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Developing a Person Centered Fear and Dementia (FaDe) assessment tool for individuals living with a dementia

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Abstract
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Publication Details

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Dementia and Fear: Developing a person centred tool for practice
Who we are?

Counselling, Information Technology, Nursing and Psychology

Academics and Practitioners

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Siyu Qian
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Nicole Carrigan
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Counselling, Information Technology, Nursing and Psychology

Academics and Practitioners

Helen Pavlik

FADe

UNIVERSITY OF WOLLONGONG
AUSTRALIA
Welcome to the Aged Dementia Health Education & Research website

Our Staff
We have a number of highly qualified research staff, collaborators and international visitors.
Learn More

Research Students
Meet our talented research students and graduates and learn about their research.
Learn More

Contact Us
Contact us for further info about any of these resources contact: adhere-enquiries@uow.edu.au
Learn More

Content Pages
The focus of this resource is improving aged and dementia healthcare services using qualitative research and practice development techniques across care settings with multi-disciplinary teams.

Our resources are as follows:
What do we know about dementia?

- Individuals living with a dementia face challenges everyday caused by difficulties with their memory and cognitive capacities.
- Individuals living with a dementia benefit from positive support of their family, friends and healthcare practitioners to live a life as full as possible.
- Nursing home care is not an inevitable part of dementia but most older people living in a nursing home
Figure 5.2 The main psychological needs of people with dementia
Ontologies of dementia

- Person centred dementia care focuses on the role of ‘malignant social psychology’ and the impact of carers on the individual (Kitwood, 1987)

- Medical model of ‘behavioural and psychological symptoms of dementia’ (BPSD) oversymptomizing the experience of living with a dementia
What do we know about dementia and fear and anxiety?

- Current focus in clinical practice and research within dementia care is on assessing and ‘managing’ BPSDs e.g. Nursing Psychiatric Inventory and the Cohen-Mansfield Agitation Inventory and a range of therapies to reduce symptoms.

- Lack of focus in clinical practice and research on the interaction between the environment and the individual (physical and care practices) e.g. decreasing fear and anxiety.

- Our literature review found a gap in current research on fear and anxiety in dementia.
Research Design: Generating content for the Fear and Anxiety in Dementia (FADe) tool

- Aim of the research is to develop a person centred observational tool which enables the user of the tool to identify fear and anxiety experienced by individuals living with a dementia.

- Practitioners part of research team to ensure FADe has face validity and it is simple to use in clinical practice.

- Combining qualitative and quantitative methods.

- Inter-disciplinary approach generating the views and perceptions from practitioners and researchers with a range of experiences.
Research Design: Generating content for the draft versions of the FADe tool*

<table>
<thead>
<tr>
<th>Stage 1: Literature review of concepts: Draft 1</th>
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</thead>
<tbody>
<tr>
<td>Stage 2: Workshop with practitioners and service managers (n=22): Draft 2 (151 items created)</td>
</tr>
<tr>
<td>Ongoing Stage 3: Q Sort activity with researchers and senior clinicians (n=32 to date and aim for 50): Draft 3 (101 items reviewed)</td>
</tr>
<tr>
<td>2016 Stage 4: Delphi survey: Draft 4</td>
</tr>
<tr>
<td>2017 Stage 5: Reliability and validity testing using observational methods: Final version</td>
</tr>
</tbody>
</table>
Q Sort: Demographic profile of participants

13%

87%
Q Sort: Demographic profile of participants cont’d

Discipline of Participants (%)

- Nursing: 60%
- Psychology: 10%
- Counselling: 20%
- Other: 10%

Percentage (%)
Q Sort: Demographic profile of participants cont’d

Role of Participants (%)

Percentage (%)

80%
70%
60%
50%
40%
30%
20%
10%
0%

Practitioner
Academic
Family carer
PhD candidate

Role
Q Sort: Categories created by participants

- Number of categories (groups of cards)
  - Mean $11.3 \pm 4.3$
  - Range: 3–21

- Similar findings for academics and practitioners (mean number of categories of 11 for both)

- Different findings between the most represented disciplines of nursing and psychology/counselling (mean number of categories 9 and 16 respectively)
Q Sort: Example of simple model

- Social Appropriateness
- Early signs of cognitive decline
- Agitated/Psychomotor
- Hypersensitivity
- Physical/speech behaviour
- Emotionally inappropriate
- Angry posture and tone
- Religiosity
Q Sort: Example of complex model

**Somatic Features**
- Breathing
- Locomotion
- Somatic complaints
- Motor control
- Facial Attributes
- Muscle tension

**Cognitive Features**
- Impoverished
- Religious thinking
- Speech
- Perseverative Behaviours

**Affect**
- Sadness
- Angry disposition
- Anger – acting out
- Self-injurious emotional regulation
- Self soothing

**Social Features**
- Engaging
- Isolating
- Dissociation
- Dependence

**Perceptual Features**
- Hypervigilance
What’s next for the FADe Tool?

- Complete Q Sort activity
- Delphi survey to develop Draft 5 to ensure items included have the highest level of agreement among participants about their representation of fear and anxiety for individuals living with a dementia
- Reliability and validity testing, including factor analysis to develop final version of FADe tool
- 2017: Launch FADe Tool
- Future studies
  - Developing digital version of tool for clinical partners
  - Filimed vignettes demonstrating the use of the FADe Tool in practice (UOW)
  - Intervention study using the fear and anxiety tool in dementia as an outcome measure
Clinical implications

- FADe tool will be used by practitioners to recognise and assess fear and anxiety experienced by individuals living with a dementia.

- FADe tool will be promoted as a tool which can be used to plan the ways in which practitioners work with individuals living with a dementia.

- FADe tool will be used to structure education activities with practitioners to create environments (physical and caring relationships) which are less fearful for individuals living with a dementia.

- Using the FADe tool has the potential to begin conversations among practitioners.
Questions and comments

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Aged and Dementia Health Research and Education (ADHERe)