

# Separated by a common language - Cognitive Interview Study on the Integrated Palliative Care Outcome Scale for People with Dementia (IPOS-Dem) in the acute care- and district nurse-/community home care setting.

de Wolf-Linder, S.<sup>1,2</sup>, Kramer, I.<sup>1</sup>, Ellis-Smith, C.<sup>3</sup>, Hodiamont, F.<sup>4</sup>, Reisinger, M.<sup>1</sup>, Gohles, E.<sup>1</sup>, Murtagh, F.E.M.<sup>2</sup>, and Schubert, M.<sup>1</sup>

<sup>1</sup> School of Health Professions, Institute of Nursing, Zurich University of Applied Sciences, Winterthur, Switzerland. <sup>2</sup> Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, UK. <sup>3</sup> King's College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, London, UK. <sup>4</sup> Department of Palliative Medicine, University Hospital, Ludwig-Maximilian-University Munich, Munich, Germany

## Background

People with advanced dementia (PwD) are affected by symptoms and needs that can be challenging for nurses and relatives to elicit. The UK-developed IPOS-Dem was translated and culturally adapted to the Swiss-German acute care and community care setting. It is a holistic, person-centred measure to aid caregivers to identify symptoms and needs in people with dementia. Content validity of the IPOS-Dem needs to be tested before detailed psychometric testing can begin.

## Aim

The aim of this project is to demonstrate content validity of the Swiss-German IPOS-Dem with nurses for the acute care and community care setting.

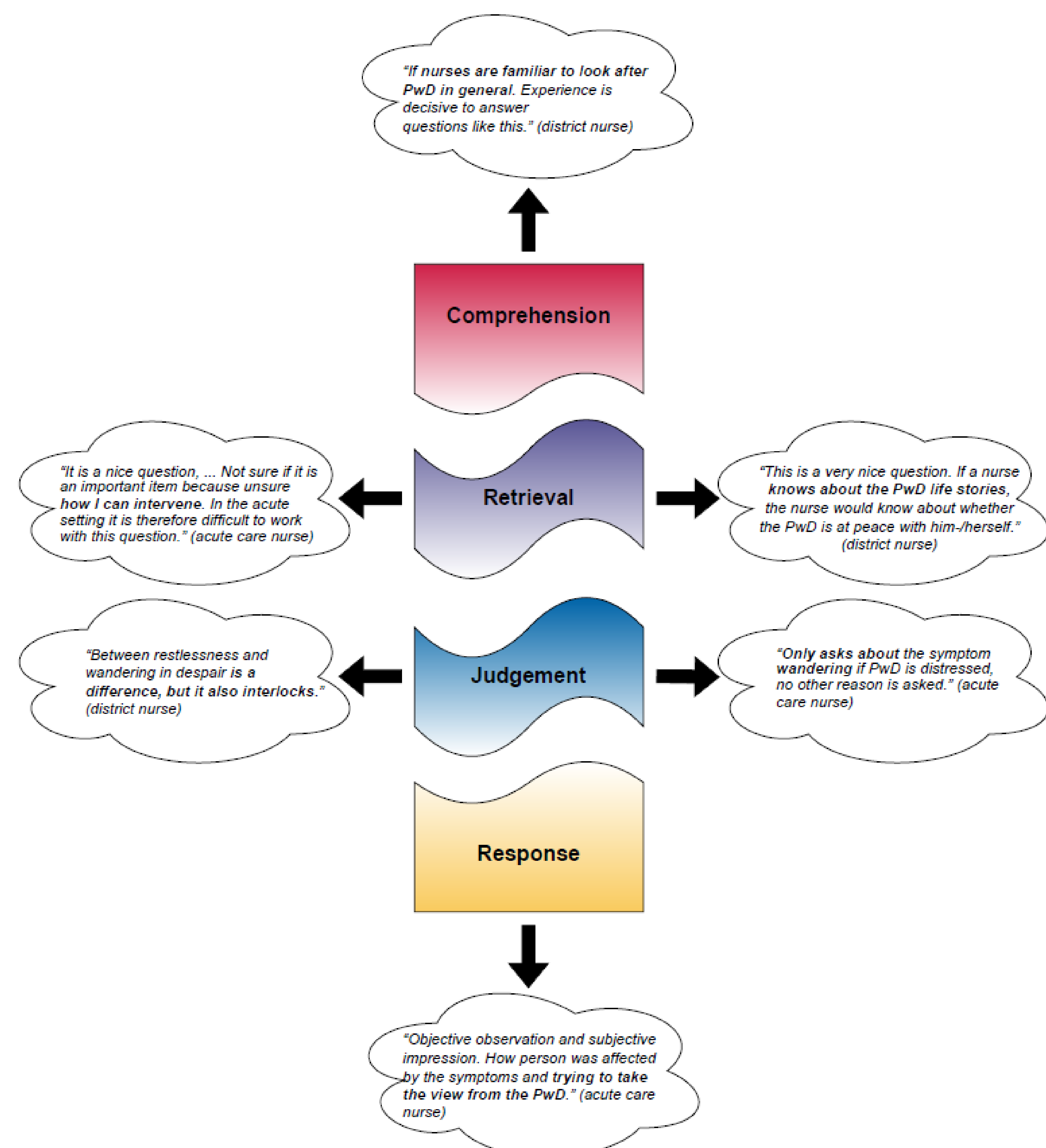
## Methods

Nurses with diploma and university degrees and relatives over 18 years were purposively recruited. We conducted cognitive interview rounds with nurses from the acute care and community care setting. Thinking-aloud- and probing questions, based on Tourangeau's (comprehension, retrieval, judgement, and response) model, were applied with each participant<sup>1,2</sup>. Interviews were transcribed and analysed from audio file whilst reading the transcript concurrently by two independent researchers. Quotes were inserted into the four domains from Tourangeau's model independently. Inconsistencies were critically discussed and resolved by consensus.

## Results I – Two rounds of cognitive interviews together

Ten interviews in three rounds were completed in spring 2021. Two relatives, five acute-care (ACNs), and three district nurses (DNs) agreed to participate. Participants welcomed the clear and understandable instructions, and description of all items. ACNs and DNs differed in judgement of items, from being able to assess the PwDs need at all (e.g. feeling sad, enjoying things), to interpreting a symptom or need, and having different concepts in mind (e.g. agitation, wandering). After analysis of the first two rounds, retrieval difficulties and differences between ACNs and DNs were identified in psychosocial items (e.g. 'feeling at peace'); ACNs were reflecting on the PwDs overall life, whilst DNs were thinking about the present and how the PwD is affected by it (Fig 1). We therefore conducted another round of cognitive interviews with nurses from each setting (acute care and community care) separately in autumn 2021.

Fig 1: Content Validity



## Results II – Third round of interviews separated

In round three the meaning of the wording of each item was well understood by district nurses. Some information in brackets could be deleted as nurses felt the item was distinct (e.g. difficulty communicating (through verbal or body language)). Acute care nurses felt that the wording of a few items should be made more explicit and added in the first, open ended question "from the person's with dementia point of view". Also, in two items, information in brackets were added for the acute care setting based on judgement from acute care nurses (e.g. limited mobility (difficulty changing position in bed), which was felt less appropriate to be added in the district nurse and community care setting. We then agreed within the study team and POS-team to do two versions, one for the acute care setting and one for the district nurse and community care setting.

## Conclusion

The IPOS-Dem has been adapted in culture and content validity, with Swiss-German versions developed for both the acute care and community care setting. Although the versions do not differ substantially, the implications for teaching- and implementation of the IPOS-Dem into routine care diverge considerably.

**References:** <sup>1</sup>Willis GB 2011, Cognitive Interview in Practice, SAGE Publications.; <sup>2</sup>Beatty PC and Willis GB 2009, Research Synthesis: The Practice of Cognitive Interviewing. Public Opinion Quarterly