Use of menstrual suppression

Report by the Victorian Senior Practitioner

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Introduction

According to the *Disability Act 2006* menstrual suppression is a reportable chemical restraint if it is used to stop behaviours of concern and is not treatment for an underlying health issue. The Victorian Senior Practitioner team monitored the use of menstrual suppression as a restrictive intervention from 2008 to 2019. Every month service providers must report their use of chemical restraint.

The Office of the Victorian Senior Practitioner has previously undertaken work to develop resources for reducing the use of menstrual suppression: *Reducing menstrual suppression for women with an intellectual disability in Victoria: A resource for support workers and disability services* (available by emailing the Office of the Victorian Senior Practitioner <victorianseniorpractitioner@dhhs.vic.gov.au>), as well as collaborating with the Centre for Developmental Disability Health Victoria to develop two menstrual management guides for carers and GPs (available at Resources – Centre for Developmental Disability Health website <https://www.cddh.monashhealth.org/index.php/resources>).

There is a lack of information around why menstrual suppression is used, and if disability service provider staff are trained in other methods of managing individuals' menstrual cycles (Carlson and Wilson, 1996).

The current menstrual suppression project was undertaken to report on the factors associated with menstrual suppression use for females with a disability reported to the Victorian Senior Practitioner. This report contains the following information:

- data from the Restrictive Intervention Data System (RIDS) of females subject to menstrual suppression
- results of legislative compliance audits of females subject to menstrual suppression
- discussion of known risks involved in menstrual suppression.

Method

RIDS data

Information was gathered about all people (*n=82*) subject to menstrual suppression reported as chemical restraint on RIDS between 1 July 2018 and 30 June 2019. The information gathered included:

- the type of contraceptive/device used, including generic and active ingredient
- the age of people subjected to menstrual suppression at the end of the captured time period
- the number of years people have been subjected to menstrual suppression
- any other restraints implemented additional to menstrual suppression.

Legislative review and identifying themes for use

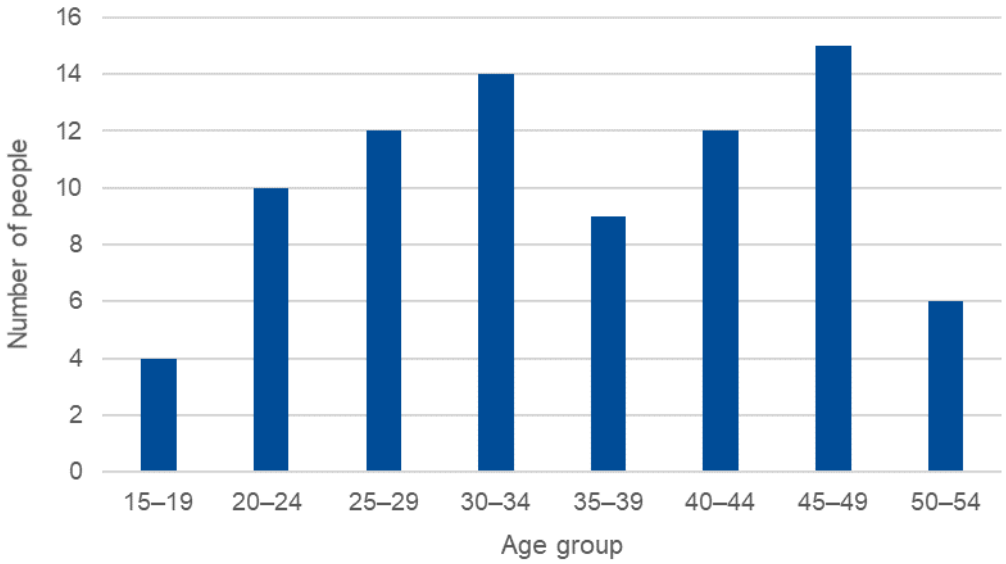
A selection (*n=23*) of behaviour support plans (BSPs) were evaluated for legislative compliance with the *Disability Act 2006*. Themes of use of menstrual suppression were also identified in BSPs for these people.

Findings

Reported data on RIDS

The average age of the study cohort (*n=82*) as of 30 June 2019 was 35.6, with an age range of 16–53 (See Figure 1). There was no apparent correlation between increasing age and use of menstrual suppression.

Figure 1: Number of people in the study cohort by age group

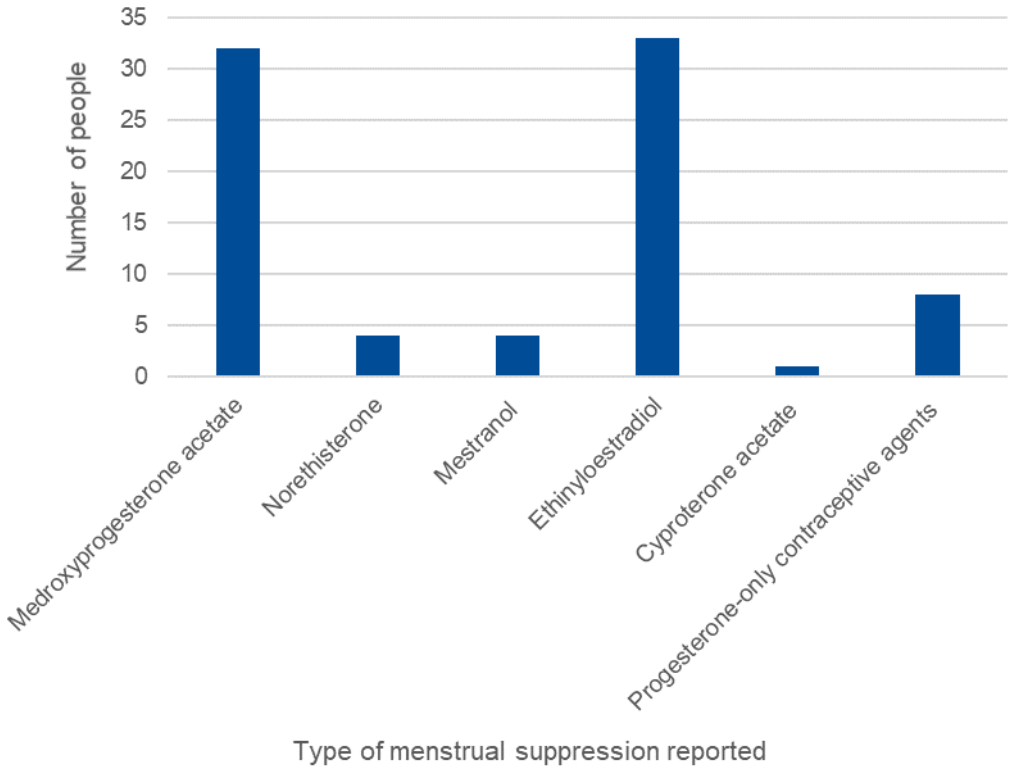


The types of contraceptives/devices used varied among the study cohort and included:

- medroxyprogesterone acetate (Depo-Provera, Depo-Ralovera Provera) (*n=32*)
- norethisterone (Primolut N) (*n=4*)
- mestranol (Norinyl-1) (*n=4*)
- ethinyloestradiol (Brevinor, Brevinor-1, Synphasic, Levlen ED, Microgynon 30, Microgynon 30 ED, Microgynon 50 ED) (*n=33*)
- cyproterone acetate (*n=1*)
- progesterone-only contraceptive agents (Levonorgestrel, Etonogestrel, Norethisterone) (*n=8*).

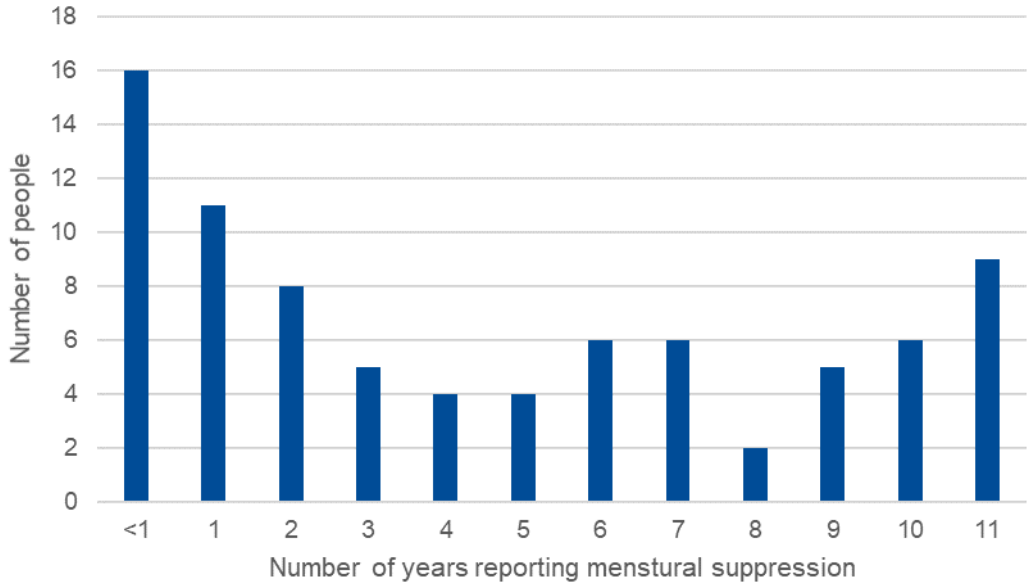
The majority of the study cohort were either reported as being subject to the use of medroxyprogesterone acetate (Depo-Provera or Depo-Ralovera Provera), which is a contraceptive injection, or ethinylestradiol, which is commonly used in the oral contraceptive pill. The average age of those reported as being subject to the use of medroxyprogesterone acetate was 39 years, while the average age of those reported as being subject to the use of ethinylestradiol was 32 years.

Figure 2: Number of people in the study cohort by type of menstrual suppression reported



Information about the length of time each person was reported as being subject to the use of menstrual suppression was gathered. This information could only be identified from 2007 onwards, following the introduction of the *Disability Act 2006* and the RIDS reporting system. The length of time people in the study cohort were reported as being subject to the use of menstrual suppression ranged from less than one year (since July 2018) to 11 years (from commencement of reporting requirements in July 2007).

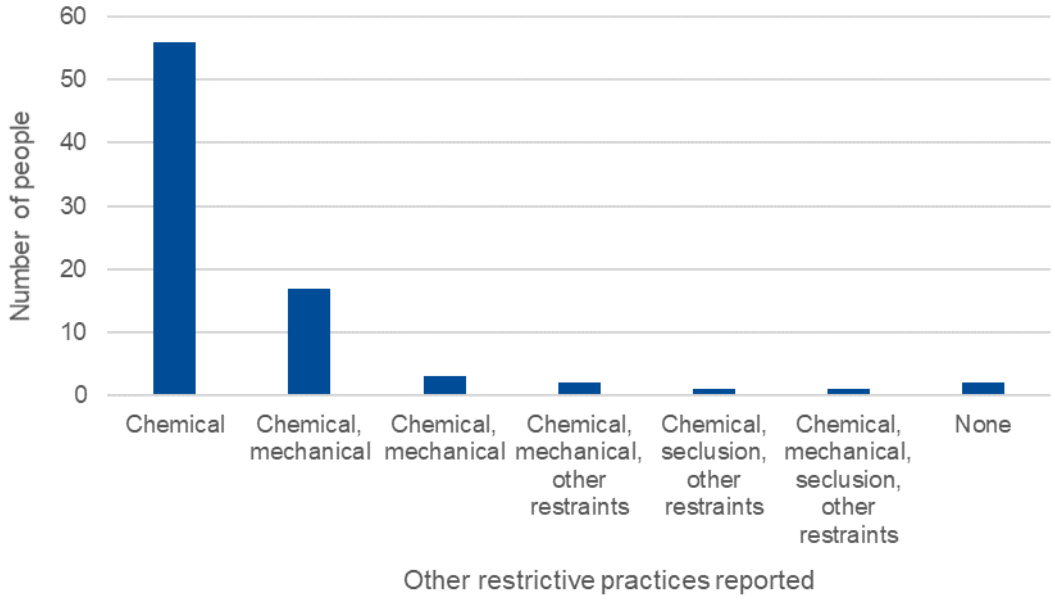
Figure 3: Number of people in the study cohort by number of years reported as being subject to the use of menstrual suppression since July 2007



The people in the study cohort also reported as being subject to the use of a range of other restrictive practices during the time period they were also reported as being subject to the use of menstrual suppression as a chemical restraint. These restrictive practices included other chemical restraint, mechanical restraint, seclusion, other restraints (such as environmental), or a combination of these restraints.

The majority of people (*n=56*) were also reported as being subject to the use of other chemical restraints, both routine use and *pro re nata* (PRN). Only two people were reported on RIDS solely for the use of menstrual suppression, with no other restrictive practices in place.

Figure 4: Number of people in the study cohort by other restrictive practices reported



Common themes and legislative review

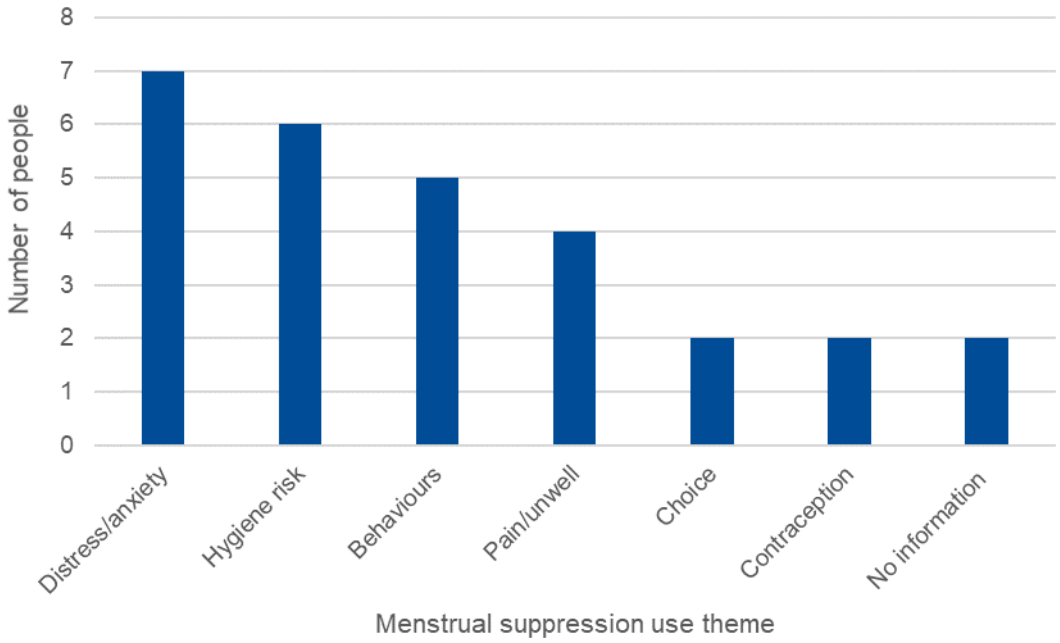
A selection of people (*n=23*) in the study were randomly selected to review their Behaviour Support Plan for common themes and legislative compliance.

Reported themes of menstrual suppression use in the BSPs were:

- to reduce distress or anxiety
- to reduce hygiene risk
- to address behaviours of concern related to menstruation
- to address pain or feeling unwell
- by choice of the person
- for contraception.

Though some uses of menstrual suppression were reported to be for the purpose of managing behaviours of concern (i.e. risk of harm to self or others), many were reported for other reasons (such as choice, distress or contraception), or no information was provided for purpose.

Figure 5: Prevalence in the BSP review cohort of menstrual suppression use themes



Note: Some BSPs included more than one theme.

In order to be compliant with the Disability Act, the following requirements must be met:

- Evidence is provided of physical harm to the person or another person.
- Evidence is provided of physical harm to the person or another person from property destruction.
- An explanation is provided of how the restraint or seclusion is used for behaviour support.
- An explanation is provided as to how the restraint or seclusion will be of benefit to the person.
- A demonstration is provided as to how the restraint or seclusion is least restrictive of the person as is possible in the circumstances.
- Physical restraint not being included in the behaviour support plan.
- The Independent Person is named.
- Emergency reporting of restrictive interventions has not exceeded indications of there being imminent risk of physical harm.
- The person with an intellectual disability is not being detained outside of the provisions of the Disability Act.
- The behaviour of concern listed in the behaviour support plan matches the behaviour category selected.
- The behaviour support plan has been reviewed and authorised by the disability service provider within the specified 12 months.
- The person is not active on RIDS without a behaviour support plan.
- Monthly reporting requirements have been met.

Five of the BSPs were identified as being non-compliant with legislation. All five that were non-compliant did not demonstrate how the restraint or seclusion is least restrictive of the person as is possible in the circumstances. One BSP was non-compliant with the first five points as listed above, as there was no behaviour of concern identified.

Risks and implications

Eighty percent of the study cohort reported being on menstrual suppression for over a year. A number of risks have been identified to be associated with long-term menstrual suppression. The most common forms of menstrual suppression reported, medroxyprogesterone acetate (Depo-Provera) and ethinyloestradiol (used in oral contraceptives), have significant long-term side effects associated with their use.

Depo-Provera decreases estrogen levels, which leads to reduced bone density and strength (Berenson, Breitkopf, Grady, Rickert, & Thomas, 2004). For those women who may not be able to exercise, or have limited exercise, there is an increased risk of losing overall bone strength. Reduced bone strength is likely to lead to bone fractures and breaks.

Taking the oral contraceptive pill (ethinyloestradiol) can increase the risk of blood clots by three to five times, which can cause heart attacks and stroke. Similarly, those who are unable to exercise, or have limited exercise, are at increased risk of blood clots (Trenor et al., 2011; Voelker, 2011).

Considering the prevalence of complex communication needs in this population, people may be unable to report pain or injury. This compounds the health risks, as people may be experiencing severe pain on a daily basis (Stallard, Williams, Lenton & Velleman, 2001).

Recommendations

- Front-line disability support workers should be trained in the long-term risks associated with menstrual suppression with the intention to encourage disability service providers to be aware of and manage health concerns that may arise due to menstrual suppression.
- The guide *Reducing menstrual suppression for women with an intellectual disability in Victoria* resource should be provided to disability service providers to inform on menstrual suppression and alternative strategies available other than menstrual suppression to manage identified concerns. A copy of the guide is available on request by emailing the Office of the Victorian Senior Practitioner <victorianseniorpractitioner@dhhs.vic.gov.au>.
- The guide *Supporting women: Information and resources for general practitioners supporting women with intellectual disabilities to manage their menstruation and associated menstrual disorders* <https://www.cddh.monashhealth.org/wp-content/uploads/2016/11/supporting-women-gp.pdf> should be provided to general practitioners.
- Disability services should develop processes to facilitate collaboration between the person, their family/decision maker, disability service provider and the prescribing doctor, in relation to the use of menstrual suppression. Disability service providers regularly report difficulty in reducing the use of menstrual suppression due to minimal involvement or opportunity for input to the process of prescription of medication. Research has shown that including all stakeholders from the outset is vital to reduce the use of chemical restraint (Shankar et al., 2019).

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