



THE UNIVERSITY OF  
MELBOURNE



# Unmet needs of women with ovarian cancer

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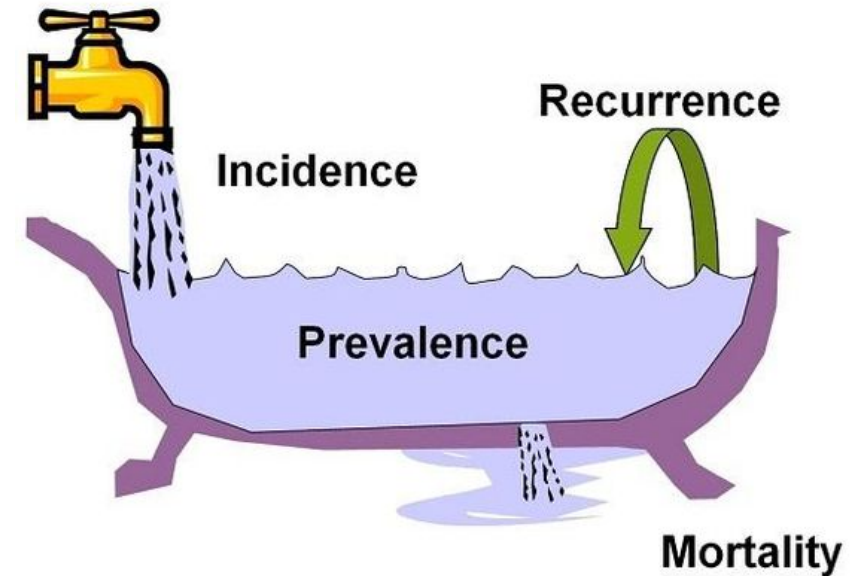
@DrPeate



# Ovarian cancer – living with ‘advanced’ disease

- ~1394 Dx annually in Australia<sup>1</sup>
- 60% Dx in advanced stage
  - poor prognosis,<sup>2</sup>
  - ~85% risk of recurrence,<sup>3</sup>
  - inferior outcomes.<sup>4</sup>
- 5 year survival rate: 44%<sup>5</sup>

Goal of **living well** for a longer period of time without disease progression

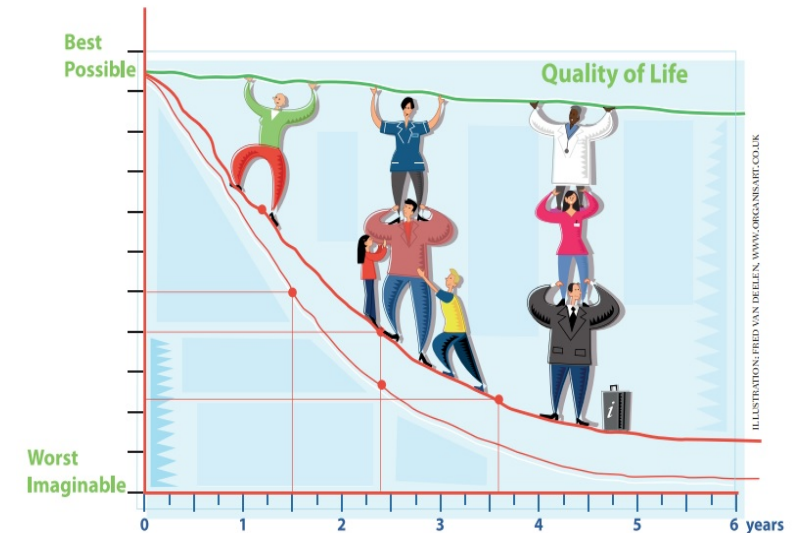


1. Cancer Council Australia  
2. Birrer M et al. Up to date 2-17  
3. Mirabeau-Beale KL et al, Gyn Onc 2009  
4. Reb AM. Onc Nurs Forum 2007

5. AIHW & NBOCC, Ovarian cancer in Australia 2010  
Image:  
<https://s-media-cache-ak0.pinimg.com/originals/b2/2f/60/b22f60a5232635ff622eab6103762314.jpg>

# 'Living well'?

- **Physical** – DFS & symptom management
- **Psychosocial/ supportive care:**
  - psychological,
  - health system and information,
  - physical and daily living,
  - patient care and support, and
  - sexuality



↑ unmet supportive care needs → ↓ QoL<sup>1</sup>

# Assessing unmet need

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- Unmet needs differ by:
  - Cancer type<sup>1</sup>
  - over the disease trajectory<sup>2</sup>
- Unmet needs tools:
  - PNPC (problems and need in palliative care)
  - NEST13 (needs near end of life care)
  - SCC (symptoms and concerns checklist)
  - SCNS (Supportive care needs survey)



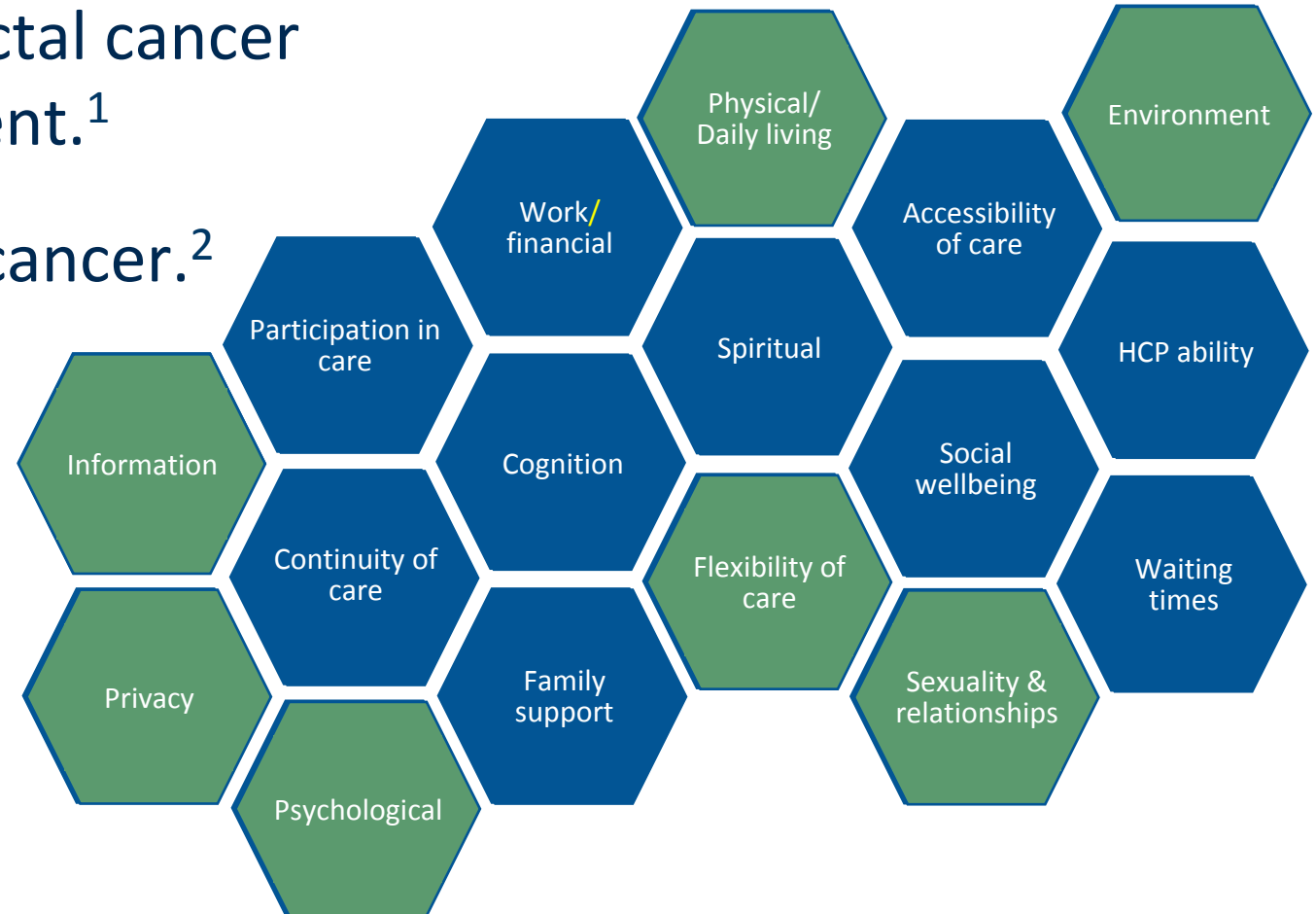
# Assessing unmet need in ovarian cancer

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- Validated in different populations
- Do not include ovarian cancer population or small subset
- Needs assessment tool in ovarian cancer population
  - Supportive Care Needs Survey (SCNS)

# Supportive Care Needs Survey (SCNS)

- Mostly breast and colorectal cancer patients in active treatment.<sup>1</sup>
- SCNS-34 used in ovarian cancer.<sup>2</sup>
- Covers 7/17 domains.<sup>3</sup>
- **Are we missing things?**



# Aim

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Identify the supportive care needs of women living with ovarian cancer

- Match between their needs and domains
- Identify needs that fall outside of the SCNS?





# Study details

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**Design:** Exploratory qualitative semi-structured in-depth interviews.

**Eligibility:** Adult ovarian cancer patients at least three months from the end of their first-line treatment.

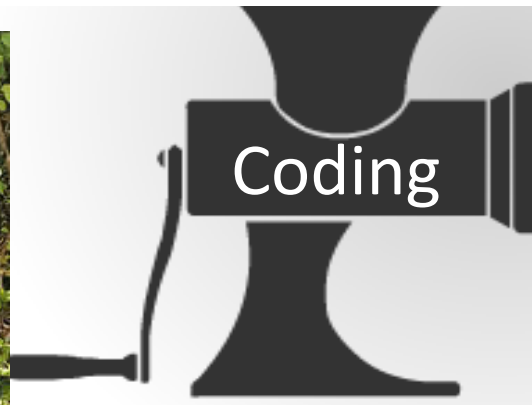
**Recruitment:** Purposive sampling of 30 patients from:

1. Gynaecologic Oncology clinics at RWH.
2. Ovarian Cancer Australia (OCA) network database.



# Analyses plan – thematic analyses

Data



Themes / theory



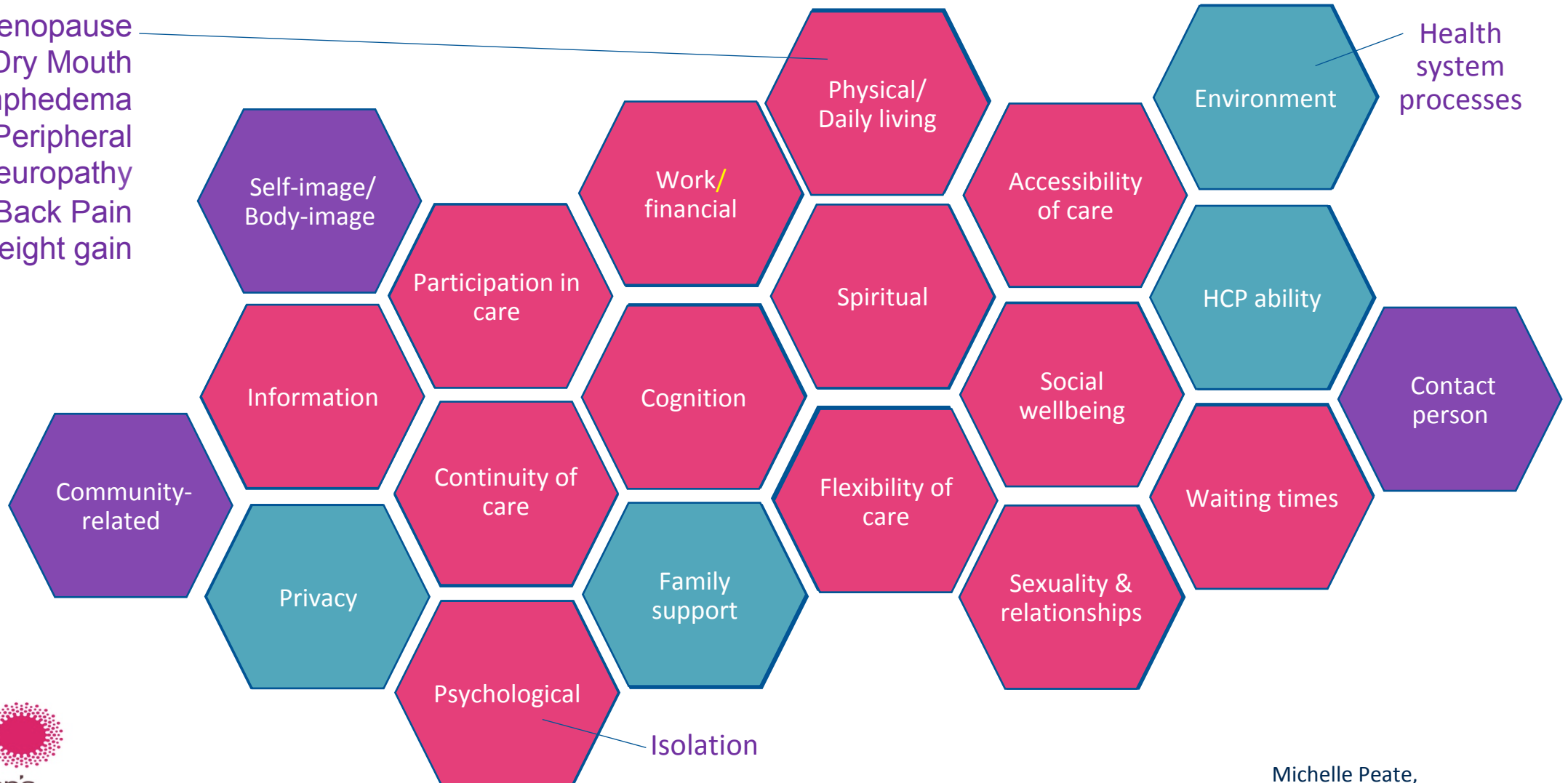
# Preliminary results (n=7)

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- 49 to 66 years
- All married
- All had serous epithelial ovarian cancer
- 6 were cancer-free (1 about to complete chemotherapy)
- year 10 (high school) to postgraduate education
- Average interviews: 59 min (range: 34 –88 min)

# Domains of **unmet** and **met** need

Surgical Menopause  
Dry Mouth  
Lymphedema  
Peripheral Neuropathy  
Back Pain  
Weight gain



# Need for a contact person/Case Manager

- Dedicated to them
- Interaction on personal level
- Some to direct questions to
- Who will guide through resources and referrals if necessary
- Anticipating needs

*“A lot of times you don't know what you need to start with, which is, ...you need somebody who's a bit more on a personal level...you're why you need someone who's going to sort of basically meet your conscious with somebody who's a specialist...” OCA011  
needs before you know you've got them in a way.” OCA006*

# Self-image/ Body-image

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- Lack of practical information
- Need for healthcare team to acknowledge and address body-image and self-confidence

*“Everyone is so quick to put down the idea that we're allowed to care about our appearance and how we look and how we feel about ourselves. And it's nearly like you've got to be ashamed of yourself to come out and say, 'but what about skin care?' It's like you shouldn't get it, it's not important. We're saying your skin gets so sensitive, how to do eyebrows and eyelashes. It's like, 'well, that's your body image.'” OCA006*

# Information needs

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- Lack of timely information
- Gatekeeping of information

*"Every appointment i had they said don't Google, it's fake it's not going to help you feel better about your situation. And yet, not give me any information. And so I felt like oh, i had to know, that's how I roll. I need to know, so better or worse I had to go in there and find out everything I could." OCA006*

# Conclusions & Recommendations

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Women that live with ovarian cancer have many supportive care needs, and the SCNS and other UMN measures are probably insufficient in capturing all of these needs

➤ Ovarian cancer module?

which can be used to assess needs to improve patient QoL and health care processes



# Acknowledgements

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**The participants**

**Thank you**

