

Q&A Summary

Establishing Effective Communication with Patients with Intellectual Disabilities:

RAFT Part 1

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1. You made a lot of great suggestions about communication barriers in the health care field. Everything you recommended seems like things that should be practiced within ALL health care settings. It seems so easy, but yet there are so many difficulties with how patients are treated, especially as it relates to communication. It is common in ALL health care settings...Why is that so?

A: People often think that communication is easy, because we do it every day. I believe that the problem starts in our educational system. Regardless of what medical profession you are in, communication is not typically a central part of the training process. We are starting to see a shift in this as there is a continued push to improve the quality of care for all patients. Additionally, in this day and age, patients are more often being treated by teams of health care professionals (HCPs) rather than a single provider. Communication is becoming even more important, not just between patient and provider but also among providers. Medical schools are recognizing the importance of communication and starting to include it in their curriculums, but we are still a long way from full integration. Training programs like RAFT are designed to increase awareness about the role of communication and also provide strategies that can be implemented immediately.

2. Why are patients with autism included in this group when they may have IQs well over 100?

A: I apologize for the confusion on this issue. The Special Olympics defines intellectual disabilities as a type of **developmental disability**. Autism is discussed as a type of developmental disability that may or may not indicate the presence of an intellectual disability. For more information please follow this

link: http://www.specialolympics.org/Sections/Who_We_Are/About_Intellectual_Disabilities.aspx

3. When you first meet patients, how will you know which accommodations they would like or need? Will they tell you?

A: Some patients/caregivers will come right out and tell you what they need from you. Others will be less open about it. Some providers that I have worked with have mentioned feeling like the patient's disability was the "elephant in the room." There is nothing wrong with addressing it. Sometimes avoiding the topic can leave patients and caregivers feeling like you do not care or are uncomfortable. This is where that follow-up step comes into play. It is important to get to know your patients on a deeper level and begin to form trusting relationships with them. The only way to learn about someone is to ask. You might ask questions like:

Are you comfortable in this space/room?

Are my comments helping you understand this procedure?

Is there anything I can do to make this process easier for you?

Is there anything you would like to see us do differently next time?

4. What tips do you have when a patient is nonverbal?

A: This is a tricky one, because every patient is different. Some nonverbal patients will have their own way of communicating with you. It is important that you pay attention and try to learn what their gestures, facial expressions, and sounds mean. You may need to rely on the caregiver to help you at first, but be sure to keep notes so that you remember for next time. Always remember to smile and be nonverbally immediate even if the patient does not reciprocate. Try out your own nonverbals (hand shake, high five, etc.) to see what they like. If you can connect with them on their level, it will help them feel more comfortable. And always remember: Do not think about this is a challenge. Think about it in terms of a need that should be met.

5. What if the patient and the caregiver's answers are different to a question?

A: This is not uncommon. Caregivers are valuable resources and they often spend so much time with the patient that they can sense what is wrong. But remember, regardless of patients' abilities to communicate, they are the only ones who truly know how they feel. A caregiver may be able to describe how their behavior has changed or what they think is wrong, but the patient is the only one experiencing the symptoms. I would trust the patient in this case. You will want to ask the same questions in a few different ways to ensure that their response is consistent. If their response is consistent, it is important to trust them. There may be another undiagnosed issue that the caregiver does not know about that is co-occurring with an existing problem.

6. What if the caregiver is not available?

A: If a patient comes in without a caregiver, this typically means that they are functioning at a level where they do not need the help of a caregiver. They may not know the answers to all of the questions, but that is ok. Do what you can with the patient. Write down questions for the caregiver, and let the patient know what you are doing so that they know the caregiver will be included. This should put them at ease but also allow them to be independent.

7. Please comment and share more resources about intellectual disabilities in minority populations with language and cultural barriers when accessing health evaluations.

A: This is an important issue to consider. There is a lot of research out there on communicating with minority and underserved populations, but less about these issues coupled with intellectual disabilities. Interestingly, a lot of the strategies for communicating with patients of different cultures are similar to what we discuss in RAFT: understanding the patient as a whole person, speaking slowly, using a translator, using multiple modalities, nonverbal immediacy, not categorizing them as a "type" of patient, etc. Remember that even if you do not speak the same language, you might need to use alternative communication such as pictures. There is a good documentary series which you can find on YouTube called *Worlds Apart*. It is focused on cross-cultural health care (not intellectual disabilities specifically), but many of their suggestions can be used in this context as well. Here is the link: https://www.youtube.com/watch?v=K5d_iPaUrWw&index=4&list=PLr6VLStmwYppPzy9GJ7xWJqv6P_HPy1B

See this link for specific information on intellectual disabilities and cultural/linguistic differences: <http://communitydoor.org.au/service-delivery/disability/how-to-hear-me-a-resource-kit-for-working-with-people-with-intellectua-6>

8. I would also think it is important to determine if the caregiver has a legal role. Guardian, etc?

A: Yes, this is correct. If you are going to let the caregiver make any legal, medical decisions for the patient, you should make sure that they have the legal right to do so. However, if the caregiver is just accompanying the patient into the appointment, this may not be the case. You always want to consult the patient to make sure that they are comfortable with this person accompanying them. However, these rules may vary by employer, so it is always best to check with your health care organization before allowing any third party to sit in on an appointment.

9. How do you deal with an overprotective caregiver when you, the professional, feel that the patient is capable of more than the caregiver allows them?

A: You may try to redirect the conversation back to the patient. Acknowledge the caregiver's insights, then say something like, "Now I'd like to hear from [patient] what he/she is experiencing." It may come to a point where you need to explain to the patient and caregiver that the patient's insights are important to you and what you do, to let them know that you are not ignoring what the caregiver has to say.

10. How do you address informed consent when you know the patient cannot make complex medical decisions, and the patient does not have a power of attorney (POA)/Guardian but has a consistent caregiver?

A: This is more of a legal question that is probably best answered by your employer/health care organization or legal professional. To protect yourself, I would say that even if a patient has a consistent caregiver, that caregiver has no legal right to make decisions unless he/she is a parent or legal guardian or has a POA.

11. How can we get a copy of Healthy People 2020?

A: This information is free and available online. Here is a link to the website: <https://www.healthypeople.gov>

Here is a link to the Disability and Health Topic

Area: <https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health>

12. Have you ever experienced a situation where the patient could actually be intimidated or fearful of their caregiver and will not reply or engage in any conversation?

A: If a patient seems reluctant to speak up in the presence of a caregiver, you might ask the patient if he/she would be more comfortable if it was just you in the room. You might also ask the caregiver to step out during questioning.

13. Does a processing delay constitute an intellectual disability?

A: The Special Olympics defines an intellectual disability as a limitation in cognitive functioning. However, individuals with learning disabilities may not have a low IQ or limitations in adaptive functioning such as communication, self-care and social skills. In some cases, it may indicate the presence of an intellectual disability but does not necessarily constitute one.

14. Do you want to address guardianship and limitations of the appointment?

A: See question 10. Again, this is more of a legal issue. The strategies set forth in RAFT are focused on communication. Regardless of guardianship or POA and who is making the legal decision, it is your duty as the HCP to make sure that you include patients in these conversations and that they are aware of what is happening. What happens afterward is legally out of your control (unless of course the patient is a danger to himself/herself or someone else).

15. Comment: You suggested the HCP be flexible to communicate interest in the member, with eye contact and possibly via physical touch (e.g., pat on the shoulder). The HCP (especially if male) may want to be cautious about that. Suggestion: check first whether that particular patient may tend to misinterpret physical touch (either as an unwelcome intrusion or as a come-on/signal for excessive intimacy).

A: Thank you for this insight. This is absolutely correct. There are obviously limitations that you will want to be aware of. For example, if the patient is of the opposite sex or if the patient does not like to be touched. I would suggest you start with a handshake or high five and see how the patient reacts. You may also consult with the caregiver about likes/dislikes.

16. Can you ask the caregiver to step out?

A: Yes, it is always acceptable to ask the caregiver to step out. Be sure to let the caregiver know that you are not hiding anything from them, nor do you find their insights to be unhelpful. You want to make sure they know that the patient is your first priority and that you want to give him/her an opportunity and the environment to express himself/herself. See question 12 for more information.

17. As a field case manager, I authorize services according to my member needs, and so a lot of the questions appear redundant. How can I avoid that when reviewing members' instrumental activities of daily living (IADLs) to evaluate if there are changes?

A: In your case, asking similar questions at every check-in serves a specific purpose and is most likely required for you to make an accurate assessment of changes. In RAFT, when we talk about avoiding redundant questions, it is more focused on avoiding the same questions in the same appointment. For example, when the nurse asks me to describe what happened, and then the physician comes in and asks me the same thing. In this case, the physician may say something like, "You told the nurse that you fell down on your bike. Can you tell me what is hurting you?" This way the patient knows that you are communicating with the other providers, and he/she does not have to explain the entire scenario again. Another example about avoiding redundant questions from appointment to appointment would be more focused on personal questions like

their favorite color. If you ask that today, write it down so that you do not ask it again next time you see that patient. In your case, the answers to your questions may change, so it is important to ask them. But you may want to start off with something like, "Last time you mentioned that xx was bothering you. Is there any improvement or worsening of the pain?"

18. Are clinicians/doctors/health care staff being trained on this topic? Do they receive training on how to work with individuals with disabilities? Where can they go for training like you presented?

A: To my knowledge, there is no comprehensive training for HCPs on this topic. Through our formative research and talking with a variety of HCPs, we found that many of them had not received training on this topic but were very interested in it. Many of them had received some training in general communication strategies and/or bedside manner, but not specifically for this population of patients. Additionally, in the pilot testing of RAFT, 96.3% of participants had never received training on the topic of communicating with patients with intellectual disabilities. The webinar that you all attended is available to the public on the OptumHealth Education website.

If you have questions regarding this document or its content, please contact: moreinfo@optumhealtheducation.com.