Drug and Alcohol Dependence 185 (2018) 266–270

Contents lists available at ScienceDirect

Drug and Alcohol Dependence

journal homepage: www.elsevier.com/locate/drugalcdep

Full length article

Addressing the public health concerns of Fetal Alcohol Spectrum Disorder: Impact of stigma and health literacy

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ARTICLE INFO

Keywords:
FASD
Health literacy
Public health
Stigma
Alcohol

ABSTRACT

Background: Fetal alcohol spectrum disorders (FASD) are a group of developmental disabilities that may result from the mother's consumption of alcohol during pregnancy. The present study examined the effects of health literacy and stigma on the public health agenda for preventing FASD.
Methods: Three hundred and forty-one participants were sampled to ascertain levels of endorsement of the public health priorities of FASD, and FASD health literacy. Stigma towards women who consume alcohol during pregnancy, and towards biological mothers of children with FASD were operationalized using ratings of difference and disdain.
Results: Public stigma towards women who consume alcohol during pregnancy was greater than stigma towards biological mothers of children with FASD. Research participants with higher FASD literacy were more likely to endorse the prevention priorities of FASD, but also more likely to endorse greater stigma towards biological mothers of children with FASD. Interestingly, those who endorsed greater stigma supported the public health priorities of FASD more strongly. Female research participants more strongly supported the prevention priorities of FASD than male participants. Male participants were more likely to endorse stigma than female participants.
Conclusions: Stigma experienced by biological mothers of children with FASD generalizes to women who consume alcohol while pregnant. Some results were contrary to expectations: stigma was positively associated with health literacy and endorsement of prevention priorities of FASD. Reasons for these findings are speculated and should be tested in future research.

1. Introduction

Fetal alcohol spectrum disorders (FASD) are a group of developmental disabilities that may result when a developing fetus is exposed to alcohol (Jones and Smith, 1973). FASD can have pervasive effects on children's cognitive and social development, leading to significant disability. Estimates suggest that FASD impacts 2–5% of children in the U.S. and Western Europe (May et al., 2014; May et al., 2009). As a result, educating women about the dangers of alcohol consumption during pregnancy has become a public health priority (CDC, 2017). This includes advising women on the use of effective birth control if they decide to consume alcohol during childbearing years. Research into behavioral health promotion has found two factors that impact public education campaigns: stigma and health literacy (National Academy of Sciences, 2016). The purpose of this study is to test hypotheses about the impact of stigma and health literacy on the public health agenda for preventing FASD.

Research distinguishes public stigma (the discrimination applied to a group when the population endorses stereotypes about that group) and self-stigma (the harm to self-esteem when a personal internalizes stereotypes about themselves; Evans-Lacko et al., 2012). Research fairly consistently suggests the public stigma of mental health and substance use disorders undermines engagement in primary, secondary, and tertiary prevention (Corrigan et al., 2014). For example, people with serious mental illness are likely to avoid psychiatric care in order to escape the egregious effects of stigmatizing labels, thereby exacerbating the chronic and disabling course of their illness. Public stigma similarly undermines primary prevention campaigns meant to impact behavioral health conditions (Rusch and Thornicroft, 2014). The focus in this paper is on the public stigma bestowed upon biological mothers of children with FASD and women who drink during pregnancy. Difference and disdain are one set of stigma markers (Corrigan et al., 2015;

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https://doi.org/10.1016/j.drugalcdep.2017.12.027
Received 16 November 2017; Received in revised form 29 November 2017; Accepted 3 December 2017
Available online 14 February 2018
0376-8716/

Link and Phelan, 2001). People with mental illness, for example, are seen as different from everyone else and disdained as a result. One study showed that biological mothers of children with FASD are viewed as more different and with greater disdain than women with several other behavioral health conditions including mental illness, substance use disorder, and jail experience (Corrigan et al., 2017a,b). Hence, we expect to show that people who endorse public stigma towards biological mothers of children with FASD are less likely to endorse the goals of public health programs for FASD.

A lesser-known question is the extent to which stigma of one condition generalizes to another (Link et al., 2004). For example, does the stigma of a serious mental illness like schizophrenia extend to more benign disorders such as depression? Of interest here is whether the stigma experienced by biological mothers of children with FASD generalizes to "at-risk" women: that is, women who consume alcohol while pregnant. The public might perceive the stigma of biological mothers of children with FASD to be "strange or alien" – and therefore of less importance in defining the public health agenda. We examine the generalization effect in this study.

Engagement in prevention programs is also influenced by health literacy, the degree to which individuals accurately understand the impact of a health condition and interventions meant to remediate it (Sorensen et al., 2012). People who are more familiar with the symptoms and disabilities of mental health or SUD challenges, as well as the range of evidence-based interventions meant to treat them, are more likely to engage in prevention (Jorm, 2012). We similarly expect people more familiar with FASD will be more likely to endorse prevention priorities for it. Research also suggests that health literacy is inversely related to stigma; i.e., those who know more about a mental health condition are less likely to stigmatize it (Jorm, 2012). Hence, we expect to show FASD literacy to be inversely associated with stigma of biological mothers of children with FASD.

Finally, the object of the FASD stigma examined in this paper – a biological mother of a child with FASD or a woman who drinks during pregnancy – and its impact on the public health priority, is obviously limited to females. However, men are included in the study because their stigma and health literacy may play an important role in the public health agenda. As partners of at-risk women, they may influence the women in regards to alcohol use while pregnant. For example, some men might ignore public health prescriptions, telling their partner it is okay to drink while they are pregnant. A final exploration of this paper is how the perceptions of the public health agenda, stigma, and health literacy vary by gender.

2. Materials and methods

Adults were solicited to participate in this study using Amazon's Mechanical Turk (MTurk), a crowdsourcing internet marketplace network that, among other things, is used to solicit participants for social science research. More than 100,000 workers from the United States are registered with MTurk (Pontin, 2007). Research is mixed regarding the degree to which demographics of MTurk workers match the US population (Buhrmester et al., 2011; Paolacci et al., 2010; Ross et al., 2010), though this is less of a problem for studies like the current one, which is more concerned about internal validity to test hypotheses. Studies have also shown MTurk to yield better data quality than other crowdsourcing platforms (Kraiger et al., 2017). A solicitation was posted on MTurk requesting workers to participate in a 21-min survey about "attitudes towards women that consume alcohol while pregnant and mothers of children with FASD, as well as the level of engagement in services and knowledge on FASD." Consistent with our commitment to pay MTurk participants minimum wage, workers completing this 21-min task were reimbursed $3.57.

Three hundred and fifty MTurk workers responded to the solicitation and were assessed for eligibility. One concern about online surveys is research participants who demonstrate insufficient effort responding (Huang et al., 2015) by failing to fully attend to task. The MTurk survey included validity questions meant to exclude people in this group who were not attending well; e.g., "Please choose the number '4' for your answer below." We also excluded people whose time on task was below minimal cutoff (5 min after viewing vignette) to complete the survey competently. As a result, 341 of 350 MTurk workers provided useable data. Prior to beginning the survey, prospective research participants were informed of study goals and methods and asked for an electronic signature of consent. The study was fully reviewed and approved by the IRB at the Illinois Institute of Technology. Qualtrics, an online self-administered survey platform, was used to administer consent form, measures, and conditions.

Using public health priorities as laid out by the Fetal Alcohol Syndrome Prevention Team at the Centers for Disease Control and Prevention (CDC, 2017), a four-item measure of FASD Public Health Priority (FASD-PHP) was developed. Research participants were asked to report agreement on an 8-point scale (8 = very much); e.g., "I am concerned about alcohol consumption during pregnancy." Individual items were summed into a total FASD-PHP score with a higher score representing greater endorsement of the public health priority. Internal consistency of the FASD-PHP was minimally adequate, $\alpha = 0.60$.

Research participants were presented a brief description of FASD: "FASD is a condition experienced by newborns often causing a range of developmental, cognitive, or behavioral problems. The child gets FASD because the mother was binge drinking or regularly heavily drinking during pregnancy." Research participants then answered three items about difference (a biological mother of children with FASD is: similar, like, or comparable to the general population) and disdain (a biological mother of children with FASD is: not good, not respected, or not favorable compared to the general population). Research participants were then given a brief description about at-risk women. "This section is regarding women who consume alcohol while pregnant which can lead to the baby being born with a Fetal Alcohol Spectrum Disorder (FASD)." Participants then answer the same three items on difference and three items on disdain with the new referent: "a woman who consumes alcohol while pregnant." After reverse scoring some items in each scale, total scores were determined, with higher scores representing greater perceptions of difference and disdain. To validate factor structure, we conducted confirmatory factor analyses of difference and disdain scales separately for the biological mother and at-risk woman. Fit indicators (normed fit index, goodness of fit index, and comparative fit index; Byrne, 1994) all met criteria (> 0.90) for both the biological mother and at-risk woman models. In addition, latent variable estimates representing loading of individual items into latent factor were significant because z-score values were strong ($p < .001$).

Jorm (2012) proposed that health literacy can be assessed using true/false or multiple choice items representing the presentation and course of a disorder: knowledge of a specific syndrome and the evidence-based interventions that treat that syndrome. Sixteen items were generated through literature review and then validated by subject matter expert, Kenneth Lyons Jones (Jones and Smith, 1973). The sixteen-item version was administered to a pilot group of 25 individuals. Items were then reduced to ten based on proportion of research participants passing each item. For example, "True or False, one to two glasses of wine per meal is the known safe amount to drink during pregnancy." Mean item difficulty found for participants in this study was 0.68 (SD = 0.20). Research participants also completed a questionnaire on their demographics.

2.1. Data analyses

Two by two (2 × 2) ANOVAs (participant gender by vignette type) were completed to examine difference and disdain perceptions across vignette type (biological mothers versus women who consume alcohol while pregnant) and participant gender. Additional ANOVAs examined differences in health literacy and FASD-PHP across participant gender.