Twenty-five years of the EdFED scale: a useful scale for measuring mealtime difficulty in older people with dementia

by Roger Watson (FRCN 2009)

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The 'EdFED' is the Edinburgh Feeding Evaluation in Dementia (EdFED) scale. 'Ed' points to where the scale was developed – Edinburgh University – and 'FED' is shorthand for 'feeding'. Finding a meaningful acronym is always challenging, but this one seems to have worked: once understood, it is easy to recall.

The development of the EdFED scale arose from my experience in clinical practice in the 1980s. I was a charge nurse in a long-term care setting for older people and the problems that older people with dementia had at mealtimes and our inability to manage these sparked my interest. Early in this journey, it was apparent that we needed some way of measuring these problems and I discovered from doing a literature search that no method existed.

I first reported the EdFED scale in a paper published in 1994 in the Journal of Advanced Nursing, the journal of which I am now the Editor in Chief. The link to that paper and its abstract are provided below.

Measuring feeding difficulty in patients with dementia: developing a scale

Abstract
Feeding difficulty in elderly people with dementia is well documented and the need for research in this area of nursing care has been raised by several authors. One hundred and twelve elderly people with dementia were entered into a study of feeding difficulty. Data were gathered by means of a questionnaire administered to the nurses caring for the patients.

The aspects of feeding difficulty which were investigated were based on reports of relevant behaviour in the literature and included refusal to eat, turning the head away, refusing to open the mouth, spitting, allowing food to drop out of the mouth and not swallowing. It was possible to arrange these different aspects of feeding difficulty under three headings: (a) refusal to eat, (b) spitting and (c) inability to swallow, and to analyse the pattern of accumulation of these feeding difficulties by means of Guttman scale analysis. According to this analysis, the feeding difficulties investigated form a cumulative and unidimensional pattern. The implications of this pattern and the possibilities for further research are discussed.

Citation
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Introduction and background

When I first started thinking about what eventually developed into the Edinburgh Feeding Evaluation in Dementia (EdFED) scale, we were beginning to see in clinical practice an increase in the number of older people as a result of the ageing population of the UK. Also, the health policy context was changing in the wake of the Griffiths report (1988) on care in the community that formed a key part of the NHS reforms under the Thatcher government. This policy had a

disproportionate effect on the care of older people. Many long-term care facilities for older people closed and an exponential rise in the nursing home industry took place. Few long-term care hospitals remained (and I worked in one), and most commercial nursing homes were reluctant to take older people with dementia, which led to a sudden increase in the number of older people with dementia being admitted to long-term care hospitals.

Older people with dementia had some common problems and among these was difficulty at mealtimes, which included difficulty with eating. These problems were matched by our apparent lack of knowledge about how to help older people with dementia to eat, as I identified in a literature review (Watson 1993). I became interested in trying to investigate and develop strategies for alleviating the difficulties.

I was unusual in nursing as I already had a PhD in biochemistry before entering nursing, which equipped me with some knowledge of research. However, I had no experience of clinical research. Naively, I set about designing a clinical trial where we would test our ability to help older people with dementia to eat and I applied for a research grant to the Scottish Office. Quite rightly, the funding was not awarded, and I received scathing feedback on the proposal. The feedback indicated I did not have a way of measuring the mealtime difficulty of the older people with dementia and, therefore, no rigorous way of measuring whether the proposed interventions would make any difference. This glaring omission led me to search the literature for a suitable measure. I found none and that set me on a course of research which has lasted for 30 years.

Measurement, scale development and psychometrics in UK nursing, with a few exceptions, were rare at the time I embarked on this work. Fundamentals such as reliability and validity were poorly understood. My own understanding of these concepts and some of the more sophisticated aspects of scale development and testing developed after I moved to the University of Edinburgh through collaboration with a psychologist – Ian Deary – in the Department of Psychology. This was a truly interdisciplinary collaboration as the problem we were investigating lay firmly in the nursing domain and the methods required to investigate it lay within psychology.

Before the involvement of Ian Deary, I was indebted to Ian Atkinson, then working in the Nursing Research Unit, who looked at some of my initial data and suggested I consider a method called Guttman scaling. This, essentially, set the pattern for my research over the next 30 years. Guttman scaling, which had been useful in the early stage of developing the EdFED (Watson 1994a, 1994b) was superseded by Mokken scaling, which was subsequently applied to the further development of the EdFED scale (Watson 1996).

Influence and impact

The idea of a scale did come from practice, but the EdFED was primarily designed as a research instrument. However, I have observed it being used for clinical assessment in the Tokyo Institute of Geriatrics and Gerontology, where it was translated into Japanese. It was adopted in the United States by the Hartford Foundation as a clinical assessment instrument for the care of older people in hospital and is still available online (Stockdell and Amella 2008). It has also been translated into and published in Chinese in Taiwan (Lin et al 2008) and in mainland China (Liu et al 2014), Italian (Watson et al 2017) and translations exist in French, German, Lithuanian, Turkish, Korean and Persian.

Alzheimer's Disease International (2014), in its report Nutrition and Dementia, referred to the EdFED as the most validated instrument for measuring mealtime difficulty in older people with dementia and cited specific aspects of the validation (Watson 1997, Watson et al 2001, Watson et al 2002). The report described the EdFED as: 'brief and simple enough to be used in routine care. It establishes the level and type of feeding disability and can be used to plan effective interventions.'

The EdFED scale also has had its critics. Some of the terminology in the scale has been criticised as being patronising and inappropriate – both the name of the scale and the way the items are expressed within the scale (for example: Does the patient refuse to open his/her mouth?). With the benefit of hindsight, I completely agree. Therefore, I have been encouraging colleagues and research students with whom I work to adopt the more general term 'mealtime', rather than focus narrowly on 'feeding'. I also believe that this is a more accurate description of the problem.

Mealtimes are a complex activity which older people with dementia must negotiate (Gallant 2019) of which eating (which implies some choice in the food eaten and in the

social aspects of mealtimes), and feeding (moving food from a plate to the mouth), are components. However, the EdFED has international currency and has already been translated into many languages, so the name and the items have been retained.

Other useful criticism has been raised; for example, if an older person with dementia is able to eat independently, there is no provision for this on the scale; nor does it provide for someone who is unable to respond and is beyond the stage where assistance with eating is no longer a valid option. I was remiss in not being consistent in labelling the various versions of the EdFED scale that are being used.

The original version contained 11 items, soon reduced to 10 items (the most commonly used version), but I have mainly used a six-item version that focuses on the behavioural aspects of mealtime. All these versions are referred to as the EdFED scale. Science is rarely as neat as we might like.

In assessing the influence and impact of the EdFED scale, it is as a research instrument that it has proved to be most useful. The EdFED was used as the main outcome measure in the first randomised controlled trial of mealtime interventions for older people with dementia in Taiwan (Lin et al 2010, 2011). In Canada, it is the main outcome measure in a national Canadian Institutes of Health Research-funded project into the nutritional status of older people with dementia in nursing homes (Keller et al 2017, Slaughter et al 2020). I am pleased that the EdFED has been picked up internationally and incorporated into such high-profile and prestigious work.

Current and future relevance

The EdFED continues to be used. Some examples of its use in research already have been provided. In my own work, the EdFED has been a key outcome measure in two recently completed PhD projects that I have supervised. One of these projects investigated environmental influences on mealtime difficulty of older people in nursing homes in Italy (Palese et al 2018a, 2018b, 2018c, Palese et al 2019a, 2019b, Palese et al 2020a, 2020b, 2020c). The other project investigated the use of spaced retrieval, a method of retraining people by using procedural memory, which is relatively unaffected in dementia and allowing time to learn over progressively longer intervals, in alleviating mealtime difficulties of older people in nursing homes in the UK (Rehman et al 2019).

Interest continues to be shown by clinicians and academics in many countries in the use of the EdFED, and I still receive requests to use it or to translate it. I have never claimed copyright of the EdFED scale and have always permitted its use and translation free of charge. In addition to some criticisms already mentioned, the EdFED scale may not contain all the possible difficulties that an older person may experience at mealtimes, including some problems that may not be directly related to eating. I encourage others to use the EdFED and to develop other more comprehensive scales. However, I always urge others who may take it forward to bear in mind that the EdFED is attractive to researchers and clinicians because it is very short and easy to use and, importantly, its psychometric properties are well established.

What the EdFED does not do is tell the practitioner how to respond to the measurements made using the scale in terms of improving help for a person who is having difficulty at mealtimes. This is a valid criticism, but the EdFED was only designed to measure and we are still largely in the dark about how, from an evidence based perspective – as comprehensive systematic reviews have consistently shown – to alleviate mealtime difficulty for older people with dementia (Abdelhamid et al 2016a, 2016b, Herke et al 2018, Watson and Green 2006). However, from my own research programme, we know that the nursing home environment has a major influence positive and negative on maintaining independent eating among nursing home residents (Palese et al 2019a). And in single-case experimental work that is still under way we have shown – using the EdFED scale as an outcome measure alongside measures of nutritional status – that spaced retrieval can be effective in alleviating mealtime difficulty.

So, 25 years on, the EdFED continues to have relevance. It certainly has a place in the history of research into dementia generally and, specifically, into mealtime difficulties of older people with dementia. My work with the scale is nearly over but I will look with interest in future at work in this area. Unless a cure is found for all the common forms of dementia, I expect the EdFED, in some form or other, will still be in use for many years.

For nurses entering clinical practice or research, I think it is important to note that

this programme of work arose directly from my observations and frustrations in clinical practice. I followed my instincts here and I hope you can do the same. It may take many years but, eventually, you may make a difference.

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