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POSTER ABSTRACT

Seeing Care Whole: A Professional Autoethnography on Envisioning Integrated Care for Persons Living with Inherited Retinal Diseases

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Background: Inherited retinal diseases (IRDs) are progressive, rare eye conditions that disrupt daily functioning, threaten one's independence, and require life-long, multi-disciplinary support. Yet care remains fragmented across genetic diagnosis, ophthalmic follow-up, low-vision rehabilitation, psychosocial support, and social services. This study asks: What would integrated IRD care look like when viewed from inside the health-system and community interfaces that people must navigate? Focusing on Singapore as an illustrative context, we seek person-centred design principles that can generalise to rare conditions with similar trajectories.

Approach: Adopting professional autoethnography (Chang, 2008; Lapadat, 2017) as methodology, this study draws on the researcher's dual role as clinician-researcher and policy practitioner. Data comprised a reflexive journal and analytic memos kept over two years of doctoral work (policy analyses, cost-of-illness work, qualitative fieldwork) and ongoing volunteering with a dedicated nonprofit; field observations from clinics, community programmes, and planning meetings; and practice documents (e.g., protocols, meeting notes). To triangulate interpretations, I incorporated de-identified, participant-provided artefacts from in-depth interviews conducted with six adults living with IRDs at two time-points over a year.

Memory work and field observations were written as vignettes; all materials were read repeatedly, coded inductively, and organised into themes using reflexive thematic analysis. Codes and candidate themes were iteratively reviewed against the corpus and the developing narrative. To enhance credibility and resonance, iterative member-checking was conducted with academic/clinical colleagues to interrogate claims, clarify blind spots, and refine interpretations, and a detailed audit trail was maintained documenting analytic decisions. The analytic product was a set of design propositions for integrated IRD care.

Results: Autoethnography surfaced the often-invisible coordination labour shouldered by people with IRDs. Re-locating that labour to health and social care teams and systems, without diminishing agency, translate experiential themes (embodiment, identity flux, social negotiation, resilience) into implementable features of integrated care. From this analysis, a coherent model of integrated IRD care takes shape. A one-door, life-course pathway provides a single entry point

and longitudinal coordination across diagnostics, ophthalmology, genetic counselling, low-vision rehabilitation, mental health, and social care, with proactive check-ins at predictable transitions such as diagnosis, disease progression, schooling-to-work changes, and parenting. People are partners in this pathway: care plans are co-produced with family involvement and peer navigation, and shared decisions explicitly engage uncertainty, hope, and risk around emerging therapies while validating coping and identity work.

The pathway also extends beyond clinics to participation and work by integrating vocational counselling, workplace accommodations, mobility training, digital accessibility, and funded assistive technologies, thereby reducing administrative burden and stigma. Delivery is anchored by enablers and safeguards, involving a named care coordinator, interoperable records, routine psychosocial screening, targeted subsidies for devices and transport, and public-facing stigma-reduction efforts.

Implications: A person-led, life-course pathway anchored by co-production, peer navigation, and coordinated rehabilitation-to-work supports offers a grounded blueprint for integrated IRD care. Although the model is based in a single health-system context and comprises of design hypotheses, not evaluated outcomes, the proposals are likely extensible to other rare, progressive conditions.