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Building Dialogues Between Medical Students & Autistic Patients: Reflections on the MD Program's Patient Immersion Experience

Sierra Casey[1], Alexander Watts[1], Michael Frost[2], Adam Kedmy[3], and Pamela Brett-MacLean[4]

[1]3rd Year Medical Student, MD Program, Faculty of Medicine & Dentistry (FoMD), University of Alberta
[2]Patient Mentor, MD Program, FoMD, University of Alberta, 2017-ongoing; artist and healthcare advocate
[3]Patient Mentor, MD Program, FoMD, University of Alberta, 2019-ongoing; BA student; advocate
[4]Associate Professor, Department of Psychiatry, Medical /Health Humanities Thread Lead, Physicianship Course, MD Program, and Director, Arts & Humanities in Health & Medicine, FoMD, University of Alberta
Corresponding author: scasey@ualberta.ca

ABSTRACT

The Patient Immersion Experience (PIE) component of the MD Program's longitudinal Physicianship course pairs medical students with individuals with chronic medical conditions to promote an understanding of the lived experience of illness. In October 2017, medical students Alec Watts and Sierra Casey were matched with patient mentor Michael Frost, an autistic person and artist. A year later, in the fall of 2018, Michael invited his autistic friend Adam Kedmy to participate in collaborating on an "Interpretive Project", a required capstone component of PIE organized by faculty lead, Dr. Pamela Brett-MacLean. Transcripts of online Google Doc conversations involving Sierra, Alec, Michael, and Adam, that took place over a 3-month period, were used to create a multimedia learning artifact that was exhibited as part of an annual Patient Appreciation Event organized at the end of the academic year. Rather than simply focusing on transmission of "information", with Sierra and Alec (as medical students) asking questions that Adam and Michael respond to, a commitment was made to an ongoing mutual exchange of ideas. Four main topics were discussed: 1) the value of open communication with others, 2) how the process of informed consent differs for autistic people, 3) hope for a better future for healthcare, and 4) moving forward. These conversations point to the relationship-enhancing possibilities of open, back-and-forth dialogue as an antidote to monological approaches to medicine, providing insights into ways dialogue can enhance both a sense of agency and relational connections, generate new creative thinking, and promote a more holistic, person-centered approach to healthcare.

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Scholarly Sidebar

*“Behind every patient is a **person with a story**.”*

A qualitative study of video-recorded patient consultations conducted by Agledahl, et al. (2011) found that an overriding focus on medical concerns led doctors to treat patients in a biomechanical manner, as objects, rarely exploring personal aspects of a patient’s healthcare condition. Recognizing that attending to the lifeworld concerns of patients that are contextually grounded in their everyday experience of situations, events, and problems in their lives leads to better healthcare outcomes (see Barry et al., 2001), Agledahl and her colleagues cautioned that “when doctors are unable to follow-up on a patient’s personal perspective, they should be aware of the moral harm caused by this rejection ... and seek to minimize it by attending to his/her humanity as far as possible within the medical setting” (p.653).

At the University of Alberta, the MD Program’s longitudinal Physicianship course (Hutchison, 2014) provides multiple opportunities for learning about patients as people with full lives and existential concerns. Introduced in 2013 as a foundational component of the Physicianship course, the Patient Immersion Experience (PIE) (Harvey, 2013; also see Kumagai, 2009) matches students with people living with chronic medical-related conditions. Over the span of two years, visiting every few months, medical students gain insight into what it is like to live with a chronic condition. This experience gives medical students an appreciation of the challenges patients and family members face on a daily basis (including navigating the healthcare system) and the influence of social determinants of health and healthcare beliefs on a patient’s illness experience.

Each fall, a “Patient Mentor/Student ‘Meet and Greet’” reception is organized to welcome each new patient mentor cohort and provide an opportunity for first year medical students to meet their newly-assigned patient mentors. Following this, medical students and patient mentors arrange to meet together two or three mutually convenient times over the course of the first year. During an initial visit, the impact of illness on everyday life, family dynamics, and coping are explored. Perceptions of good communication and how relationships with healthcare providers impact one’s illness experience provide a focus for discussion during the second visit. How illness can lead to stigma and expose patients to bias is discussed during the third visit. The following year, patients are invited to share what it was like to experience receiving a serious, life-altering diagnosis. At some point over the two years, students accompany their patient mentor to an appointment with their doctor to experience a medical visit from the perspective of both the patient and someone supporting a patient, rather than as a healthcare provider. A Patient Appreciation Event, which includes an Interpretive Project exhibition is organized during the second year. Thanks and lessons learned are shared during a final meeting between students and their patient mentor. This final meeting might occur before or following the Patient Appreciation Event.

The PIE Interpretive Project provides an opportunity for students to work through a process in which they collaboratively explore and expand on new insights, understandings, ideas, or questions that were inspired by their experience of visiting with their patient mentor(s).The students make this visible to share with others using various media, materials, and approaches. Students are invited to propose an “arts-based” interpretive project or “creative/innovative” project (e.g. speculative or design-inspired). Conducting a data-based research study and presenting findings via a poster is not an option.

The Interpretive Project offers a creative, inquiry-oriented approach to learning. Following from Siegel (1995), transmediation—the act of translating an early provisional understanding from one sign system (e.g., words, or text) to another sign system (e.g., drawing, music, etc.)—“increases students’ opportunities to engage in generative and reflective thinking processes because learners must invent a connection between the two sign systems, as the connection does not

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exist a priori" (p.455). The act of transmediation promotes the development of new and enhanced meanings and insights (also see Suhor, 1984). Of particular relevance to medicine, the Interpretive Project offers medical students an opportunity for living through uncertainty, learning, or coming to know through doing, and also for appreciating the creativity of their fellow students and the great potential of collaborative undertakings. Similar initiatives at other medical schools in Canada, the US, and the UK that include creative capstone projects have been associated with enhanced appreciation of patients' illness experiences among medical students (Jones, Kittendorf, & Kumagai, 2017).

We invite individuals with a diagnosis that impacts their life in a significant or daily manner, who have regular contact with the healthcare system, and live within approximately 40 km radius of the University of Alberta campus, who are interested in learning more about the opportunity to volunteer as a Patient Mentor with the MD Program to send an email to patient.immersion.experience@ualberta.ca to request further information.

Introduction

> *In medical school we are taught to have scripted "monologic" interactions with our patients which do not provide space to truly get to know the patient. Something special happens, however, when human beings meet and interact: ideas are created that are greater than the sum of what each individual brings to the conversation.*
>
> Casey, Watts, Frost & Kedmy, 2019, Interpretive Project Artists' Statement *excerpt.*

In October 2017, first year medical students Sierra and Alec were matched with Michael, an autistic volunteer patient mentor. Early visits focused on exploring challenges Michael experienced obtaining the healthcare he needs. Sierra and Alec learned about the difficulties Michael had communicating his healthcare needs, including his sensory differences which made routine procedures, such as dental work, excruciating. During this period, Michael shared different arts-based projects he had created to communicate aspects of his experience of healthcare as an autistic person, including a photographic collage, video-based digital story, and card-based dialogue game.

About a year later, Michael, Sierra, and Alec began to discuss possibilities for an interpretive project to fulfill Sierra and Alec's capstone project requirement. At this point, Michael invited his autistic friend, Adam, to join the group. Having read some work by John Shotter, a communications theorist, Alec and Sierra wanted to expand beyond typical one-way, or monological, doctor-patient communication, in which physicians direct a line of questioning that a patient then answers (Katz et al., 2004; Shotter, 2013). A dialogical approach was adopted to ensure everyone felt heard, respected, and validated.

Influenced by many of the same theorists and philosophers as Shotter (such as Bakhtin), Frank (2005) asserts that dialogue "depends on perpetual openness to the other's capacity to become someone other than whoever she or he already is" (p.967). According to Frank, dialogical research emphasizes ontological entanglements. These entanglements result in engagement in "struggles of becoming; its focus is stories of struggle, not static themes or lists of characteristics that fix participants in identities that fit typologies" (p.968). Further, dialogical reports provide open-ended accounts of how those involved "came together in some shared time and space and had diverse effects *on each other*" (p.968, original emphases).

The intention was to engage in a fully open, relationally-responsive dialogue without a preconceived agenda. Using Google Docs as an online "forum," everyone could ask and respond to questions as they explored their experiences, perspectives, thoughts, and hopes for healthcare. Sierra and Alec, as medical students,

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wanted to engage in a dialogue that avoided prescriptively foregrounding their hypotheses about autistic people's lives. Michael and Adam, as autistic people, wanted to be listened to and understood. Michael and Adam also wanted to understand what Sierra and Alec thought was important to be a good doctor. Michael's artwork helped to frame discussions.

The interpretive project that they created, entitled "Building Dialogues between Medical Students and Autistic Patients," included voice recordings of excerpts from their online conversations. It also included a 3D virtual reality photosphere of one of Michael's photographic collages, as well as a long text transcription of the dialogical inquiry. The following edited summary has been excerpted from the open, dialogical conversations they engaged in using Google Docs from January to March 2019, which led to the multimedia project they created and exhibited as part of the MD Program's Patient Appreciation Event in April 2019.

Communicating with Others

> *… while some of the communications directed toward us can change us simply in our* knowledge, *others - that influence our* orientations - *can change us in our very ways of* being in the world ...
> Shotter, 2013, p.13 (original emphases)

Sierra: Something special happens when human beings meet and interact openly: ideas are created which are greater than the sum of what each individual brings to the conversation. In our learning of how to conduct patient interviews in medical school, we are taught to have monologues with our patients. Patient interviews demand that medical students ask questions that patients answer. We learn what doctors call "illness scripts": complexes of symptoms and history that fit a given illness. We are taught to elicit answers that fit within certain scripts. In these monologic interactions with our patients, doctors ask, the patient responds. According to Adam and Michael, this prevents "off-script patient communication", wherein the physician or medical student can learn about the patient's holistic, non-medicalized needs as well as their medical ones.

Michael: Monologues establish a power imbalance where the doctor decides how the conversation goes with no feedback from the patient. For us, this means that some doctors are a good fit for us while others are not. The way Adam sees it, "that doctor didn't hear me how I need; new doctor time." When I find when I feel like a doctor or dentist doesn't understand, I instead try to force the interaction to go better.

Adam: With a power imbalance, the patient must be resourceful and put in more effort, like showing up in-person instead of using the phone to book an appointment. Often, the doctors' test for patient involvement during a meeting is a social cue that is missed. The social cue was testing something else, and we missed this purpose. Monologue then follows. If there is dialogue, my masking becomes irrelevant to the doctors' analysis skills; I can tell them what I feel and how I need care and improve my involvement explicitly. With dialogue, the "complicating factors" in our communication can be addressed, whereas in traditional doctor-patient monologue, the patient must be aware of these factors and know how they work already. It needs to be explicit.

Adam & Michael: When two people use monologue as a discussion method, the more vulnerable suffers. To learn from the more powerful one, more effort is necessary. This is our autistic experience. We need bilateral validation for our theories and experiences to be validated with your thinking. We need to validate your reasonings and experiences so we can trust you. These small needs must be met before continuing. Asking would ordinarily be no problem, but when you can't hear us in your voice, you move on without us. There are many reasons we are not heard: how we say it or when we miss an important detail or exaggerate can be ignored "reasonably." In any case where monologue is necessary—due to urgency and time

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limits or if the patient is unconscious—returning to dialogue at the earliest practical moment is necessary to have inclusion between care provider and patient.

Sierra: In my longitudinal interactions with both of you, Adam and Michael, I have learned to recognize several ways I elicit a dialogical rather than monological conversation with patients. I noticed that in the text conversation through Google Docs with Michael and Adam, I was able to learn more about their condition and their view of the world when I asked certain questions. For example, picking up on a statement they made and simply saying "I noticed you said "x" or what do you mean by that" would often elicit incredibly insightful answers. Repeating what they said in a way that made sense to me would often result in them correcting: "actually no, the way you understand it is not the way I understand it".

There are times when this approach to eliciting a dialogue may be too time-consuming. Like Adam mentioned, in emergencies, there may not be time to have a back-and-forth conversation with a patient, and monologue allows the healthcare provider to get the necessary information in the shortest possible time. However, once this emergency is over, a dialogical conversation can always begin.

Alec: While medicine has moved slowly away from a paternalistic approach, it can still be present in what we observe and are taught as medical students. In this project, dialogue in the truest sense occurred, as there were no set expectations, agenda, or leader for our conversation. Contrast this with the standard patient interview, in which doctors often enter a patient encounter with a) expectations; b) an agenda; and c) an often under-recognized aura of power, privilege, and authority.

Analysis "Sensory-Informed Consent to Care"

> *" ...as long as the physician searches for answers only in order to accept or reject his/her own hypotheses, the interactional context stays monological"*
> Seikkula, et al., 1995, p.66

Sierra: Informed consent and shared decision-making, the processes by which the doctor and patient discuss treatment options and come to conclusions about the treatment course to follow, are the cornerstone of modern patient-centered care (Elwyn et al., 2012). During our five official PIE visits with Michael, we had the opportunity to observe him receiving care from his dentist and his primary care doctor. We noticed that his understanding of consent to a procedure did not always align with his provider's understanding of consent, often preventing him from receiving the care he needed.

Shared decision-making is especially important when working with people with sensory differences. This is because a treatment that appears benign can be excruciating for them. From our discussions, I realized how important it is to verify with patients what their specific concerns are about a procedure. It took Michael many months of conversations with his dentist to find a way to be comfortable with the dental work he needed because his understanding of the informed consent process was different than other dental patients'.

Michael: I understand that the power structure of the social environment in a clinic or hospital is unidirectional for reasons designed by care providers. In this structure, patients are identified by their deficits, causing vulnerability. Because it is a unidirectional system, it must promote belonging as an essential part of the mutual, reciprocal consent to care process. In the role of an autistic patient, I'm learning to express my needs while acknowledging the provider's right to safety in their workplace. I value active reciprocal participation in the consent process because it influences the design of the healthcare I receive. I find genuine consent to be absent in the healthcare system. I regularly encounter this absence both as a volunteer respite

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worker, and as a patient. Multiple factors influence the consent process, including workplace policies, workplace layout, the social environment, mutual consent, sensory experience in the space, even the culture of the caregiver, as well as other features.

As an autistic patient, I am frustrated that the social environment, whether designed or accidental, prevents valid consent. I hope that one day informed consent to care will be intentionally designed to include all influencing factors, and all forms of verbal and non-verbal communications. This will allow for true consent rather than relying on the patient's ability to overcome social and mental barriers of communication.

Sierra: Consent is not just a box to be ticked. Consent to care is an ongoing process that should be revisited at each step in the procedure. For true consent, the healthcare provider must explain the procedure at each step and confirm with the patient that they are willing to go on. I realized through discussions with Michael that this ongoing consent to care is a right of all patients, not merely important for patient comfort.

Alec: Informed consent is a critical opportunity for clinicians to address questions or concerns patients may have and to make decisions with the patient's best interests at heart. Often in the busy environment of hospitals and clinics, consent is treated as merely a formality or a legal requirement. Through our conversation, I came to understand that informed consent is much more than just a piece of paper and a signature; it is the foundation of an ongoing partnership and alliance between care provider and patient. Many of Michael's difficulties in receiving quality oral healthcare stem from a lack of mutual understanding with his dentist regarding what he needs for comfort and safety. Standardized appointment consent forms barred Michael from making small adjustments to his procedure so that his experience could be within his sensory tolerance. There was no mutual plan until dental students took the time to stop and listen to what he needed and wanted. Ultimately, a much better outcome was achieved. Informed consent shouldn't be viewed by the clinician as a burden or simple documentation task, because, if done thoroughly, it can improve the patient's trajectory and outcome of care.

Adam: I grew up hearing public service announcements and classroom public agendas demanding I explore consent responsibly. I have learned that, for true consent, both people have to know in a bidirectional way what is known by both persons, and both have to agree to partake in the experience that is about to happen. I've always had to have the experience to know if I wanted to agree. With doctors, I know to ask for more explicit dialogue than others need. I might say, "I get nervous if I don't know what's happening. Describe what's happening for my care, please?" I even ask for them to narrate procedures they are doing in the room, or what happens when they leave. I will ask for alternatives if I don't like where my care is headed. I understand this as a right by definition of healthcare. Some doctors have told me that they will not adjust, and I need another doctor to meet that need. In those cases, I ask if they have a doctor in mind, and they usually do.

I don't have the same positive responses from doctors when I tell them, "I'm autistic, I'll get nervous if I don't know what's happening. Describe what's happening for my care, please?" They tend to treat me dismissively, as if suddenly I can't interact the same way as I could seconds before I announced, "I'm autistic." So I don't tell doctors my identity anymore, only my needs.

If anything in my script goes wrong, I have to make it feel acceptable (for us both) that I'm contradicting "the way it's done." This is not an intuitive autistic action - we like to meet (and exceed) expectations. Unlike others, I have practiced many strategies to navigate healthcare. Making physicians aware that "a professional office is batches of mild trauma to some people" can start helping us all.

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Hope for a Better Future for Healthcare

> *Instead of expecting our* thinking *to turn* inwards *to tell us what next* to do, *we must turn* outwards *to 'see' what is before us afresh, with the hope that a new way forward can be opened up* ....
> Shotter, 2016, p.21 (original emphases)

Adam: When we started, we all hoped for a dialogue that gave insight into the experiences of the other side of doctor-patient relationships. We have achieved this, and it empowers us in our various roles of that dialogue. Michael and I learned how to better communicate with physicians, while Alec and Sierra learned about the parts of our journey through the medical system that are often hidden by coping strategies or doctors' professional preconceived notions. Having gained and shared personal understandings, I *hope* this experience can be generalized and replicated, teaching more people on both sides of the conversation to help themselves and each other.

Alec: Medicine as a profession demands practitioners be realists as we manage patients' expectations around diagnosis, treatment, and prognosis, using objective evidence and past experience. As I got to know Michael and Adam, I came to realize that hope does not have to be limited to desire for favorable patient outcomes based on treatment or "good genes." Rather, in empowering the patient as a care provider and fostering hope from start to finish, hope itself can be the medicine.

Despite good intentions by practitioners, the care Michael and Adam receive often lacks an element of hope-building and empowerment they yearn for. Although Adam and Michael could have become cynical and disengaged, they are just the opposite. These two individuals are filled with hope and empowerment to not only better their own lives, but to help others in similar circumstances. They demonstrate how powerful patients themselves can be in charting their own outcome or prognosis, regardless of clinician input. It serves as a reminder that we as future physicians should make every effort to build on patients' preexisting sense of self-efficacy, because it can be such a powerful prognostic indicator to a patient's long-term well-being.

Sierra: The Patient Immersion Experience allowed me to explore the doctor-patient relationship through a different lens. Michael has worked for years with members of the Faculty of Medicine & Dentistry at the University of Alberta to innovate systems and approaches to better serve the healthcare needs of autistic individuals. As more medical students go through the Patient Immersion Experience, I hope they will see the degree to which patients must advocate for themselves. In recognizing this self-advocacy, I hope that students will better be able to support patients by acting as advocates for them.

Michael: I am grateful to Adam for all the help he has been with clarifying my thoughts and ideas. I thank Alec and Sierra for offering me "fresh lenses" and the collaborations through which I have continued expanding upon my ideas. My collaboration with these people has renewed my hope. Without allies, I fear that society cannot care about my physical health as an autistic person. While I realize I must bring with me information about my care, in this situation, I have been able to show how a system must care for me, not toward me or about me. I'm optimistic that I might overcome the related communications challenges that sensory overstimulation causes me, and that some aspects of this ongoing collaboration can help others living with a disability.

Moving Forward

> ***The great dialogue . . . is organized as an unclosed whole of life itself, life poised*** on the threshold.
> Bakhtin, 1984, p.63 (original emphases)

Alec: Physicians face many challenges in their daily practice, and this brings potential for burnout. In

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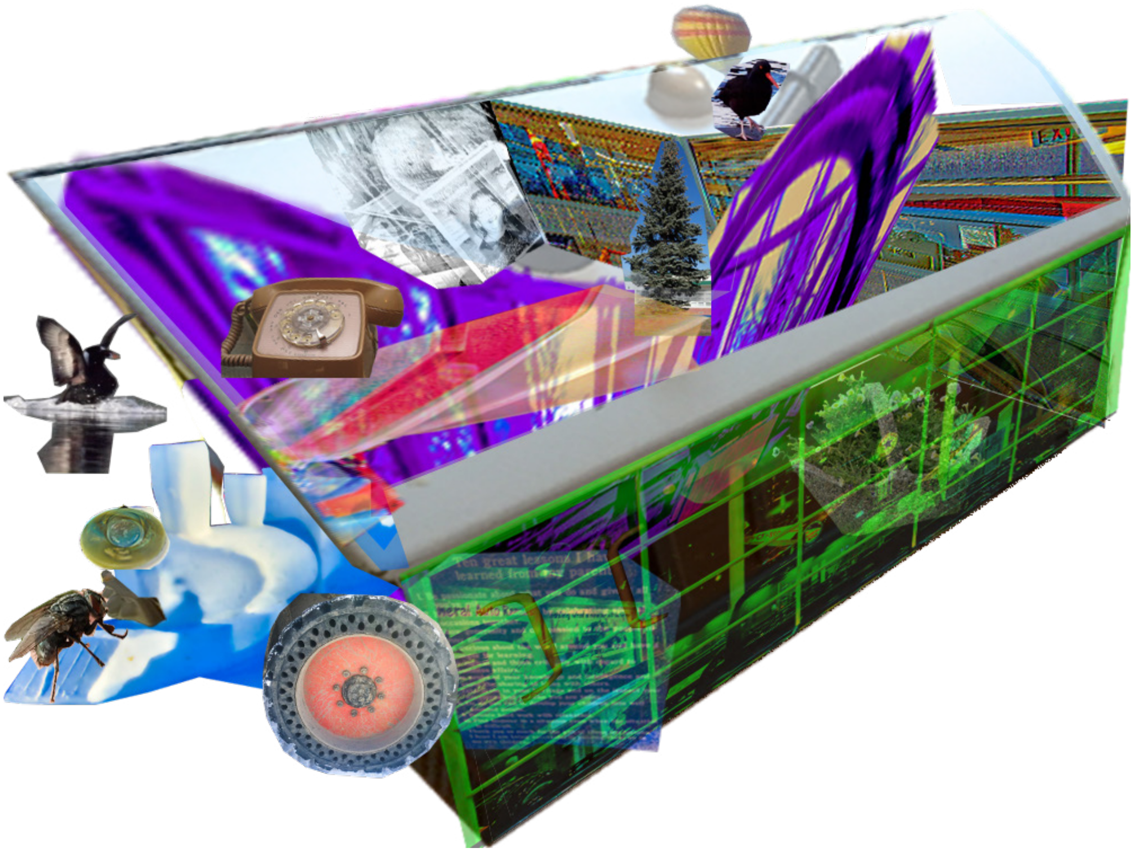
conversation with Michael and Adam, I realized that physicians don't have to travel their path alone: family, friends, and even patients can be a valuable source of inspiration, support, advice, and wisdom if we let them in. While we hope as physicians that our experience caring for patients will go smoothly, the reality is that difficult diagnoses and challenging situations will lie ahead. Feeling drained at times is a normal part of everyday medicine.

How can we change our system to energize physicians and reduce burnout? Throughout our online discussions, I felt like I got more out of the interaction than what I put in. This is a testament to not only Michael and Adam's efforts, but also to the power of feeling like you are a part of something bigger than yourself. I hope that in the future medicine will allow patients meaningful opportunities to speak their truth, because, without those truths, we lose the vital human aspect of medicine that makes it so rewarding.

Michael: I often use collage as an artistic medium by which to express and understand my thoughts. Currently, I am exploring the complex interrelationships between privilege and vulnerability. In the dynamically reciprocal experience of vulnerability, our current care system alternates between tacitly condoning my vulnerability, or tactfully reframing it or reinforcing the stigma society places on seeking care. In this context, I am further exploring ways to contribute to and help create the community I want to live in, and work in.

I have also started exploring how more inclusive, supported decision making and consent structure would empower me to be more independent. The community living collage I created, called "Reflections on my world, Visions for my community," expresses my vision for my community and how I want to work within the system to outsource my executive functioning



In this collage block, I (Michael) explore the idea that dialogues involve more than the spoken word, as well as the idea that dialogue can occur without words being spoken by one's self and other parties.

challenges to a third party. Then I could work in my community without my weaknesses causing social problems.

I am continuing to explore three critical areas in another collage. First, I am exploring my consent to care experience using mutual consent. For me, it includes respecting the sensory environment and social environment to improve my ability to access the oral healthcare I need. Second, I explore how the related process of supported decision-making I see (as part of the true informed consent to care process) will grant me a degree of self-determination. I have been seeking this since I reached the age of majority. Third, I am conducting explorations of my own care needs in the context of what role I will contribute to an experience of genuine belonging. I hope for design improvements that help us all.

Sierra: Working closely with Adam and Michael has opened my eyes to how being an autistic person affects every interaction one has within the healthcare system. I think with programs such as the Patient Immersion Experience, medical students and doctors will think more about how patients might experience their care. Instead of seeing an appointment as a thing they do many times a day, the doctor will see it as a potentially life-changing experience for the patient. Instead of handing a consent form to a patient and asking them to sign on the line, the doctor might spend time asking questions about the patient's thoughts and concerns. Having experienced medical appointments from a patient's perspective, they will know how much planning and effort goes into attending such an appointment. I will consider whether my patients need more time to think or whether the procedure might be particularly unpleasant due to sensory differences. I will spend more time actively listening and less time talking. Most of all, I will listen to what the patient is telling me they need the most in that moment.

Adam: In learning with Michael, Sierra, and Alec, I have learned more about how assumptions in the medical system are realized. Alec and Sierra's shared experiences have given me an understanding about the needs and experiences of doctors for a more effective place to start. Michael's experience has brought me closer to people I advocate for, giving me more tools to share my own experience.

I hope that I find more doctors who hold dialogues like Sierra and Alec. Rather than needing our stories to fit their "boxes," they adjusted their ears to hear our stories and they adjusted to our narratives in order to understand our needs. Once they understood our needs, they walked through solutions with us, exploring side effects and consequences as we needed, discovering further the ways we needed to discuss them. Working with them always left me energized, excited, and feeling included. It was nice to have this setting where the "other person" puts in as much or more effort than I did to understand my communication needs. It was a first and would solve my doctor issues if it were the standard.

Endnote

Dr. Pamela Brett-MacLean: Frank (2004) characterizes much of medicine as monological, with doctors viewed as "the one cognitive subject in the consulting room, and the patient … the object for that cognition" (p.101). Further, just as the physician "dreams the monological authority of being the single unquestioned voice," he suggests that within a biomedical context, patients dream of "the monological passivity of having this other pronounce their truth." Frank asserts that this model does not work for either physicians or patients. Rather, healing "requires each to give up his or her respective dream" (p.103).

In this inquiry, Sierra, Alec, Michael, and Adam made effective use of Google Docs as a digital polyphonic technology through which they were able to explore their different experiences and perspectives as medical students and autistic persons and develop new understandings through dialogical attunement. Their conversations point to the relationship-enhancing possibilities of open, back-and-forth dialogue as an antidote to monological approaches to medicine. They

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provide insights into ways dialogue can enhance both a sense of agency and relational connections, generate new creative thinking, and promote a more holistic, person-centered approach to healthcare while creating new possibilities for going forward together.

Congratulations to Sierra, Alec, Michael, and Adam, for all they have accomplished through this unique, thought-provoking, creative inquiry, and for the hope they have engendered for the future of healthcare for us all. Sensitivity and responsiveness to patients as human beings—recognizing their dignity and full humanity, ensuring their experience, views, and perspective are fully considered—will undoubtedly contribute to the healing of patients and the recovery of a more humane medicine.

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Notes

1. Michael and Adam are aligned in relation to this: In the disability world, the question of how best to describe those who have autism - person-first (“person with autism”) vs. identity-first (“autistic person”) - is the subject of debate (Shakes & Cashin, 2019). In this article, we wish to use identity-first language, which is also what is preferred by a majority of our autistic adult peers. Identity-first language has become the norm for identifying groups that share similar experiences (“religious person” or “Canadian person”). Person-first language makes it sound like autism is a disease, or a bad thing, which takes control away from the individual regarding their personhood. I am an autistic man, living to be respected, not to be cured.

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Works Cited

Agledahl, K.M., Gulbrandsen, P., Førde, R., & Wifstad, Å. (2011). Courteous but not curious: How doctors' politeness masks their existential neglect. *Journal of Medical Ethics, 37*(11), 650-654.

Bakhtin, M. (1984). *Problems of Dostoevsky's poetics* (C. Emerson, Ed. & Trans.). Minneapolis, MN: University of Minnesota Press.

Barry, C.A., Stevenson, F.A., Britten, N., Barber, N., & Bradley, C.P. (2001). Giving voice to the lifeworld: More humane, more effective medical care? A qualitative study of doctor–patient communication in general practice. *Social Science & Medicine, 53*(4), 487-505.

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision making: A model for clinical practice. *Journal of General Internal Medicine, 27*(10), 1361-1367.

Frank, A.W. (2005). What is dialogical research, and why should we do it? *Qualitative Health Research, 15*(7), 964-974.

Frank, A.W. (2004). *The renewal of generosity: Illness, medicine, and how to live.* Chicago, IL: University of Chicago Press.

Harvey, J. (2013). *Every patient is a person with a story: Patient mentors share their time and experiences to help teach first-year medical students.* Retrieved November 30, 2019, from https://www.ualberta.ca/medicine/news/2013/october/every-patient-is-a-person-with-a-story.

Hutchison, C. (2014). *Launching a physicianship course: Positive response for first year of new program.* Retrieved November 28, 2019, from https://www.ualberta.ca/medicine/news/2014/may/physicianship-course.

Jones, E.K., Kittendorf, A.L., & Kumagai, A.K. (2017). Creative art and medical student development: A qualitative study. *Medical Education*, *51*(2), 174-183.

Katz, A.M., Shotter, J., & Seikkula, J. (2004). Acknowledging the otherness of the other: Poetic knowing in practice and the fallacy of misplaced systematicity. In T. Strong & D. Pare (Eds.), *Furthering talk: Advances in the discursive therapies* (pp.33-51). Boston, MA: Plenum Press.

Kumagai, A.K. (2009). The patient's voice in medical education: The Family Centered Experience Program. *AMA Journal of Ethics*, *11*(3), 228-231.

Seikkula, J., Aaltonen, J., Alakare, B., Haarakangas, K., Keranen, J., & Sutela, M. (1995) Treating psychosis by means of open dialogue. In S. Freidman (Ed.), *The reflecting team in action.* New York, NY: Guilford Press.

Shakes, P., & Cashin, A. (2019). Identifying language for people on the autism spectrum: A scoping review. *Issues in Mental Health Nursing, 40*(4), 317-325.

Shotter, J. (2013). The transmission of information: An "awful deformation" of what communication really is. *Proceedings of the 70th New York State Communication Association, 2012,* Article 3.

Shotter, J. (2016). *Speaking, actually: Towards a new "fluid" common-sense understanding of relational becomings.* Farnhill, UK: Everything is Connected Press.

Siegel, M. (1995). More than words: The generative power of transmediation for learning. *Canadian Journal of Education*, *20*(4), 455-475.

Suhor, C. (1984). Towards a semiotics-based curriculum. *Journal of Curriculum Studies, 16,* 247-257.

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