

## Chapter 27

# Teaching Menstrual Care to a Student With Autism Spectrum Disorder in a School Setting

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### EXECUTIVE SUMMARY

*There is a lack of training for parents, school staff, and residential staff aimed at helping persons with intellectual disabilities acquire menstrual self-care skills. This may be due in part to the sensitive nature of this topic, the aversion to performing menstrual care for individuals with a disability, and the lack of empirically supported training protocols. This chapter critically reviews behavior analytic research on menstrual care that has been published in peer reviewed journals. This is followed by a case illustration using behavior analytic methods to teach menstrual self-care skills for a student with autism spectrum disorder in a public school setting. Evaluated using a multiple baseline across behaviors design, it was shown that the student increased her independent performance of selected menstrual self-care skills.*

### INTRODUCTION

While consulting as a Behavior Analyst to public school Autism programs, I would continuously run into issues in Middle Schools about who was going to teach the students menstrual care skills. Typically, information on menstrual care is learned through television commercials, pamphlets, books, magazines, family members, and through health class in school. For students who do not learn through these methods, or have access to this information due to restricted educational settings, menstrual care education is limited or completely missing. Within the Middle schools with whom I consulted, some school staff suggested that it was the nurse's, the teacher's, or even the occupational therapist's responsibility to teach students menstrual care skills. I ran into this problem across many schools and in many different states, and could never find a clear solution or a curriculum to follow. This chapter presents the research literature on teaching menstrual care and a case study in which menstrual care was taught to a young girl with autism spectrum disorder (ASD) and intellectual disabilities (ID).

DOI: 10.4018/978-1-6684-3542-7.ch027

## **LITERATURE REVIEW**

In my quest to find a solution, I searched the research literature. A survey of school nurses supported the thought that menstrual care instruction should be provided by teachers (Tse & Opie, 1986), though no study was found on teachers' perception of who should teach the skill. A study by Rodgers (2005) found that younger individuals with intellectual disabilities, aged 15-24, were being taught menstrual care by teachers, which could reflect a pattern of young people being cared for at home in recent years. By remaining at home instead of residential facilities, public schools are increasingly receiving these individuals as students and have the responsibility to provide menstrual care instruction in the school setting. Early studies on menstrual care were conducted in residential facilities (Hamilton, Allen, Stephens, & Davall, 1969; Hamre-Nietupski, & Williams, 1977; Richman, Reiss, Bauman, & Bailey, 1984), with more recent studies conducted in school settings (Altundağ, & Çalbayram, 2016; Epps, Stern, & Horner, 1990; Richman & Ponticas, 1986) or in a home setting taught by school staff (Ersoy, 2009). Rodgers and Lipscombe (2005) found that younger individuals were more likely to have been taught to manage their own menstrual care, and were significantly more likely to have been taught menstrual care by a teacher, than individuals a decade older.

The lack of systematic teaching procedures for parents, school, and residential staff may be due to lack of training and the aversion of performing menstrual care for, or with, the individual with ID. Carlson and Wilson (1996) showed that only 5-24 percent of residential care staff had received any training about menstrual care for individuals with high support needs; the remaining 76-95 percent had not received any training (Rodgers & Lipscombe, 2005). Occupational Therapy (OT) literature provides some input on training in menstrual care for those with intellectual and other disabilities, but OT textbooks do not refer to this issue nor provide training (Carlson, 2002).

Medical and cultural attitudes toward individuals with ID play a primary role in menstrual care practices (Servais, 2006). A study by Carnaby and Cambridge (2002) showed an aversion to providing menstrual care by staff via a rating scale. Staff had consistently high ratings (dislike) for intimate care, with menstrual care rating the highest for the day unit. Providing menstrual care, and other intimate care, can be considered 'dirty work' and is undervalued both by service providers and by the wider society (Wolf, 1986 as cited in Clark, 2006). This aversion to menstrual care training may be part of the reason for the lack of research and training in the area of menstrual care training.

## **Daily Living Skills**

Adolescents with ASD or ID often have difficulty learning to independently perform daily living skills. Independent daily living skills are pivotal skills that enhance the quality of life and independence of individuals with disabilities (Ferretti, Cavalier, Murphy, & Murphy, 1993), and are integral to everyday routines, including the skill of menstrual care.

A study by Rodgers and Lipscombe (2005) reported that females who could dress themselves independently or with assistance, were taught menstrual care 200 percent more often than those who could not. According to the US Census Bureau (2017), 193,401 females aged 5-17 years old have a self-care disability in the United States. A self-care disability is identified as having difficulty dressing or bathing (US Census Bureau, 2017). A significant number of individuals with disabilities will require support from caregivers to complete daily living skills. Therefore, an indicator that an individual may require

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