Excellent. So I think we'll just do some final reflections before we sign off.

Lelainia Lloyd**24:41**

One thing that I wanted to share was that, i've polled my students over the years about how much education they get around disability, and it was shocking to me that the majority of them said they get about an hour.

That's a lecture by a prof and it's not enough. Because the medical system is inherently ableist and inaccessible. And I can say that as somebody who's a wheelchair user, the environment is just not welcoming for wheelchairs, which is crazy when you think about it, right? If you don't expect people in wheelchairs and with disabilities and mobility aids coming into a hospital, where would you expect them? So I think. In terms of the value for students to meet somebody who has a disability and to understand some of the challenges that go with that also makes them more empathetic. It's simple things. Like you go into a waiting room and there's all these chairs set up, but there's no space left for a wheelchair. It's from the littlest thing right up into larger things. And like for example I have a friend who's disabled by arthritis, and she's been in a wheelchair since she was 15, and she's never had a pap smear or a mammogram because they're not accessible. It affects people's ability to

receive routine care and, it's not something that's talked about. So these are the kinds of things that I share with my students and I advocate for, because they're going into these environments and it's not just that they're learning when they are working in an environment like a hospital or a medical center, whatever it is. They're able to model the kind of care that we all wish we would receive, and their peers are learning from them. So that's super powerful because it's a ripple effect. And that really, lets you know that the time that you've spent with them, it will continue to ripple out because they'll model that for their immediate coworkers, and then those coworkers learn it and they start doing it and it just goes and goes, right? And that time is really valuable in order to be able to explain some of the challenges that we face as people with disability within the system.

Pooja Kadakia**27:22**

This is somewhat related, but somewhat unrelated to what Lelainia just talked about. But my final thoughts at least are to do with being a partner and I think the one thing I want to leave with people who have either participated in the program or are thinking of participating in the program is the gem lies in learning what it means to really be a partner in care. And using the wheelchair example, I think it's easy to choose one of two sides where you either try to get your patient out of the wheelchair or you forget about it entirely to focus on something else, and it's really one or the other. And the Health Mentors Program does a really good job of providing a third option of accepting the wheelchair as a part of a person and then advocating for a system that accommodates that and celebrates that. Rather than viewing it as a problem or sweeping it under the rug as something irrelevant to you. I think in medicine we are so problem oriented and that at time is very needed. There are definitely times where you don't need to focus on people's entire life stories and societal circumstances when things are going rough and you need to do something about it. But there are definitely a time and space in your continuity of care to view your patients as partners and to find that middle ground with them as human beings rather than as cases or problems that you need to fix. And so, for anyone who's hoping to go through it or has gone through, they really invite them to take the time to think about what mentors have prioritized and valued in their life, and how your job in the little ways can really advocate for those values. So you really are the definition of a partner.

Mandy Young**29:07**

Yeah, the program basically takes what the students are learning in the textbook and brings it to life.

Lelainia Lloyd**29:14**

It reminds them that we're not just a problem or a diagnosis. We're still human beings on top of everything else. We're just like you. We just live with a few more challenges. And I always say people are. Tabs, temporarily able bodied because even as we age, we need glasses, we might need hearing aids. It's the only visible minority that anybody can become a part of at any given moment. The understanding of the disability world is really important.

And I did wanna say one more thing about the program. Sure. I feel there's a quote that I feel very. Much resonates with this program and it's that the purpose in life is to plant trees under



whose shade you do not expect to sit. And we're planting those seeds with our students and we may not always get the chance to have the experience of having care provided by somebody who is a graduate of the program.

However, I've had it happen to me twice now in two different settings. I had two new. Nurses that were graduates of the program. And I could feel the difference in the care, and I also got to witness them modeling that for their coworkers. And you hope you're making a difference. But that really validated for me that we were. And they weren't my students, but they were someone's students. All of that time and energy and love and care that's been showered on them during this program, it comes to fruition whether we see it or not, it's happening and it's really exciting and that's why I keep doing the program.

Dr. Barbara Lee**31:04**

I do wanna just ask one more question. It may or may not make it into the episode but just as I'm thinking about our podcast it was starting in social work and then expanding out to other disciplines. And especially there's an interdisciplinary element to the program. If you can each share a little bit about what that's looked like and what that means.

Lelainia Lloyd**31:29**

I think the most important part of it is the fact that, the students are in their own discipline and they're learning in a silo in a lot of ways. And so this is the first time that they get to meet people who will become their colleagues when they are out in the world doing their jobs. And so it's their first opportunity to make those connections and to understand what the other disciplines do. For example, nobody knows what the OT does, the occupational therapist. And we do go around and we share what, what we wanna share about those different disciplines. So, it helps them become a better referral maker because they'll be like, oh yeah, I remember that. The OT can do, can help somebody get a wheelchair, they'll help with funding and they'll help with choosing the right thing and connecting them with vendors and all of these things. Those connections are really important. It also helps them understand that collaborative care is a part of care. Because a lot of times there's no communication between the doctors on somebody's care team or the nurses or the OTs. Nobody will pick up the phone. And we really need them to be team players, especially for those of us who have complex care. And so this fosters that idea and sets the stage for it.

Pooja Kadakia**32:57**

What she said, that's exactly what happened. I had zero clue what an OT did prior to this program. It's very classic right now where I work where before somebody gets discharged, they get seen by PT, OT, Home Care, and they get lumped together and it's really easy to remember. Those are not the same thing. They're not three of the same person. They do completely different things. And if one thing is a barrier to discharge or requires additional support, understanding what that actually does and knowing who to talk to and how to have those conversations in a valuable way has been a bit of a game changer for me. At least, it was something I could advocate for throughout medical school and now feel incredibly comfortable working with as a resident physician, going and talking to my colleagues who have years of experience on me about what I can do from a medical standpoint, what they



can do, how we can work together to advocate for my patients. Because my goal is not necessarily to get them at a hospital as fast as possible, but to get out of the hospital as safe as possible with the best supports in place for a long lasting improvement in health. And so I think the beauty of having this interdisciplinary forum was for perspective, for values, for priorities, and then ultimately to determine how I could best lead the team and refer to who I need to refer, how to defer to their guidance, and how to really bring that team spirit to helping patients succeed in and out of hospital.

Mandy Young

34:32

Yeah. And the program is set up, so each month that they meet together. Is a different topic. And so the mentor shares a little bit about their experience on that topic, and then they go in a circle around how are you learning this topic in your program and how does that look different in each of the programs? And you'd think it would look the same, but it isn't the language that people use that the approach they use is different. So the students are learning with the. Person, the patient partner at the center of it, but they're really learning from one another as well in a really rich way.

Lelainia Lloyd

35:16

And I think too, as a health mentor, I'm learning right along with them. Often, they're sharing perspectives that are different than mine. Because we have multicultural differences, we have gender identity differences, all kinds of things. And it's really opened up my eyes. And I have to say too, that when you're having these interactions, it reminds us as patients that all healthcare providers started out bright eyed, and they had this desire to care for people and to help them. And the system is difficult, and it can really take it out of you. So it's a good reminder to me when I've had tough interactions with some of my team that they weren't always like this, and to have more compassion for them as well.

Mandy Young

36:15

Okay. Thank you both for this conversation. It was really enjoyable and I hope to have more of them.

Dr. Barbara Lee

36:23

Yeah. Thank you so much. That was a beautiful- thank you!

[Outro Theme Music]

Dr. Barbara Lee

36:27

You've been listening to *The Knowledge Exchange: A Partnership-in-Action Podcast*! I'm Dr. Barbara Lee, your host, and executive producer. Our production team for this episode includes Michelle O'Kane, Cathy Jiu, Maddie Cathcart, Qian Zhou, and Safiya Bhinder. Our cover art is by Cathy Jiu and our open-source music is called Motivational Day, Audio Coffee by Denis Kyshchuk. Thanks for listening!