

Enhancing Care for Patients with Intellectual and Developmental Disabilities: A Critical Assessment Based on Nurses' Experiential Reflections

John P Bartkowski^{1*} and Courtney K Barrie²

¹*Department of Sociology, University of Texas at San Antonio, USA*

²*Project Coordinator, Office of Student Advocacy and Anti-Violence Education, St. Mary's University of San Antonio, USA*

***Corresponding Author:** John P Bartkowski, Department of Sociology, University of Texas at San Antonio, USA.

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Abstract

People with intellectual and developmental disabilities (IDD) are medically underserved, thereby exhibiting both acute and chronic health disadvantages. Many medical providers - physicians in particular - do not have a working knowledge of the unique medical needs of patients with IDD. In addition to this IDD knowledge gap, the interactions of healthcare professionals with such patients sometimes reflect the wider society's discomfort and intolerance toward people with IDD. This study uses experiential reflections from nurses and direct service providers who commonly treat patients with IDD to promote the enhancement of medical care to this vulnerable population. As frontline health workers, their insights illuminate current gaps and improvement opportunities concerning advocacy, treatment plans, and the delivery of effective care for patients with IDD.

Keywords: Nurses; Direct Service Providers; Physicians; Clinicians; Disabilities; Intellectual Disability; Developmental Disability; IDD; Qualitative

Abbreviations

DETECT: Developmental Evaluation, Training and Educational Consultative Team of Mississippi; IDD: Intellectual and Developmental Disabilities; DSP: Direct Service Provider

Introduction

Given their role as patient advocates, nurses and direct service providers (DSPs) often function as primary medical caregivers of patients with intellectual and developmental disabilities (IDD). The experiences of these caregivers allow for valuable opportunities to consider barriers to medical access for people with IDD and promising avenues for clinician education. This qualitative study is based on experiential reflections shared by nurses and DSPs at a series of statewide trainings delivered within a Southern state in the United States that has a robust population of patients with IDD. The specific state is not identified to preserve confidentiality. The approach used here is that of experiential reflection on patient cases using prompts featured on a qualitative questionnaire. Rather than focusing on a single patient or particular condition, as does a conventional case report, we contend that there is remarkable value in collating the case experiences of a group of healthcare providers and distilling broader insights from their collective experiences. Our qualitative approach is not designed to generate knowledge that is generalizable to healthcare workers as a whole, but instead reflects an effort to identify common

patterns and complex processes that can influence the quality of care provided to patients with IDD. Where appropriate, the posture we adopt in this study is critical of treatment as usual because the themes conveyed in the narratives shared by nurses and DSPs often highlight their observation of adverse physician-patient encounters. Insights from these experienced frontline healthcare providers are valuable inasmuch as they identify healthcare barriers that, if overcome, could significantly improve the quality of care for patients with IDD. The value of this learning opportunity is underscored by the fact that family physicians and other healthcare providers are increasingly needed to deliver medical services to patients with IDD who have been transitioned from institutionalized settings to community residences.

This project was undertaken as part of a larger evaluation and quality improvement initiative conducted for DETECT of Mississippi [1]. DETECT is the Developmental Evaluation, Training and Educational Consultative Team of Mississippi [2]. DETECT of Mississippi is a state-funded organization dedicated to helping patients with IDD access quality care. Apart from DETECT's focus on provider education through information dissemination and training, the agency facilitates patient-provider connections in Mississippi [3-5]. In addition, key principals in DETECT have also provided trainings outside of the state of Mississippi due to its successful implementation of various programs for Mississippians with IDD [1]. A series of these trainings provided in another Southern state served as the impetus for the findings reported in this study. Nurses and direct service providers in this unnamed state participated in multiple educational conferences in 2016 and 2017. At these conferences, DETECT administered continuing education on the medical needs of patients with IDD, including common illnesses and associated symptoms unique to the IDD population. These conferences also offered opportunities to learn about effective and ineffective strategies nurses and DSPs had observed in the treatment of patients with IDD.

The essential role of DETECT and organizations like it is underscored by decades of research which reveals that patients with IDD are especially vulnerable to morbidity - chronic and acute conditions - as well as premature mortality when compared with the general population [1,6-15]. Health disparities among people with IDD are among the most profound that social researchers have observed in all groups facing health disadvantages. Given these egregious disparities, various efforts have been undertaken to improve the quality of care delivered to patients with IDD, and nurses have figured prominently in such initiatives because they are typically the lead point of care to this highly vulnerable group [16-20]. Previous research indicates that nurses' experiential expertise as the primary conduit of sustained care to patients with IDD places them in a unique position to reflect on and recommend improvements in effective IDD care [17-20].

Qualitative methods have been shown to be a particularly rich medium through which to gather insights on this important topic [12,20]. In recent qualitative research, for example, nurses have discussed their care provision strategies for patients with IDD in the context of the nurse-patient dyad; they have also described how they commonly serve as a bridge across otherwise disparate systems (medical care, disability advocacy) in an effort to provide quality care to such patients [20]. In short, nurses are self-aware of their status as an important patient-provider intermediary and take most seriously the role of interlocutor and advocate. These qualities make them excellent sources of information to identify what is done well and poorly with respect to physicians' IDD care while also pinpointing opportunities for improvement. Moreover, nurses' insights are delivered in the context of cultural dynamics in medicine (gendered physician-nurse hierarchies) [11,14] as well as the profession's structural factors (relatively poor Medicaid reimbursement rates that sometime discourage physicians' sustained attention to such patients, of which those with IDD are vastly overrepresented) [21].

Materials and Methods

The data used for this study are qualitative in nature and are designed to examine narrative recollections of the experiences of nurses and DSPs in IDD care provision. The open-ended questionnaire invited attendees at continuing education conferences to share observations from their clinical experiences (see appendix for questionnaire). Among the 193 healthcare providers responding to the questionnaire, most (70.5%) were registered or licensed practical nurses. The respondents were very experienced, with an average of more than nine years serving patients with IDD. Respondents reported providing current treatment to a median (midpoint) of 20 patients after maximal outliers were removed. (Five people reported treating over 1,000 patients with IDD. We have no reason to doubt the accuracy of this information, but its inclusion in background statistical calculations significantly skews the distribution). Data were analyzed with

various sensitizing concepts (potential themes suggested by prior research) in mind, including the observation of adverse physician-patient encounters, challenges related to IDD patient advocacy in the context of nurse-physician relationships, gaps in medical education, deficient treatment plans, and other related areas. The authors adhered to analytical strategies commonly employed by qualitative researchers [22].

Our reporting style also follows scholarly conventions that govern qualitative methods. Consistent with the approach commonly used by qualitative researchers, our results are reported in a manner that foregrounds respondents' own words. Our goal is to feature the questionnaire respondents' own voices in an effort to foster an understanding of their experiences and perspectives. This goal is central to qualitative investigations in which questions are intentionally open-ended. We have grouped together quotes that address similar themes to provide a holistic rendering of participants' standpoints, where appropriate through a series of bullet-pointed quotes for any particular theme, while also offering both breadth and depth to their reflections. Because a questionnaire was administered to solicit handwritten responses, the quotes are not as lengthy as they would be if qualitative interviews had been conducted. Nevertheless, the wealth of reflections across various questions from nearly two hundred respondents provides ample material for rich analysis.

Results and Discussion

Barriers to care advocacy for patients with IDD

Attendees who responded to the questionnaire reported various barriers in advocating for the proper care of their patients with IDD. Many observed a pervasive lack of physician awareness about symptoms of health issues commonly faced by patients with IDD, which is alarming in the context of greater reliance on community physicians to provide care. One nurse commented, "Many nurses aren't given the opportunity to directly communicate with MDs. It'd be beneficial when educating MDs to explain they should have more of an open mind when communicating with nurses in the IDD field. It'd provide more positive outcomes for the individual with effective communication". Others recounted specific incidents of poor physician communication:

- "MD discharged [patient] due to behavioral problems. MD refused hands-on assessment".
- "Many physicians lack formal education specific to the ID/DD population, so at times it is difficult to advocate for the individuals".
- "Working with psychiatrists can be very difficult. Many will not take the time to understand developmental disabilities".
- "I've worked in the past in the emergency room and several doctors looked first only at IDD diagnosis. It was frustrating to try to convince them that behaviors for them (negative) are a lot of times related to illness or pain. Individuals were admitted to psych and then found out to be [having] medical problems".
- "Coordinating the plan of care that meets the individual who has [medical] needs. Physicians are usually not aware of where or what is involved with individuals with disabilities".

Several providers described physicians' intemperance toward patients with IDD and their caregivers. Physician frustration with unanticipated challenges often resulted in inadequate treatment plans and, in some cases, prolonged suffering and incurred additional trauma for patients with IDD:

- "I was making a suggestion to add something for indigestion and the doctor just got up from the desk, closed the chart, and didn't order it. The patient suffered for another week".
- "An individual had a diagnosis of bradycardia and a congenital heart defect. I asked the primary care provider for a referral to a cardiologist for continued evaluation. However, the primary care physician became irate, stating that he was more than qualified to evaluate and treat the individual. [He said] that if I was not happy with the services, I could find the individual another primary care physician".

- “[I] recommended a second opinion be obtained from a physician other than the PCP. Had a second opinion MD call me asking me if I had lost my mind, telling me I should be glad the PCP had accepted this individual [patient] in their practice”.
- “I have been told by a PCP that, ‘Until you get MD behind your name, you can’t tell me nothing’”.
- “Personal experience: Twin sister with a behavioral health crisis (undiagnosed schizoaffective disorder) diagnosed with ‘constipation’ by major teaching hospital. Behavioral health crisis was not addressed and led to multiple psychiatric hospitalizations before diagnosis. Caregiver and family concerns were ignored”.
- “One community provider reported to me that the local PCP [primary care physician] caring for three individuals in one home made the decision that he was no longer going to provide care, as they [the patients] were a lot of trouble”.

Status disparities, especially between nurses and physicians, were another barrier to the effective treatment of patients with IDD. Some physicians were unwilling to consider input from other care providers, such as nurses, who had greater expertise treating patients with IDD. One nurse recounted that the “physician screamed at me that he was the physician and I was only the nurse” while another had a “pervasive attitude of I know all I need to know about dealing with patients. Seemed my input was dismissed and put aside as if of no importance whatsoever”. Another respondent concluded, “Physicians at times see nurses as inferior rather than really seeing them as a partner-in-care who can give the MD valuable information about the IDD client”. Another encouraged, “Please listen to the IDD nurse. She knows the individual better than you do”. Similar observations were echoed in other respondents’ comments:

- “Physicians need to be more open-minded to suggestions that staff [who are] advocating for the individuals offer. [Physicians should] not take [suggestions] as personal attacks on their abilities”.
- “[Let physicians] know it is not us [nurses] trying to make things difficult for them. Just need the state-required information”.

Nurses and DSPs suggested that all of these barriers can be overcome through sound clinician education programs as well as enhanced collaboration between physicians, nurses, and other caregivers. The following quotations spoke to common themes evident in the questionnaire data:

- “Don’t be afraid to learn. Caregiver and families are your best resource”.
- “I think a state-mandated training for physicians to educate them about our IDD population would be very helpful. Maybe physicians would be more accepting to treating our individuals”.
- “[Have] intellectual disability specialty physicians train other physicians as to their special needs”.

Gaps in medical education

It has been extremely rare for physicians and other medical providers to receive education about IDD while in medical school or another formal education program [6,7,9,15,17]. When physicians launch their careers with a dearth of knowledge about common illnesses and symptom manifestations among people with IDD, they are often ill-equipped to provide accurate diagnoses and appropriate treatment options. The vast majority of those who responded to the questionnaire shared accounts of physicians and hospital staff who lacked the needed education to provide quality treatment to patients with IDD. In one case, a patient visiting a major teaching hospital was diagnosed with constipation. While this diagnosis was not medically inaccurate, the nurse indicated that it did not account for clear signs of a larger behavioral crisis that created challenges in delivering fully effective treatment. Instead of accepting input from the attending nurse or securing information from family caregivers, the neuropsychiatrist “threw up their hands and said there was nothing that could be done, as this was the [patient’s] personality”. Another account resonated with this experience: “During a visit with an endocrinologist, the individual [patient] was having behavioral issues due to diabetic meds lowering blood glucose, leading to moods and behaviors of aggression for the individual”. However, the endocrinologist interpreted these patient actions as patient defiance. Physicians may adopt what could be called medical myopia. As one nurse put it, “Discussing behaviors individuals display as their way or primary method of communication when the individual is communicating pain. But the physician says the individual is displaying a particular behavior because of the intellectual or developmental disability. The physician does really look for medical ways to rule out what could be happening”.

Another explained, "Had a patient with significant weight loss over several months. Although we were able to show data to the MD, he did not want to address the weight loss or give a diagnosis of malnutrition. Patient was 5'6" and 102 lbs". After numerous hospitalizations, the patient was finally given a diagnosis of schizoaffective disorder. A neuropsychiatrist's response indicated a lack of awareness about medical research that warns of the frequency of co-occurring mental health conditions among patients with IDD [8,16]. Even psychiatrists, who are trained to recognize mental health conditions, are not always adequately educated to care properly for patients with IDD. In fact, problematic experiences with mental health providers, such as misdiagnoses and minimally effective psychotropic medications, were frequently indicated by questionnaire respondents as a barrier to patients receiving appropriate care. "A patient was started on Seroquel without any new issues. The doctor was very angry when asked the reason for starting Seroquel and tried to discharge the patient... for asking for an explanation [of medication] and informed consent".

Misdiagnoses could also occur in other ways. In some cases, patients with IDD who manifested behavioral difficulties were wrongly admitted to psychiatric facilities when a physical factor alone was the cause of the behavioral challenge. One registered nurse with over twelve years of experience treating patients with IDD previously worked in an emergency room and described how "doctors looked first at only the IDD diagnosis, and it was frustrating trying to convince them that [patients' negative] behaviors [are often] related to illness or pain. Individuals were admitted to a psych [psychiatric] ward and were then found out to have medical problems". In another example, a nurse with three years of experience described how a patient was discharged from the hospital, but within about an hour started "profusely sweating" and became physically disoriented. The residential staff attempted to contact the patient's primary care provider, who refused to see the patient. Within four hours of the patient's original discharge from the hospital, she was readmitted with bilateral pneumonia and sepsis, which ultimately caused the patient's death. Current medical research stresses the need to evaluate patients with IDD for physical issues, such as gastrointestinal upset, physical pain, or other more serious illnesses before assuming a mental health issue or simply attributing patients' behaviors to their cognitive disabilities [1-5]. However, physicians are often unaware of current best practice care for patients with IDD, and their lack of expertise can result in negative patient outcomes [10,13,17].

Medical treatment plan deficiencies

Before becoming full-fledged physicians, medical students swear an oath to "do no harm" as healthcare providers. While the vast majority of physicians have the best of intentions to adhere to this sworn standard, they often lack the education and experience needed to make decisions about appropriate treatment regimens for patients with IDD [6,9,10,13,15,17]. Even when the diagnoses rendered are correct, patients with IDD may respond in an atypical fashion to traditional medical interventions. Many nurses and direct service providers who responded to the DETECT questionnaire described experiences in which physicians provided inappropriate care or treatment plans to patients with IDD.

A registered nurse with four years of experience advocating for patients with IDD described a harrowing experience about a male doctor who refused to follow advice about helping his female patient with IDD feel more comfortable before undergoing an invasive gynecological procedure. This nurse explained that she had "requested medication for [an] individual who was undergoing a routine PAP smear. [The physician] refused, stating that he could handle it, there would be no problems. [The patient] had a horrible experience - family and staff had to hold her down". This physician failed to consider differences in cognition that are common among patients with IDD. His unwillingness to consider the nurse's counsel created, or at least exacerbated, an emotionally traumatic experience for his patient.

Another nurse with ten years of experience described a patient incident that could have been avoided: "Recently, a physician ordered a restraint to wrap around an individual's chest and contracted arm - upper and lower - to prevent self-injurious behaviors in the form

of hitting [the patient's own] lower jaw. No dental or pain or constipation checks had been done". This situation reveals that the physician was unaware that self-injurious behaviors among patients with IDD can indicate physical discomfort and may not require a physical restraint if appropriate treatment can be administered to address the condition's root cause.

It is critical that physicians and medical students become acclimated to the distinctive needs and health issues experienced by people with IDD. Without adequate education and exposure, healthcare providers are hard pressed to improve services to patients with IDD. Moreover, because this vulnerable population increasingly relies on community clinicians to meet their healthcare needs, the medical community should take immediate steps to prepare students in health professions to deliver compassionate and effective care for patients with IDD. To enhance treatment planning and monitoring, the following recommendations were offered by questionnaire respondents:

- "Training on how to positively address behavior and positive interaction with individuals with IDD".
- "Patient-centered education".
- Using "CEUs/medical school courses" to provide training in treatment regimens for patients with IDD.
- "Formal training during school. Annual competency check-offs".
- "Web-based training and summits with clinical experts".
- "Education provided by experienced healthcare providers. Also, online, self-directed courses".
- "Brochures of services and guidelines of standards of practice, especially with routine and preventive healthcare maintenance".
- "More collaborative efforts (teaming up with various providers to promote awareness)".
- "More resources and education to school and organizations, etc".
- "Include [IDD education] in nursing and physician programs".
- "I feel [state departments focused on IDD healthcare] should be reaching out to learning institutes on behalf of this population to increase awareness and education of needs".
- "Speaking to doctors' offices and medical or nursing students. Offering clinicals".
- "More training for residents".
- "Make this an ongoing effort so as to maintain and uphold improvements in healthcare of individuals".

Clearly at the top of this list of responses for treatment plan improvements is additional physician education and training on appropriate healthcare practices for patients with IDD, whether in medical school or as continuing education for practicing physicians. This trend is emergent in medicine but has hardly achieved strong momentum, as underscored by the range of responses featured on completed questionnaires.

Medical discrimination

A troubling issue noted by many nurses and other caregivers was the influence of some physicians' ableist assumptions about the quality of life among patients with IDD. Ableism is prejudice or discrimination in favor of able-bodied persons and often results in a failure to recognize the unique situations of people with IDD. Ableism can sometimes function as an implicit bias of which the person harboring these attitudes is not consciously aware. In such cases, ableist assumptions can be especially difficult to change because awareness of the problem is not even evident to the medical practitioner.

In some nurses' accounts, ableist orientations led to patients being eased into death rather than being helped through treatable conditions. Many nurses and caregivers cited instances in which physicians refused to treat illness aggressively in patients with IDD because

they believed the patient did not have a sufficient “quality of life” despite information to the contrary provided by family, nurses, and other daily caregivers. In one case, an emergency room physician was said to have stated that patients with IDD “aren’t meant to live long and have no quality of life”. Although the nurse attempted to advocate for the patient, explaining that the patient enjoyed his life and that many patients with IDD live to an advanced age, especially with proper care, the physician “disagreed and talked the family into a Do Not Resuscitate” order. The conclusion from such thinking, according to this nurse, was quite troubling: “It seems many physicians feel [patients with IDD] have a very poor quality of life, thus measures to improve physical problems should be minimal”.

Several nurses described situations in which physicians refused to provide patients with IDD a “hands on” assessment, or in which physicians “fired” patients with IDD for being “too much trouble”. Other nurses explained that when they requested better care for a patient, some physicians met their demands by stating that the patient should be “grateful” they are being given any medical care at all. In another example, a nurse worked with physicians who opted not to treat issues such as joint problems in patients with IDD, resulting in the patient’s escalating pain and decline in mobility. One registered nurse with over seven years of experience explained that she once had a patient with IDD who was vomiting and producing small bowel movements. Although the medical staff discussed constipation as a probable cause for the patient’s symptoms, the physician declined to evaluate the patient. Ultimately, the patient developed a bowel impaction, which caused unnecessary and prolonged patient discomfort.

In another instance, a registered nurse with nearly eight years of experience assisting patients with IDD described the time she had a patient who would aspirate (breathe fluids into the lungs) regularly, a problem experienced by a disproportionate percentage of people with IDD that is medically solvable. This patient, however, eventually developed pneumonia. The doctor responsible for the patient during a hospital stay chose not to continue treatment and ordered hospice care instead. The nurse explained, “We had to fight for treatment. [The patient] recovered and returned home. She ultimately did succumb [to the illness], but had more time with her family after [being] discharged from state hospital”. When patients and their families seek treatment, they expect compassionate, comprehensive treatment plans from their healthcare providers. Unfortunately, caregivers of people with IDD sometimes find themselves wrestling with physicians who embrace ableist views that are all too prevalent in society at large but that can be especially dangerous in medical settings. One respondent commented that standard expectations in awaiting medical care such as queuing can cause additional problems for patients with IDD: “Long wait times are very problematic for anyone, and can be extremely difficult for [patients] with IDD. We have had to leave a doctor’s office without being seen, due to [long wait times]”.

Sometimes ableism manifests unconsciously, due to organizational or environmental flaws, rather than individual physicians’ discomfort toward patients with IDD. Some nurses and caregivers pointed out the need for clinics to be more accessible to patients with disabilities. For example, many caregivers who regularly accompany patients with IDD to their doctor’s appointments indicated that restrooms in medical offices are often too small to accommodate patients who have wheelchairs or who need assistance from another person during a stop at the restroom. Other questionnaire respondents discussed having very long wait times in doctors’ offices, despite having set up appointments well in advance. Patients with IDD often do not have the cognitive ability to wait calmly and quietly for an extended period of time in an unfamiliar location. Long wait times can result in the patient becoming prohibitively anxious and/or having an involuntary bowel movement.

Many nurses and service providers also voiced frustration about Medicaid reimbursement rates for their patients with IDD. Their experiences at doctor’s appointments led them to believe that physicians often do not take enough time for patients who are on Medicaid because of the low reimbursement rate for those appointments. Medicaid funding and reimbursement rates for patients with disabilities

vary yearly and by state, sometimes reducing physician participation. Frustrations with the Medicaid system may serve as a mechanism to cause or exacerbate medical professionals' negative feelings toward treating patients with IDD.

It is quite likely that many serious health conditions among patients with IDD could be avoided if properly educated and mindful physicians provided appropriate care when patients originally present with routine problems. The discriminatory narrative that people with IDD are unable to live high quality lives is only true if medical providers and daily caregivers refuse to support both the unique and mundane needs of such patients. It is imperative that the medical community develop an appreciation for the diverse definitions of living a "quality life".

Barriers to collaborative care

In the medical profession, there is a hierarchy between nurses and physicians [11,14]. Given their more extensive training and ultimate responsibility for diagnosis and treatment, physicians have greater decision-making power. However, nurses commonly have more experience delivering care to patients with IDD. And, in their role as patient advocates, nurses may also develop a close relationship with family members who are intimately acquainted with the needs of patients with IDD. Consequently, the institutional structure of healthcare can invite challenges in delivering collaborative care to patients with IDD even if such collaboration would improve healthcare delivery. As one nurse pointedly put it concerning a memorable encounter with a patient with IDD: "The doctor appeared scared and unsure of what to do ... We gave as much information as possible. We felt they blew off our concern for the individual".

Many of those who responded to the DETECT questionnaire described how status differentials between nurses and physicians impinged on the treatment that was provided to patients with IDD. In many cases, physicians utilized their position of greater status in a fashion that, whether inadvertently or not, could undermine patient care. Several registered nurses with many years of experience described situations in which physicians berated them for requesting additional care for the patient, or for offering treatment suggestions.

One registered nurse with ten years of experience, as previously noted, described an instance when she requested that her patient be given a second opinion. She detailed how the second opinion physician called her back, "asking me if I had lost my mind, and telling me that I should be glad the primary care provider had accepted the [patient] in their practice". In another example, a nurse with two years of experience was faced with an "irate" primary care provider who was offended when the nurse asked that her patient be referred to a cardiologist for multiple heart conditions. In response to being asked for a referral to the cardiologist, the primary care physician announced that he was "more than qualified to evaluate" the patient, and he further instructed the nurse to find another primary provider if she was unhappy with his services. Another nurse explained that physicians would hang up on her while she was still talking and delay answering her pages for assistance.

Physicians' dismissal of nurses' input about patient care is not altogether surprising. Extensive research has unearthed the social status and gender hierarchies that are often evident in the medical profession [11,14]. However, when treating patients with IDD, an experienced nurse can be a vital resource. If training on the treatment of patients with IDD is offered to medical providers, such training would do well to help physicians recognize how to consider and enlist nurses' experience as a valuable resource in the treatment of patients with whom physicians themselves might have little prior exposure.

Recommendations and Prospective Solutions

Although the current healthcare situation for patients with IDD presents significant challenges, there are several promising paths forward. Questionnaire respondents shared many practical suggestions for improving physician knowledge and skills about IDD. Further-

more, some respondents provided examples of physicians who embraced a proactive and collaborative approach that could be a key for delivering excellent care to patients with IDD.

A registered nurse with five years of experience caring for patients with IDD described an instance when she was able to help a physician reconsider and ultimately overcome some of his initial biases about people with IDD and their families. A female patient was admitted to the intensive care unit, but hospital staff was suspicious of the patient's mother because she had become unable to provide care and had placed the patient in a home. According to the nurse, "The [physician] and staff interpreted... that the mother did not love or care about her daughter". After the physician became willing to listen to the mother's experience and knowledge about the patient's health, the hospital staff made beneficial changes. According to the nurse, "once [the physician] did listen to mom, the daughter was treated appropriately and was released". This account highlights the critical need for collaboration in the development of treatment plans for patients with IDD. All people involved in this circumstance were key conduits in the provision of care. The nurse advocated for the patient, the doctor became willing to understand the patient's individual needs, and the mother was able to provide critical information that allowed the physician to respond to the patient's needs. "The physician took the time to listen [to our] concerns and updates, and [then completed] follow ups".

In general, questionnaire respondents reported that their best experiences in attempting to educate physicians occurred when physicians adopted active listening attributes and treated other patient caregivers as partners in providing healthcare. Caregivers also appreciated experiences in which healthcare providers were able to find alternative ways of communicating information to patients who were nonverbal. Ultimately, questionnaire responses indicated that positive healthcare experiences occurred when the physicians were willing to engage in the due diligence needed to offer accurate diagnoses and generate effective treatment plans. Asked about a positive experience in care provision, one nurse shared: "When a physician demonstrated active listening and explored options to rule out what's happening with the individual". Another nurse commented based on a prior positive experience: "Have a case conference with physicians on the subtle changes in health conditions of an individual". Yet another explained: "Had a quick chat with a physician in town about our services during a stakeholder meeting. He was very receptive and took information and used it".

Of course, nurses and other direct service providers should not be considered the sole source of physician education for patients with IDD. Conference attendees also stressed that healthcare professionals ought to receive ample education about IDD from diverse sources while engaged in a formal education program. Included in that formal education should be training to recognize signs and symptoms of common ailments among people with IDD, prevalent co-occurring conditions, and alternate methods for interacting with non-verbal patients. Strategies for involving a team of caregivers in the development of patient treatment plans were also recommended as a training topic. Additionally, many caregivers stressed the need for physicians to receive mandatory continuing education on complex medical conditions such as IDD. A number of respondents recommended that continuing education could be offered in "lunch and learn" seminars at doctors' offices and in hospitals so that physicians would have easy access to quality information. Additionally, some respondents suggested that research articles highlighting best practices for treating patients with IDD be distributed to physicians who may be too busy to seek out new material on their own time.

As demonstrated by the abundance of insights shared by attendees of the continuing education conferences organized by DETECT, there are numerous barriers to quality healthcare for people with IDD. However, many serious healthcare issues faced by patients with IDD could be addressed if physicians' lack of education on this topic was remedied. Some discomfort physicians have when working with patients with IDD could be alleviated if they were armed with information and given the opportunity to engage with members of this

population, particularly before becoming licensed to practice. Education and contact are the keys to reducing the intemperate and even discriminatory reactions sometimes exhibited when physicians treat patients with IDD [12,13]. One nurse shared this observation: “Incorporate this education into the medical school curriculum. If they didn’t get training in the art of communication and the need to respect other healthcare providers, they need some kind of mandated training”. Another commented: “More education starting with med school. My experience is that IDD has replaced the lowest rung on the ladder as that of ‘this population is unworthy of any extensive patient-centered care’ instead of geriatrics”. One respondent suggested a variety of training modalities: “Face-to-face training with continuing follow-up via webinars or continuing education. ‘Rotations’ would be awesome!” Another chimed in, “Healthcare providers need to attend continuing training about IDD to stay abreast and have an understanding of the population we serve”. Such orientations are prevalent in the wider society but can be especially harmful when health conditions and medical treatment options are being considered.

Conclusion

This study has highlighted the ways in which firsthand accounts of the experiences conveyed by nurses and direct service providers can shed light on the challenges, deficiencies, and potential solutions associated with physician-delivered healthcare to people with intellectual and developmental disabilities. Our study distilled key themes evident in the qualitative responses shared by this important set of healthcare providers. Our study recognizes the unique vantage point of those who are not in positions of power and who therefore must be cognizant of their contradictory status position relative to physicians in medical hierarchies (greater frontline experience in treating IDD without the decision-making authority enjoyed by physicians). We found that nurses’ experiential reflections prompted remarkable insights into subpar medical service delivery with respect to patient-centered care, medical education, treatment plans, and other areas of physician-patient engagement. Poignant recollections were even shared concerning medical discrimination. These same respondents recommended possible solutions going forward, including greater IDD-focused medical education and team-based approaches to medical service delivery that couple various forms of knowledge. Learning from the experiences of nurses and direct service providers who have a track record of treating patients with IDD could move the field forward in many significant ways. Additional research on this topic could entail a deeper immersion into the experiences of nurses through in-depth interviews and ethnographic fieldwork. While such work is underway [18], there is still much to learn. Also, an effort to track clinician education programs more carefully with rigorous evaluation methods pertaining to changes in physicians’ attitudes toward patients with IDD would advance the field [1].

People with IDD increasingly rely on community resources to secure quality healthcare, dentistry, vision care, and other services. Therefore, many questionnaire respondents charged that a coordinated effort is needed to ensure that medical providers and other key community members (e.g., healthcare navigators) are prepared to meet the needs of the population. Until people with IDD are afforded the same kind of quality medical services that most people expect to receive when visiting a doctor, members of this population will quite likely continue to have poorer life outcomes, such as frequent illness, untreated mental health issues, and early death. An old adage charges, “You’re only as strong as your weakest link”. Efforts should be undertaken to ensure that there are no weak links in the medical care provided to patients with IDD. People with IDD do face some specific health challenges, but certainly can live fulfilling, happy, strong, and long lives when medical providers, caregivers, and community members come together to meet their distinctive healthcare needs.

Appendix: DETECT Nurses Conference Questionnaire

Nurses can be an important source of physician education. Please describe your experiences concerning patients with intellectual and developmental disabilities (IDD). You may use the reverse side of this page as needed.

1. Which one of the following best describes you?

NP

RN

LPN

Other _____

2. For how long have you provided treatment in any form to patients with IDD? ___ years ___ months
3. To how many patients with IDD do you currently provide care? (If none, indicate zero.) ___ patients
4. Please describe a negative experience you had in attempting to educate a physician about patients with IDD. In other words, when did your attempt to educate a physician about IDD not work out as you had hoped?
5. What recommendation on IDD-related physician education would you offer given this negative experience?
6. Please describe a positive experience you had in attempting to educate a physician about patients with IDD. That is, when did your attempt to educate a physician about IDD work well?
7. What recommendation on IDD-related physician education would you offer given this positive experience?
8. What resources are likely to be most effective in educating healthcare providers about IDD?
9. Any other insights on improving healthcare provider education about IDD would be appreciated. Thanks!

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Conflict of Interest

The first author served as an independent evaluation contractor under the auspices of Bartkowski & Associates Research Team for DETECT of Mississippi and was compensated at a market-competitive rate for providing these services. DETECT of Mississippi had no role in the design of the study apart from providing feedback on a preliminary draft of the questionnaire and reviewing an earlier draft of the results. The analyses and interpretation of data were conducted independently, as were the writing of the manuscript and the decision to publish the results.

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