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Tips for health care providers on talking with patients who have intellectual and developmental disabilities about COVID-19

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Abstract

Background: One in four American adults reports having at least one disability. The COVID-19 pandemic has disproportionately impacted people with disabilities and widened already-existing health disparities and inequities. For many people with intellectual and developmental disabilities (IDD), these disparities are compounded by literacy limitations that make it challenging to access, understand, and act upon critical COVID-19 prevention information.

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Disclosure statement

No potential conflict of interest was reported by the author(s).

Ethical approval

This statement was already provided in the narrative above, but it is: RTI International's Institutional Review Board reviewed the audience research activities and determined them to be exempt.

Methods: Using a design thinking framework, we conducted interviews with 27 caregivers of adults with IDD who also have extreme low literacy (ELL) to assess COVID-19 information needs and recommendations for how health care providers could best provide COVID-19 information. Based on our findings, we developed a draft tip sheet to help health care providers communicate with adults with IDD/ELL about COVID-19. We then tested the tip sheet with six health care providers via a focus group discussion. We refined and finalized the tip sheet based on our focus group findings.

Results: Caregivers noted the importance of visual aids, repetition, empathy and addressing the person with IDD/ELL directly when discussing COVID-19. Many health care providers indicated that the tip sheet would be most helpful for those with limited experience with patients with IDD/ELL and specific instructions for implementing the tips would be important.

Conclusions: We developed an evidence-informed tip sheet to facilitate communication between health care providers and adults with IDD/ELL and their caregivers, particularly around COVID-19.

Keywords

Health literacy; COVID-19; low literacy; intellectual and developmental disabilities; disabilities

Introduction

The COVID-19 pandemic has had a devastating and disproportionate impact on people with intellectual and developmental disabilities (IDD). People with IDD have experienced a higher incidence of COVID-19 than people without IDD and are also more likely to be hospitalized from COVID-19 complications and to die from COVID-19 [1]. Although research on literacy levels among people with IDD is limited [2], available evidence suggests that many people with IDD are nonreaders or emergent readers [3] and are more likely than those without IDD to perform at the lowest literacy levels [4]. Thus, people with IDD/extreme low literacy (ELL) may have challenges understanding public health messages about how to stay safe from COVID-19, even if these messages meet current plain language or clear communication standards. As the COVID-19 pandemic persists and evolves, there is an urgent need to improve messaging about COVID-19 and emergency preparedness for people with IDD/ELL.

Health care providers (HCPs) are a trusted source of information for people with IDD, and effective patient–provider communication is essential for achieving positive health outcomes for patients with IDD [5]. However, HCPs frequently cite communication concerns as a challenge to providing high-quality care to patients with IDD [6]. A 2017–2018 study that explored physician perspectives on communicating with people with disabilities found that physicians did not use standardized approaches for communicating with patients with IDD, often did not directly engage the patient with IDD because of their perception of the patient’s inability to make their own decisions, preferred to communicate with caregivers despite concerns over patient consent, and only sometimes used visual aids to assist in communication with patients with IDD [6]. Notably, physicians in this study cited the need for more accessible informational material to improve communication with patients with disabilities.

To meet the information needs of adults with IDD/ELL and to help HCPs more effectively communicate with this patient population, the Centers for Disease Control and Prevention (CDC) funded and collaborated with RTI International to develop a suite of resources about COVID-19 and emergency preparedness for people with IDD/ELL, their caregivers, and HCPs. Below, we discuss our approach for developing, testing, and refining one of CDC's resources – a tip sheet for HCPs on talking to patients with IDD/ELL about COVID-19. Our approach was informed by three rounds of audience research to ensure that this tip sheet reflected what caregivers of adults with IDD/ELL wanted HCPs to know about communicating with this patient population and served as a useful resource for HCPs.

Methods

We used a design thinking framework to guide the development, testing, and refinement of a tip sheet for HCPs on how to effectively communicate with patients with IDD/ELL about COVID-19. Design thinking is an interactive process that focuses on forming a deep understanding of your audience (i.e. product users) and includes five key steps: empathizing with your audience, defining audience needs, ideating, prototyping, and testing [7]. We specifically conducted a series of interviews with caregivers of adults with IDD/ELL to inform the development of the tip sheet and then conducted a focus group with HCPs to test and refine the tip sheet. To reach our audience and identify participants, we worked with national and community-based disability-serving partners to disseminate information about our study to priority audiences. Interested individuals responded to a web-based screener, and those who were eligible were scheduled for virtual interviews and a virtual focus group, which took place in the Spring and Summer of 2021. RTI International's Institutional Review Board reviewed the audience research activities and determined them to be exempt.

During our first phase of audience research, concept testing, we conducted nine semi-structured, dyadic interviews with English-speaking adults with IDD/ELL and their caregivers to explore the idea of a tip sheet to help HCPs communicate more effectively with their patients with IDD/ELL about COVID-19. Concept testing was guided by the following research question: What do caregivers suggest HCPs should know about how to communicate with people with IDD/ELL, especially related to COVID-19? Specifically, we told caregivers 'We are considering creating a tip sheet for health care providers' and asked, 'What do you wish health care providers knew about communicating with [name of person with IDD/ELL]? What tips would you give them?' and 'How about tips for communicating about COVID-19?'

In our second research phase, material testing, we conducted another round of nine semi-structured, dyadic interviews with English-speaking adults with IDD/ELL and their caregivers as well as nine interviews with Spanish-speaking caregivers of adults with IDD/ELL. In these interviews, we solicited additional insights from caregivers about the HCP tip sheet prior to developing a prototype of this material and testing it with HCPs. We shared with caregivers, 'We are developing a tip sheet for health care providers' and asked, 'What tips would you like to see for health care providers on how to communicate information about COVID-19 to [name of person with IDD/ELL]?' Based on the finding from the first two phases of audience research, we developed a one-page tip sheet for HCPs on talking to patients with IDD/ELL about COVID-19.

Finally, we tested the tip sheet with HCPs to gather their overall reactions to the tip sheet as well as suggestions for improvements. We conducted a focus group with six HCPs – including three specialty physicians, two primary care physicians, and one primary care nurse practitioner – who worked across a variety of health care settings (e.g. group practice settings, hospitals, academic medical centers) and regularly saw patients with IDD/ELL. We asked focus group participants a series of questions to elicit their overall reactions to the tip sheet. We asked whether the tips represented new information or were strategies they were already implementing, if the tips were helpful, and which tips were most and least helpful. We also asked what other tips or strategies they thought would be helpful for HCPs like themselves, if there were any communication challenges with patients with IDD/ELL that the tip sheet didn't address, and about the most common communication challenges that they encountered with their patients with IDD/ELL. Finally, focus group participants provided suggestions to make the tips more actionable and to aid uptake of the tip sheet by busy HCPs.

Following the interviews and focus groups, we conducted a rapid thematic analysis. First, we assembled participant responses into a meta-matrix organized by interview question and participant. A meta-matrix is a way to structure data that facilitates both an indepth analysis of individual responses as well as a comprehensive assessment across responses [8]. Next, we identified themes and patterns across participants. We selected the final five tips by triangulating the communication needs identified in the interviews with people with IDD/ELL and their caregivers and the feedback we received from HCPs in the focus group.

Results

In our interviews with caregivers of adults with IDD/ELL, participants stressed the importance of using visual aids – such as posters, social stories, and flyers – to help facilitate discussion and understanding with adults with IDD/ELL during doctor's visits. For instance, one caregiver of an adult with Autism shared that it would be helpful for HCPs to have 'visual aid materials of what to expect for that particular type of [doctor's] visit' and specifically suggested social stories that describe 'what's going to happen and why.' Another caregiver of an adult with IDD/ELL suggested, 'if there were posters … we could use [those] to reinforce [desired behaviors] while we're in public and show that everyone does it.'

A few participants shared that it is especially important for HCPs to practice empathy and patience when talking with adults with IDD/ELL, and to repeat key messages to aid comprehension of the person with IDD/ELL. Participants also suggested that, in situations where a caregiver is attending the medical appointment with the person with IDD/ELL, HCPs engage directly with the person with IDD/ELL, while also using the caregiver as a resource to aid communication. If needed, the HCP can ask the caregiver about the best way to communicate with the person with IDD/ELL and/or ask them any clarifying questions about what the person with IDD/ELL is communicating. For instance, one caregiver of an adult with Microcephaly noted that they wished HCPs would ‘take the time to talk to the caregiver about what [the person with IDD/ELL] is trying to say.’ Another caregiver of an adult with Down Syndrome shared:

> We’re fortunate enough that we have a doctor who’s specialized in Down Syndrome, and she’s seen Down Syndrome from birth to adulthood. We initially went to another doctor, and she didn’t communicate to [the person with IDD/ELL] at all, and she didn’t explain anything … I wish more mainstream doctors would have materials like this and say, ‘Wait a minute. I have a patient with ID, and they’re still a person, and Mom may be here, but we still need to go over this.’ That’s not something I think they do very well.

Caregivers also noted the importance of easing the worries of people with IDD/ELL about COVID-19. These caregivers said that the COVID-19 pandemic is often frightening for people with IDD/ELL and it is important to acknowledge those fears.

Finally, caregivers recommended that HCPs keep communication as simple and literal as possible. One caregiver of an adult with Down Syndrome recommended:

> I would tell [HCPs] to keep it simple because our kids are very literal … [get] straight to the point. Use pictures because these kids get them. They like illustrations. They’re simple enough to understand … They’re looking at you. You’re a doctor. Show them. You know everything, you’re smarter than Mom in their eyes. [HCPs] need to know how to communicate with our kids and not overwhelm them.

From these interviews with caregivers, we developed a draft tip sheet for HCPs and tested it with six HCPs who have adult patients with IDD/ELL. Overall, the HCPs had positive reactions to the tip sheet. Several noted that the tip sheet would be particularly useful for HCPs who have limited experience with patients with IDD/ELL. For example, one provider who directed a Down Syndrome program at a children’s hospital commented, ‘I like this [tip sheet]. It has some good messaging that probably feels intuitive to us but probably not to people who don’t work with this population as much.’

HCPs requested that the instructions for how to implement each tip for communicating about COVID-19 be as specific as possible. Additionally, feedback from HCPs indicated that the tip sheet should link to specific resources for patients with IDD/ELL that adhere to the communication strategies included in the tip sheet. For instance, a provider with a specialty practice focusing on medically fragile and behaviorally complex patients with developmental disabilities suggested:

> I think show [HCPs] rather than tell them. Give [HCPs] specific examples about what kinds of things to show [patients with IDD/ELL]. Scripts and things, examples of how to keep it plain rather than patronizing … So more demonstrating [what to do], that’s how doctors learn rather than telling them what to do. I don’t

> know that they'd be able to translate those instructions [in the tip sheet] into something useful.

Discussion

This study is unique in that we used a design thinking approach to gather and triangulate feedback from caregivers of adults with IDD/ELL, who are well-versed in the communication needs of the people they support, as well as HCPs, who are the intended audience of the tip sheet discussed in this paper. By obtaining multiple perspectives, we were able to develop a tip sheet of communication strategies that caregivers of adults with IDD/ELL believed were most important and package these strategies into a useful and easy-to-use format to aid the adoption of these strategies by HCPs.

Caregivers of adults with IDD/ELL recommended specific interpersonal communication skills for HCPs, including practicing empathy and patience, and engaging directly with the person with IDD/ELL, while also using the caregiver as a resource to aid communication. Caregivers also recommended that HCPs communicate using simple sentences and language and incorporate visual aids. In addition, they wanted HCPs to remember that adults with IDD/ELL process information literally, so they should avoid using metaphors and figures of speech. When shown the draft tips provided by the caregivers, HCPs recommended that the tips include concrete instructions for implementing them and links to resources they can use themselves and share with patients.

Based on these findings, we recommend five key strategies for talking to patients with IDD/ELL about COVID-19 (see Table 1). While these strategies were derived from conversations with caregivers about communicating with people with IDD/ELL about COVID-19, these strategies can be applied to communication with people with IDD/ELL more broadly.

In addition to the communication strategies provided in the tip sheet, HCPs can also use CDC's Stay Safe from COVID-19 materials – which cover basic topics, like getting the vaccine, wearing a mask, keeping a safe distance, washing your hands, and getting a COVID-19 test – to facilitate communication with their patients with IDD/ELL about COVID-19. While these materials are not the focus of the current paper, they were developed as part of the same CDC-funded work.

Our research to improve communication between providers and their patients with IDD/ELL adds to an existing body of evidence. For example, Ziviani et al. [9] found that people with IDD wanted general practitioners to demonstrate warmth and interest in them and were annoyed when doctors minimized eye contact. These authors also found that general practitioners did not identify interpersonal or relational aspects of the medical encounter as being most important. These findings highlight the disconnect between providers and their patients with IDD regarding communication priorities. Our tip sheet provides simple strategies – for example, showing patients with IDD/ELL that providers are listening and making sure providers are speaking directly to them in simple and clear terms – to help providers more effectively connect and communicate with their patients with IDD/ELL.

Boardman, Bernal and Hollins [10] also developed guidance for psychiatrists, however these recommendations are not packaged for easy use in a clinical setting. Finally, Vanderbilt Kennedy Center [11] developed a webpage for primary care providers that provides tips across five areas – establishing rapport, choosing appropriate language, listening, explaining clearly, and communicating without words – that are similar to the recommendations we created, but are only available online, do not have visual aids to support the tool, and are not in a printable format.

Strengths of our tip sheet include that it was informed by conversations with both caregivers of people with IDD/ELL and HCPs who serve this patient population; is packaged in a brief, printable format for easy reference and use in a clinical setting; and can be found on CDC's website, which is easy to access and widely available. However, this study is not without limitations. Our development and testing of this tip sheet were based on a small sample of participants (27 caregivers and six HCPs). Additionally, we opted for a single-page format so that the tip sheet would be easy for HCPs to use and reference in a clinical setting, but this limited the strategies to only the most salient and relevant communication needs expressed by caregivers of people with IDD/ELL.

Conclusions

Throughout the COVID-19 pandemic, HCPs have been working tirelessly to help their patients prevent and treat COVID-19. Yet, providers often do not have the resources or receive the training they need to meet the unique communication needs of their patients with IDD [12]. Using a design thinking framework to gather input from caregivers of adults with IDD/ELL and HCPs who serve this patient population, we developed a tip sheet that is readily accessible to HCPs online and is easy to use in clinical settings. The goal of this evidence-informed tip sheet is to facilitate communication between HCPs and adults with IDD/ELL and their caregivers, particularly around COVID-19. Now more than ever, we need additional evidence-based tools and materials – tested with people with IDD with diverse communication abilities and literacy levels – to help ensure that people with IDD/ELL and their caregivers have the information they need to protect themselves from COVID-19.

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Table 1.

Talking to Patients who have IDD/ELL about COVID-19.

1. **Keep it simple.** Stick to short words and sentences when you can. Many people with IDD/ELL process information in a literal way, so it is best to avoid metaphors and figures of speech.

2. **Show that you are listening.** The COVID-19 pandemic has been hard for everyone, but people with IDD/ELL may face additional challenges. Show your patient that you understand by listening to their concerns, then repeating what you have heard in your own words.

3. **Say it in pictures.** When you recommend protective behaviors like wearing a mask or keeping a safe distance, use literal, realistic images to help your patients with IDD/ELL visualize those behaviors. When possible, break behaviors down into a series of steps, using one image to illustrate each step. You can also use visual schedules with pictures to help patients understand what to expect in new situations.

4. **Include everyone in the conversation.** If your patient with IDD/ELL brings a caregiver or support person to their appointment, be sure to include everyone in the conversation. When you are asking questions or sharing information, always talk to your patient directly. Then, as needed, check in with their caregiver or support person to learn more and make sure everyone is on the same page.

5. **Repeat key takeaways.** For people with IDD/ELL, repetition is key. As you are wrapping up your visit, take time to repeat the main ideas you want your patient to take away from the conversation.