**Primary Care of Adults with Intellectual Disabilities: A Curricular Approach**

***Background***

 After the deinstitutionalization of patients with intellectual disabilities worldwide, care for patients with intellectual disabilities has moved into the community setting with the majority of patients’ obtaining care from local primary care physicians.1 Patients with intellectual disabilities comprise two percent of the general population and due to improved medical care, are expected to live longer than ever before leading to more age-related health problems such as hypertension, diabetes, and arthritis.2 The percentage of the general population comprised of people with intellectual disabilities is expected to increase due to continued increase in longevity. Patients with intellectual disabilities have been noted to have poorer health outcomes compared to the general population, which is particularly evident in patients with severe intellectual disabilities.3 They are more likely to have untreated, yet treatable, simple medical conditions, untreated specific health issues related to individual disability, and a lack of general health promotion and screening.1 Compared to the general population, adult patients with intellectual disabilities are less likely to undergo routine health screening with decreased rates of blood pressure monitoring, height and weight measurement, mammography, and cervical cancer screening.1,4 Poorer health outcomes are unlikely due to lower levels of contact with primary care physicians as research suggests similar visit regularity as compared to the general population.4 Previous research investigating the barriers to providing adequate care to patients with intellectual disabilities documented practicing family medicine physicians report a lack of sufficient knowledge due to little or no formal training, lack of confidence or discomfort with patients, and unfamiliarity with the community as barriers.2,5,6 Proposed solutions to improve health disparities in this population include improved education for physicians.

***Methods***

 Current research related to improved educational efforts regarding the care of patients with intellectual disabilities has focused on medical students, practicing physicians or practicing nurses.7,8 In an effort to improve family medicine physician comfort providing care to patients with intellectual disabilities, an educational curriculum addressing improved understanding of the most common barriers to providing care to patients with intellectual disabilities along with presenting solutions to overcoming these barriers was created and implemented as part of the required residency educational seminars at the Boston University Medical Center Family Medicine Residency program. A pre- and post-intervention study design was utilized. The participants included the twenty-six residents in the program (minus the resident implementing the curriculum). The curricula included three separate hour long lectures focused on providing primary care to adult patients with intellectual disabilities entitled (1) Barriers to Health Care (reviewing the most common barriers to care documented in the literature as well as proposed solutions to these barriers), (2) Health Screening (review of the potential differences in the screening recommendations for patient with intellectual disabilities compared to the general population as documented in the literature), and (3) Effective Communication (review of patient communication preferences along with effective strategies to improve communication between physicians and patients as documented in the literature). All the lectures were created by a third year family medicine resident after performing a fairly thorough and comprehensive literature review. All three lectures were subsequently evaluated by an attending physician in the Boston University Department of Family Medicine specializing in the care of patients with intellectual disabilities with additional suggestions and recommendations given to improve the utility of the lectures. The design of the curricula focused on stimulation of thought and discussion related to the subject matter along with proposal of strategies to improve care instead of recommending specific protocols. The pre- and post-intervention surveys assessed the comfort level of residents in caring for adult patients with intellectual disabilities including the abilities to coordinate patient care, understand the barriers affecting patient care, identify strategies for overcoming barriers, understand patient communication preferences, facilitate effective triadic communication, provide appropriate preventative care, and utilize available resources related to the care of patients with intellectual disabilities. A sample survey is included above.

**Rate the following statements as:**

**Agree strongly, Agree, Neither, Disagree, or Disagree strongly**

1. I feel comfortable communicating with adult patients with intellectual disabilities.
2. I feel comfortable examining an adult patient with an intellectual disability.
3. I feel able to provide excellent primary care to adult patients with intellectual disabilities.
4. I feel able to coordinate care for adult patients with intellectual disabilities.
5. I feel I have a basic understanding of the health disparities affecting adult patients with intellectual disabilities.
6. I feel I have a firm understanding of the barriers impacting delivery of primary care to adult patients with intellectual disabilities.
7. I feel I am able to identify potential strategies for overcoming the common barriers to providing adequate health care to adult patients with intellectual disabilities.
8. I feel I have the tools to adequately obtain an appropriate history from an adult patient with intellectual disabilities.
9. I feel I understand the communication preferences of adult patients with intellectual disabilities.
10. I feel able to facilitate effective triadic communication with adult patients with intellectual disabilities and their care givers.
11. I feel I have the tools to troubleshoot obstacles in order to provide excellent primary care to patients with intellectual disabilities.
12. I feel able to provide appropriate preventative care to patients with intellectual disabilities.
13. I feel I know what resources are available to assist me in deciding which screening tests are appropriate for my adult patients with intellectual disabilities.
14. I feel the amount of training I am receiving in residency will allow me to adequately care for patients with intellectual disabilities.

***Results***

 Of the twenty-five family medicine residents in the Boston University Medical Center Family Medicine Residency program, nineteen (76%) completed the pre-intervention survey. Prior to the intervention, residents at all educational levels reported lack of confidence in their abilities to adequately provide excellent primary care, coordinate patient care, identify strategies to overcome barriers, understand patient communication preferences, facilitate effective triadic communication, troubleshoot obstacles, and identify resources available to assist with deciding on appropriate screening test for adult patients with intellectual disabilities (lack of confidence defined as < 30% of residents documented agree or strongly agree with the affirmation of ability to adequately perform the listed task). Of note, all residents surveyed reported concerns related to the amount of training available during residency to become proficient in providing adequate care to this patient population. Sixteen residents (56%) completed the post-intervention survey; however, as not every resident who participated in the curricular intervention attended all the lectures, some residents attending the first two lectures may have failed to attend the third in which the survey was distributed. This phenomenon is further highlighted by the post-interventional survey responses regarding the number of lectures attended with four (25%) residents attending one lecture, four (25%) residents attending two lectures, six (37.5%) residents attending all three lectures, and two (12.5%) residents failing to document lecture attendance. After the intervention, all the previously documented areas of deficiency improved to > 50% confidence in the ability to perform the listed tasks with the exception of ability to provide excellent primary care (decreasing from 26% confidence to 25% confidence after the intervention).

 Interestingly, the residents surveyed reported increased confidence in the residency program’s ability to provide adequate amounts of training related to the care of patients with intellectual disabilities (increasing from 0% confidence to 44% confidence after the intervention). These results indicate increased educational efforts at the resident training level lead to improved confidence in ability to provide adequate care for patients with intellectual disabilities.

***Discussion***

 Research demonstrates physicians’ desire further education regarding providing care to patients with intellectual disabilities with proposed recommendations for improved educational efforts focusing on increasing physician knowledge base, improving doctor-patient communication, and exposure to the community of adults with intellectual disabilities.1,2,5,6 Previous studies focused on educational interventions noted improved knowledge, attitudes, and comfort towards patients with disabilities in addition to improved self-efficacy.7,8 The educational intervention described above focused on improving family medicine residents’ understanding of the challenges involved in providing care for adult patients with intellectual disabilities along with presenting proposed solutions to those challenges demonstrated improved confidence in the ability to provide comprehensive care. These results suggest in addition to educational efforts focused on improving knowledge, communication, and exposure, providing a curriculum focused on improving primary care physicians understanding of the potential barriers and challenges faced when caring for patients with intellectual disabilities should improve physician ability to provide appropriate care with the hopes of decreasing health disparities. Combining the curricula implemented above with community-based exposure to adults with intellectual disabilities would allow residents opportunities to utilize and refine strategies, therefore, should be the focus of further research into educational curriculum to improve care to patients with intellectual disabilities.

***References***

1. Lennox NG and Kerr MP. “Primary health care and people with an intellectual disability: the evidence base.” *Journal of Intellectual Disability Research.* 1997 Oct;41(5):365-372.
2. Wilkinson J, Dreyfus D, Cerreto M, et al. ““Sometimes I Feel Overwhelmed”: Educational Needs of Family Physicians Caring for People with Intellectual Disability.” *Intellectual and Developmental Disabilities*. 2012 Jun;50(3):243-250.
3. Krahn GL, Hammond L, and Turner A. “A Cascade of Disparities: Health and Health Care Access for People with Intellectual Disabilities.” *Mental Retardation and Developmental Disabilities Research Review.* 2006;12:70-82.
4. Whitfield M, Langan J, Russell O. “Assessing general practitioners’ care of adult patients with learning disability: case-control study.” Quality in Health Care. 1996 Mar;5(1):31-35.
5. Lennox NG, Diggens JN, and Ugoni AM. “The general practice care of people with intellectual disability: barriers and solutions.” *Journal of Intellectual Disability Research.* 1997 Oct;41(5):380-390.
6. Millar L, Chorlton M, and Lennox N. “People with intellectual disability: Barriers to the provision of good primary care.” *Australian Family Physician.* 2004 Aug;33(8):657-658.
7. Melville CA, Cooper SA, Morrison J, et al. “The outcomes of an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary health care services.” *Journal of Intellectual Disability Research.* 2006 Jan;50(1):11-17.
8. Woodard LJ, Havercamp SM, Zwygart KK, et al. “An Innovative Clerkship Module Focused on Patients with Disabilities.” *Academic Medicine.* 2012 Apr;87(4):537-542.