SMOKING HABITS OF IN-FAMILY CAREGIVERS OF CHILDREN WITH SPECIAL HEALTHCARE NEEDS: A CASE STUDY

by

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Abstract

The purpose of this study was to understand the smoking habits of caregivers of children with special healthcare needs (CSHCN) in an inner-city, low-income population. CSHCN have a chronic physical, developmental, behavioral, or emotional condition, which require more health and social services than children generally (McPherson et al., 1998). Over 11 million children in the United States have a special healthcare need (DRC, 2009/2010). Caregivers who smoke are at risk of developing serious adverse health outcomes. Yet, there is little known about the smoking habits of caregivers of CSHCN. A qualitative descriptive design was used to elicit smoking history, frequency and triggers among caregivers of CSHCN who smoke. Data were collected using a semi-structured, one-on-one interview guide and a demographic survey. The interview was audio recorded and transcribed verbatim. Data were analyzed using content analysis. This case study uncovered feelings of guilt associated with smoking and caring for a CSHCN, smoking urges being predominately mental not physical, smoking as an escape, smoking as a social behavior and smoking as a stress reliever. This information contributes to understanding smoking practices of caregivers and emphasizes the need for continued research to further understand cravings and their relationship to caring for a CSHCN.

Keywords: smoking, caregiver, special health care needs, children, qualitative description

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Background

Children with special healthcare needs (CSHCN) represent a population that face daily challenges, many of which have been studied in detail. Children with special healthcare needs are defined as, "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138). Based on statistics from the National Survey of Children with Special Health Care Needs (NS-CSHCN), 11.2 million children in the United States have a special healthcare need (Data Resource Center for Child and Adolescent Health [DRC], 2009/2010). With such a large population, it is increasingly important to study topics related to children with special healthcare needs and providing their care. Often, many caregivers engage in smoking, for various reasons, which further impact their health both physically and psychologically.

Smoking is a negative health behavior that has been studied and linked to many adverse health effects. According to the CDC, tobacco usage is still the single greatest preventable cause of disease and death in the US, and smoking cigarettes kills more than 480,000 people in America yearly. Additionally, smoking damages almost all organs in the body and is associated with heart disease, stroke, and lung cancer (U.S. Department of Health and Human Services, 2014). With all the negative effects related to smoking, people continue to smoke against medical advice.

Review of Literature

To review the previous literature, database searches using key terms such as smoking, smoking habits, children with special healthcare needs, special needs children and caregiving were used. Extensive previous research on the physical and psychological effects of both caring

for a CSHCN and smoking independently exist. The evidence found regarding effects of smoking and being the caregiver of a CSHCN was moderate as majority of the studies were qualitative in nature. The literature lacks quantitative research including randomized control trial studies. The quality of the studies reviewed was moderate because they were well-conducted studies with effective data collection and analysis procedures. Evidence could be stronger with the inclusion of repetition of studies as well as future quantitative research. No previous research was found relating caring for a CSHCN and smoking habits, suggesting deficient knowledge of the relationship between the two.

Children with Special Healthcare Needs

According to a qualitative study focused on accessing healthcare and services for African American parents of CSHCN, the barriers affecting care of their child were transportation, lack of social support, deficient care coordination, difficulty managing errands, and deficient knowledge of their child's disease (Mendes, 2016). Caregivers faced barriers to attaining health care and supplies for the CSHCN. Caregivers of CSHCN have been studied in detail to determine the challenges and health effects of providing care for children with special needs. Studies show that being a caregiver, especially in children with special needs, is related to psychosocial and physical health effects; however, a deficiency in the data remains regarding the smoking habits of caregivers of CSHCN.

Psychosocial effects of caregiving.

Caregivers have been shown to have worse health, related to providing care, than those who provide care for a typically developing child. In a meta-analysis study by Miodrag, Burke, Tanner-Smith & Hodapp, parents of children with disabilities and chronic health conditions reported worse health and greater health problems (2014). This study investigated the

relationship between physical health and being a caregiver. Similarly, in an international study of mothers with children with intellectual disability or autism spectrum disorder, early mortality and primary causes of death were studied. It was determined that the main causes of death were cancer, misadventure and cardiovascular diseases. Misadventure was defined as homicide, suicide or accidental death. Having a psychiatric disorder had a greater impact on mortality than having a child with intellectual disability or autism spectrum disorder. Mothers with both a psychiatric disorder and a child with an intellectual disability had the lowest survival rate of 90%. The presence of psychiatric disorders decreased survival rate independently of having a child with a disability. Mothers of children with intellectual disability or autism spectrum disorder were 35-40% more likely to die of cancer, 2.5 times more likely to die from cardiovascular diseases and twice as likely to die due to misadventure (Fairthorne, Gammond, Bourke, Jacoby & Leonard, 2014). Caring for a child with special healthcare needs impacts the parent physically and psychologically. Psychiatric disorders carry a risk of increased mortality, especially combined with having a child with a disability.

In addition to poor health outcomes, caregivers reported increased depression and increased incidence of chronic health conditions. According to an international cohort study of 8,568 primary caregivers of school children, caring for a child suffering from a developmental disability was related to an increased risk of depression. Additionally, problematic child behavior explained the increased risk of depression in the parents (Gallagher & Hannigan, 2013). Increased risk of depression is common in caregivers of CSHCN and has been well documented in past studies.

Another concern related to caring for a child with special healthcare needs is the presence or absence of positive coping strategies. In a cross-sectional, international study, 184

parents of children with autistic disorder participated, it was determined that accepting responsibility was the single mediator strategy to deal with stress and quality of life. Accepting responsibility was defined as accepting the reality of having the problem and being able to choose the outcome and take control of their actions. The results supported the role that coping strategies have in the association between stress and quality of life. The only moderator strategies related to stress and quality of life were seeking social support and escape avoidance (Dardas & Ahmad, 2015). The role of coping strategies is important in increasing quality of life, and healthy coping strategies are essential for improved health outcomes for caregivers.

In a similar international, quantitative study of 136 parents, 54% of which had children with autism spectrum disorder, it was determined that parents of children with ASD reported increased parental stress, increased depression symptoms, and engaged in increased maladaptive coping (Lai, Goh, Oei, & Sung, 2015). Caregivers are at risk for increased stress, depression, and maladaptive coping mechanisms, which further increases negative health outcomes. A third study focused on coping of parents with special health care needs who lacked a health care home. The secondary analysis study of 18,352 families of CSHCN showed that a causal relationship is present related to having a partial health care home and increased parental coping (Drummond, Looman & Phillips, 2011). The presence of supportive resources for parents caring for CSHCN is necessary in allowing caregivers to cope in a healthy manner and provide adequate care for the child.

Caregivers are not the only part of the family care unit that is affected by caring for a CSHCN; families experience burdens related to finances and care. A longitudinal study of 84 caregivers of medically complex or medical technology-dependent children, the study found that fatigue is a major issue plaguing caregivers as well as emotional effects. Parents report feeling

frustrated, anxious, angry, helpless, hopeless, and socially isolated. Also, 82% of the participants reported family daily activities problems. Due to high care needs, 80% of parents feel their employment decisions were affected. Parents reported feeling tired and found it difficult to find time for social activities, and the families lacked social support (Caicedo, 2014). This study highlighted the family health and functioning burden as well as the care and financial burden of caring for a CSHCN.

Physical effects of caregiving.

Compared to psychosocial effects, physical effects of caregiving have been studied, but less extensively. A cross-sectional study of parents of children with developmental disabilities and parents of typically developing children explored the role of stress, social support and blood pressure. The study found that parents of children with developmental disabilities had higher blood pressure on a daily basis. Additionally, social support had a buffering effect in explaining the difference in blood pressure between the two groups of parents. Parents with increased social support showed lower blood pressure readings (Gallagher & Whiteley, 2012). Caregivers experience higher blood pressure related to caregiving, but social support plays an important role in decreasing blood pressure.

Stress is another concern related to being a caregiver of a CSHCN. A cross-sectional, international study of 86 caregivers and 87 children with a disability examined chronic stress (based on hair cortisol concentrations) related to body weight, BMI, and other obesity measures among disabled children. The study found that caregiver hair cortisol concentrations, a chronic stress biomarker, were positively and significantly associated with child weight, BMI, and neck/waist/hip circumference. This suggests that chronic stress in caregivers was an important risk factor for obesity in children with disabilities (Chen et al., 2015). The relationship between

chronic caregiver stress and increased child obesity measures could show that reducing caregiver stress could impact the childhood obesity epidemic.

Caregivers of CSHCN also experience effects related to sleep and memory. A quantitative study of 172 parents, found that parents of typically developing children experienced reduced time in falling asleep, increased total sleep, and better sleep quality than parents of CSHCN. Additionally, parents of CSHCN experienced poorer prospective memory. Parents of CSHCN also were more than 3 times more likely to report poor health compared to parents of typically developing children (Mcbean & Schlosnagle, 2015). Caregivers of CSHCN experience poorer sleep, health and memory compared to parents of typically developing children. Memory and sleep quality are important factors in allowing caregivers to adequately care for a CSHCN. A similar study also found interesting results related to memory failures in caregivers of children with autism. This international, quantitative study, it was determined that caregivers of children with autism reported increased levels of stress and showed cognitive dysfunction based on greater memory failures on every day tasks. Memory failures on every day tasks were greater in caregivers with a higher perceived stress scores (Lovell, Elliot, Liu, & Wetherell, 2014). Caregivers have been shown to have more memory failures, especially when higher stress levels are present.

A quantitative, international study of 148 mothers studied the relationship between sleep disruptions, health and care responsibilities in mothers of children with disabilities. The study determined that subjective mental health, general health, vitality, social functioning, and ability to fulfill the emotional aspects of life decreased with an increase in frequency of sleep interruption. Mothers who experienced more frequent interrupted sleep experienced poorer

health (Bourke-Taylor, Pallant, Law, & Howie, 2012). Sleep disturbances in caregivers affects their health, care abilities and functioning.

Smoking

Smokers continue to smoke and their motivations are important in understanding the reasoning behind continuation of smoking despite health risks. In a cross-sectional, international study, 8,465 participants were studied to determine self-perceived smoking motives. The study found that the most frequent motives for continued smoking were enjoyment and stress relief. Men reported enjoyment and liking being a smoker, whereas women reported stress relief and weight control. Younger smokers recognized smoking as a way to socialize and older smokers reported enjoyment (Fidler & West, 2009). The enjoyment and stress relieving aspects of smoking are barriers to cessation. Additionally, many of the caregivers of CSHCN are women, and women more frequently use smoking for stress relief, which is an interesting dynamic.

Negative effects of smoking.

Smokers have been shown to suffer from a decreased quality of life related to their habits in addition to the negative health outcomes. A quantitative, international study examined smoking and health-related quality of life in 12,926 participants. The study results were smoking was significantly associated with health-related quality of life. The more frequently a person smoked, the worse quality of life they experienced from their smoking habits regardless of additional biological, clinical, lifestyle and socioeconomic behaviors (Vogl, Wenig, Leidl, & Pokhrel, 2012). Smoking not only affects physical health but also reduces their quality of life.

The negative health effects of smoking have also been studied in caregivers and have shown that being a caregiver for a child with a disability is related to perceived stress and shortened salivary telomere lengths. Telomere length is a biomarker of chronic stress over a

period of several months. In a cross-sectional, international study, 90 caregivers were identified as the primary caregiver of a child with a disability. The results of the study showed 44% of caregivers reported smoking. Smoking and increased perceived stress levels are significantly related to shorter salivary telomere length in caregivers. Also, 6.5 years of life can be lost related to high-perceived stress levels in caregivers of children with disabilities (Chen et al., 2014). Smoking and chronic stress have physical effects on telomere length and life expectancy.

An additional aspect of health that is affected by smoking is sleeping habits. An international, case-control study was conducted that included 2,314 participants that are "healthy" smokers who do not have a medical or psychiatric co-morbidity. It was determined that, with excluding comorbidities, smokers suffered from significantly affected sleep quality. When adjustments were made for age, BMI, education, income, depressiveness, alcohol use, attention deficit hyperactivity symptoms, anxiety and perceived stress, smokers continued to be at a higher risk of impaired sleep latency, sleep duration, and poor sleep quality but have a lower risk for daytime dysfunction. Smokers had increased sleep latency, sleep duration of less than six hours, sleep disturbance and decreased sleep quality (Cohrs et al., 2012). Sleeping habits and quality are affected by engaging in smoking.

Smoking and caregiving.

The health effects of smoking and caring for a CSHCN have both been studied and documented in detail, but there is deficient information regarding the relationship between smoking and caregiving. One study exists that examines the relationship between smoking and increased smoking in caregivers of patients with Alzheimer's. The secondary data analysis of 642 caregivers revealed that 39 % of caregivers smoked and of those that smoked, 25% reported an increase smoking in the past month. Age was the single explanatory variable of smoking

status and depression was the single stressor, which significantly explained smoking increase. Caregivers who reported fewer coping resources also experienced a smoking increase. Less caregiving skills is related to a smoking increase (Salgado-Garcia et al., 2015). Caregivers felt that when they did not have the necessary information to provide caregiving skills they felt higher stress levels. Additionally, caregivers who smoked reported an increase in smoking related to depression, and decreased coping skills.

An additional concern related to caregiving is the role of secondhand smoking related to caregiving and the effects it has on the care and child's health. According to the US Department of Health and Human Services, 41,000 of smoking related deaths are due to exposure to secondhand smoke (U.S. Department of Health and Human Services, 2014). Secondhand smoke includes smoke in the air as well as the smoke released from the lungs and thirdhand smoke is present in residues on surfaces. In a position statement on tobacco exposures, Anne Turner-Henson explains that secondhand smoke exposure is strongly associated with early health consequences and it contains more than 4,000 chemicals. Smoke in the home affects all members even when they are not in close proximity to the smoker. Additionally, secondhand smoke is linked to asthma exacerbation, low birth weight, respiratory risk and risk of sudden infant death syndrome (2013). Children can be exposed to smoke on clothing and in the air, which puts them at greater health risks. The decision to smoke by caregivers not only affects their health but also the child with special healthcare needs they are caring for.

An abundance of data exists regarding the physical and psychosocial health effects of both smoking and being a caregiver independently; however, a lack of knowledge exists related to smoking habits specifically in caregivers of CSHCN. Deficient knowledge is available regarding smoking habits related to caregiving, and many variables are present that could affect

these behaviors such as stress, coping, and caregiving. This study aims to explore smoking habits of caregivers of CSHCN and add knowledge to this topic. The purpose of this study is to describe the smoking habits of in -family caregivers of a CSHCN in a low-income, inner city population. The study will identify smoking history, frequency and smoking triggers in parents of CSHCN.

Context of Study

A windshield survey of the rural county in eastern NC with a population of 126,000 people was conducted (US Census, 2010). Based upon the windshield survey performed in the county on a single day, many indicators of poverty were present in the area surrounding the school that was the site of the project. An indicator of poverty seen was that people were in insufficient clothing for the temperature. Additionally, the houses were in need of repair, vacant, boarded-up, barred windows, windows lacking screens, poorly maintained, and trash was piled on porches in the downtown area near the school. Presence of smoking and purchasing cigarettes was observed. Many people were walking to and shopping at quick marts for cigarettes, alcohol and junk food that were visible in their hands. Anti-tobacco advertisements heard on radio and anti-tobacco billboards are present warning the public about tobacco effects. There were a multitude of elementary, middle, and high schools in surrounding areas. Large ranges of social and economic conditions existed through various parts of the community. A school-based health center is located inside the middle school and there are 6 total clinics in different schools. Nurse practitioners work together with a full time RN and staff to serve schools with a high prevalence of children who require on-site primary care services.

Secondary data showed the high level of poverty and smoking in this rural county in Eastern North Carolina. According to the County Health Rankings, the percentage of current

adult smokers was 20% compared to 19% in North Carolina. Additionally, the top performers in the US had an adult smoking rate of 14%. The county in this study also had a 36% rate of children less than 18 years of age in poverty, compared to 24% in North Carolina and 14% by the top US performers (University of Wisconsin Population Health Institute, 2016). According to the US Census from 2010, the percentage of children with a disability in North Carolina was 4.9% in metro areas compared to 7.7% in non-metro areas (US. Census Bureau). The presence of children with special healthcare needs puts the population at further risk for not having adequate access to necessary resources. According to the county School's website, the percentage of CSHCN in the school-based health center was 26%, compared to the state average of 12.5% (2014).

The school population included a total of 333 students, and the school based health center served 227 students, which is 68.2 % (_____ Initiative for School Health Annual Report, 2015-2016). The school population included 6th, 7th and 8th graders. The school's ethnicity and race report revealed 89% African American students, 5% Hispanic/Latino students, 3.9% White students, 0.3 % Native Hawaiian/Pacific Islander students, and 1.5% with two or more race categories (School Enrollment Summary, 2016-2017). Additionally, 26 % of the children have special health care needs, and a high population of children receiving free and reduced lunch (_____ County Schools, 2014). This study took place as part of a seven-week community health clinical rotation with a school nurse preceptor of a baccalaureate-nursing program.

Methodology

This case study of one mother of two CSHCN used a qualitative descriptive design to elicit descriptions of her smoking history, smoking frequency and smoking triggers. Qualitative description aims to determine a complete summary of incidents in ordinary circumstances and

attains honest and unembellished information on particularly relevant subjects to researchers (Sandelowski, 2000). Participants were recruited through advertisements in urban and rural settings. The inclusion criteria were participants must be 18 years or older, must speak English, and must be the primary caregiver of a child with special healthcare needs. Exclusion criteria included the caregiver being diagnosed with an intellectual disability.

This case study was conducted in a school-based health center in eastern North Carolina with a high percentage of CSHCN. The caregiver of CSHCN attending this public school was invited to participate. IRB approval was granted and the participant completed an informed consent. One participant was interviewed using a semi-structured, one-on-one interview guide and a demographic survey. The interview was audio recorded and transcribed verbatim. Data was analyzed using content analysis. Some details were removed from this case study that could indirectly identify the participant or her family. Partners in this study were the, school nurse in the school-based health center, and faculty mentor.

Findings

The case study participant was a 29-year-old petite woman, with a nuclear family. She was a married mother of two children who have developmental and behavioral disorders and one typically developing child with very high intelligence. She was, energetic, punctual, professional, inquisitive, articulate, and answered questions fully. She frequently checked her messages, and was apologetic and explained that she had another meeting to follow. She was very interested in Autism research and excited to participate in research. The participant stayed to the agreed upon time limit, and hurried away to go to her next meeting.

This caregiver reported a smoking history of 10 years, except during pregnancy and breastfeeding. During that time, the smoking frequency was a pack a day with routinely

scheduled smoke breaks. Recent hospitalization caused her to quit smoking for the past month. Analysis of the transcript revealed six factors that described this mother's smoking including: a) feelings of guilt associated with smoking and caring for a CSHCN; b) smoking urges; c) smoking as a stress reliever; d) smoking as an escape; e) smoking as a social behavior; f) smoking triggers and cessation. The study uncovered emotional, mental and social relationships between smoking and caregiving.

Guilt

The participant described feelings of guilt associated with having a CSHCN. The participant stated, "I know there's a lot of guilt when you have a kid with autism. I mean there's a lot of guilt." She continued,

> for example, with my son, I mean I smoked, this was before I found out I was pregnant, so technically, I smoked while I was pregnant. I mean it was for two, three weeks, but I did. I was in the military with him. I was exposed to things in the military, you know, hazardous chemicals.

Other factors were present that were related to the guilt she felt related to having children with autism. She explained other factors when she stated,

> I did smoke with her, umm, before I found out I was pregnant and, just, I eat different foods, ways. I'm a terrible eater. My eating habits are probably worse than a toddler's… so, there's that, you know, did I not eat enough vegetables? you know…

She also stated, "I didn't take my prenatals [vitamins] the way I should of. You know, and all the vaccines and crap that was pumped into me in the military." She describes the guilt,

> there's all that guilt 'cuz you just don't know. Or, then you're like, well is he really autistic….so, you're like, is that my problem? Am I being lazy parenting? And that's

> just, I guess that would be the guilt. Like, is he not talking because I didn't expose him enough, I didn't socialize him enough, I didn't teach him enough?

The participant explained that guilt came from possibly smoking prior to finding out she was pregnant, raising her voice at her children unintentionally, being exposed to chemicals in her work, and guilt for not taking prenatal vitamins as strictly as recommended. She also explained that life would never be the same with special needs children, and that also added to the guilt experienced. She described her oldest son with autism. She stated,

> he was diagnosed with autism when he was around 4. I kinda knew it around 2 or 3, but I didn't really wanna say it because no one really wants to…so we kinda just said developmentally delayed and then eventually autism.

She also described things she would not experience with her daughter. She explained, "I see four-and-a-half year old girls right now gettin' their nails done and… she, she can't, she don't even know what nail polish is… so, its just, I guess guilt, and maybe…jealousy." The participant feels guilty for the things she will not be able to do with her daughter because of her severe autism. She stated, " it sucks but…she's still special."

Another indication of guilt surrounding her smoking was that she kept her smoking from her children. She made it very clear that her children were not aware of her smoking habits. She explained, "I'd go outside, go out in the backyard, and ya know, hide it from them." She continued, "'cause I don't want them to see that". Her husband and family were aware of her smoking, but not her children. She kept her smoking from her children by scheduling smoke breaks into her routine. She stated,

> I'd kind of schedule my night, ya know, I would like put the kids in the bath, then when they're in their room, have a cigarette, and then give them dinner and then go have a cigarette. Kinda schedule my night around when I could have a break.

She continued, " 'cuz the kids didn't know, they just thought mommy was taking out the trash or I'd say getting something out of the car." She described how her typically developing child despised smoking, because he learned about the negative health effects in school. She stated, "they [the children] didn't know. And they hate smoking! I mean I hate it." She described the comment her son would make to smokers. She explained, "he will, stranger or not, he will walk up to you and tell you ' you need to stop because you will die'. " She explained that she "had to hide it [smoking]" from her children, which was an additional indicator of guilt.

Many of the participant's family members smoked previously and quit, and encouraged her to quit. She explained,

> we all used to smoke but my mom quit, my sister quit, and my other sister quit. And I found that when you quit, I guess you're more anti-smoking than people who have never smoked, 'cuz my mom hates it now.

Her family members nag her to quit. She described the nagging when she stated, "[they] big time nag me. Big time, especially when I got sick." Pressure from her family to quit smoking was an added source of guilt.

Smoking Urges

The participant described the urge to smoke as predominantly "mental" rather than physical. The participant explained, " I think it's [cravings/smoking] more mental than physical, because when I was sick, I was able to go a week straight without even wanting one." She also stopped smoking during pregnancy and breast-feeding. She stated, "I didn't even crave it… I

didn't even want it when I was pregnant… and when I was breastfeeding I didn't even want it. And when I was sick I didn't even want it." She related smoking to more of a habitual behavior, and lacked physical symptoms of craving when she was not smoking. Smoking was more psychologically driven in her opinion.

Stress Reliever

The participant revealed that smoking was a stress reliever. She explained, "Under stress you just can't stop thinking about that cigarette and how it will distress you in a second." She described the feeling of decreased stress when she was able to smoke. The cigarettes became a dependable way to de-stress. She stated, "I guess just that it was a stress reliever, I guess for me." She described working in a lawyer's office where she was "swamped" with work and described, "really needing to smoke." During her time as a teacher, she described the difficult workload and how she felt she needed to smoke. She explained,

> one of my coworkers that I go on break with, we work together very closely, we have the same students and everything, would smoke every break. And so it would calm her down, and I'd see that and stuff so I'd be like, alright, well then, you know what, I need one to calm me down.

Smoking was a stress reliever for both her and her coworker.

An Escape

Smoking was described as an escape when the participant described how she went outside, away from her children or took a break from the workplace. She stated, "I got to look forward to going out for that 5 minutes and I wasn't getting bugged or annoyed or harassed." She continued. "It was just an escape, I had 5 minutes to myself and no one bugged me." Smoking

allowed the participant to have a break and have some personal time away from the behavioral issues presented by her children and the strains of the classroom. She explains,

> it can get very stressful trying to figure out how to teach, how to get the test scores up, how to manage the behavior, how to differentiate when you have- I have 23 kids with IEP that I gotta know all of those. I'm teaching 85, and it's just, it gets very stressful 'cuz you have parent meetings everyday and they wanna know, well, why is my child failing, and its just so much is put on you.

In this regard, smoking was an individual behavior that allowed her to have alone time. When she was with her kids or at home, smoking was a break that provided individual quiet time.

Social Behavior

The participant described smoking as a social behavior when she stated, "It calms me down and everyone's doing it." Additionally, it was a social time that was spent with co-workers. She explained, " [The participant with a co-worker] would smoke every break." Smoke breaks gave her an opportunity to socialize with friends and co-workers.

The participant explained that she began smoking because, "Everyone's doing it." She continues, "I literally just did it [smoked] 'cuz everyone did it." This reveals the social nature of smoking in this participant. The participant described being in the military and stated that everyone in her branch of the military smoked. The environment of colleagues smoking she felt pushed her towards the behavior. She explained, "I started [smoking] with the military." She continued, "I was 19 when I joined and everyone did it." During work, the military, and teaching smoking was a social behavior that encompassed having a break and being able to talk with coworkers.

Smoking Triggers and Smoking Cessation

She explained that additional triggers for her to smoke besides stress were, "social stress, or like if I would just get really hungry, I would have a cigarette, 'cuz I knew it would curb my appetite." Smoking was used to suppress her appetite during long days. She continued, " 'cuz snacking a lot, like, especially teaching, you could snack a lot if you teach." She explained that after quitting she snacks more. She stated, "[smoking] used to curb my appetite. And I've noticed since I've quit I've been snacking a lot more again." She explained that she did try to quit using various methods. She stated, "I tried Chantix when it was first out, but it game me crazy dreams." She continued, "the only thing that worked for me was pregnancy and [being] sick. Other than that I was never able to quit on my own." The only effective smoking cessation practices for this participant were breastfeeding, pregnancy, and becoming sick with pneumonia.

Autism and Vaccination

An interesting topic that came up in conversation was vaccination and autism. The participant did not vaccinate her second child at first, because she believed her first son's development of autism was related to vaccination. She stated,

> he literally changed over night and it was right around when he had his MMR vaccine. It was literally like maybe a week after he had that vaccine where he just topped talking. It was literally like a switch went off.

She continued, "so with her [daughter], I didn't vaccinate her, but then the same thing. Around the 18 month mark." She explained,

> I should say with my son, he was good 'til around 18 months…so that's when I did pull all of his vaccines 'cuz he had the MMR shot right around that time, so I blamed the vaccines. I mean I really did. I-, I did the whole correlations slash causation thing, so I

didn't vaccinate my daughter at all, and then she had autism, worse than he did. So, she's thankfully up to date and everything now.

She described her personal experience with "blaming" the autism on the vaccinations her son received.

Discussion

Findings of guilt in this case study are supported by an article by Fernańdez-Alcántara et al., that found parents of children with autism experienced strong levels of grief. The article stated, "The ASD diagnosis implied the loss of a life project as parents and of the future they had imagined with their child"(2016, p. 316). Having a child with CSHCN will involve a drastically different life than expected. Additionally, the article stated, "Guilt appeared around the causes of the disorder and their possible implication in its etiology" (2016, p. 317). The participant explained that she felt she was partially responsible for both of her children's diagnoses'. Both this case study and this article support the existence of guilt from a variety of factors associated with having a CSHCN.

Smoking urges being more "mental" is supported and negated by an article with mixed findings on tobacco dependence. The article by Joseph DiFranza had mixed findings on tobacco dependence being physical and psychological. The article stated, "Although some smokers report that tobacco withdrawal causes hand tremors, the symptoms of physical dependence on tobacco are mostly psychological: impatience, irritability, anger, bad mood, restlessness, insomnia, agitation and difficulty concentrating " (2016, p. 8). The article continued, "Although it would be difficult to prove an absolute, it appears likely that tobacco dependence always involves physical dependence" (2016, p. 8). It seems as though the participant recognized a lack of many physical symptoms when she was not smoking and noticed more psychological symptoms. This topic

requires further research, because the psychological and physical dependence of tobacco smoking have both been supported by previous research, and a combination of the two may be present during cessation. While the participant quit smoking at the time of the interview, it is unknown if she relapsed and went back to smoking.

Related to the finding that the participant did not smoke during pregnancy or breastfeeding, an article by Leung & Davies, studied smoking cessation strategies in pregnant women. It found that, "incentives combined with behaviour therapy appear to show the greatest promise for abstaining in this population" (2015, p. 796). The participant did not use any assistance from behavior therapy or incentives to stop smoking; however, it has been effective in other women.

An additional study by Murphy, Dunney, Mullally, Adnan, & Deane, examined smoking behavior during pregnancy and found that, " almost 60% of prior smokers attending for antenatal care had made a decision to quit smoking by the time of the first antenatal visit" (2013, p. 3864). The study also found that the women who decided to quit smoking did so by self-motivation and their smoking behavior did not vary much during their pregnancy. Mothers that continued to smoke were associated with social disadvantage, alcohol use during pregnancy, and prior illicit drug use (Murphy, Dunney, Mullally, Adnan, & Deane, 2013). This relates to the participant in this study because she decided to quit, which was self-motivated, right when she found out she was pregnant. She also did not have any of the risk factors related to smoking continuation such as social disadvantage, alcohol use, or illicit drug use.

Moore, Blatt, Chen, Van Hook, & DeFranco studied factors related to smoking cessation in pregnancy and found that beginning prenatal care early was associated with increased smoking cessation in pregnancy. Additionally, mothers who began breastfeeding prior to leaving

the hospital were more likely to have early smoking cessation related to being motivated by improved outcomes for their child. Smoking cessation teaching by a physician was a strong motivator in changing tobacco use (2016, 2015). This study was similar to the participant because she was self-motivated to quit smoking during pregnancy and breastfeeding. The participant breastfed her second child, but not her first child because she quickly returned to work in the military and it was too difficult to breastfeed at work.

The participant explained that she did not smoke during pregnancy, but relapsed back to smoking after her first pregnancy, and explained she did not breastfeed. The participant breastfed her subsequent two children, but relapsed to smoking after breastfeeding was complete. Post-partum smoking relapse is very common and has been studied by various researchers. In a study by Stotts, DiClemente, Carbonari, & Mullen, it was found that 68% of mothers returned to smoking upon follow-up. The breakdown was that 44% of mothers relapsed by 6 weeks post-partum, 55% relapsed at 3 months post-partum, 53% relapsed at 6 months post-partum, and 58% relapsed at 1-year post partum (2000). The relapse rates for mothers that smoke prior to pregnancy are very high.

In a study of post-partum smoking relapse of cluster subtypes of mothers, it was found that 35% of the mothers relapsed to smoking by 2 months post-partum. Additionally, 50% of the mothers in the high-risk cluster relapsed by two months (Simonelli & Velicer, 2012). An additional study examined the proportion of women who relapsed to smoking post-partum from 2000-2011, breaking it down state by state. The study found that from 2003-2011 there was a significant decrease in postpartum relapse. Also, an estimated 44% of women relapsed after delivery during 2009-2011 (Rockhill et al., 2016). Post-partum relapse to smoking is a common problem for mothers who smoke, including this participant.

This mother's description of smoking as a stress reliever is consistent with a study conducted by Fidler & West, which found that the most common reasons for smoking are enjoyment and stress relief (2009). It is known that smoking is related to decreased stress; however, determining if smoking physically and/or psychologically reduces stress remains to be determined. Additionally, the study by Fidler & West found that weight control is a common reason in women for smoking (2009). The participant described using smoking to curb her appetite, and that she had increased her snacking since quitting.

Her description of smoking, as an escape, relates to smoking as a coping mechanism, which was supported by an article by Dardas & Ahmad. The article found that the only moderator strategies related to stress and quality of life are seeking social support and escape avoidance (2015). Escaping the problem is a coping mechanism, and smoking was an escape for the participant in this case study.

The finding of smoking as a social behavior is consistent with the findings of Fidler & West, which were that younger smokers identify smoking as a way to socialize with others (2009)**.** The use of smoking as a socialization mechanism further supports the social aspect of smoking. The participant began smoking at the age of 19 years old. Being a young smoker, and starting when she joined the military where the social norm was smoking, she adopted smoking as a social behavior, like the young smokers in this study.

This study is the first known to examine the role that smoking plays for a caregiver of a CSHCN. The factors of guilt, stress, coping mechanism all play a role in the relationship between smoking and being a caregiver of a CSHCN. This case study has revealed that caregiving causes increased stress and guilt in this participant, and that smoking is related to decreasing stress and being an escape for her. It is possible that there is a link between smoking

and the relief of some of the stress related to caring for a CSHCN, but further research is necessary. This case study can only report the findings specific to this one participant.

Limitations

A limitation of this case study is that the findings from one participant are not generalizable to other caregivers of a CSHCN. Another limitation is the lack of data saturation related to a single participant. Additionally, the case study participant had multiple CSHCN, which could affect the findings compared to a parent of a single CSHCN.

Conclusion

This case study is the first known to elicit descriptions of the smoking history, frequency and triggers of one mother of two CSHCN. This study explores the role of smoking related to caregiving, which was previously a gap in the literature. The study strength is that it will contribute to the literature on smoking habits of caregivers of CSHCN. The challenge found in this case study is willingness of caregivers to participate and the need for additional participant recruitment.

Stress and caregiving are smoking triggers and are related to an increase in smoking frequency. This information contributes to understanding smoking practices of caregivers and emphasizes the need for continued research to further understand cravings and their relationship to caring for a CSHCN. Future research should focus in on studying smoking habits of caregivers of CSHCN and also on understanding cravings and their relationship to caregiving.

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