Slide 1: Ill-being and the politics of compulsory positivity in the chronic illness experience.
[Title slide including presenter name and affiliation and the Curtin University logo]

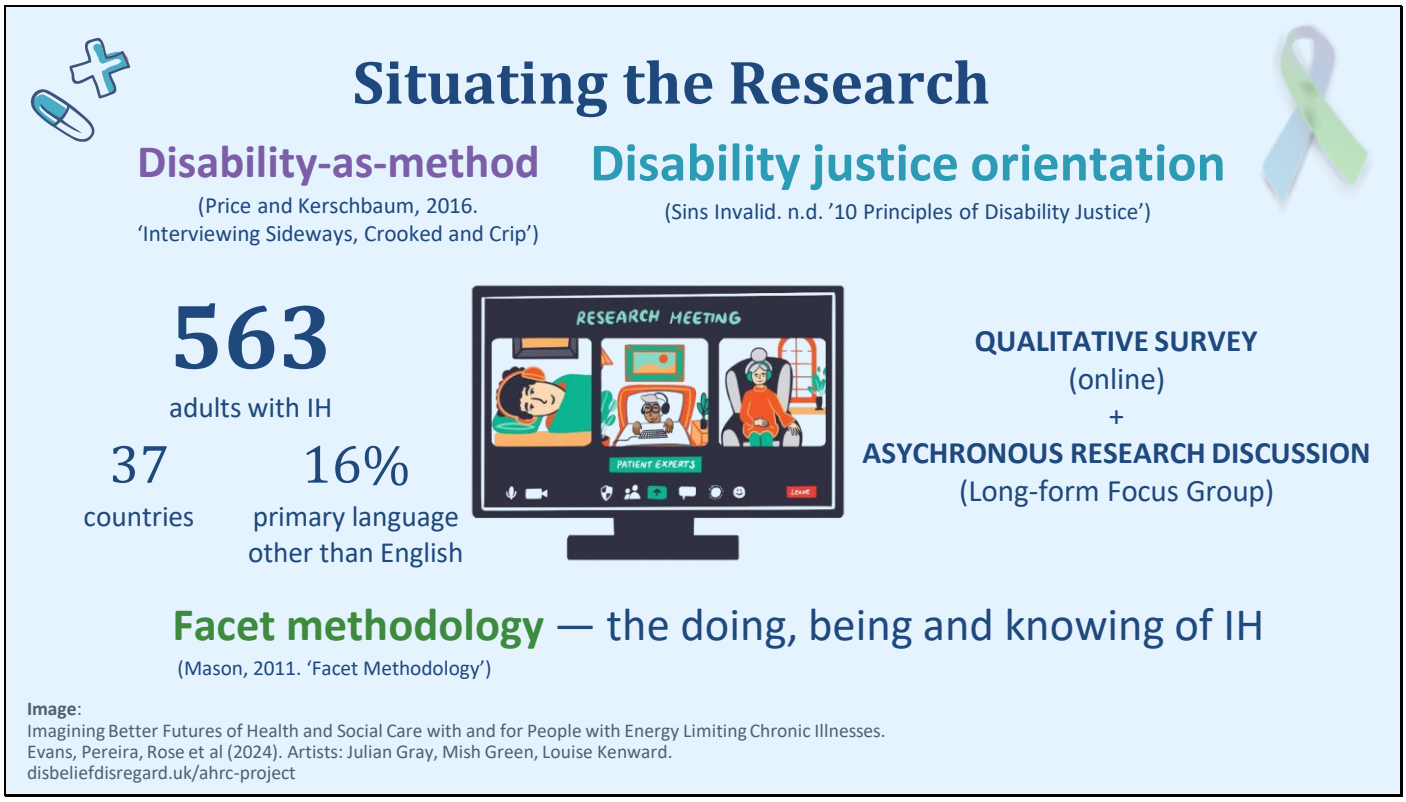


- Acknowledgment of country –
  - I live and work on the lands of the Kombumerri people. I also acknowledge the Wudjuk people of the Noongar nation, where Curtin University lies, and pay my respects to all First Nations across this land I call home.
  - I recognise that First Nations knowledges have always been built and shared through a community of practice, and respect their continuing contribution to our society.

- In this presentation, I introduce ill-being as a way of thinking about negative sentiment in chronic illness-disability.
  - I position ill-being as an expression of both the embodied experience and the socio-political conditions that shape it, rather than as pathology or maladjustment.
- My argument is that crip negativity, and the refusal to perform positivity, may be one of the more persistent, if quieter, forms of everyday resistance for people living with chronic illness-disability

Slide 2: Situating the Research

[Research overview slide displaying key details of the study, accompanied by an illustration of remote research meeting with researchers shown in bed and on a lounge). Text includes participant numbers and demographics (563 participants, 37 countries, 16% non-English speaking), methodology (disability as method, disability justice orientation and Facet Methodology) and methods (qualitative survey and asynchronous discussion group)]



- IH — Intracranial Hypertension, also known as Idiopathic Intracranial Hypertension or Pseudotumor Cerebri — is a rare and complex neurological chronic illness-disability.
- To date, IH research has focused on biomedical issues and the clinical presentation, and the lived experience is largely missing from the dominant narrative.
- My doctoral study is the largest global qualitative study of the IH lived experience, with 563 adults across 37 countries, and 16% participating in a language other than English.
- I used two lines of inquiry - a qualitative survey and a long-form asynchronous discussion group, analysed through facet methodology to explore the doing, being and knowing of IH.
- The research approach was underpinned by disability-as-method (Price & Kerschbaum) and a disability justice orientation (Sins Invalid), centring experiential expertise and building the research around the needs and rhythms of the IH community.
- I'm using IH as a case study here, but I think the argument extends to chronic illness-disability more broadly, especially other rare or contested conditions where the lived experience is routinely devalued and dismissed

Slide 3: The Problem: Embodied Reality and the Demand for Positivity

[Screenshot of a Facebook discussion thread, showing multiple participant responses to a question about the silver linings of living with IH, demonstrating a refusal to the demand for positivity]

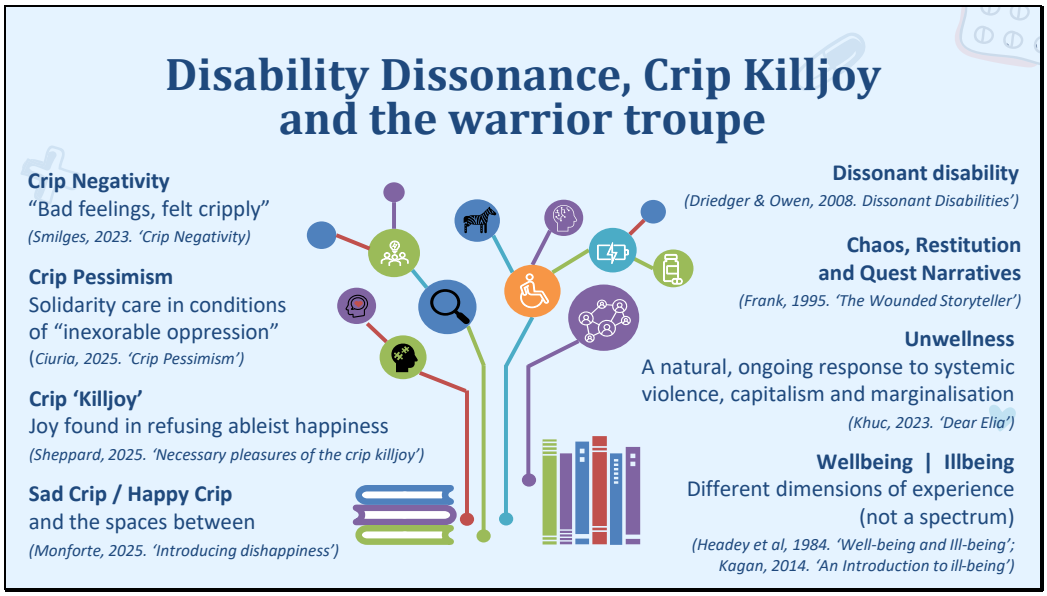


Image:
Raw Data
Moes, 2025. 'Doing, Being and Knowing Intracranial Hypertension'

- Participants were quick to point out that IH plays a role in every aspect of daily life, and there is "nothing that it doesn't affect".
    - The positive aspects of IH came up as a participant-led discussion, but focusing on the positives proved difficult for most.
- When asked about the silver linings, many refused the framing altogether, saying "There are no 'good' parts of this" and that IH was "dull grey at best".
    - Some felt this focus perpetuated a toxic positivity, when the IH experience was typically far from it.
- Ill-being expressed this way isn't negative in an explicitly negative sense, but an expression of the *impact* IH has on quality of life.
- Participants could still name some positives, like increased empathy and appreciation for the "small things", but these need to be decoupled from the expectation of positivity.
    - As Kelly F put it: "I'm not grateful for this experience. I acknowledge that it's part of my life, but not a blessing. I am resilient and determined, and while IH has illustrated that, it's not the reason I am those things."
- This sets up the problem, which is a persistent social and clinical expectation that chronically ill and disabled people orient toward resilience, inspiration porn, and compulsory positivity.
- This connects to Parsons' (1951) sick role, where social legitimacy is granted in exchange for orienting toward recovery and complying with medical authority.
    - Within this logic, negative expression, such as grief, anger or refusing to "think positive", can be read as social deviance.
    - For people with chronic illness-disability, the conditions of the sick role aren't available. The condition isn't temporary, and the promise of recovery often doesn't arrive.
- So, the demand for positivity reproduces the sick role, and graphic, embodied expressions of ill-being push back against it, often as a form of self-preservation.

Slide 4: Disability Dissonance, Crip Killjoy and the Warrior Troupe

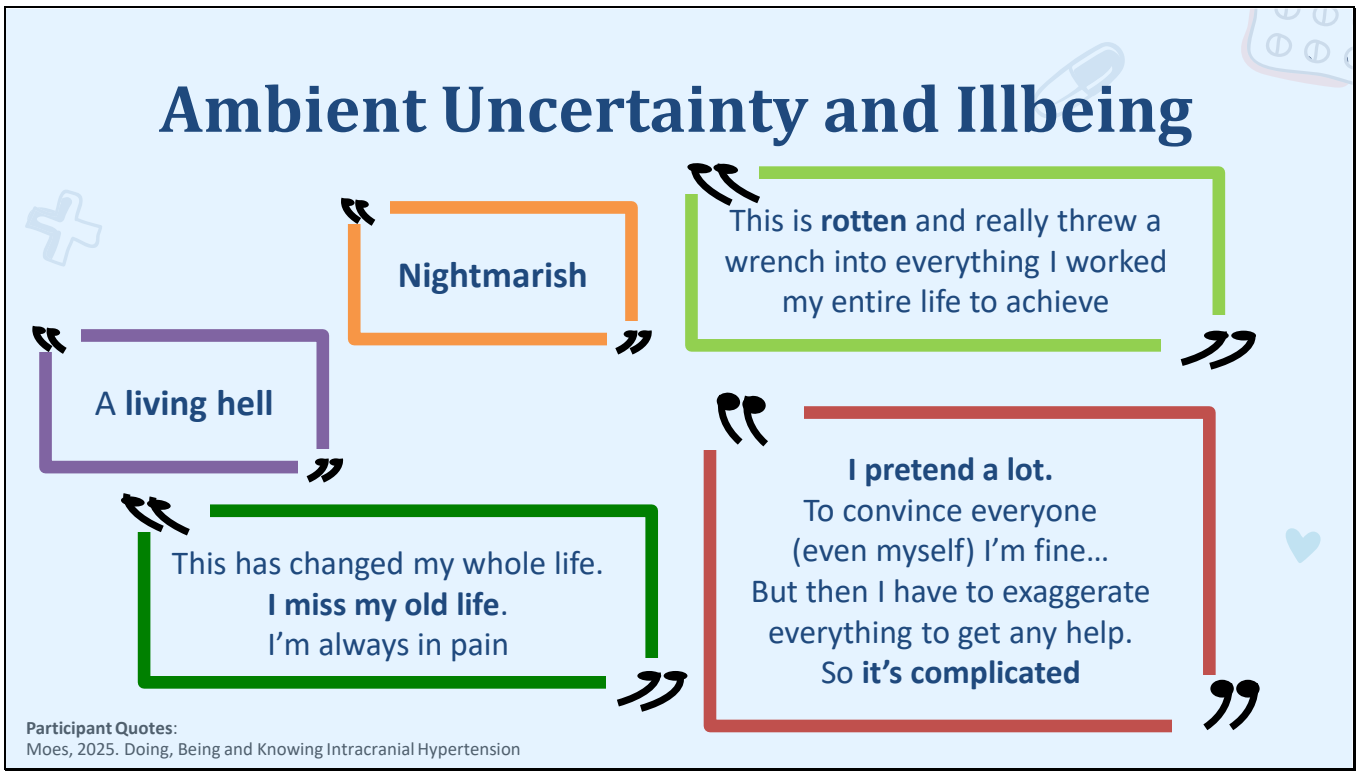
[A central diagram of books with diverse branches. Surrounding text maps the theoretical landscape, across Crip theory, disability studies, illness narratives and wellbeing discourse]



- My theorising is not new -- A growing body of scholarship refuses normative and performativity of positivity in disability and chronic illness, each working from a slightly different angle.
- Logan Smilges (2023) describes crip negativity as "bad feelings felt cripply" — the non-normative ways disabled people experience negative emotions with some regularity, such as pain, shame, exhaustion and anger.
    - Smilges positions these feelings as valid forms of disabled knowing, and argues we need to make room for the "messier, meaner ways systemic ableism operates".
- Mich Ciuria's (2025) turns to the notion of crip pessimism draws on Cherry's (2020) solidarity care, arguing for care in conditions of ongoing oppression, extended because people deserve it rather than as a means to a grand objective.
- Emma Sheppard's (2025) crip killjoy is a refusing figure who turns against the ableist happiness object, the promise of a non-disabled future, and finds joy in that refusal.
    - The crip killjoy holds space for ambivalence and discomfort without needing those feelings to become politically productive. As Sheppard puts it, the crip killjoy "is not here for answers".
- Likewise, Mimi Khuc (2023) frames "unwellness" as a natural and ongoing response to systemic violence and marginalisation, with all of us "differentially unwell".
- Javier Monforte (2025) maps the sadcrip and the happycrip, as two of four achetypes in their "dishappiness" typologcy - The sadcrip is tragedy, while the happycrip is the supercrip and the object of inspiration porn.
- Driedger and Owen (2008) describe dissonant disability, where the embodied realities of chronic illness sit uneasily within available frameworks of disability, neither fully claiming them nor being claimed by them.
- Similarly, Arthur Frank's (1995) chaos, restitution, and quest narratives give us a framework for illness narratives, yet the chronic illness experience maps uneasily across all three.
- From a psychological perspective, Headey et al. (1984) and Kagan (2014) position ill-being as distinct from well-being, rather than the other end of the same spectrum. As Kagan notes, folding these states into wellbeing overlooks specific problems.
- What these frameworks share is a refusal to read negative sentiment as pathology, which opens conceptual space to theorise ill-being as a legitimate expression of the lived experience.

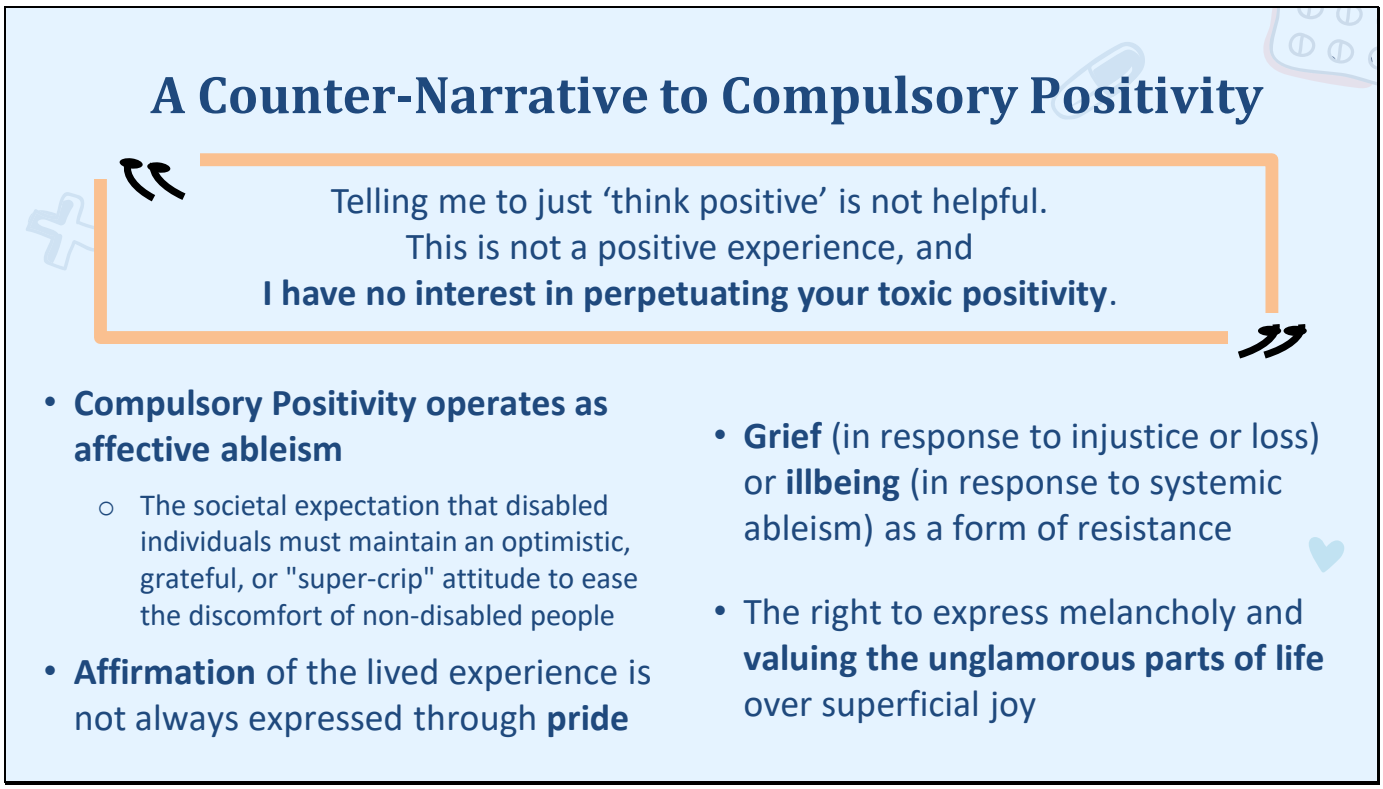
Slide 5: Ambient Uncertainty and Ill-being

[Visual text boxes with participant quotes expressing negativity and impacts of living with IH]



- Life with IH is characterised by what Margaret Price refers to as 'ambient uncertainty' - an omnipresent unpredictability that runs through daily life, including fluctuating symptoms and typically inadequate healthcare responses.
- Participants recognise the misalignment between their lived experience and the clinical interpretation of IH, and often feel dismissed or misunderstood by healthcare providers.
    - When the lived experience is shaped by ongoing uncertainty, inadequate care and epistemic invalidation, ill-being becomes something of a default state, and in turn generates a collective crip negativity.
- So when participants describe IH as "nightmarish" or "a living hell", they're describing their embodied experience.
    - The intensity of the language they choose reflects the intensity of the lived experience, and the challenge of conveying it to others who routinely minimise or dismiss it, or who try to reframe it under normative social constructs of 'disability', 'health' and 'illness'.
- The collective narrative more closely resembles Frank's (1995) chaos narrative than the restitution or quest narratives often imposed on chronic illness.
    - Embedded within a curative framework, people with IH hold hope for remission, but when this doesn't materialise, the sense of ill-being deepens.
    - The quest narrative also becomes entangled with a "warrior" identity, which, like the supercrip, is often more palatable to others.
- Participants describe having to perform normativity, and often positivity, for different audiences, even their doctors.
    - As one participant explained: "I pretend a lot. To convince everyone, even myself, I'm fine... but then I have to exaggerate everything to get any help. So, it's complicated."
- This performance then becomes a form of self-preservation that also contributes to ill-being.
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Slide 6: A Counter-Narrative to Compulsory Positivity
[A central participant quote expressing they have "not interest in perpetuating your toxic positivity", followed by text presenting points around compulsory positivity as affective ableism, counter-narrative positions and the right to melancholy and valuing unglamorous parts of life over superficial joy]



- I argue that Compulsory positivity operates as affective ableism – where chronically ill and disabled people feel pushed into more acceptable or palatable emotional performances.

- The societal expectation that disabled individuals must maintain an optimistic, grateful, or "super-crip" attitude in order to ease the discomfort of non-disabled people is a ableist demand.
    - The refusal of negative expression re-inscribes the ableist expectation that disabled life must be redeemable and converts it an individual problem in mindset.

- Smilges (2023) makes a similar point, noting that disabled people are too often "expected to be pleased each time our basic access needs are met".

- This expectation can also be felt within disability pride and the affirmative model.
    - Swain and French's (2000) affirmative model of disability grounds emancipatory practice in positive shared identity and disability pride, which is important – however, for many people with chronic illness-disability, disability pride may not be an available or authentic position – complicated by dissonance around the disabled identity, and whether one is 'disabled enough', alongside the dynamic, fluctuating chronic illness experience

- The argument here is not *against* the affirmation model – but that expressions of grief, illbeing, melancholy and the crip kill-joy, might reclaim and reframe the affirmation of the disabled experience as one that does not need to be expressed through positivity or pride.

    - Expressing ill-being in graphic, embodied terms is what allows the full weight of the experience to be known.

Slide 7: Resistance, Embodiment or Meta Self-Care?
[Three text points presenting key theoretical arguments on epistemic environments shaping the lived experience, crip feelings as active reclamation, and crip futurity]



- So I leave this question deliberately open
- Negativity is not inherently negativity.
  Ill-being is an expression of the relational, environmental, cultural and political influences that shape how we understand our worlds
- crip negativity is perhaps both a reflection of the embodied experience, and a mode of critique.
  - "Crip feelings, felt cripply" often refuse to perform normativity or wellness – and may be an active reclamation of the lived experience, a response to an ableist world and resistance to compulsory positivity
- Kafer (2013; 2021) asks what it means to imagine crip futures within normative and ableist temporal frameworks – noting a lack of recognition and support contributes to negative futurity and the difficulty of being able to reliably predict or plan for the future.
  - Rather than committing to perfectibility, Rice (2017) argues for futures that are open to possibility and built in response to disability.
- Together, these framings allow us to position the graphic, embodied expressions of ill-being in chronic illness as a form of active resistance to the terms on which chronically ill and disabled people are expected to narrate their lives.
- Illbeing also sits in conversation with Riggare et al's (2026) notion of meta-self care – the process through which people with chronic illness develop the knowledge, skills and understanding needed to live what they themselves consider a worthwhile life.
  - The refusal to perform positivity, and expressions of illbeing may be understood as a form of resistance, or as a form of meta-self care
  - Likewise, crip negativity is part of how people with chronic illness-disability come to know their own conditions, navigate systems and preserve their epistemic sovereignty against demands to narrate their experience on someone elses' terms.
- So the provocation I leave you with is – If expressions of illbeing are forms of meta-selfcare - if they are part of the ongoing process of knowing chronic illness-disability - then what are the implications for how we read and respond to negative self-expression?

-- End Slide –

[Closing slide with presenter contact details, including a QR code linking to presenter website, alongside a blue and green IH awareness ribbon]



Kelly Moes, PhD
Adjunct Research Associate
Centre of Culture and Technology, Curtin University
kellymoesresearch@gmail.com
https://kellymoes.owlstown.net/

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