Fetal Alcohol Spectrum Disorders (FASD): Promoting International Awareness through Ambassadors and Collaboration

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Abstract

Fetal Alcohol Spectrum Disorders (FASD) are a group of health conditions caused by the consumption of alcohol during pregnancy. Alcohol use by pregnant women is a global public health issue with lifelong consequences to the baby. In Brazil, despite educational campaigns on the problems of drinking while pregnant, many women continue to drink regardless of their pregnancy status. Currently, nursing curricula do not include in-depth information around FASD. Therefore, the purpose of this paper is to focus on the need for the inclusion of alcohol and FASD education in Brazil by incorporating a role for the student nurse as an FASD prevention ambassador. Student nurse ambassadors can promote FASD prevention through educating fellow students and nursing professional. An infographic to provide FASD facts for patients, nursing students, and nursing staff has been developed. Because nurses are key figures in providing patient care, they are ideal advocates for FASD prevention.

Keywords: fetal alcohol spectrum disorders, alcohol, nursing education, student leadership

Introduction

Fetal exposure to alcohol can result in a variety of short- and long-term sequelae, including physical, behavioral, cognitive, and learning disabilities which vary in severity, and collectively are referred to as fetal alcohol spectrum disorders (FASD), all of which disorders are preventable with the cessation of alcohol use during the prenatal period. However, to assure and promote prevention, it is paramount that not only women, but also their healthcare professionals, have adequate knowledge on the risks of alcohol use in the prenatal period, and the subsequent potential for FASD. One means to deliver this knowledge is through the provision of ambassadors who are dedicated to promoting awareness of alcohol consumption to not only healthcare professionals, but also the public.

Fetal Alcohol Spectrum Disorders (FASD)

FASD encompass a number of conditions occurring on a continuum with distinguishable diagnostic criteria: fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), and neurobehavioral disorders associated with prenatal alcohol exposure (ND-PAE) (Hoyme, et al., 2016). Most profoundly affected, children with FAS will present at birth with facial dysmorphia to include short palpebral fissure length, smooth philtrum, and a thin upper lip (Hanson, Jones, & Smith, 1976), growth restrictions, and central nervous system abnormalities; however, those with pFAS can present with the same functional disabilities as their FAS counterparts but may present without the hallmark physical features. Even more difficult to discern is ND-PAE; individuals with ND-PAE may exhibit more covert symptom manifestations that are not noted or observed until later in life, rendering them unlikely to be engaged in treatment which can result in further developmental and psychosocial delay. Other symptoms of FASD, which may occur broadly and across the spectrum, include: microcephaly, short stature, low body weight, poor coordination, hyperactive behavior, difficulty with attention, poor memory, learning disabilities, speech and language delays, intellectual disability, vision or hearing problems, and cardiac or renal abnormalities (May, Gossage, Kalberg, Robinson, Buckley, Manning, & Hoyme, 2009).

While physical symptoms may be identified at birth, cognitive and behavioral issues may only manifest as the individual ages and subsequently result in academic, social, or occupational dysfunction. Individuals with FASD are at higher risk than the general population for co-morbid psychiatric diagnoses, criminal behavior, incomplete education, homelessness, and unemployment (Caetano, Ramisetty-Mikler, Floyd, & McGrath, 2006; Brown, et al., 2014). Both the short- and long-term consequences of prenatal alcohol use can result in individual patient problems, dysfunctional family relationships, and excessive costs to healthcare systems. The diversity of FASD symptomatology that can occur may also lead to a misdiagnosis for a child with a missed opportunity for early, focused treatment that can improve quality of life (Centers for Disease Control and Prevention [CDC], 2016). The potential gravity of lifelong consequences highlights the need for public health approaches to mitigate alcohol use amongst women at-risk for pregnancy.

While the prevalence of FASD are difficult to elucidate throughout international domains, alcohol use does present as an understudied public health crisis in Brazil. A survey of 62,986

Brazilians found that past thirty-day alcohol consumption was reported by 26% of respondents; unfortunately, however, over half of these respondents engaged in binge drinking or other hazardous alcohol use (Macinko, Mullachery, Silver, Jimenez, & Morais Neto, 2015). Further, another Brazilian study found that alcohol was implicated in one-third of unintentional fatal injuries (Andreuccetti et al., 2017). In women, specifically, there is unfortunately a paucity of literature evidence on alcohol use amongst Brazilian women, yet it has been established that Brazilian women lack informed treatment on the impacts of fetal alcohol exposure and the importance of prenatal cessation (de Oliveira, dos Santos, Alvarez, Enokibara, & Medeiros, 2016). Further, there is a high pattern of consumption of alcoholic drinks by Brazilian women, which may indicate FASD prevalence in the country is higher than reported. According to the World Health Organization (WHO, 2014) beer represents 60% of the alcoholic drinks consumed in Brazil, and Brazil is the third largest producer of beer in the world. Production is associated with an increase in alcohol consumption among youth, including women as indicated by information from the WHO (2014): 18% of Brazilian women binge drink, defined as the consumption of four or more alcoholic drinks during one occasion. Additionally, one recent study found that rates of alcohol use treatment attrition in Brazilian women receiving care during the antenatal period were high, with 45% of women failing to complete treatment, highlighting the need for increased emphasis on treatment across the continuum (Avilla, Surjan, de Fátima Ratto Padin, Canfield, Laranjeira, Mitsuhiro, 2017). Additionally, one recent study found that up to 50% of children in a Brazilian orphanage had known histories of fetal alcohol exposure, and 47% of these children had one or more neurodevelopmental, behavioral, or cognitive diagnoses (Strömland et al., 2015).

Educating Providers about FASD

While healthcare providers have been aware of the correlation between birth defects or neurodevelopmental delays and prenatal alcohol exposure for over 30 years, prenatal alcohol use remains a major a public health concern. Rates of alcohol use amongst pregnant women in the U.S., unfortunately, exceed 10% (Tan, Denny, Cheal, Sniezek, & Kanny, 2015), and may be attributable to lack of appropriate education delivered during perinatal care. Further, because approximately 50% of pregnancies are unplanned (Finer & Henshaw, 2006), and pregnancy may not be identified until after 4-6 weeks post-conception, it is critical that all women of childbearing age are provided with accurate information on the potential risks of alcohol use.

Because nurses are consistently rated as the most trusted professional (Gallup, 2017), they are uniquely positioned to provide prevention strategies towards the reduction of alcohol use during pregnancy and associated FASD. Foremost, according to the U.S. Surgeon General, there is no safe amount of alcohol, safe type of alcohol, or safe time to consume alcohol during the prenatal period. Women must be provided with clear and consistent messaging from nurses and healthcare professionals, and abstinence from consuming alcohol should be encouraged throughout pregnancy (Popova, Lange, Probst, Gmel, & Rehm, 2017). Alcohol screening and brief intervention (alcohol SBI) is an evidence-based modality that can be implemented by nurses to 1) identify women using alcohol in hazardous amounts via a validated screen, and 2) provide informed education via a brief intervention in hopes to enhance motivation towards behavioral change. Through screening using an evidence-based tool such as the Alcohol Use Disorders Identification Test (AUDIT) (Babor, Higgins-Biddle, Higgins, Gassman, & Gould, 2004) to assess

alcohol use and providing information to avert FASD through brief interventions (BI), nurses have a critical role in the elimination of this preventable disorder. Unfortunately, there is limited education on substance use, including FASD and alcohol SBI, specifically, throughout most nursing curricula. Therefore, novel interventions must be implemented and leveraged to assure the implementation and sustainability of content related to FASD and alcohol SBI within Schools of Nursing.

FASD Ambassadors

One often overlooked opportunity to eliminate the gap between evidence-based information regarding FASD and clinical practice is through that of FASD ambassadors. An ambassador is a person or a professional who enthusiastically supports, defends, or fights for an evidence-based belief or principle and speaks publicly in support of that belief or cause. The FASD ambassador is an individual who promotes FASD prevention through implementing alcohol SBI training for nurses and all healthcare professionals, and through facilitating educational messages to the public whenever and wherever possible within their sphere of professional influence. Bazzo and colleagues (2017) found support for international collaborative campaigns to improve FASD education, and this project utilizes a similar framework but emphasizes student nurse ambassadors as a means for evidence-based dissemination to both students and practicing nurses.

The University of Pittsburgh School of Nursing, in collaboration with the University of Alaska, Anchorage and the University of California, San Diego have identified three types of FASD ambassadors: executive ambassadors, nurse leader ambassadors, and student ambassadors. The executive ambassadors are health administrators who advocate for the implementation of alcohol SBI for FASD prevention in organizations or healthcare systems. Nurse leader ambassadors are those who advocate for and promote alcohol SBI for FASD prevention and skill development in their respective clinical settings; and student ambassadors are ambassadors who disseminate and promote FASD awareness while still in school among their peers or professional nurses while at clinical education sites. The role of an ambassador can result in both short- and long-term outcomes, which include increased understanding regarding the benefits of alcohol screening for the prevention of FASD and an increase in the number of healthcare professionals who include alcohol SBI into their clinical practice, respectively. This paper describes an international partnership to: 1) collaborate with the Universidade Federal de Sergipe School of Nursing in Brazil to promote alcohol SBI for FASD prevention through student nurse education via a visiting student scholar program, and 2) advocate for alcohol SBI training for practicing nurses in Brazil by unique use of a student nurse ambassador.

Partnership and Student Nurse Ambassador Action

The Universidade Federal de Sergipe School of Nursing in Brazil and the University of Pittsburgh School of Nursing have a mutually approved and organized visiting nursing student scholar program. During a visiting scholar period at the University of Pittsburgh School of Nursing, sponsored by the Capes Foundation within the Ministry of Education, Brazil (Process-88888.800410/2014-00), a Brazilian student participated in research and education activities on alcohol SBI and FASD prevention for 15 weeks. The student participated in the school's FASD

prevention grant activities in collaboration with and consent from the University of Alaska, Anchorage and the University of California, San Diego. The student reviewed Institutional Review Board (IRB) modules prior to the start of activities, attended biweekly grant meetings, reviewed modules developed by the grant team on alcohol SBI and FASD, and visited the Institute for Research, Education and Training in Addictions in Pittsburgh, PA (USA) to review alcohol education, training activities, and programs related to substance use. The student's knowledge gains, provided intense motivation to make a difference in his country of origin, and his professional dedication to patient care led to his request to become a student nurse ambassador with the help of the FASD grant-funded team. Discussion with the team and the student's Universidade Federal de Sergipe School of Nursing faculty resulted in the development of a student project for feasible implementation in Brazil. To promote effective and efficient FASD awareness, the student's strategy was to design an informational infographic, using the website Piktochart.com. The focus of the infographic created over a one-month time span by the student and the team emphasized FASD for education and prevention activities in Brazil.

The first step in the preparation of the infographic was to review the literature pertaining to FASD including causes, signs, and symptoms. The student met with two librarians at the University of Pittsburgh Health Sciences Library system to determine the frequency of alcohol use among Brazilian women and FASD in that country. The second step was the actual infographic design which was developed in both English and Portuguese, the official language of Brazil. Images meant to facilitate the viewer's understanding of the messages were used throughout the infographic. The images were selected for a fast transmission of the information by visual communication.

The third step was a pilot, performed by the grant team with student involvement. The team and students, composed of Portuguese and non-Portuguese speakers, analyzed the English and Portuguese-language versions of the infographic to determine how effective the images were and how well they could understand the information being depicted. The fourth step was team approval of the infographic followed by a second pilot by a Brazilian faculty member at the University of Pittsburgh, for further review and refinement of the infographic. This faculty member works in the Latin American Studies Center and is the advisor for the Brazilian exchange program. Upon his review of the infographic, positive feedback was provided to the grant team. With the advisor approval, step five for the student involved contacting the Universidade Federal de Sergipe School of Nursing. He explained the project to the dean, discussed the importance of the student nurse ambassador role for FASD prevention; subsequently, the infographic was sent to Brazil along with an ambassador information handout and alcohol SBI information.

As a result of the ambassador's motivation and investment in FASD prevention, copies of the infographic were posted in strategic locations readily visible to patients, nurses, and physicians in the Hospital Universitário de Sergipe, the institution where nursing students have most of their classes and clinical rotations. In addition, School of Nursing alumni also received a copy of the Portuguese-version of the FASD infographic.

Of further importance and impact in FASD prevention, a FASD 101 Primer Course developed by the University of Pittsburgh School of Nursing will be offered for free to the Universidade Federal de Sergipe School of Nursing faculty and students. The school has about 300 students, who will have access to the FASD 101 Primer Course to learn about alcohol SBI and FASD prevention for use throughout their nursing career to positively impact patient care in Brazil.

Conclusion

Alcohol use remains a public health issue in Brazil; nonetheless, there is a lack of substance use related content in nursing curricula (Pillon, Luis, & Laranjeira, 2003), including that regarding FASD and alcohol SBI. This project describes a novel intervention via the utilization of international student nurse ambassadors in the development and dissemination of FASD and alcohol SBI-related content. It is critical that educational materials, such as the developed infographic, are accessible not only to nursing students, but also to nurses and all medical staff to ensure the delivery of evidence-based information to women of childbearing age (Kelley & Aston, 2011).

There is a great need for FASD education and prevention measures in Brazil. High alcohol consumption and the lack of information about its negative effects on fetal development makes this country a prime candidate for the role of FASD prevention ambassadors. Nursing student ambassadors who advocate for FASD awareness and prevention in a Brazilian institution is critical for FASD awareness and prevention. This paper supports the crucial investment in alcohol SBI for FASD prevention through integration in nursing curricula so that over time, all nurses will educate women who plan to become pregnant and expecting mothers about the risks of alcohol consumption during pregnancy as routine care delivery.

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Notes

For more resources and to view the Alcohol and Pregnancy infographic, please visit: nursing.pitt.edu/sbirt

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