The Use of Proxy / Informant Reports for People with Dementia

Abstract:
The progressive deterioration of cognitive and functional abilities in people with dementia presents a number of practical problems for the measurement of health outcomes using self-report or direct questioning methods. These include: a poor psychometric evidence base for the use of self-report health status instruments for people with cognitive impairment; the need for better survey design for older people using universal design principles; the time constraints involved with assessment; as well as test administration issues like test-taker inattention and compliance, or alternatively, test-taker burden and distress. In response to these and other problems an alternative measurement approach has developed. This approach, here described as proxy measurement, uses proxy or surrogate reports of symptoms by carers or clinical informants in close contact with the person with dementia.

This example of knowledge transfer from the Dementia Outcomes Measurement Suite (DOMS) project is designed to help busy clinicians and researchers ensure best practice with the application of proxy measurement. It highlights the key issues in relation to proxy measurement, including:

- When to use proxy measures;
- Best practice in the use of proxy informants;
- Factors affecting proxy ratings;
- The advantages and disadvantages of proxy reports;
- A survey of the available instruments;
- and the latest research developments in the field.