Coding high volume, longitudinal, qualitative data within a realist evaluation: lessons from the D-PACT study

? Problem

- Inclusion: It can be difficult for people with dementia to respond to questionnaires, affecting their inclusion within evaluations
- Ability to establish outcomes within realist evaluations (REs): items from questionnaires often don't neatly map on to all outcomes within realist programme theories (PTs), yet quantitative findings are often relied upon by commissioners. Interview data may not always provide outcome data, especially when participants have cognitive challenges.

Our solution

- Provide high volume, longitudinal qualitative case study findings – where (programme theory) outcomes were aggregated but also explained – providing a robust comparison point to quantitative outcome measures.
- Challenge: while this type of data use is recommended in RE, published REs typically do not use this type of data, resulting in a lack of guidance.

How we did it

- PTs were divided into two tiers, each with its own coding framework, allowing coders to focus on specific parts, reducing burden of knowing/covering the entire theory.
- Provided training and manuals on D-PACT PTs and RE coding process (including NVivo instructions), built familiarity and understanding - improving coding consistency.
- Coders worked in separate NVivo files, which were later merged, reducing risk of software crashes and access issues.
- Researchers were assigned specific participant cases to code all related data, ensuring they could link data across various sources. Researchers kept memos, and tracked coding progress - facilitating reflection, progress checks, and smooth coding transitions between researchers (if needed).
- Coder were asked to identify data by first looking for instances where a clear intervention action (mechanism-resource) had occurred, rather than looking for all outcomes (which may not be related to intervention).
- NVivo was used for initial data sorting and mapping. Detailed analysis was conducted in Excel, which better supported chronological organisation, data linkages and case comparisons.
- When transitioning to Excel, PTs were simplified. Instead of detailing personalised intervention actions (e.g., providing information on financial support), these were grouped into broader categories such as tailored information, socio-emotional support, practical help. The delivery of personalised actions, in specific contexts, were still captured in data examples placed under these broader CMOs, but the process sped up.

Challenges and lessons

- Staff turnover due to short contracts led to a loss of experienced coders, hindering consistency.
- Data collection delays postponed coding activities.
- The coding framework was too detailed, with too many mechanism options for each theory, delaying progress. A simpler NVivo framework would have sufficed, with detailed analysis managed later in Excel.
- Programme theory changed substantially from feasibility to evaluation, making simply mapping data to existing programme theories challenging (was a lot of inductive work).
- The use of traditional date formats (e.g., 20.04.2020) made organising data chronologically challenging. The YYYY-MM-DD format would have been more effective.

Supplementary information

What is the D-PACT study?

5-year programme of research funded by the National Institute for Health and Care Research (NIHR) to develop and evaluate the value/impact of a Dementia Support Worker (DSW) role based in GP practices.

Phase 1 (feasibility) of D-PACT began in 2018. Here we developed the prototype intervention and developed/elaborated programme theory (PT) statements. The project's PT (underpinning the D-PACT intervention) explains how beneficial, intended (and unintended) change is generated by how people with dementia and carers respond to D-PACT DSW's support.

Phase 2 (realist evaluation) began November 2021 as longitudinal mixed-methods study, where the PT was further elaborated and refined.

DPACT
Dementia Support Study

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- The #BetterPoster movement by Mike Morrison https://osf.io/ef53g/

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