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Educational and Occupational Aspirations Among Mothers Caring for a Child with Smith-Magenis Syndrome

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Abstract This study explored educational and occupational goals of mothers caring for a child with Smith-Magenis syndrome (SMS). Data were collected from 97 mothers ($M_{\text{age}}=41.31$ years, $SD_{\text{age}}=9.60$) via online survey. Results showed that 63.0% of mothers earned an undergraduate or professional degree, while 55.0% desired to further their education. Those who gave birth to their first child during young adulthood were more likely to complete an undergraduate or graduate degree than those who were younger when their first child was born ($\chi^2=34.53$, $p=.003$). Overall, 34.1% reported low occupational satisfaction, while 36.5% reported high satisfaction. Approximately 45% desired to change occupations. Caregiver well-being, satisfaction, self-efficacy, depressive symptoms, and fatigue together predicted occupational satisfaction beyond the influence of education obtained or household income ($\Delta R^2=.28$, $\Delta F(5,74)=4.93$, $p=.001$). Independently, occupational satisfaction was directly influenced by caregiver satisfaction ($B=.23$, $p=.04$) and well-being ($B=.09$, $p=.01$). Mothers caring for a child with SMS express distinct challenges in meeting educational and occupational goals while balancing caregiver demands. Clinical and research implications are discussed.

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According to the U.S. Department of Health and Human Services (HHS 2008), in 2005, 21.8% of U.S families were raising a child with special health care needs. McPherson and colleagues defined children with special health care needs 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. 137). Caring for a child with special health care needs requires many additional responsibilities and sacrifices for the caregivers. Such responsibilities and sacrifices have been reported by mothers of children diagnosed with Smith-Magenis syndrome (SMS), a chromosomal disorder affecting 1 in 25,000 births worldwide that is characterized by craniofacial anomalies, feeding problems, developmental delays, intellectual disability, chronic sleep problems, attention deficits and hyperactivity, rapid mood fluctuations, and self-injurious behaviors (Foster et al. 2010; Elsea and Girirajan 2008; Smith et al. 2010). These caregiver challenges are faced not only during the child’s early development but across the lifespan, as individuals with SMS are typically unable to care for themselves independently as adults (PRISMS 2007). Caregivers participating in this study reported the following with respect to the demands of raising a child with SMS:

As her primary caregiver I have given up everything that I have known—my career, my dreams, my friends...the list goes on. I did this so that at some point in her life she hopefully can venture out on her own with support and have a fulfilling, happy, loving life. When (if) that happens that will mean more to me than any college degree I would have obtained if she wouldn’t have come into my life.

- Mother of a 14-year-old diagnosed with SMS

Almost all of us feel INCREDIBLY ALONE. In our family, we originally planned to have my husband be the stay-at-home parent (I love my profession and have a better income; he loves children even more than I do), BUT he was unable to cope with being fulltime caregiver to our child with SMS. This has resulted in a reversal to more traditional roles (he works fulltime but makes too little to support the family; I work half-time and am also fulltime mom). It has been profoundly stressful to me, and our financial situation is a bit depressing considering our ages and levels of education. This is a common result of having a child with a disability.

- Mother of a 16-year-old diagnosed with SMS

The preceding quotes coincide well with studies suggesting that working parents who are caring for a child with disabilities face numerous challenges when attempting to balance their work and family responsibilities (Hodapp et al. 1998; Rosenzweig et al. 2002). Often the child’s healthcare appointments must be scheduled during parents’ workdays, health crises can interrupt work and family life, and parents must make childcare and special education arrangements.

Caregivers must find ways to cope as they try to integrate demands of employment and family life. Previous studies have shown that parents of individuals with developmental disabilities have decided not to pursue graduate school, forgo occupational development and advancement opportunities, or have changed their occupational goals (Barnett and Boyce 1995; Case-Smith 2004; Freedman et al. 1995; Parish 2006; Porterfield 2002).

However, little is known about the compromises caregivers of a child diagnosed with SMS have made in their education and occupational plans, how satisfied caregivers are with their current occupations, or how occupational satisfaction is related to caregiver emotional and behavioral well-being. The demands of raising a child with SMS are complicated by the cardinal signs of this condition, including chronic sleep disorder, self-injurious behaviors, and constant attention-seeking behavior (Elsea and Girirajan 2008). Thus, three primary research questions were investigated: (1) What are the current educational levels attained and occupations held by mothers with a child with SMS?, (2) What are the educational and occupational goals of these mothers?, and (3) How is occupational satisfaction related to demographic factors such as age and education level and psychosocial factors such as symptoms of depression, quality of sleep, caregiver satisfaction, caregiver self-efficacy, and caregiver well-being? Results of this study are utilized to explore methods of identifying educational and occupational satisfaction and goal attainment among SMS caregivers.

Methods

Procedure and Recruitment to Study

This study was approved by the VCU Institutional Review Board. An exploratory cross-sectional design was utilized, with participants completing a self-report online questionnaire created as part of a larger study via a survey development program called *Inquisite*. Potential participants included mothers of individuals diagnosed with SMS. Mothers were at least 18 years of age at the time of participation and English-speaking. Introductory e-mails were sent through the PRISMS (Parents and Researchers Interested in Smith-Magenis syndrome) and Yahoo SMS Listserves. This e-mail informed eligible participants of study objectives, consent procedures, and offered a web link to an online survey if they chose to participate and the option to request a paper version of the questionnaire as an alternate means of participation. All data were collected from May through September 2007. All participants were fully informed of the research questions under investigation, including specific factors (e.g., depression symptoms) being analyzed. Data were collected anonymously, meaning that participants did not provide their names or the names of their children at any point during the online questionnaire.

Participants

Participants included 97 mothers ($M_{\text{age}}=41.36$ years, $SD_{\text{age}}=9.60$ years) of children diagnosed with SMS. A demographic questionnaire was used to gather information

regarding gender, race/ethnicity, level of education achieved, level of education desired, income, number of children in the family, age of the child with SMS, employment status, current occupation, and occupation desired. As shown in Table 1, among participating mothers, 93.8% were White/Caucasian, 92.7% had attended at least some college, 62.8% had a household income of more than \$60,000 per year, and 77.3% were married. Eighty-two of 97 mothers (84.5%) reported having multiple children. Mothers reported the average age of their child with SMS was 12.91 years ($SD=9.04$). The children were predominantly female (58.0%) and Caucasian/White (90.0%). Additional demographic and instrumentation information can be found in Foster et al. (2010).

Measures

Parental Sense of Competence Scale (PSOC) (Gibaud-Wattston and Wandersman 1978). The PSOC contains 17 items answered on a 6-point Likert scale (1 = strongly disagree, 6 = strongly agree) that assess parenting satisfaction and self-efficacy. Higher scores indicate greater parenting self-esteem. Wording was modified from mother or father to reflect a more general caregiver role. Sample items included: “Being a caretaker is manageable, and any problems are easily solved” and “I honestly believe I have all the skills necessary to be a good caretaker to my child.” The PSOC has been utilized to assess parenting competency among parents of typically developing children as well as parents of children with intellectual disabilities (Hassall et al. 2005; Johnston and Mash 1989). High internal consistencies have been reported for the subscales (α coefficient of .82 for satisfaction and .70 for self-efficacy) (Gibaud-Wattston and Wandersman 1978). Cronbach’s α for this study was .74 for caregiver satisfaction and .78 for caregiver self-efficacy.

Center for Epidemiologic Studies-Depression Scale (CES-D) The CES-D is a 20-item global scale developed to measure depressive symptomology in the general population (Radloff 1977). A Likert scale for each item is scored from 0 (rarely or none of the time) to 3 (most or all of the time) to produce a range of possible scores from 0 to 60. Scores ranging from 0 to 15 indicate *minimal* depressive symptoms, 16–23 *mild* depressive symptoms, and ≥ 24 *moderate/severe* depressive symptoms (Rushton et al. 2002). Sample items included: “I felt that I was just as good as other people” and “I felt hopeful about the future.” Reliability and validity of the scale have been tested in both general and clinical populations, yielding very good internal consistency for the general population ($\alpha=.85$) and a psychiatric population ($\alpha=.90$) (Radloff 1977). Acceptable discriminate and concurrent validity have been reported for the CES-D using community and psychiatric samples (Weissman et al. 1977). Cronbach’s α for this study was .93.

Sleep Questionnaire Participants are asked to complete a sleep questionnaire (Maas 1998). This 14-item questionnaire asks mothers to explore their sleep behaviors specifically related to how fatigued they feel throughout the day using true/false responses. Sample items include “It’s a struggle for me to get out of bed in the morning” and “I feel slow with critical thinking, problem-solving, and being

Table 1 Participant demographics

Variable	<i>n</i> (%)
Race/Ethnicity	
Caucasian/White	91 (93.8%)
Latino/Hispanic	3 (3.1%)
African American/Black	2 (2.1%)
Biracial/Multiracial	1 (1.0%)
Current age ^a	
26–39	40 (41.7%)
40–59	51 (53.1%)
60 or older	5 (5.2%)
Age at birth of oldest child ^a	
Under 18	4 (4.2%)
18–25	40 (41.7%)
26–39	51 (53.1%)
40 or older	1 (1.0%)
Highest Level of Education Completed ^a	
High school	7 (7.3%)
Some college	29 (30.2%)
Associate's degree	14 (14.6%)
Bachelor's degree	25 (26.0%)
Some graduate school	6 (6.3%)
Graduate/professional degree	15 (15.6%)
Annual Household Income ^b	
Less than \$15,000	2 (2.1%)
\$15,000–\$24,999	3 (3.2%)
\$25,000–\$34,999	6 (6.4%)
\$35,000–\$44,999	11 (11.7%)
\$45,000–\$59,999	13 (13.8%)
More than \$60,000	59 (62.8%)
Marital Status	
Married	75 (77.3%)
Single	5 (5.2%)
Divorced	12 (12.4%)
Separated	1 (1.0%)
Living with parent of child w/SMS	3 (3.1%)
In contact with other parent	1 (1.0%)

Portions of this table are published in Foster et al. (2010). *n*=97

^a 1 participant chose not to answer this question

^b 3 participants chose not to answer this question

creative.” The greater the number of items endorsed, the greater the likelihood of fatigue and possible sleep-related problems. Cronbach’s α was .69 for this study.

Caregiver Well-Being Scale Tebb’s (1995) Caregiver Well-Being Scale is built on a health-strengths model (Weick 1986) that asks participants to rate their level of well-being on a Likert scale of 1 (never) to 5 (always). The scale was created based upon a sample of individuals caring for adults or children who were either disabled, severely developmentally delayed, or chronically ill as well as caregivers of typically developing children. Sample items included: “I feel that I am able to express laughter and joy” and “I feel that I am able to attend to medical and dental needs.” Berg-Weger and colleagues (2000) reported an α coefficient of .91 for the basic needs subscale (22 items) and an α coefficient of .81 for the activities of living subscale (23 items; Berg-Weger et al. 2000). The overall α coefficient was .94. Convergent and discriminant validity were verified with a correlation of .69 between the two subscales. Construct validity is established through factor analysis while criterion validity is supported through the concurrent validity of this measure to a measure of depression. The overall Cronbach’s α for this study was .96.

Educational and Occupational Status Mothers were asked to provide information concerning the highest level of education obtained, the highest level of education they would like to obtain, their current occupation, and the ideal occupation they would like to achieve. Educational responses were provided on 6-point Likert-scale (1 = less than a high school diploma, 6 = graduate/professional degree). Occupational responses were provided in an open-ended response format and categorized based on the U.S. Department of Labor’s Standard Occupational Classification (SOC) system (2010).

Occupational Satisfaction A 5-item measure (Greenhaus et al. 1990) was used to assess occupational satisfaction among mothers. This 5-item measure utilizes a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree). Sample items included “I am satisfied with the success I have achieved in my career/occupation” and “I am satisfied with the progress I have made toward meeting my overall career/occupational goals.” Cronbach’s α for this scale has been reported at α =.80 (Greenhaus et al. 1990); Cronbach’s α for this study was .94.

Data Analyses

This study aimed to explore education and occupational aspirations and challenges faced among mothers caring for a child diagnosed with SMS. Descriptive statistics, correlations, and Pearson chi-square comparisons were utilized to explore aspects of education and occupational attainment, goals, and satisfaction. Hierarchical regression analyses were utilized to examine ways in which caregiver well-being, perceptions of caregiver competence (care giving satisfaction and self-efficacy/confidence), sleep behaviors, and symptoms of depression may relate to occupational satisfaction.

Results

Correlational Analyses

Significant relationships between occupational satisfaction and other demographic and psychosocial variables under investigation were assessed and are shown in Table 2. A significant difference in occupational satisfaction was observed as a function of the highest level of education obtained ($\eta=.49$, $p=.001$), with those obtaining a high school degree or high school equivalency reporting the lowest occupational satisfaction ($M=11.50$, $SD=5.09$) and those reporting some graduate school level training endorsing the highest level of occupational satisfaction ($M=22.83$, $SD=2.40$). Greater occupational satisfaction was associated with higher income ($r=.31$, $p=.004$), feeling less depressed ($r=-.28$, $p<.01$), and feeling more rested ($r=.22$, $p<.05$). Mothers who reported being more satisfied with their occupations also reported feeling more satisfied with their care giving role ($r=.43$, $p<.001$) and having greater caregiver well-being ($r=.49$, $p<.001$).

Education

The highest level of education achieved by the participants and their educational goals were compared to determine how many mothers wanted to further their education. As shown in Table 1, seven mothers (7.3%) completed high school or earned a high school equivalency, 29 (30.2%) completed some college, 14 (14.6%) earned an associate's degree, 25 (26.0%) earned a bachelor's degree, 6 (6.3%) earned some graduate level credits, and 15 (15.6%) held graduate or professional degrees. Overall, 55% of mothers reported a desire to further their education. At each level of education achieved, with the exception of those obtaining graduate or professional degrees, 50% or more of the mothers desired to further their education (Fig. 1). For example, among mothers whose highest level of education was a high school diploma or high school equivalent, 57% reported a desire to advance their formal educations. For those who had obtained an associate's degree, 64% stated that they would like additional education.

The age at which mothers had their first child was assessed to explore relations between having a child and educational attainment. For the mothers who had their

Table 2 Intercorrelations among psychosocial variables

Variable	1	2	3	4	5	6
1 Occupational Satisfaction	–					
2 Depression	-.36***	–				
3 Sleep	.22*	-.52***	–			
4 Caregiver Well-Being	.49***	-.76***	.50***	–		
5 Caregiver Satisfaction	.43***	-.58***	.43***	.60***	–	
6 Caregiver Self-Efficacy	.20	-.46***	.29**	.43***	.39***	–

$n=97$; * $p<.05$, ** $p<.01$, *** $p<0.001$

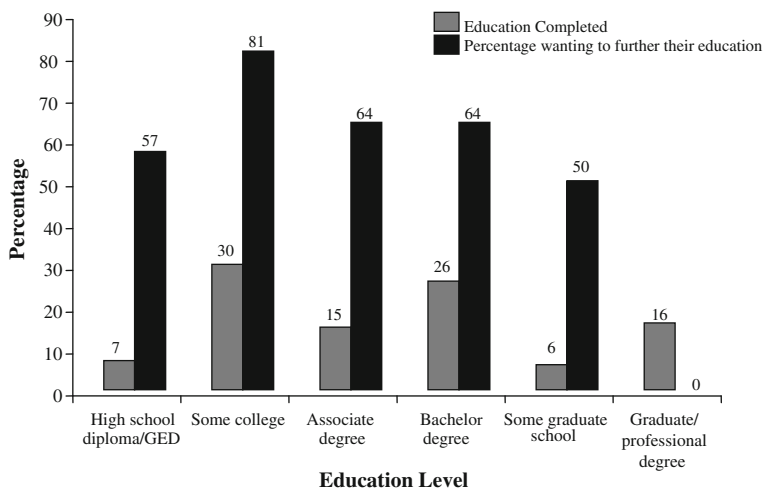


Fig. 1 Education attainment and goals. Level of education attained by mothers of children with Smith-Magenis syndrome (*gray*). The percentage of women in those categories who would like to further their education is shown in *black*

first child as adolescents (i.e., less than 18 years old, $n=4$), 100% have obtained some college credits. For the mothers who were emerging adults (i.e., ages 18 to 25, $n=40$) when they had their first child, 82% attained a high school education or some college credits, while 18% have obtained a degree (associate, bachelor, or graduate degree). Data show that of the mothers who were young adults (i.e., ages 26 to 39) or adults (ages 40 or older) when they had their first child, 16% attained a high school education or some college credits, while 84% obtained a degree. The data indicate that mothers who had their first child after age 25 were more likely to obtain a college degree than mothers who had a child as adolescents or emerging adults ($\chi^2=34.53, p=.003$). In other words, mothers who have their first child at an older age (i.e., after the completion of emerging adulthood) are more likely to have completed a college degree than those who have children during what are typically considered high school and college years (i.e., adolescence and emerging adulthood). The age of the mothers at the birth of their first child was unrelated to the mothers' educational goal ($\chi^2=14.42, p=.49$). Furthermore, mothers' age at the birth of her child diagnosed with SMS was also unrelated to mothers' education obtained ($\chi^2=16.45, p=.09$) and her reported educational goals ($\chi^2=5.36, p=.86$).

Occupations

Mothers were asked to indicate their current occupation and their occupational goals. The occupations reported (current and desired) by the participants comprised 16 out of the 23 major occupational categories based on the U.S. Department of Labor's Standard Occupational Classification (SOC) system (2010). Table 3 depicts a comparison of the 74 out of 97 mothers who reported both their current occupation and desired occupation. These percentages were also compared to the national averages of females over age 16 currently working in various occupational categories, as indicated by the U.S. 2008 census data (U.S. Census Bureau, 2008).

The categories with the highest representation of current occupations among mothers of children diagnosed with SMS included Personal Care and Related Occupations (31.1%), Education, Training, and Library Occupations (9.5%), Office and Administrative Support Occupations (10.8%), Management Occupations (13.5%), and Healthcare Practitioners and Technical Occupations (10.8%). By comparison, within the SOC national sample of females, 2.6% reported Personal Care and Related Occupations, 4.2% reported Education, Training, and Library Occupations, 10.6% reported Office and Administrative Support Occupations, 3.6% reported Management Occupations, and 3.7% reported Healthcare Practitioners and Technical Occupations.

Of the 74 mothers who reported their occupational goal, 45% of the mothers indicated that they desired an occupation outside of their current profession. Within the Personal Care & Related Occupations category, 87% of the participants indicated that their current occupation is Homemaker, and 13% stated they are Daycare Providers. Interestingly, this category was noted to have the largest decrease from

Table 3 Comparison of mothers' current occupations, occupational goals, and national averages

Occupational code	Current occupation $n=74$ (%)	Occupational goal $n=74$ (%)	National average of females 16 and over $n=143,195,793$ (%)
Architecture and Engineering	5.4	1.4	.3
Arts, Design, Entertainment, Sports, and Media	2.7	5.4	.9
Business and Financial Operations	1.4	1.4	2.4
Community and Social Services	1.4	6.8	1.0
Computers and Mathematics	1.4	1.4	.6
Education, Training, and Library	9.5	16.2	4.2
Food Preparation and Service Related Occupations	2.7	1.4	3.0
Healthcare Practitioners and Technical Occupations	10.8	17.6	3.7
Healthcare Support	1.4	4.1	2.0
Legal	2.7	1.4	.6
Life, Physical, and Social Science	0	1.4	.4
Management	13.5	16.2	3.6
Military	1.4	0	^a
Office and Administrative Support	10.8	4.1	10.6
Personal Care & Related Occupations	31.1	17.6	2.6
Sales and Related Occupations	4.1	4.1	5.6

^a National Census Data included only the Civilian Employed Population

mothers' current occupation to their occupational goal. Of these participants, 56.5% indicated that their occupational goal was outside of the Personal Care Occupations category. More specifically, of the 56.5% of mothers in Personal Care Occupations who reported a desire to change occupations, 53.8% reported a desire to be in Healthcare Practitioners or Support Occupations with 23.1% reporting a desire to go into Education, Training, and Library Occupations, 15.4% reporting a desire to go into Arts, Design, Entertainment, Sports and Media Occupations, and 7.7% reporting a desire to go into Community and Social Services Occupations.

Occupational Satisfaction

Participants were asked to indicate their occupational satisfaction to date. Among these mothers, 34.1% reported low occupational satisfaction, 29.4% reported moderate occupational satisfaction, and 36.5% reported high occupational satisfaction. A hierarchical regression analysis (Table 4) was conducted to explore potential caregiver-related variables including caregiver well-being, caregiver satisfaction, caregiver self-efficacy, depression symptoms, and fatigue, which may be significantly related to self-reported occupational satisfaction. Based on significant correlational analyses, education obtained and household incomes were considered as covariates. The entire model was found to be significant, $F(7, 74)=5.42, p<.001$, and accounted for 34% of the variance in caregiver well-being ($R^2=.34$). Caregiver well-being, caregiver satisfaction, caregiver self-efficacy, depressive symptoms, and fatigue significantly predicted the changes in occupational satisfaction beyond the influence of education and income, $\Delta F(5, 74)=4.93, p=.001$. Together, caregiver well-being, caregiver satisfaction, caregiver self-efficacy, depressive symptoms, and fatigue accounted for 28% of the variance in caregiver well-being ($\Delta R^2=.28$). Independently, occupational satisfaction was directly influenced by caregiver satisfaction, $B=.23, p=.04$, which accounted for 4.0% of the unique variance in occupational satisfaction ($sr^2=.04$), and caregiver well-being, $B=.09, p=.01$, which accounted for 6.2% of the unique variance in caregiver well-being ($sr^2=.06$).

Discussion

Raising a child with developmental disabilities can add significant demands on parents and families that affect career and occupational choices and opportunities, as well as day-to-day activities and needs for the individual and family. Smith-Magenis syndrome (SMS) represents a complex developmental disorder that has a consistent behavioral phenotype across those affected, including a chronic sleep disorder that begins at approximately 18 months of age and continues throughout the lifespan (Elsea and Girirajan 2008). This sleep disorder is at the root of the behavioral problems, which include aggressive and self-injurious behaviors, such as nail-yanking, skin-picking, and head-banging, obsessive and compulsive behaviors, eating disorder, and violent temper tantrums (Elsea and Girirajan 2008). The consistent behavioral phenotype found in SMS makes this population unique for assessing the effects of life-long care for a person with a complex developmental and behavioral disorder. The overarching goal of this study was to examine the

Table 4 Summary of hierarchical regression analysis for influences of caregiver well-being, caregiver satisfaction, caregiver self-efficacy, depressive symptoms, and fatigue on occupational satisfaction

Variable	<i>B</i>	<i>SE B</i>	β	<i>sr</i> ²
Step 1				
Highest Level of Education Completed	.55	.44	.14	.02
Annual Household Income	1.40*	.54	.29*	.08*
Step 2				
Highest Level of Education Completed	.27	.42	.07	.00
Annual Household Income	1.25*	.48	.25*	.06*
Caregiver Satisfaction	.23*	.11	.26*	.04*
Caregiver Self-efficacy	-.08	.12	-.07	.00
Fatigue	-.14	.23	-.07	.00
Caregiver Well-being	.09*	.04	.41*	.06*
Depression	.05	.08	.10	.00

$R^2 = .12$ for Step 1 ($p = .007$); $\Delta R^2 = .28$ for Step 2 ($p = .001$). * $p < .05$

educational and occupational choices and effects among mothers caring for a child with SMS and how those choices and opportunities are related to occupational satisfaction.

The first two primary research questions from this study sought to (1) identify the current educational levels attained and occupations held by mothers with a child diagnosed with SMS and (2) explore the mothers' educational and occupational goals. Data showed that, with respect to education, nearly all mothers had completed at least some college credits, with 48% obtaining a bachelor's degree or beyond. Although all mothers in our sample were able to earn at least a high school education, those who were older when their first child was born were significantly more likely to go on to higher education and earn college degrees. Our results are consistent with population based studies in the U.S., which also reported that mothers who delay child birth until age 30 or later were significantly more likely to have completed 12 or more years of education and that these educational rates have continued to increase over the past 30 years (Heck et al. 1997; Klepinger et al. 1995). The majority of mothers also reported a desire to further their educations, which may suggest that these mothers feel inadequately fulfilled in their care giving roles or meeting other life goals.

With respect to current occupations held by mothers of children with SMS, as delineated by the U.S. Department of Labor's Standard Occupational Classification (SOC) system (2010), participants most often reported an occupation within the Personal Care and Related Occupations category (31.1%), with the majority of these mothers reporting they were homemakers (87%) or daycare providers (13%). A significant number of mothers also reported occupations in Education, Training, and Library Occupations, Office Administrative Support Occupations, Management Occupations, and Healthcare Practitioners and Technical Occupations. When looking more closely at those reporting Personal Care and Related Occupations, the large percentage of mothers with a child diagnosed with SMS reporting these occupations

is significantly greater than the percentage of females aged 16 or greater in the general U.S. population indicating such occupations, with only 2.6% of the general population fitting into this category. This significant difference is consistent with research indicating that in families with children with developmental disabilities, mothers often quit their jobs or reduce their work hours to work as homemakers or daycare providers (i.e., Personal Care Occupations) until their children were older and/or had established formal educational or care giving services that enabled the mothers to return to work (Freedman et al. 1995; Parish 2006). Moreover, a large portion of mothers who are currently in the Personal Care occupations indicated that they wanted to change occupations, with more than half expressing interest in Healthcare Practitioners or Support occupations. Overall, the percentage of those expressing a desire to work in both Healthcare fields increased well beyond the national average. However, this is consistent with research, which finds that having a child with a development disability influence parents' occupation decisions. Freedman and colleagues found that parents often switched occupations to Healthcare or Education fields because of their own experiences and interactions with personnel in these fields (1995).

The third primary question examined through this research evaluated how occupational satisfaction related to demographic factors such as age and education level and psychosocial factors such as symptoms of depression and anxiety, quality of sleep, caregiver satisfaction, caregiver self-efficacy, and caregiver well-being. Mothers varied significantly with respect to self-reported occupational satisfaction, with approximately one-third reporting high satisfaction, one-third reporting moderate satisfaction, and one-third reporting low satisfaction. Several factors were identified as being related to occupational satisfaction. Mothers with higher household incomes, better quality of sleep, and fewer symptoms of depression and anxiety reported higher occupational satisfaction. The data also suggested that occupation satisfaction is an important factor for the caregiver, such that higher occupation satisfaction relates closely to higher caregiver well-being and higher caregiver satisfaction. In the regression model, caregiver satisfaction appeared to be especially salient in relation to occupational satisfaction such that those who were more satisfied as caregivers also found greater satisfaction in their occupations. This finding is significant when considering the potential positive impacts on family and individual functioning when caregivers feel satisfied in their caregiving roles and career development.

Limitations of this study included sample size and bias within the sample. The sample represented an estimated 20% of the registered parents of PRISMS, the SMS support group. Not only does this equate to a relatively small sample size as compared to the possible number of parents who had the opportunity to participate, given the online anonymous survey approach utilized for data collection, there is no way to know how those who chose to participate may have varied from those who did not. The sample represented in this study is well-educated, with almost 50% reporting that they have attained a bachelors degree or higher. Furthermore, the majority of participants were married and financially stable. Such individuals are likely to have better access to support services for themselves and their child. Interestingly, however, these parents continue to report significant desires to achieve more with respect to educational and occupational goals. It is possible that those

who chose not to participate are significantly different from those who participated in both demographic backgrounds and perceptions of their educational and occupational attainment. While the identified limitations make generalization of results challenging, this exploratory study provides a solid foundation upon which to consider further studies and possible interventions aimed at supporting parents of children with SMS in both their caregiving efforts and the attainment of educational and occupational goals.

In summary, Smith-Magenis syndrome is a complex neurological disorder that, like many disorders, includes intellectual disabilities; however, the complex behavioral issues make SMS distinct from other neurodevelopmental syndromes. Persons with SMS have severe sleep disturbances, with nighttime awakenings and frequent daytime napping, complicating normal rest and activity for caregivers. In addition, self-injurious behaviors are common, as are rage attacks/outbursts and attention seeking behaviors, which further disrupt regular occupational activity and the mental health of the caregiver. Finding employment that is satisfying, flexible, and supportive of the complex family situation is a challenge for most caregivers.

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