THE OHIO STATE UNIVERSITY

Occupational therapy's distinct value in promoting sexual health and menstrual hygiene

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Objectives

1. Identify the need for safe sexual health practices for individuals with intellectual and developmental disabilities.
2. Describe evidence-based practices for sexual health education.
3. Recognize *occupational therapy's role* in safe sexual health practices and menstrual hygiene management for individuals with *intellectual, developmental and physical disabilities and vision impairments*.
4. Identify strategies for effective sexual health education and menstrual hygiene management in various clinical settings for individuals with various disabilities.
5. Explain future directions for research and program development to promote safe sexual health practices for individuals with intellectual and developmental disabilities.

Intellectual & Developmental Disability (I/DD)

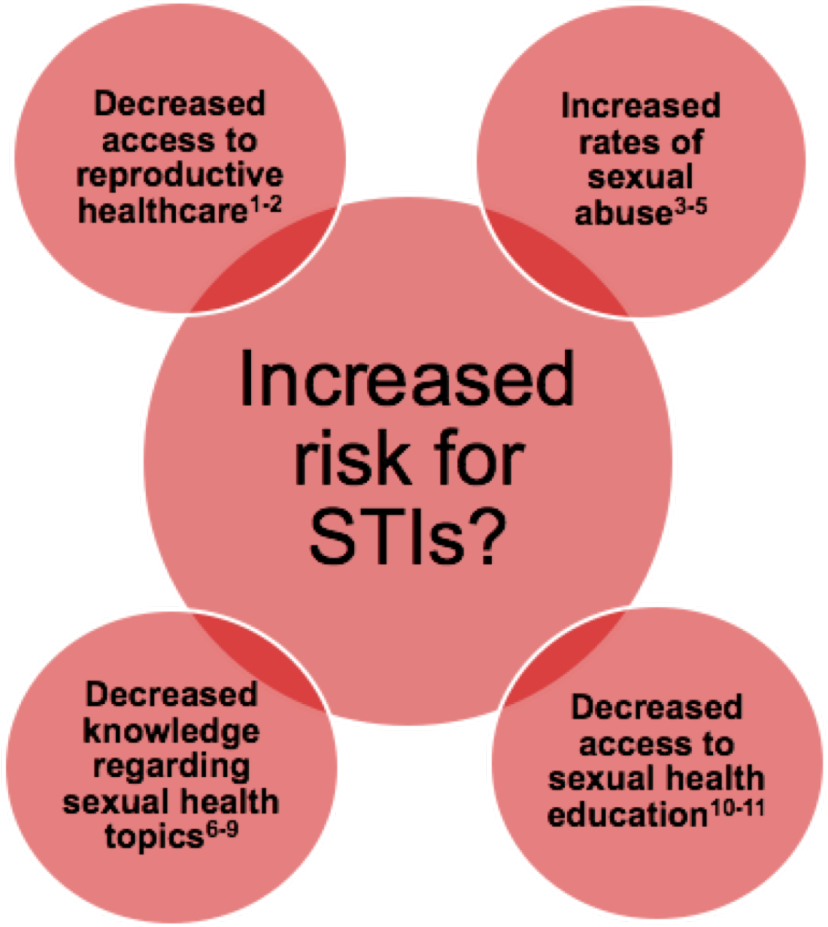
1. Limitations in intellectual functioning and adaptive behavior before the age of 18 years.
   a. Intellectual functioning includes conceptual skills
   b. Adaptive behavior covers social and practical skills

(American Psychiatric Association, 2013)

2. Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas before the age of 22 years.

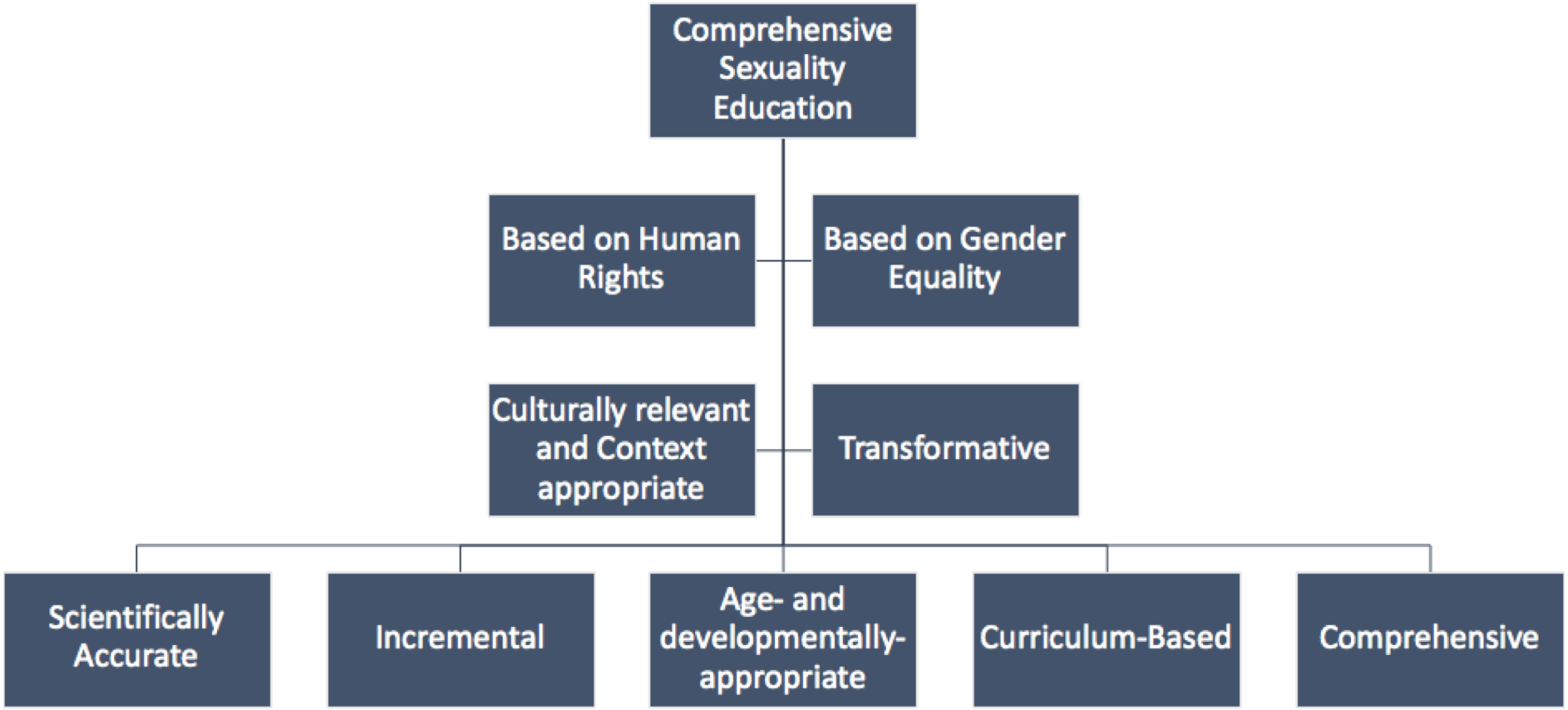
(Centers for Disease Control and Prevention, 2018)

Background



1-2: Greenwood & Wilkinson, 2013; Havercamp & Scott, 2015
3-5: Jones et al., 2012; Spencer, 2005; Sullivan & Knutson, 2000
6-9: McDaniels & Fleming, 2016; McGillivray, 1999; Conod & Servais, 2007; McCabe & Schreck 1992
10-11: Evans et al., 2009; Bernert & Ogletree, 2013

Best Practices for Sex Education



(United Nations Educational, Scientific and Cultural Organization, 2018)

Best Practices for Sex Education

- Teaching and learning about the cognitive, emotional, physical and social aspects of sexuality.
- It aims to equip children and young people with knowledge, skills, attitudes and values that will empower them to:
  - Realize their health
  - Well-being and dignity
  - Develop respectful social and sexual relationships
  - Consider how their choices affect their own well-being and that of others
  - Understand and ensure the protection of their rights throughout their lives.

(United Nations Educational, Scientific and Cultural Organization, 2018)

5.2 Overview of key concepts, topics and learning objectives

Key concept 1: Relationships	Key concept 2: Values, Rights, Culture and Sexuality	Key concept 3: Understanding Gender
Topics:	Topics:	Topics:
1.1 Families	**2.1** Values and Sexuality	**3.1** The Social Construction of Gender and Gender Norms
1.2 Friendship, Love and Romantic Relationships	**2.2** Human Rights and Sexuality	**3.2** Gender Equality, Stereotypes and Bias
1.3 Tolerance, Inclusion and Respect	**2.3** Culture, Society and Sexuality	**3.3** Gender-based Violence
1.4 Long-term Commitments and Parenting		

(United Nations Educational, Scientific and Cultural Organization, 2018)

Key concept 4: Violence and Staying Safe	Key concept 5: Skills for Health and Well-being	Key concept 6: The Human Body and Development
Topics: **4.1** Violence **4.2** Consent, Privacy and Bodily Integrity **4.3** Safe use of Information and Communication Technologies (ICTs)	Topics: **5.1** Norms and Peer Influence on Sexual Behaviour **5.2** Decision-making **5.3** Communication, Refusal and Negotiation Skills **5.4** Media Literacy and Sexuality **5.5** Finding Help and Support	Topics: **6.1** Sexual and Reproductive Anatomy and Physiology **6.2** Reproduction **6.3** Puberty **6.4** Body Image

Key concept 7: Sexuality and Sexual Behaviour	Key concept 8: Sexual and Reproductive Health
Topics: **7.1** Sex, Sexuality and the Sexual Life Cycle **7.2** Sexual Behaviour and Sexual Response	Topics: **8.1** Pregnancy and Pregnancy Prevention **8.2** HIV and AIDS Stigma, Care, Treatment and Support **8.3** Understanding, Recognizing and Reducing the Risk of STIs, including HIV

(United Nations Educational, Scientific and Cultural Organization, 2018)

What impact does this have?

Comprehensive sexual education is EFFECTIVE in:

- Delayed initiation of sexual intercourse
- Decreased frequency of sexual intercourse
- Decreased number of sexual partners
- Reduced risk taking
- Increased use of condoms
- Increased use of contraception

(United Nations Educational, Scientific and Cultural Organization, 2018)

OTs Role

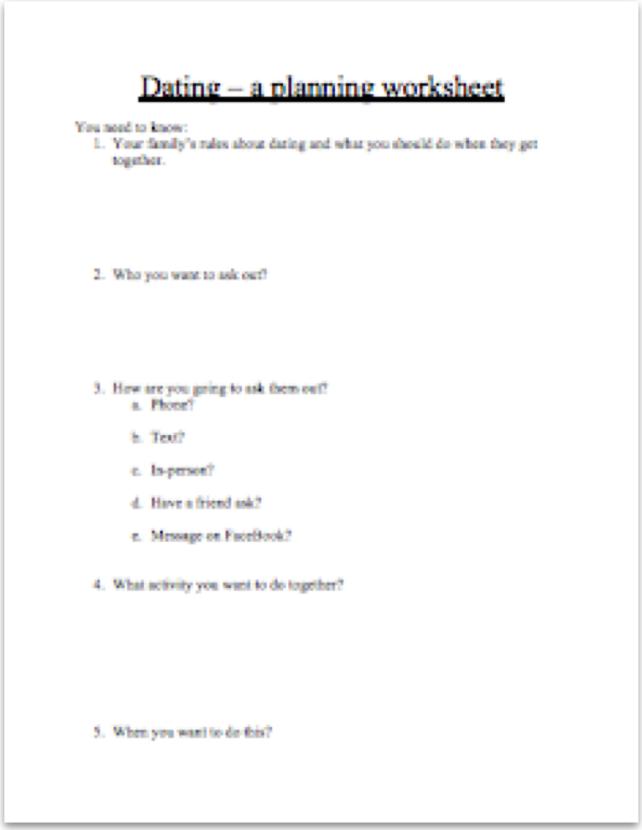
"An occupational therapist will try to find out why a client cannot do what they would like or need to do."

(Canadian Association of Occupational Therapy, 2016).

This should include sexual health and menstrual hygiene!

Intellectual Disability

- Impaired cognition
  → Impacts on communication, planning, asserting self (enthusiastic consent), and problem solving. May impact ability to identify and report unsafe situations.
  - Planning dates and possible sexual scenarios in advance
  - Environmental adaptations to reduce distractions



Dating – a planning worksheet

You need to know:
1. Your family's rules about dating and what you should do when they get together.

2. Who you want to ask out?

3. How are you going to ask them out?
   a. Phone?
   b. Text?
   c. In-person?
   d. Have a friend ask?
   e. Message on FaceBook?

4. What activity you want to do together?

5. When you want to do this?

Intellectual Disability

- Challenges with adaptive behavior

  → Decreased independence in ADLs specific to dating:

  - Hygiene
  - Dressing
  - Transportation
  - Self-Feeding & Cutting Food

Photo Source: https://slate.com/human-interest/2013/06/fork-and-knife-use-americans-need-to-stop-cutting-and-switching.html

Autism Spectrum Disorders

- Deficits in social communication & social interaction → Impacts social-emotional reciprocity, conversation skills, sharing of emotions, verbal and nonverbal communication, facial expressions and gestures
  - Social skills training
  - Education on relationships (types, boundaries)
  - Identification and understanding of emotions
  - Sexual self-advocacy training to explore, identify, and communicate their preferences

Autism Spectrum Disorders

- Restricted, repetitive interests → May impact speech, adherence to routines, intensity & focus of interests/conversations, and/or sensory processing
  - Social skill training; education on developing & maintaining relationships
  - Environmental adaptations; sensory processing differences
  - Exploration and identification of equipment that supports sensory needs: what to use, what to avoid

Down Syndrome

- Impaired attention → Impulsivity, poor judgment, short attention span
  - Sexual self-advocacy training/coaching, environmental adaptations to reduce distractions
- Hearing loss → May impact communication
  - Environmental adaptations to reduce distractions and improve accessibility on dates

Photo Source: https://www.someecards.com/love/dating-relationships/down-syndrome-couple-married/

Physical Disabilities

- Balance, Posture, Range of Motion, Spasticity & Strength → May impact trunk control/balance during sexual activities
  - Task-analyze different positions/equipment (leg restaints, bondage sets, sex slings)
- Grip, grasp, dexterity → May impact ability to put on a condom/penis
  - Education on sexual self-advocacy

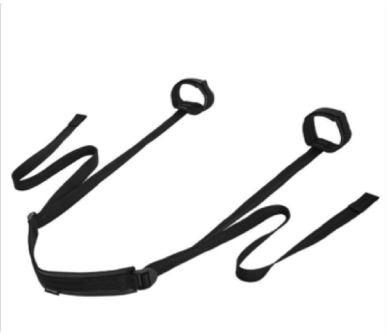
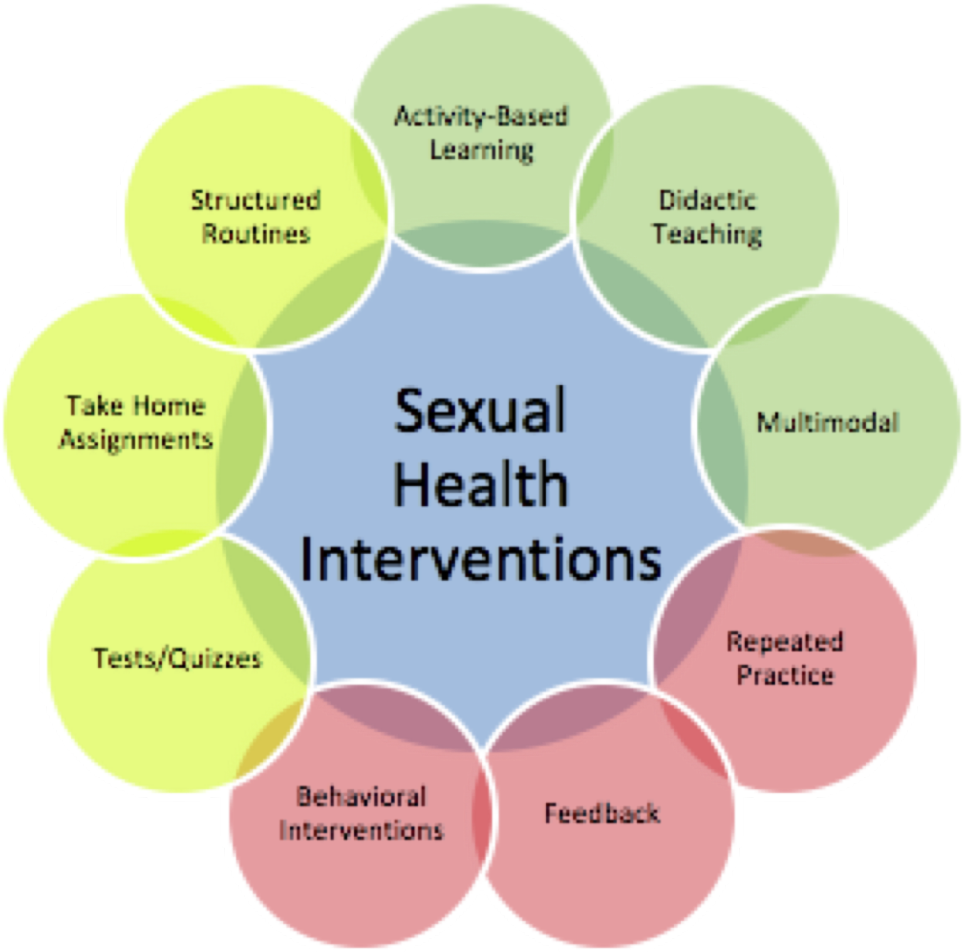


Photo Sources:
https://www.sportsheets.com/blogs/sex-blog/sex-with-cerebral-palsy-toys-comfortable-positions-keep-you-in-the-moment-2018-3-13;
https://www.sportsheets.com/blogs/sex-blog/maintaining-intimacy-quadriplegic-couples-guide-paralyzed-sex-2018-1-18

Evidence-Based Practices



(Schmidt, Brown & Darragh 2019)

Practice Recommendations

- Create a safe space!
- Accessible & inclusive evidence-based resources
  - Images & videos (Corona et al., 2016; Dekker et al., 2015; Garwood & McCabe, 2000; Visser et al., 2017)
  - Didactic teaching (Corona et al., 2016; Dekker et al., 2015; Garwood & McCabe, 2000; Visser et al., 2017)
  - Activity-based learning: modeling, rehearsal & role play (Dekker et al., 2015; Garwood & McCabe, 2000; Pask et al., 2016; Visser et al., 2017)
  - Games (Gontijo et al., 2015)
  - Yoga* (Swanton et al., 2017)
  - Meditation* (Swanton et al., 2017)
  - Sensory-based strategies* (Swanton et al., 2017)

* indicates literature by occupational therapists.

Connecting MHM

- **Menstrual hygiene management (MHM):** day-to-day tasks a woman undertakes to control/manage her menstrual flow (McGregor, 2018)
  - "Hygiene" vs. medical "management" (eg. contraceptives)
  - "Woman" used for people with female reproductive organs who have begun menstruating, vs "girls" who have not yet begun menstruating.
- Sexual health education

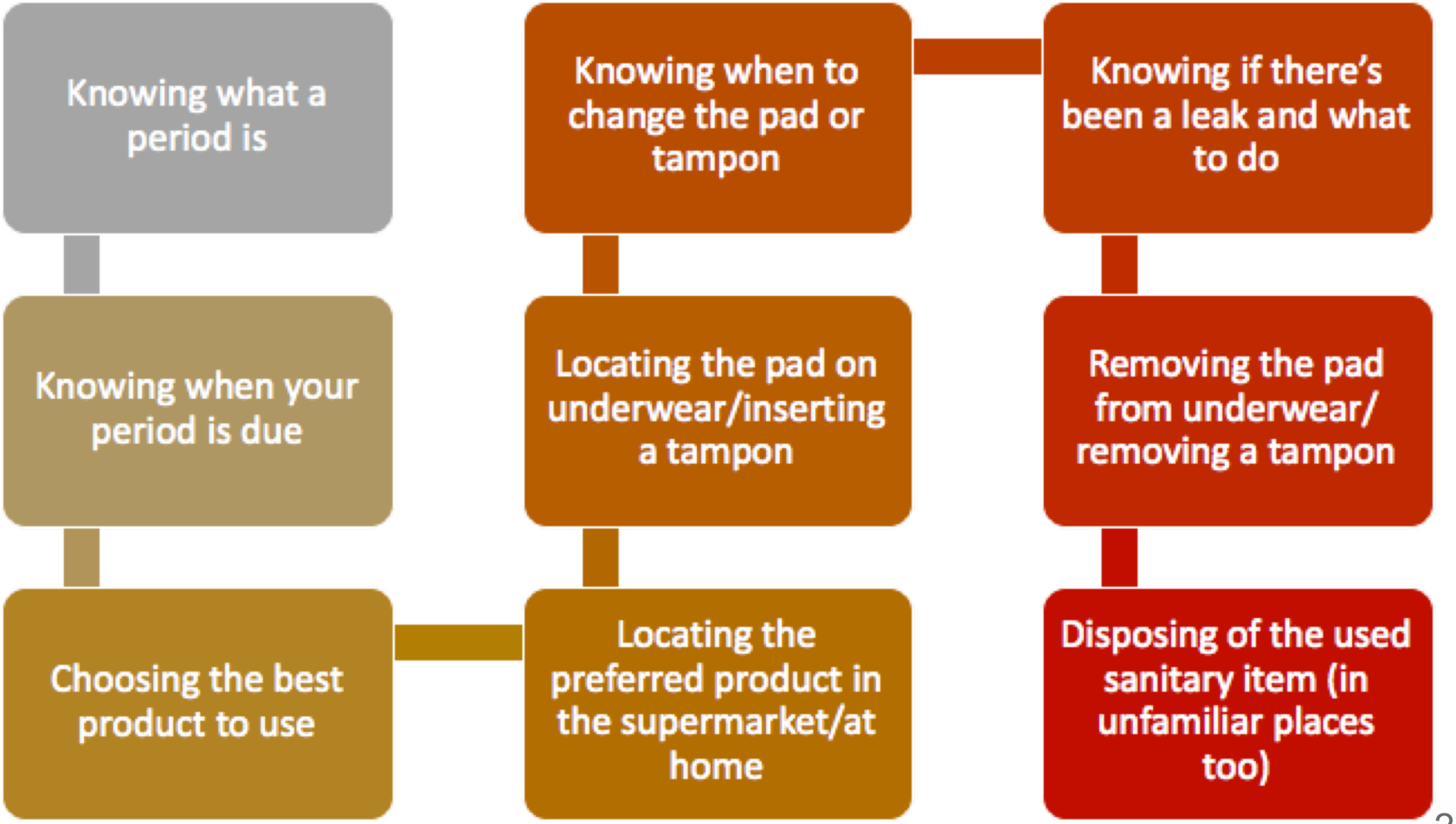
  → sexual health organs

  → female reproductive organs

  → menstruation

  → menstrual hygiene management

MHM Task Analysis



Sanitary products

Photo source: Freya McGregor, 2014

Sanitary products cont.

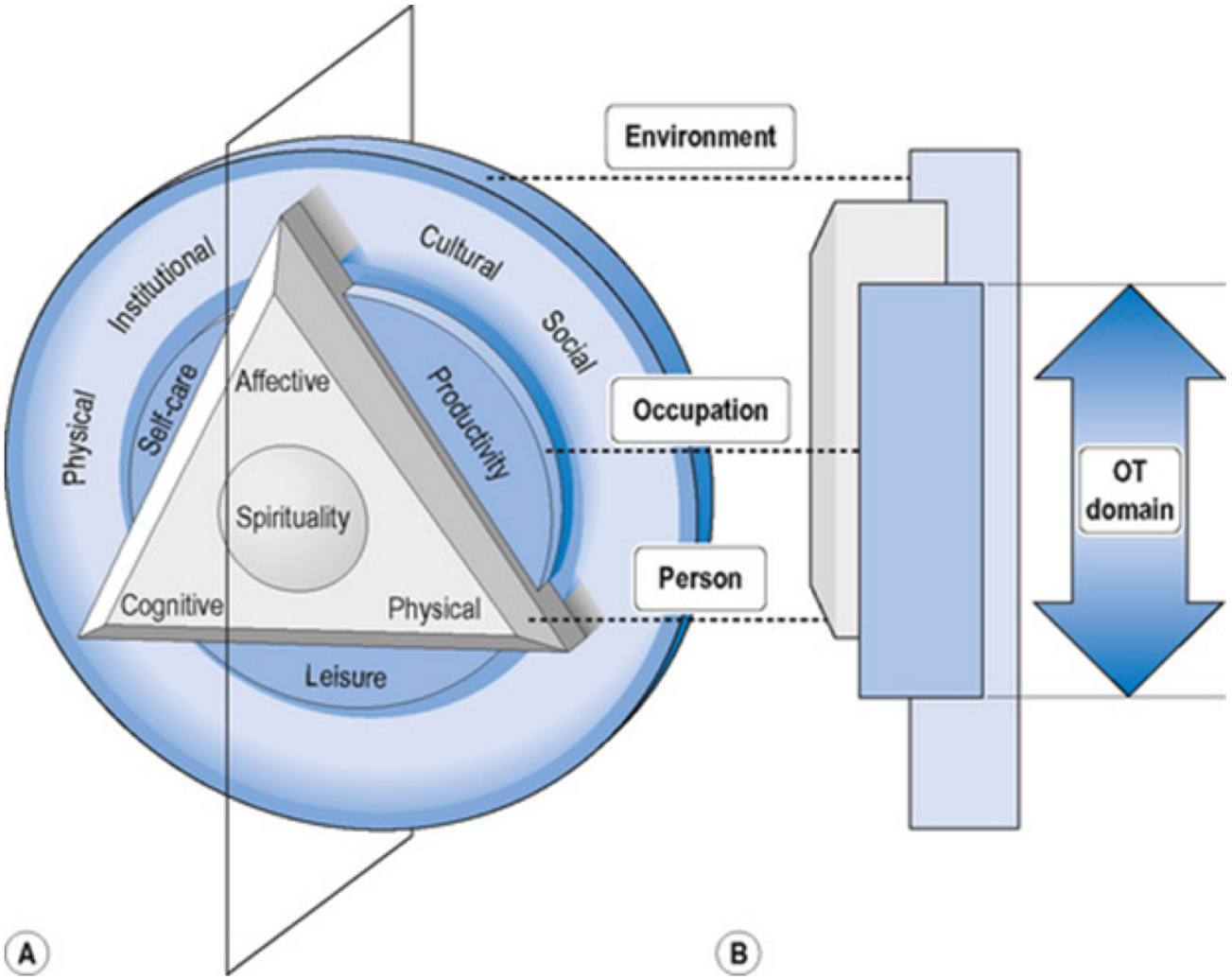
Menstrual Cup

Photo from: https://shop.rubycup.com/shop/ruby-cup-small/

Period and leak-proof underwear

Photo from: https://www.modibodi.com/periods-underwear/

OT Role in MHM: CMOP-E



(Townsend & Polatajko, 2007)

OT Role in MHM cont.

- Survey of carers of women (n=103) aged 12-18 years with CP in Australia: 45% of respondents did not participate in school, social activities or physical activities during their menses.

(Zacharin, Savasi & Grover, 2010)

- Women aged 14-55 years (n=452) with intellectual disabilities and/or their carers in England: No one had tried to teach menstrual care tasks to 29% of the women. Regardless of task or level of disability, women were more likely to be independent if someone had tried to teach them.

(Rodgers & Lipscombe, 2005)

MHM Challenges for Women with I/DD

"For young women who are very dependent for self-care, reassurance and acceptance of menstruation may be the main aim, rather than teaching of skills."

(Taylor et al., p.7, 2010)

- Achieving independence in pad changing (Carlson & Wilson, 1996)
- Understanding the physiological processes that results in the flow of a blood like substance (Carlson & Wilson, 1996)
- Understanding social norms re: non-disclosure of evidence of menstruation (Carlson & Wilson, 1996)
- Sensory sensitivities → discomfort from pads (Quint, 2008)
- Communicating premenstrual discomfort (Carlson & Wilson, 1996)
- PMS symptoms may be different eg. tantrums, self-harm, seizures (Quint, 2008)
- Tampons may increase spasticity (Duckworth, 1986)
- Providers' attitudes: can vary in multiple realms, not always consistent (Carlson & Wilson, 1996)

Strategies for I/DD

- Early education for parents and girls: may help reduce behavioural issues (Burke et al., 2010)
  - Sensory sensitivities (Piandes, 2019)
  - Trialing pads and tampons (Piandes, 2019)
  - Using red food dye in water on pads (Piandes, 2019)
- Consistent approach across all caregivers and environments (Taylor et al., 2010)
- Use a paper or app calendar/diary, recording duration, heaviness, symptoms and strategies that help relieve symptoms, created and updated by the woman herself (Burke et al., 2010; Taylor et al., 2010)

Strategies for I/DD cont.

- Outline with fabric markers on underwear where pad should go (Piandes, 2019)
- Use clear and simple language (Quint, 2008)
- Repetition of topics over time (Quint, 2008)
- Visual aids: pictures, signs, symbols (Quint, 2008)
- Anatomically correct models/dolls (Quint, 2008)
- PMS relief: massage, warm drinks, hot water bottles, decreased activity demands, pain relieving medication (Carlson & Wilson, 1996)
- Ethics re: contraceptive pill/hysterectomy
  - NB: Hysterectomy ≠ oophorectomy, so will not affect PMS mood/behaviour (Grover, 2011)

Strategies to use for Physical Disabilities

- Change pads every 4 hours to prevent overflow (Taylor et al., 2010)
- Underwear with a plastic crotch or waterproof underwear that extends up the back to the waist area, especially if sitting all day (Friedmann, 1980; McCarthy, 1981)
- Incontinence pads, overnight or if the woman has difficulty changing pads herself (McCarthy, 1981)
- Gauze wrapped around top of catheter: may prevent leakage along catheter tubing (McCarthy, 1981)
- To wash the vaginal area: baby wipes, a commode or bowl, warm water and splashing, a bidet. Ensure area is totally dry, especially if seated all day (McCarthy, 1981)

Strategies for Physical Disabilities cont.

- Kneeling on the floor may feel more stable (Duckworth, 1986); or lying on her back (McCarthy, 1981)
- A loop tied in the tampon string may be useful to 'hook' with fingers or a long-handled hook (stabilized on the floor?) to remove tampons (McCarthy, 1980; Friedmann, 1980)
- Parkinson's Disease and medications: periods may be heavier and harder to manage; motor symptoms may be worse during period (Tolson et al, 2002)

Strategies for Visual Impairment

- 'Tuning in' to pre-menstrual syndrome symptoms
- Aligning fold in pad with forward seam of underwear gusset
- Feeling weight of pad with hand under underwear gusset
- Colour of packaging/feeling pads through outer packaging
- Orientate to sanitary disposal bin before sitting down
- Bring your own ziplock bag/wet wipes to public toilets
- Wearing dark coloured clothing/wash outer garments daily
- Orientation and mobility specialist for learning the location of items in the supermarket vs online shopping
- Organisational strategies, eg. taking plenty when going away

(McGregor, 2014)

Don't forget:

- All people have the right to healthy sexual relationships if they desire them!
- The level of intellectual disability does not necessarily correlate to a woman's ability to perform menstrual self-care tasks independently
  - → Do not make assumptions about potential independence based solely on level of disability
- If women with intellectual disabilities can perform MHM tasks independently:
  - More privacy
  - Less time needed with carer → Eases carer burden

Future directions for you as an OT

- Encourage colleagues to discuss sexual health and MHM with each other and clients through:
  - Informal conversations
  - In-services
  - Upskilling personal care staff
- Discuss sexual health and MHM with clients in a normalising matter-of-fact way. Include this in your occupational profile.
  - → The more you do this, the less awkward it will get!
- Talk with your students about sexual health and MHM; let them practice with you before talking with a client
- Offer specific suggestions to help address any concerns
  - Offer resources for families and children
  - Educate on sexual self-advocacy
  - Intervene when needed to improve independence!

Questions?

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Case Study 1: Sadie

- 15 year old female
- Hemiparetic CP: wears a splint to maintain thumb abduction
- Mild intellectual disability; communicates verbally
- Community-based outpatient clinic
- Goals related to dressing, cooking, executive function
- During one session she tells you she has a boyfriend and that they're going to have their first date at his house when his parents aren't home, but asks you "please don't tell her parents!"

What follow up questions do we need to ask Sadie?

Would you intervene? If so, how?

How would you address her parents given the information that you have?

Case Study 2: Felix

- 14 year old male
- Autism Spectrum Disorder, mild intellectual disability, limited verbal skills, not currently using an alternative augmented communication device
- School-based sessions to address typing and executive function
- Teacher reports Felix is having increased difficulty with attention and has been rubbing his penis in class
- Parents report Felix is also rubbing his penis at home in front of sister
- Parents report not talking with Felix about puberty, saying they don't know how to explain so that he will understand

The teacher has asked you if you have any suggested strategies.

What are some additional questions you may need to know?

What are some intervention strategies you may try with Felix?

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