PAPER 1. DEVELOPING NEW ITEMS FOR PAIN, ANIXETY & LOW MOOD TO BE USED ALONGSIDE ASCOT

MiCare HQ Webinar

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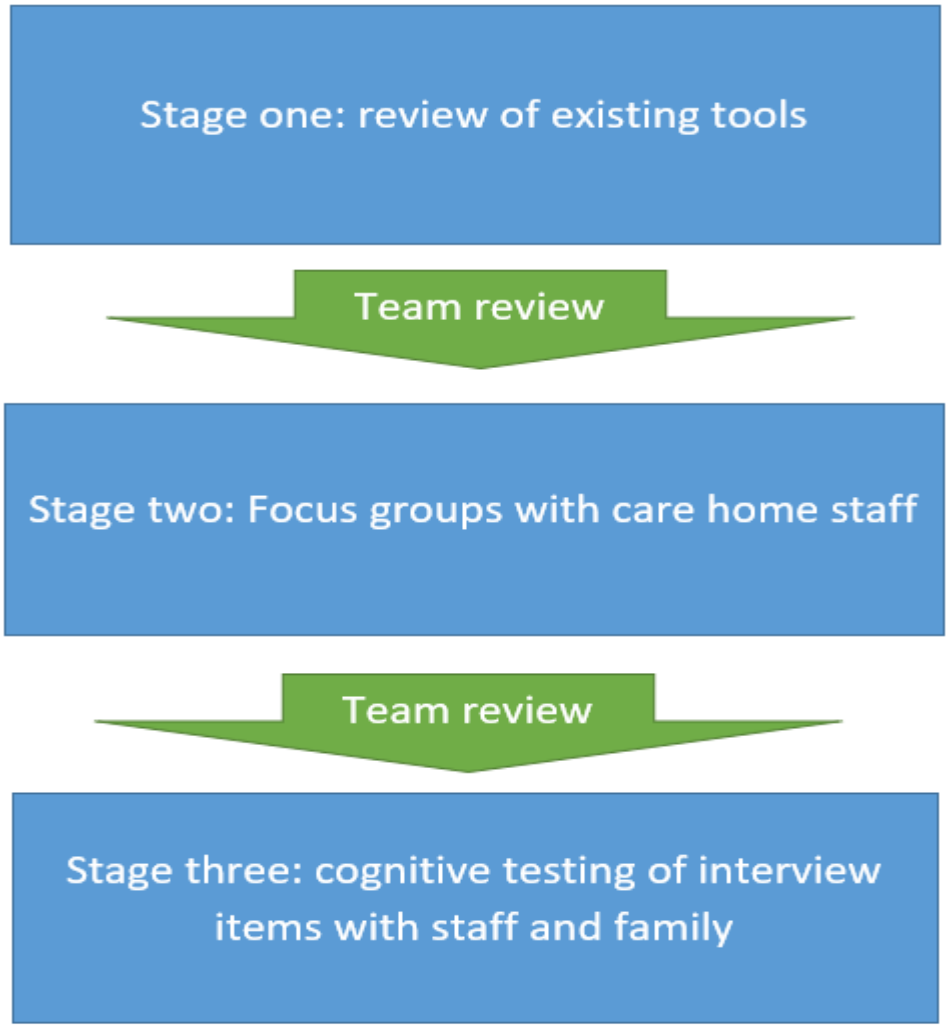
AIMS & BACKGROUND

- To develop new health-related quality of life (HRQoL) items of pain, anxiety, and mood for use with older care home residents who cannot self-report.
- Sit alongside the care home version of ASCOT.
- Uses a multi-methods approach to rate a resident's SCRQoL and estimate the impact of service on a resident's SCRQoL:
  - Observation of daily life.
  - Structured interviews with staff.
  - Structured interviews with family members.
  - Multi format interview with residents.
- Why measure these aspects of a resident's life?
  - Prevalence.
  - Negative impact of…
  - Under-recognition/under treatment.

METHODS


Stage one: review of existing tools
Team review
Stage two: Focus groups with care home staff
Team review
Stage three: cognitive testing of interview items with staff and family

FINDINGS: Review of existing tools

Pain tools

- 22 tools reviewed.
- Most tools focus on intensity of pain.
- Different modes (self-report, observation, proxy report).
- Self-reported tools designed for people living with mild levels of dementia.
- A number of validated observational tools specifically for people with more severe levels of dementia.
- Observational tools look for behaviours associated with pain.
- Multi-mode collection viewed as a positive.

Anxiety/depression tools

- 23 tools reviewed.
- 11 measured anxiety, 11 measured depression, 1 measured both.
- Tend to focus on symptoms to establish if a person has depression or anxiety.
- Different modes (self-report, proxy report, clinician rated, observation).
- Self report tools most common.
- Several proxy and clinician rated tools.
- Only two truly observational tools.

FINDINGS: Team review one

- Ensure our work not just replicating existing and (sometimes) well validated tools:
  - Our focus was on domains as part of a quality-of-life tool (ASCOT), not diagnosis or treatment.
  - ASCOT method unique in estimating impact of the service.
  - Focus on frequency not intensity of symptoms.
- Separate domains for anxiety and depression.
- Not clinical measures.
- Draft questions and responses for each domain.
- An example…

Which of the following statements best describes how often you think [the resident] feels down or depressed?

I think [the resident]…

- Hardly ever feels down or depressed
- Occasionally feels down or depressed
- Often feels down or depressed
- Constantly feels down or depressed

I think [the resident]…

- Never feels down or depressed
- Rarely feels down or depressed
- Sometimes feels down or depressed
- Often feels down or depressed

FINDINGS: Focus groups

- Three focus groups with care home staff (22 participants).
- Care workers, nurses, managers and other support staff.
- Three PPI co-researchers helped the team plan and carry out the focus groups.
- Focus groups had three sections:
  - Signs of pain, anxiety, depression
  - Words used to describe pain, anxiety, depression
  - Reflection on draft questions
- PPI co-researchers also fed into understanding the findings

FINDINGS: Focus groups

Signs of pain, anxiety, depression

- Staff able to talk about a range of behaviours that may indicate pain, anxiety or depression.
- Indicators reflected the literature/tools.
- Overlap between behavioural indicators for the domains.
- Some staff struggle to distinguish between anxiety and depression.
- Some suggest knowing the resident well is the key to interpreting behaviour.

Words used to describe pain, anxiety, depression

- Most staff constrained by wording of existing tools:
  - E.g. Abbey Pain Scale: mild, moderate, severe.
- Some like to use the words residents use.

FINDINGS: Focus groups

Reflection on draft questions

- Two domains per group.
- Think about a resident and answer the question.
- Facilitated discussion.
- Most people able to answer the questions.
- Concerns around the term ‘never’, especially in the anxiety domain.
- A few people felt that they were being asked to make a clinical judgement about domains and felt uncomfortable, as not clinicians.

FINDINGS: Team review 2

- Included PPI input.
- Discussed questions and responses in light of focus groups
  - Is ‘never’ an appropriate option in our new domains?
  - Decided to cognitively test both response scales.

- Reviewed signs of anxiety, depression & pain:
  - Alongside review material, provides a basis for observational guidance.

FINDINGS: Cognitive testing

- 37 interviews (16 relatives, 21 care home staff).
- Collection of data on how people answer questions.
- Data collected in three stages.
- Revisions between each stage.

FINDINGS: Cognitive testing

Stage one (14 interviews)

- Two different four-level scales.
    - The scale containing ‘never’ ruled out.
    - Feels depressed interpreted as a clinical diagnosis changed to low mood.

Stage Two (13 interviews)

- Tested one four level scale and one three level scale and the term low mood.
    - Four level scale preferred by respondents.
    - Low mood a better term than feels depressed.

Stage Three (10 interviews)

- Tested the four-level scale as well as testing complimentary questions on SCRQoL without services (expected).

CONCLUSION

For each domain:

- Observational/rating guidance.
- Care home resident interview questions.
- Family/staff interview questions.

- Tested in the next stage of the study.

CONCLUSION

19. Pain - current

Key indicators for expected needs in the presence of services	
To make this rating, you need to consider how often the resident is in pain. There are a number of behavioural indicators of pain. We list them below, but when rating you need to be aware that many can also be indicative of other states, such anxiety or feeling down. To clarify the meaning of the observational evidence you should consider it in conjunction with the interview evidence. You may also want to follow up observed behaviour with specific questions in the interviews with the resident or staff/family. Remember when rating, that if the resident manages their pain (via medication or other techniques), or staff help them to manage their pain, you should make your rating by considering the resident's experience with this in place. Behavioural indicators of pain: Vocalisations (including moaning, groaning, crying, sighs, screams, negative, combative or disapproving speech, repeated calling out, asking for help, using pain words such as "ouch" or "that hurts", decreased communication), Changes to breathing (such as laboured breathing, gasping, hyperventilation), changes to bodily movement (such as being tense, rigid, restless, fidgeting, pulling knees up, striking out, flinching, arched, jerking, rubbing or holding on to areas of the body/face). S/he might also try to protect themselves (by avoiding certain positions, avoiding usual activities, restricting or advoiding movement). Changes to facial expression (such as grimacing, frowning, clenched jaw, quivering, furrowed brow, clenching teeth, looking withdrawn), changes to mental status (increased confusion, irritability, upset, distress, anger), challenging behaviour (aggression, hitting out at other or objects), physiological changes (such as sweating, shaking, cold/clammy, changed appetite, difficulty sleeping).	
Ideal	The resident is hardly ever in pain

CONCLUSION

17. Which of the following statements best describes how often you think [the resident] feels down or has a low mood?

> ***Interviewer prompt:***
> *If needed, please prompt: When answering the question think about [the resident's] situation at the moment.*

I think [the resident]…

Please tick (☑) one box

Hardly ever feels down or has a low mood	☐
Occasionally feels down or has a low mood	☐
Often feels down or has a low mood	☐
Constantly feels down or has a low mood	☐

CONCLUSION

8. Which of the following statements best describes how often you feel worried or anxious?

Interviewer prompt:

If needed, please prompt: *When answering the question, think about your situation at the moment.*

Please tick (☑) one box

I hardly ever feel worried or anxious	☐
I occasionally feel worried or anxious	☐
I often feel worried or anxious	☐
I constantly feel worried or anxious	☐

DISCLAIMER

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