Revealing the Unseen
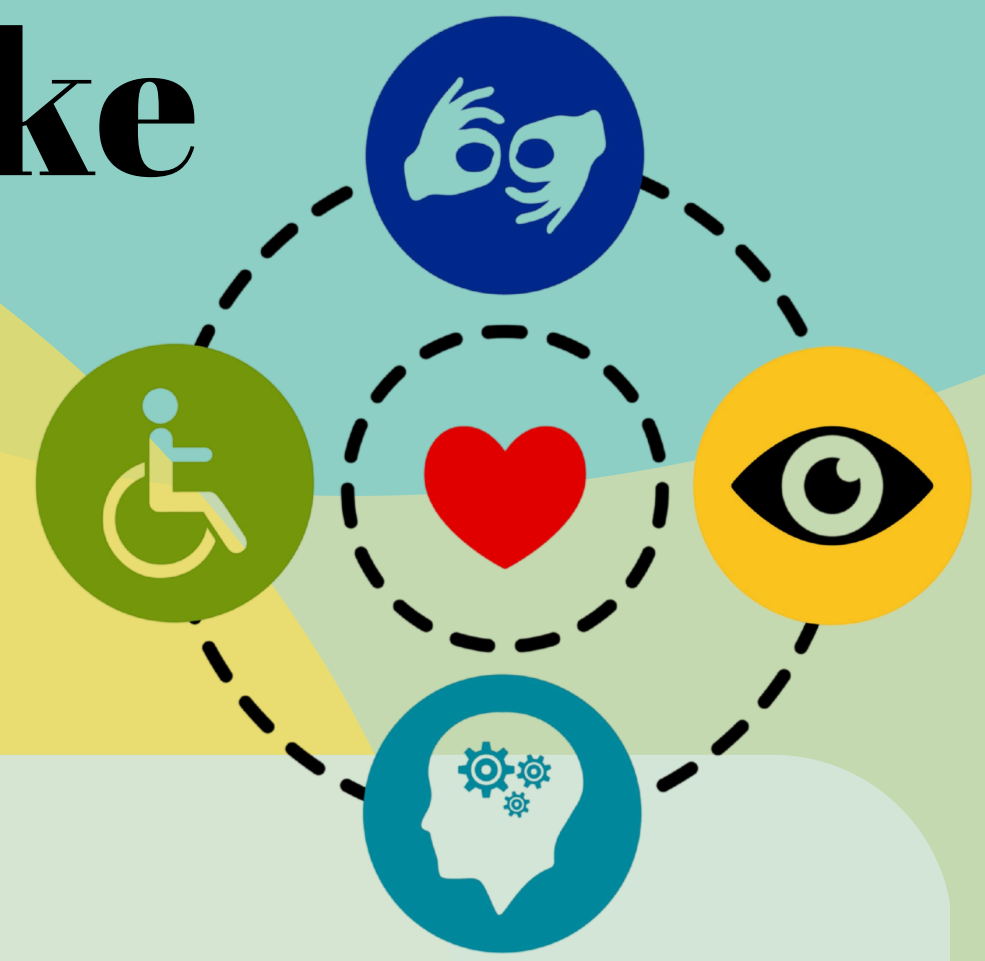
Exploring and showcasing invisible impairments in stroke

Lewis Jefferson[1], Stephen Dunne[1], Kristofor McCarty[1] and Kamlesh Mistry[2]

[1]Department of Psychology, Northumbria University (Newcastle), UK

[2]Department of Computer and Information Sciences, Northumbria University (Newcastle), UK

Background

Invisible Impairments

- Invisible impairments/disabilities are those that are not immediately apparent to onlookers[1].
- Difficulties stem from society's primacy of vision[1].
- Affected individuals regularly need to decide whether to pass as able-bodied or disclose their impairment[1-2].
- Passing means having to uphold able-bodied expectations[1-2].
- Able-bodied appearance incongruent with disabled identity[1-3]
- Disclosing means having to prove impairment to others, facing doubt, disbelief, and derision[4].
- In either case, these individuals face increased psychological burden and overlooked needs[2].

Stroke

- 100'000 strokes per year[5]
- Mortality decreased from 66,726 in 2001 to 36,771 in 2018[5].
- More people surviving stroke, with 1.3M survivors in UK[5].
- Post-stroke disability prevalence between 24% and 49% worldwide[6].
- Most impairments resulting from stroke are invisible to others:
  - Fatigue[7], cognitive/visual[8-9], pain[10], hemiparesis[11], depression[12]
- Post-stroke invisible impairments are markedly impactful in the contexts of:
  - Accessing healthcare[13], returning to work[14], social life[4], and family life[15-16].

Rationale and Aims

1. No studies principally focus on exploring lived experience of invisible impairment in stroke survivors as a category.

2. Findings that do exist relating to post-stroke invisible impairments are sparse, fragmented, and tied to the specific contexts and aims (e.g., return to work) of their primary studies.

3. There are no apparent efforts to develop an awareness intervention to improve this situation.

A systematic review, reflexive thematic analysis, and the development of an AR awareness intervention will address these gaps. PPI group assisting at each stage.

Methodology

Systematic Review and Meta-Ethnography

- Systematic search:
  - Systematic search using search string reflecting invisibility, impairment and stroke (682).
  - Abstract (452) and full-text screening (23).
  - Quality appraisal using CASP[17] and descriptive data extraction.

- Meta-ethnography[18] adapted for health research[19-21]:
  - Articles are read, first- and second-order concepts/metaphors are noted and tabularised in Excel. Notes are also made about potential relationships between studies.
  - Studies are translated into each other, with concepts treated as analogous of others.
  - Translations are synthesised in a reciprocal, refutational and/or line-of-argument synthesis.
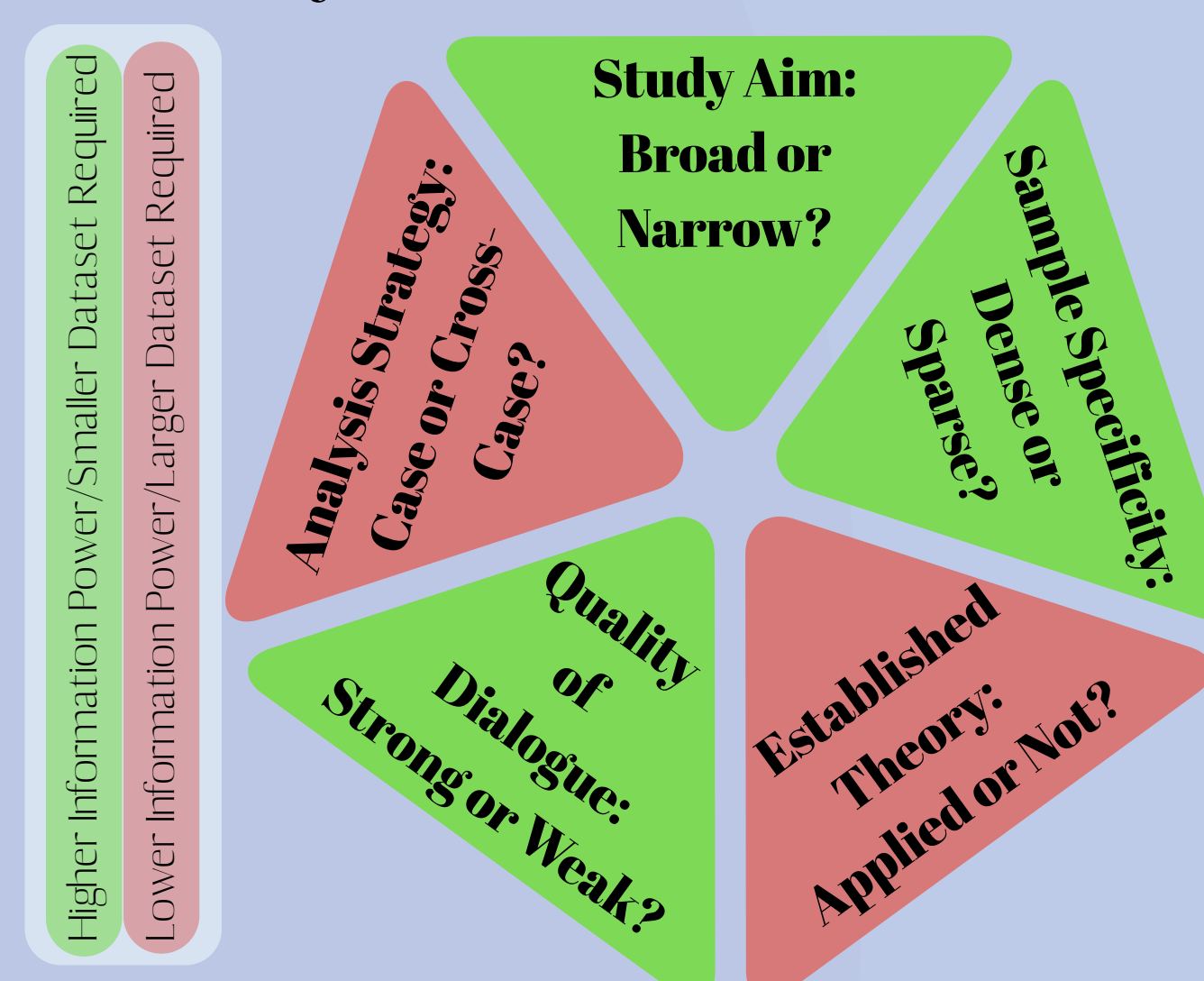
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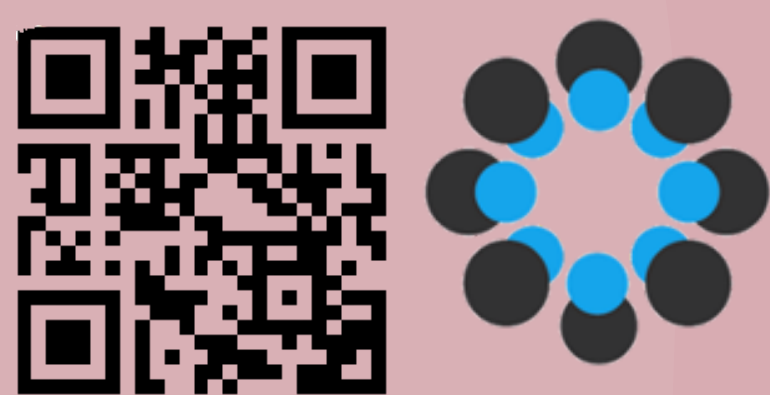
Reflexive Thematic Analysis

- **Recruitment:** Dataset size determined by previous work + information power[22].

Study Assessed on Five Dimensions:

- Higher Information Power/Smaller Dataset Required
- Lower Information Power/Larger Dataset Required
- Analysis Strategy: Case or Cross-Case?
- Study Aim: Broad or Narrow?
- Sample Specificity: Dense or Sparse?
- Quality of Dialogue: Strong or Weak?
- Established Theory: Applied or Not?

- **Analytical procedure:**
  - The six stages of Braun and Clarke's[23] thematic analysis
    - Familiarisation
    - Generating codes
    - Generating initial themes
    - Developing and reviewing themes
    - Refining, defining and naming themes
    - Producing the report.

Pre-reg:

- Initial goal of 15: revised upon reaching
- Interview schedule based on previous findings and refined through PPI piloting and evaluation.
- **Reflexivity:**
  - Reflexivity is being increasingly applied in qualitative research to improve rigour.
  - Involves explicit acknowledgement and reflection of personal values, assumptions, experiences and perspectives on the data and topic, and how these guide the research process.
  - A Reflexive journal is kept to document these in relation to each stage of the research process.

Augmented Reality (AR) Programme Simulating Visual Impairment (VI)

- AR programme will be designed and developed to simulate VIs.
  - VIs are one of the most common post-stroke invisible impairments at 60% [24].
  - Scenarios and visual impairments will be based on findings from RTA and previous work.
  - Potential scenarios could involve completing tasks in occupational (office/production line), home (reading), or public (busy high street) settings.
  - Potential VIs could include visual field deficits, visual neglect, agnosia, and oculomotor impairments[9].
- AR will be reviewed internally by PPI group, and then piloted with stroke stakeholders:
  - E.g., carers, family, employers, healthcare professionals, policymakers
  - Range of evaluation measures under consideration, such as a pre-post knowledge questionnaire, qualitative interviews, and objective stress measurements such as GSR and heart rate.
  - Findings will be fed back into improving the AR programme.

Implications

- Address the analytical gaps in stroke research by focusing explicitly on invisible impairments and their psychosocial consequences.
- Develop and evaluate an immersive educational tool using AR to simulate lived experiences of visual impairment after stroke.
- Promote empathy and understanding among direct and indirect stakeholders of stroke (e.g., carers, family, employers, clinicians, policymakers).
- Support long-term quality of life improvements for stroke survivors through better recognition and accommodation of invisible impairments

References