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Factors Associated with Informant-Reported Cognitive Decline in Older Adults: A Systemised Literature Review

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Abstract

Background: Dementia diagnoses are typically made where there is a significant, progressive decline in cognitive functioning. Evidence of such decline is increasingly established through information provided by informants. However, some studies demonstrate that informant reports may not always be accurate, and may be biased by extraneous factors. This review aimed to elucidate factors that have been identified as potentially having some influence on informant reports of cognitive decline.

Method: A search of PsychInfo, ASSIA, PubMed and Web of Science databases identified 13 peer-reviewed studies that met criteria for inclusion in the review.

Results: Reviewed studies provide some evidence for associations between informant-reported cognitive decline and demographic characteristics (patient age, education, ethnicity and informant gender), clinical factors (dementia severity, diagnosis, behavioural disturbance, everyday functioning) and psychological factors (patient depressive symptoms and neuroticism, informant psychological distress and burden). Several methodological limitations of the evidence base were identified.

Conclusion: Findings suggest that informant-reported cognitive decline may not always be wholly reliable in that information holds potential to be influenced by both patient and informant characteristics. Clinical and empirical implications are discussed.

Keywords: *Dementia, Cognitive Decline, Memory Assessment, Cognitive Assessment, Informant*

Introduction

The dementias are recognised as neurodegenerative conditions, causing irreversible decline in intellectual, social, physical and psychological functioning; individuals living with dementia typically experience a progressive loss of skills, social roles, psychological wellbeing and the ability to autonomously carry-out everyday activities (Department of Health, 2009a; Frank et al., 2006). Consequently, some individuals living with dementia require increased levels of support as the condition progresses, most commonly provided in their own homes by informal carers, such as spouses and adult children (Etters, Goodall & Harrison, 2007). As such, dementia holds the potential to have a profound impact on both those living with the condition and those who support them. Indeed, caring for a person with dementia has been associated with an increased risk of psychological and physical health problems (Van Der Lee et al., 2014). This can be understood in terms of caregiver burden; “the degree to which a carer’s emotional or physical health, social life or financial status suffer as a result of caring” (Zarit et al., 1986, pp. 261). Research suggests that caregiver burden is associated with negative outcomes for carers (e.g. depression, reduced quality of life) and those diagnosed with dementia (e.g. reduced quality of life, moves to residential care settings) (Etters et al., 2007).

Dementia Assessment and Diagnosis

Progressive decline in cognitive functioning is a key feature of dementia and it is advised that assessment should involve standardised psychometric tests, which examine a range of skills (e.g. American Psychiatric Association; APA, 2002; British Psychological Society & Royal College of Psychiatrists; BPS & RCP, 2007; Guideline Adaptation Committee, 2016; World Health Organisation; WHO, 1992). However, such instruments provide a comparison to age-matched norms only at a single time point (Quinn et al., 2014) and may be affected by a variety of factors, including education level, sensory difficulties and language ability (Mackinnon & Mulligan, 1998). Given this, and the potential inaccuracies within the self-reports of those referred for memory assessment (referred to throughout as “patients”) (Quinn et al., 2014; Lehmer et al., 2015), gaining the perspective of an informant who is familiar with the patient’s pre-morbid and current cognitive functioning, has become an increasingly

important practice (Neumann, Araki & Gutterman, 2000; Quinn et al., 2014). Indeed, and unlike the assessing clinician, informants are more likely to have known the patient for long periods of time and may be better placed to notice early symptoms of dementia (McLoughlin et al., 1996), changes in cognitive functioning, and to notice any discrepancies between functioning at home and during formal assessment. Research suggests that informant-reported cognitive decline (IRCD) has the potential to be as effective as standardised psychometric tests in screening for dementia (Jorm, 1996) and unlike psychometric tests, is unaffected by the identified patients' premorbid cognitive functioning or physical ability (MacKinnon & Mulligan, 1998). As such, the importance of incorporating informant information within cognitive assessments has been highlighted in international guidelines (APA, 2002; BPS & RCP, 2007; Guideline Adaptation Committee, 2016; McKhann et al., 2011; Phillips, Pond & Goode, 2011; WHO, 1992).

In clinical practice, an informant's perspective is incorporated through informal interview or the administration of a standardised questionnaire (Mackinnon & Mulligan, 1998; Quinn et al., 2014). Such questionnaires ask informants to consider a patient's cognitive functioning in everyday life compared to functioning earlier in life. Instruments that are frequently used for this purpose include the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) (Jorm & Jacomb, 1989), the Eight-Item Informant Interview to Differentiate Aging and Dementia (Galvin et al., 2005) and the Cambridge Mental Disorders of the Elderly Examination (CAMDEX) Informant Interview (Roth et al., 1986).

Despite the variety of questionnaires designed to capture informant information pertaining to cognitive decline, concern exists regarding the accuracy of IRCD. Ross et al. (1997) reported that informants did not report cognitive problems in 21% of patients who were later diagnosed with dementia, and Kemp et al. (2002) found that 40.5% of informants gave responses inconsistent with clinician ratings in at least one of four cognitive domains examined. Informant reports of other aspects of patient functioning have been suggested to be influenced by factors other than patient cognitive functioning (Snow et al., 2005). As such, it has been suggested that a variety of factors may bias IRCD, highlighting a

need for research to identify informants who may be less likely to provide accurate information (Jorm, 1996; Magaziner, 1997).

Rationale and Summary

Although informant-reports have demonstrated resistance to factors that potentially bias patient self-reports and standardised psychometric tests, there is concern that extraneous factors may influence the reliability of such reports (Jorm, 1996). Given that information provided by informants may, in part, inform a diagnosis of dementia, it is vital to gain an understanding of this. While some studies have explored factors that may be associated with, or potentially influence IRCD, to date there has been no comprehensive review of the literature pertaining to this topic.

Method

The present review evaluated qualitative and quantitative studies from peer-reviewed journal articles in order to identify factors that have been found to be associated with IRCD in older adult populations. Factors associated with IRCD included, but not limited to, patient or informant demographic (e.g. age), psychological (e.g. affective state), physical (e.g. physical health) and relationship characteristics (e.g. relationship type) but excluded neurological or biological factors. Due to the paucity of literature in this area, studies that explored factors associated with the accuracy of IRCD by means of comparison with psychometric tests were included in the review. However, studies which primarily aimed to add to the knowledge base pertaining to specific measures (i.e. to determine psychometric properties or validate use within specific populations) were excluded.

Search Strategy

A search of the databases PsychInfo, ASSIA, PubMed and Web of Science, a search of the literature was conducted from 1.7.89 until 1.7. 17. The following terms were used: [informant *or* carer *or* proxy *or* collateral] and [cognitive decline *or* cognitive functioning *or* cognitive impairment] and [elderly *or* aged *or* older adult].

Inclusion and exclusion criteria. The search results were limited to those published in the English language and peer-review journals. Abstracts were read and full text articles obtained if this

indicated that the paper reported an association (or lack thereof) between patient or informant factors and IRCD amongst older adults. The reference lists of all relevant papers were subsequently hand-searched and any additional, relevant studies were retrieved and also included in the review (Figure 1).

[Insert Figure 1 here]

Overview of Studies

In total, the literature search identified 13 studies that met the review's inclusion and exclusion criteria (Table 1). Ten of the thirteen studies identified employed a cross-sectional design, two employed a prospective cohort design with cross-sectional analyses (see Gavett et al., 2011 and Jorm et al., 1998) and one employed a purely prospective cohort design (see Kemp et al., 2002). All of the studies used quantitative methods to examine relationships between IRCD and identified variables. All but one study (Jorm et al., 1994) used a standardised questionnaire to measure IRCD. Most used the full or abbreviated version of the IQCODE, whilst three used the CAMDEX Informant Interview.

[Insert Table 1 here]

The search identified three groups of factors examined in relation to IRCD (namely, patient, informant and patient-informant relationship factors) and so the review is structured accordingly. Using a framework derived from a previously published review (Sherer et al., 2002) as based on guidelines for evaluating research in neuropsychology (Heaton et al., 2002), each study was given a quality rating (i.e. "flawed", "marginal", "acceptable" and "commendable") to aid in its interpretation.

Results

Patient Factors

Most studies included in the review examined variables pertaining to patients when exploring IRCD (n = 12). For ease of interpretation, these variables were categorised into demographic characteristics, clinical and psychological factors (see Table 1).

Demographic characteristics.

Age. Seven studies examined the relationship between patient age and IRCD. Five found a positive association between age and IRCD without controlling for other variables; with informants

reporting significantly greater cognitive decline on a survey (Jorm et al., 1994) and the IQCODE (Farias et al., 2004; Kirkevold & Selbaek, 2015; Nygaard et al., 2009; Persson et al., 2015) with increasing age.

Ross et al. (1997) explored factors contributing to failure to recognise cognitive decline via the IQCODE, and concluded that informants were less likely to accurately identify significant decline in older patients. In contrast, a high quality prospective study found that patient age did not differ between those who under-reported (mean age = 80.3), over-reported (mean age = 80.3) or accurately reported cognitive decline on the CAMDEX (mean age = 79.0; Kemp et al., 2002).

Two studies used multivariate analysis to explore associations further. Farias et al. (2004) reported that age remained a significant predictor of IQCODE score after controlling for cognitive variables, whilst Kirkevold and Selbaek (2015) observed that age was no longer associated with IQCODE score when patient gender, everyday functioning, neuropsychiatric symptoms and medical health were included.

Gender. Five studies included gender as a potential correlate. Although three of these concluded that IRCD, as reported by the IQCODE, was not significantly associated with patient gender (Farias et al., 2004; Kirkevold & Selbaek, 2015; Nygaard et al., 2009), two reported a significant, albeit weak, association. Jorm et al. (1994) identified a trend for informants to report greater cognitive decline on a survey of male patients, whilst Persson et al. (2015) found the opposite; in that being female was associated with greater IRCD on the IQCODE. Both studies were deemed to be of good methodological quality, however differences in the samples (i.e. diagnosis, proportion of females) and measurement of IRCD, may explain the differing results.

Education. Five of the reviewed studies examined the association between education and IRCD. Jorm et al. (1994) found that education was not significantly associated with cognitive decline as captured by an informant survey. Two studies, utilising the IQCODE, reported an association; Persson et al. (2015) concluded IRCD increased as years of education increased, whilst Farias et al. (2004) reported that fewer years of education was associated with greater cognitive decline. Kemp et al. (2002) concluded that education was predictive of informants under-reporting (but not over-reporting) cognitive decline, whilst Ross et al. (1997) found that informants were more likely to fail to recognise decline in less educated

patients. Notably, there were differences between studies in terms of which country they were conducted (Norway, Hawaii, USA and Australia) and the culture from which the populations were derived (e.g. Japanese-American, Hispanic). The impact this might have had on educational quality and attainment needs to be considered.

Ethnicity and language. Three studies explored ethnicity and/or language as a potential correlate. Jorm et al. (1998) found that being a native English speaker was not associated with reported decline on the IQCODE. However, the patient sample was entirely male, raising questions regarding generalisability. Farias et al. (2004) examined the combined impact of ethnicity and language (i.e. Hispanic-English, Hispanic-Spanish, Caucasian-English) and found that ethnicity-language group significantly predicted IQCODE score. Specifically, more Caucasian-English group members scored in the lower ranges than the higher ranges of the IQCODE, whilst both Hispanic group scores were equally distributed. Within the Hispanic groups, Spanish speakers scored significantly higher than English speakers.

In a study of Caucasian-Americans and African-Americans, Potter et al. (2009) found there were no differences in mean IQCODE score between Caucasian-Americans and African-Americans in those with no significant cognitive decline or dementia, but that Caucasian-Americans had significantly higher IQCODE scores than African-Americans with cognitive impairment not fulfilling criteria for a dementia. Multivariate analysis, including age, gender and education as covariates, suggested that ethnicity impacted the association between IQCODE score and subsequent dementia diagnosis. Here, IQCODE score was associated with dementia and milder cognitive impairment (not fulfilling criteria for dementia) in Caucasian Americans but only associated with dementia in African-Americans.

Occupation. Only two studies included occupation type as a potential correlate of IRCD. Jorm et al. (1998) coded occupation according to Holland's (1959) categories and found that IQCODE score did not significantly differ between different occupational groups. O'Connor et al. (1989) grouped participant-informant dyads according to their combined working history or social class and found no significant differences in mean informant score, via the CAMDEX, across social class, for those with mild, moderate or severe cognitive impairment.

Clinical factors.

Dementia diagnosis and severity. Four studies evaluated the impact of diagnosis and dementia severity on IRCD. Using the Clinical Dementia Rating scale (Hughes et al., 1982), Ross et al. (1997) observed a significant difference in the number of informants who failed to recognise cognitive decline in those with very mild dementia (52%; Clinical Dementia Rating = 0.5) and those with mild to severe dementia (13%; Clinical Dementia Rating \geq 1). The authors discuss that those in the very mild dementia group may not have had a dementia syndrome, and so symptoms may have been subtler, however O'Connor et al. (1989) found similar results, with informants' CAMDEX scores increasing with dementia severity (Roth et al., 1986). Further, Potter et al (2009) found IQCODE scores for African-American participants differed between cognitively normal patients (Mean = 2.9) and those with dementia (Mean = 3.8), but not patients with cognitive impairment without dementia. In Caucasian-American participants, IQCODE scores of cognitively normal patients significantly differed to those with cognitive impairment and patients with dementia at time of assessment.

Ross et al (1997) found that there was no significant difference in the percentage of informants who failed to recognise cognitive difficulties between patients with Alzheimer's disease (21%), vascular dementia (18%) or Parkinson's disease with dementia (10%). Kemp et al. (2002) noted that under-reporting cognitive difficulties was predicted by sub-clinical dementia whilst over-reporting cognitive difficulties was predicted by reporting on those who met dementia diagnostic criteria.

Neuropsychiatric symptoms. Four studies explored neuropsychiatric or behavioural symptoms as a correlate. Using two versions of the Neuropsychiatric Inventory, Persson et al. (2015) and Kirkevold & Selbaek (2015) found that cognitive decline, measured using the IQCODE, increased as Neuropsychiatric Inventory score increased. Although less methodologically robust, O'Connor et al. (1989) measured the frequency of behavioural and psychological symptoms, as rated by a psychiatrist, and similarly found a positive association with CAMDEX informant scores. Using the Behavioural Pathology in Alzheimer's Disease Rating Scale (Reisberg et al., 1987) Ross et al. (1997) found that informants were more likely to recognise cognitive decline in patients with poorer scores.

Everyday functioning. Five studies explored the relationship between patient everyday functioning and IRCD. All measured everyday functioning using standardised measures; including the instrumental activities of daily living (ADL) scale, personal ADL scale (Lawton & Brody, 1969), the Adelaide Activity Profile scale (Clark & Bond, 1995) and a modified version of the Blessed Dementia Scale (Tomlinson & Roth, 1968).

Ross et al. (1997) noted that informants were more likely to recognise problems in male patients with poorer scores on the Blessed Dementia Scale. Conversely, in a prospective study, Gavett et al. (2011) found that IQCODE scores were negatively correlated with Adelaide Activity Profile scores ($r = -0.15$) which remained associated with the change in Adelaide Activity Profile scores over three years (albeit within a somewhat unrepresentative all-female sample). Kemp et al. (2002) found that instrumental ADL score was higher for informants who over-reported, but not those who under-reported, cognitive difficulties. Despite this, instrumental ADL score was not a significant predictor of under-reporting or over-reporting compared to accurate reports in binary logistic regression analysis.

Two studies found IQCODE scores were positively associated with instrumental ADL scores (see Kirkevold & Selbaek, 2015; Persson et al., 2015). Kirkevold & Selbaek (2015) also found an association with personal ADL scores. Notably, in a multivariate linear regression, along with age, gender, neuropsychiatric symptoms and medical health, instrumental ADL but not personal ADL remained significantly associated with IQCODE scores.

Physical health. Only one study, by Kirkevold & Selbaek (2015), included a measure of general physical health. This study used the General Medical Health Rating (Lyketsos et al., 1999), which considers the patients past and current medical history, and determined that IQCODE score was negatively associated with General Medical Health Rating score. Subsequent multivariate linear regression showed that this association remained, but became positive in nature, after including age, gender, instrumental ADL and neuropsychiatric symptoms. The authors did not discuss this finding; nonetheless, it is possible that the additional variables acted as moderators or mediators, or that there were

issues with multicollinearity. Regardless, the study sample was comprised of those receiving social support or in-home nursing, limiting generalisability.

Psychological factors.

Personality. One study explored the impact of patient personality on IRCD. Using the Eysenck Personality Questionnaire Revised (Eysenck, Eysenck & Barrett, 1985), Jorm et al. (1994) found that informant reports of intellectual decline were weakly and positively associated with patient neuroticism ($r = 0.12-0.14$).

Anxiety and depression. One study included explored patient anxiety as a potential correlate of IRCD. In this study, Jorm and colleagues (2004) measured anxiety using nine questions from a previously published study (i.e. Goldberg, Bridges, Duncan-Jones & Grayson, 1988) and found that symptoms were not associated with IRCD. Of the four studies that explored patient depression, three used standardised measures; the Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young & Shamoian, 1988), the Geriatric Depression Scale (Yesavage et al., 1983) and the Hamilton Depression Rating Scale (Hamilton, 1960), whilst Jorm et al. (1994) again used nine questions from a previous study (i.e. Goldberg et al., 1988). Jorm et al. (1994) found that depressive symptoms were only positively associated with informant reports of memory decline that interfered with life.

Kirkevold & Selbaek (2015) and Gavett et al. (2011) concluded that patient depressive symptoms (using the Cornell Scale and Geriatric Depression Scale respectively) were positively associated with IQCODE score. In contrast, Ross et al. (1997) found that Hamilton Depression Rating Scale was not associated with informants' ability to recognise cognitive problems. However, this study used a sample that was comprised of participants all of one gender (i.e. male), culture (i.e. Japanese-American) and recruited from a small Hawaiian island.

Informant Factors

Interestingly, few studies examined factors belonging to the informant in relation to IRCD ($n = 6$). These were categorised into those that investigated demographic characteristics and those that explored psychological factors.

Demographic characteristics.

Age. Two studies considered informant age as a potential correlate of IRCD (Farias et al., 2004; Jorm et al., 1994) neither of which found a significant association. This is inconsistent with suggestions that more educated informants may be more “sensitive to cognitive decline” (pp. 10; Ross et al., 1997).

Gender. Three studies explored the association between informant gender and IRCD. Two (Jorm et al., 1994; Nygaard et al., 2009) found no significant association, however Nygaard et al. (2009) did when gender was entered as a composite variable with relationship type. Farias et al. (2004) reported an association; with male informants giving disproportionately lower scores than females.

Psychological factors.

Carer burden. Two studies (Nygaard et al., 2009; Persson et al., 2015) explored the association between carer burden and IRCD. Both used the Relative Stress Scale (Greene, Smith, Gardiner & Timbury, 1982) and found a positive association between IRCD and carer burden. Using cut-off scores of 23 (low risk) and 30 (high risk) for the Relative Stress Scale, Nygaard et al. (2009) grouped informants into those who were at high-risk or low-risk of psychiatric morbidity, and concluded that IQCODE score significantly differed between risk groups. Further, burden was found to interact with patient-informant relationship and informant gender, in that being a female spouse interacted with burden to influence IRCD.

Psychological distress. Two studies explored the impact of the informant’s psychological wellbeing on IRCD. Jorm et al. (1994) found informant reports were significantly associated with informant symptoms of anxiety and depression. Using the 12-item General Health Questionnaire (Goldberg, 1992), Hanson & Clarke (2013) found that greater psychological distress was associated with a lower IQCODE score in the overall sample, but not in a dementia-only sample.

Relationship Factors

Several studies examined factors pertaining to patient-informant relationship. Factors included relationship type, relationship quality and frequency of contact.

Type of relationship. Two studies found a significant association between relationship type and IRCD as measured by the IQCODE. Persson et al. (2015) found spouses reported greater cognitive decline, whilst Nygaard et al. (2009) concluded spouses reported lower cognitive decline than non-spouses. In the latter, relationship type was found to interact with informant gender in influencing IQCODE score.

In contrast, two studies observed no association between relationship type and IRCD (via the IQCODE and CAMDEX informant interview). Kemp et al. (2002) found that relationship type was not predictive of underreporting or over-reporting cognitive difficulties on the CAMDEX, whilst Ross et al. (1997) observed no difference in the percentage of informants who failed to recognise cognitive difficulties between spouses (19.2%) and non-spouses (25.3%), or sons (22%) and daughters (31%).

In another study, informant report (as measured by the Blessed Dementia Scale) was found to correlate with objective scores for spouses and first-degree relatives but not second-degree relatives (McLoughlin et al., 1996). **Frequency of contact.** Two studies included frequency of contact as a potential correlate of IRCD. McLoughlin and colleagues (1996) grouped informants into those that, (1) lived with the patient, (2) had contact one to seven days a week or (3) had contact less than one day a week. Frequency of contact here was found to impact informant report accuracy; with only those living with the patient giving reports of cognitive decline associated with standardised tests. Conversely, Kemp et al (2002) grouped informants into those who (1) lived with the patient, (2) saw the patient four to seven times a week, (3) one to three times a week and (4) every two to four weeks, and concluded that frequency of contact did not impact informants underreporting or over-reporting of cognitive difficulties.

Quality of relationship. Hanson & Clarke (2013) explored the impact of expressed emotion (i.e. the attitudes of individuals towards a family member encountering marked cognitive difficulties) on the discrepancy between self-reported and informant-reported cognitive ability. Using the Five-Minute Speech Sample (Magana et al., 1986) as a measure of expressed emotion, and after adjusting for patient

depression (i.e. Geriatric Depression Scale) and informant distress (i.e. General Health Questionnaire), these authors found that expressed emotion was not associated with IRCD. However, expressed emotion was associated with the discrepancy between self-reported and informant-reported decline (as captured by the IQCODE), which they subsequently suggested may reflect where an informant is more critical or emotionally over-involved.

Discussion

A search of the published literature identified only 13 studies which explored variables potentially associated with informant reports pertaining to progressive cognitive decline amongst older adult populations. The paucity of research in this area is surprising, in light of suggestions that extraneous variables (for example, those linked to informant characteristics) may influence reports of cognitive decline (Jorm, 1996). In view of the function of such reports, in informing, and potentially supporting or adversely impacting on investigations into dementia, the importance of understanding the characteristics of reliable informants has been highlighted (Neumann et al., 2000; Ready, Ott & Grace, 2004).

Patient demographics

The review found some evidence to support an association between IRCD and patient demographics, specifically age and education. The latter association is surprising given that the use of informant reports might, in part, reflect attempts to minimise the influence of pre-morbid functioning on standardised psychometric tests (Jorm, 2004), but might be explained by pre-morbid functioning shaping patient activities so that informants are more or less able to recognise deficits. Unexpectedly, in light of this finding, the review found little evidence for an association between IRCD and patient occupation although it is worth noting that studies in this area were rated as being of "marginal" quality, in view of several methodological limitations.

Two studies explored and identified a relationship with ethnicity (Potter et al., 2009) and language (Farias et al., 2004). Minority groups were noted to have higher informant ratings of cognitive decline (Farias et al., 2004); fitting with research that suggests that such groups are at greater risk of developing dementia (Gurland et al., 1999) and that caring practises and perceptions of older adults differ across

cultures (Yaffe et al., 2002). This finding is also interesting when understood within the context of the perception that standardised tests, designed to assess cognitive functioning, are not independent of ethnicity/culture (Kirkevoid & Selbaek, 2015); suggesting that informant reports may not provide a means of addressing this. No evidence was found for an association between IRCD and gender.

Clinical variables

Some evidence was found for associations between IRCD and dementia diagnosis and severity (including the impact of marked cognitive impairment on everyday functioning).

Evidence was also found for associations with neuropsychiatric symptoms (i.e. behavioural disturbances) and physical health. Such findings may not be entirely unexpected; with symptoms and behaviours displayed by those living with dementia, potentially influencing informants in their ability to recognise cognitive decline (possibly linked to experiences of burden).

Notwithstanding the above, little evidence was found for an association between patient anxiety symptoms and informant ratings (with only a single study, by Jorm et al., 1994, exploring and reporting on this relationship). There was more support, including that from a longitudinal study (see Kirkevoid & Selbaek, 2015) for an association between depressive symptoms and IRCD. One study (again by Jorm et al., 1994) provided support for a relationship, albeit weak, between personality factors (expressly, patient extraversion or neuroticism) and IRCD.

Informant factors

Few studies explored variables pertaining to informants themselves. Those that did provided some, albeit limited, support for an association between informant education level and IRCD (see Farias et al., 2004). No support was found for an association between informant age and IRCD (with only two studies exploring this area) and evidence was mixed in terms of a relationship between informant gender and IRCD.

Studies provided some evidence for an association between IRCD and carer burden and psychological distress. However, a paucity of research in the area was again noted.

Interestingly, in a study by Nygaard and colleagues (2009), relationship type and gender interacted with carer burden to influence informant ratings of cognitive decline. This finding fits with research on carer burden in dementia, which suggests that female caregivers are more likely to experience a greater degree of burden and that providing such care is more difficult for spouses (Brodaty & Donkin, 2009).

Only one of the studies that explored the potential impact of psychological distress was given a rating of “acceptable”. Expressly, Jorm and colleagues (1994) found that informants reported greater cognitive decline as symptoms of anxiety and depression symptoms increased. It is plausible, as observed by Del-Ser et al. (1997), that informant’s might overestimate cognitive decline “due to their own anxiety and uncertainty” with the aim of “obtaining more clinical care and social support” (p. 7).

Relationship Factors

The nature of the patient-informant relationship was the most investigated variable within the studies under review, though results were inconclusive. Two studies found an association (see Nygaard et al., 2009 and Persson et al., 2015), whilst four studies concluded that there was no association between relationship type (i.e. spouse, child, friend, other relative) and IRCD.

It is plausible that this association might be confounded by other factors, such as frequency of contact and relationship quality (Ablitt, Jones and Muers, 2009), however, only one study (by Persson et al., 2015) accounted for frequency of contact and none considered relationship quality in their exploration of relationship type.

Two studies explored the association between frequency of contact and IRCD (see Kemp et al., 2002 and McLoughlin et al., 1996); reporting mixed evidence with several methodological limitations noted. Only one study explored quality of relationship, finding no association with IRCD (although the authors recognised the study as potentially underpowered) (Hanson & Clarke, 2013).

Methodological Issues

Using predefined quality criteria, only one of the studies included in the review was rated as “commendable”, nine were rated as “acceptable” and three were rated as “marginal” (see Table 1).

Study design. As described previously, many of the studies included in the review employed a cross-sectional design. Although the quality of the majority of these was rated as being “acceptable”, not all conducted multivariate analyses (e.g. O’Connor et al., 1989) and some did not include other potentially important variables. Nygaard et al. (2009), for example, observed that their model explained only 18% of the variance in the IQCODE. It is particularly notable that none included informant cognitive ability as a potential correlate. This is surprising given that it is reasonable to assume that spouses were likely older adults themselves, which along with the prevalence of dementia in older adults, makes it possible that some may have been experiencing similar difficulties themselves. Such cognitive impairment would likely impact the validity of informant measures; highlighted by Ross et al. (1997) who excluded patient-informant dyads on the basis of informant cognitive ability.

Of those studies that employed a prospective or longitudinal design, only one stratified its sample so that more ‘accurate’ informants acted as a control group (see Kemp et al., 2002), limiting the ability to infer causal associations within results.

Sample. Generally, methods through which required sample sizes were determined were not made explicit. One study noted that analyses may have been underpowered; reducing the likelihood of detecting significant associations between identified variables, were associations to exist (see Hanson & Clarke, 2013). In addition, few studies provided sufficiently detailed information on those who did not participate in the research. Only one study conducted a comparative analysis (see Gavett et al., 2011), where the authors observed that those who did not participate were less educated and had a lower baseline cognitive function, calling into question the external validity of findings.

It should be noted that studies used narrow inclusion and exclusion criteria, and that individuals from lower socioeconomic status and poorer educational backgrounds were potentially under-represented. In some cases, studies included only male patients (e.g. Jorm et al., 1998), spouses as informants (e.g. Hanson & Clarke, 2013) and excluded patients residing in residential care (e.g. Kemp et al., 2002). Studies also excluded those with co-morbid psychiatric diagnoses (e.g. Persson et al., 2015) and with sensory difficulties (e.g. McLoughlin et al., 1996). Although this lack of diversity may have improved

internal validity, it may be unrepresentative of the older adult population accessing clinical or memory assessment services; which is largely heterogeneous with multiple morbidities (Barnett et al., 2012).

Outcome measures. Encouragingly, most studies used standardised psychometric tests, which have been validated in older adult and cognitively impaired populations. However, the wide range of measures used makes it difficult to draw comparisons between studies. Many of the studies included in this review used the IQCODE to capture IRCD. Although frequently used in clinical practice, with a plethora of support for its use in research (Harrison et al., 2014; Quinn et al., 2014), as a self-report tool the IQCODE is likely to be vulnerable to various biases.

Where a discrepancy between IRCD and the change in a standardised test was reported (see Gavett et al., 2011), it is possible that the length of the study (3.5 years) may have impacted on findings, since the IQCODE considers current functioning as compared to that of 10 years prior.

Clinical Implications

Guidelines recommend the inclusion of informant reports of cognitive decline within the memory assessment process (BPS & RCP, 2007). Such information plays a pivotal role in the assessment and diagnosis of dementia, and as such, the findings of this review hold potentially important clinical implications.

Evidence, as included within this review, that IRCD may be shaped by extraneous factors indicates that informant ratings may not be a valid or reliable means of obtaining such information. This could be of particular interest, since the use of informant information in the assessment of dementia has been suggested as a means of overcoming limitations of standardised measures of cognitive functioning; particularly with regard to being potentially biased by patient educational level and physical ability (MacKinnon & Mulligan, 1998). Indeed, informant information has been suggested to be useful where the validity of tests normative sample and cut-off scores are called into question, such as where patients pre-morbid functioning is well above or below average. However, this review raises questions about the use of informant reports in clinical and memory assessment services, where such information, if

unreliable, could lead to patients receiving inaccurate diagnoses, the actioning of inappropriate referrals (e.g. for more in-depth psychometric testing or neuroimaging) or signposting to support services.

Research Implications

Although the present review highlights that the existing literature has investigated a multitude of factors in relation to IRCD, further research is warranted. In particular, the review highlights how few studies have explored the relationship between psychological factors pertaining to the patient and informant, and IRCD. Those that have provide some evidence for an association between IRCD and patient depressive symptomatology and informant psychological distress, whilst further support comes from studies focussing on the psychometric properties of the IQCODE (see Jorm, 2004 for review).

Specifically psychological factors relating to the informant, such as affective state and subjective burden, may be potentially important to investigate in that the informant's own emotional and psychological wellbeing might bias their perception of the patient's cognitive functioning. Further, it is possible that a patient's affective state might impact a multitude of variables, including cognitive functioning and informant burden, which potentially influence the informant's perception of cognitive functioning and consequently IRCD.

Similarly, future studies should include other potentially important informant-related variables, such as age, quality of life and cognitive ability. Future research might also aim to unpick the influence of relationship factors (type of relationship, quality and frequency of contact) on informants' perception and recognition of patient cognitive decline.

Additionally, the review highlighted the lack of studies using a prospective or longitudinal design. Longitudinal studies that aim to investigate relationships between identified variables and IRCD would be helpful in drawing conclusions regarding causality. Research utilising multivariate analyses is also needed, to explore the relative contributions of extraneous factors in explaining the variance in IRCD, whilst the lack of studies with a sufficiently large and representative population is something that future research might helpfully aim to address.

It is worth noting that most studies were conducted in the USA, New Zealand or Norway, potentially limiting the generalisability of the results to elsewhere in the world. Further research may be needed to ascertain patient and informant correlates of IRCD in the memory assessment process in other countries (e.g. UK, Australia), wherein informant reports are routinely used.

Conclusions

Despite the paucity of research in this area, and the methodological limitations inherent within the studies reviewed, the present review provides some evidence for associations between informant-reported cognitive decline and factors other than those relating to patient cognitive functioning. Given the use of informant reports, in informing dementia assessments, and the importance of such reports being reliable, findings hold potentially important clinical implications. In light of the methodological limitations of the studies reviewed however, further research is required before definitive conclusions, about what makes a reliable informant, can be drawn. In particular, future research should aim to investigate the relationship between IRCD and potentially important informant-related factors, such as subjective burden and cognitive ability, as well as psychological factors (i.e. depressive and anxiety symptomology) pertaining to the patient and those relating to the patient-informant relationship.

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