

BACKGROUND

- Body image distress (BID) is prevalent in adolescent and young adult (AYA, ages 15-29) cancer survivors with long-term quality of life implications but few recommended treatments.¹
- While engaging in a writing intervention, AYA cancer survivors shared their experiences of BID with candor in follow-up interviews
- **We present a reflexive thematic analysis embedded in phenomenological methodology of this content to further explore BID in AYA cancer survivors.**

METHODS

27 AYA cancer survivors with BID engaged in a writing intervention designed to mitigate these symptoms

24 AYAs engaged in follow-up interviews and discussed the BID experience in detail

Reflexive thematic analysis of interview content to generate themes with potential clinical implications

Example End-of-Study Interview Questions

Can you tell us how body image distress may have started for you in your cancer experience?

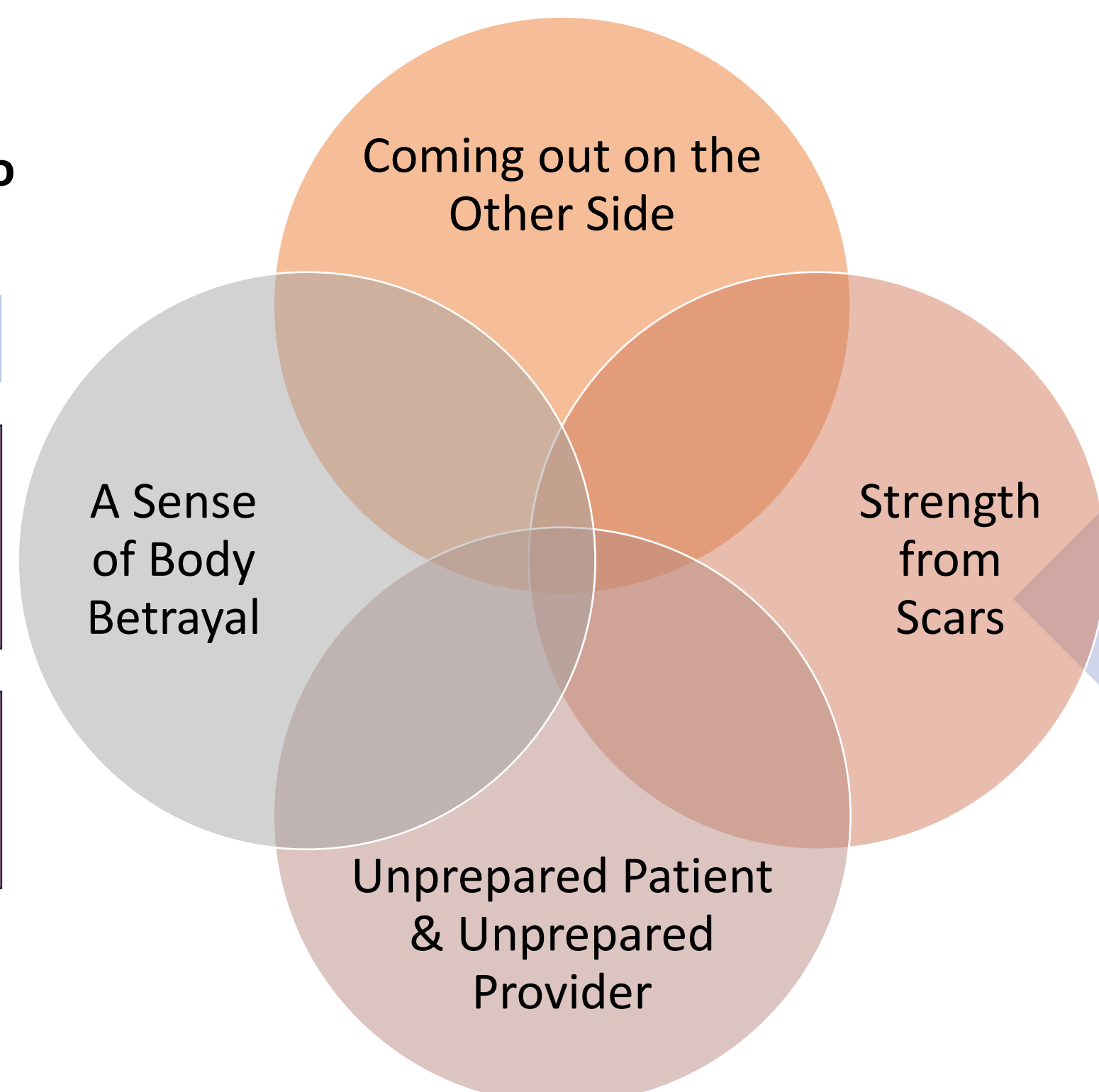
Probe: Did this pre-exist your diagnosis? Did it change during treatment or after treatment was completed?

Would you recommend writing to a friend who may have similar body image distress?

Probe: If you could design a program that supports adolescent and young adult cancer survivors with body image distress, what might that look like?

Early Generation Coding

Early coding resulted in the identification of multiple subthemes related to BID that persisted across interviews. A subset of these is shown here:



Trauma-Informed Care: an Impactful Intervention in Qualitative Research

- In retrospect, this study modeled trauma-informed care (TIC) across the entirety: from recruitment, weekly calls with participants, and the end of study interviews.
- Principles of safety, trustworthiness, transparency and empowerment shaped the study; as well as a flexible structure, an emphasis on participant storytelling, and consistent researcher voices across each phase of the study.
- This experience suggests a TIC approach in research encounters with AYA cancer survivors to improve the depth and candor of responses, as well as provide opportunities for healing among participants during a study.

RESULTS & CONCLUSIONS

Emergent Themes & Representative Quotes

Reconciling Intellectual & Emotional Understanding of Anticipated Body Image Changes

It is very overwhelming. No one really sat me down and went through the process step by step of this is what it's going to look like. Even I wasn't expecting until like, right before surgery that I was going to wake up looking like [that].

- PE, 24 yoF with phyllodes tumor

We are a Community, but We Lack a Community

It was sort of, I felt like I was kind of on my own to kind of deal with some of these after-effects. And I feel like, at least from my perspective. Once I finished treatment, it's like 'Okay, you're kind of on your own now.' And that's just been hard because I'm still adjusting to the body image changes and to this new post-cancer me in a physical sense.

- MH, 35 yo F with breast cancer

What We Gained and What We Lost

And I think, gosh, there are times where I feel really good and really proud of myself and proud of what my body's been able to get through. Then there are times I feel really scared and is this pain from metastatic cancer that developed? Your mind goes in so many places.

- SG, 34 yoF with breast cancer

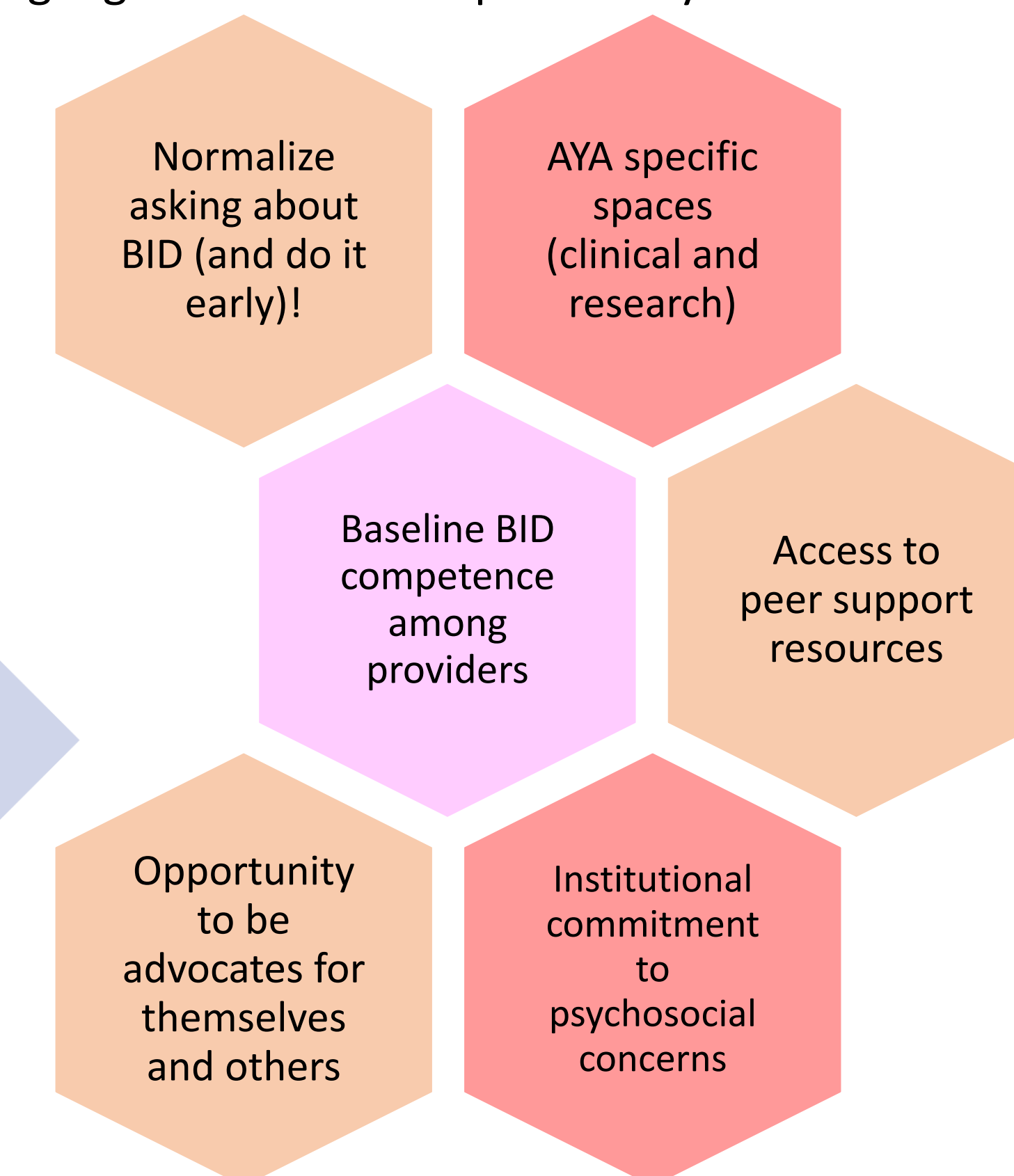
BID as a Source of Guilt and Shame

The first oncologist I had, they especially focused on outcomes, like, your outcomes are really good. We have really favorable numbers for you. And I was like, this treatment is killing my sex drive, making me gain weight and that disconnect was hard to wrap my head around.

- AO, 27 yoF with sarcoma

AYA Survivor Wants and Needs

In keeping with TIC principle of collaboration, we highlight the desires expressed by AYAs:



FUTURE DIRECTIONS

- Evaluating an EW intervention for BID in multiple scenarios (group setting, while on active treatment)
- Prioritizing trauma-informed care as a model for structuring AYA cancer survivorship care.
- Continued utilization of AYA cancer survivors as advocates for addressing gaps in care.

REFERENCES

1. Lehmann, V., et al. (2015). Body image in cancer survivors: a systematic review of case-control studies. *J Cancer Surviv*, 9, 339-348
2. Harris M., Fallot R.D. Envisioning a Trauma-informed Service System: A Vital Paradigm Shift. *New Dir. Ment. Health Serv.* 2001;2001:3-22