



## COVER SHEET

---

Sullivan, Karen A. and Muscat, Tracey (2005) Attitudes towards the diagnosis of Alzheimer's disease carers and non-carers. *International Journal of Therapy and Rehabilitation* 12:pp. 379-386.

Accessed from <http://eprints.qut.edu.au>

Copyright 2005 MA Healthcare Ltd.

This project was funded in part by research grants awarded to Karen Sullivan by the Alzheimer's Australia Research Foundation (QUT project number 150600-0090/53), the Alzheimer Association of Queensland (QUT project number 150620-0002/53), and the Queensland University of Technology (QUT project number 150620-0001/08).

Attitudes towards the diagnosis of Alzheimer's disease carers and non-carers.

Karen Sullivan, PhD, & Tracey Muscat  
Queensland University of Technology, Queensland, Australia

Correspondence concerning this article should be addressed to Karen Sullivan at the School of Psychology and Counselling, Queensland University of Technology, Carseldine campus, Carseldine Queensland 4034, Australia. Email: ka.sullivan@qut.edu.au.

Abstract

**Background** The primary focus of studies on preferences regarding the disclosure of Alzheimer's disease diagnoses has been the preferences of AD-carers. Relatively few studies have investigated such preferences in other groups, nor have the reasons behind such preferences been widely or systematically investigated.

**Objectives** To provide some preliminary data on AD-disclosure preferences among non-carer older adults and to compare this data to that of AD-carers; to investigate reasons underlying disclosure preference among carers and non AD-carers, and; to explore the level of AD knowledge among carer and non-carer samples and investigate its relationship with disclosure preferences.

**Methods** Participants were 20 elderly adults who were not caring for a relative with AD, and 16 older adults who were caring for an AD relative. Participants completed a modified AD knowledge test and a test designed to measure the reasons for and against disclosure of an AD diagnosis.

**Results** AD knowledge among AD carers was significantly higher than among non-carers. Views about disclosure of AD diagnoses did not differ between groups though generally opinions were pro-disclosure (at least 85% of the overall sample opted for disclosure). No significant differences were found when preferences for disclosure for oneself versus a significant other were compared. Similar reasons for disclosure were given by carers and non-carers, and included factors such as the persons' right to know their diagnosis.

**Conclusions** Older Australians overwhelmingly supported disclosure of AD diagnoses, whether or not they had previously been through the diagnostic process.

**Keywords:** dementia, Alzheimer's disease, diagnosis, disclosure

Knowledge of Alzheimer's disease and attitudes towards its diagnosis among older Australian adults and carers of people with Alzheimer's disease.

The issue of Alzheimer's Disease (AD) disclosure preferences is one that continues to be of interest, particularly given reports that practice in this area is not consistent with patient preference (e.g., Pinner, 2000). In particular, it appears that disclosure does not occur as often as it might, based on people's current preferences (see Bamford *et al.*, 2004). A factor that might be contributing to the gap between preference and practice is the nature and extent to which people's attitudes towards AD diagnosis disclosure may be changing. Little is known about this since there has been no longitudinal study examining changing attitudes towards AD-diagnosis

disclosure, but review of the literature provides some indication of trends in AD disclosure preferences.

In 2004, Bamford and colleagues systematically reviewed 59 papers related to the disclosure of AD-diagnoses. Approximately half of the papers identified by Bamford *et al.* ( $n = 20$ ) reported on practice in relation to disclosure (i.e., reports from professionals in relation to disclosure practices), approximately 17 papers examined reports of practice (e.g., carer report of GP practice), and a further seven papers (approximately) described the response of patients or their carers to being told a diagnosis (e.g., effects on self-esteem)<sup>1</sup>. The remaining 12 papers dealt with the issue of beliefs about disclosure, and most of these assessed beliefs after disclosure had occurred (e.g., among AD carers). Only three studies assessed the disclosure preferences of people with no current, primary AD-carer role (e.g., adults in general; Erde *et al.*, 1988; Holroyd *et al.*, 1996; Sullivan and O’Conor, 2001b), yet this is the group that is arguably the most likely to be confronted with the prospect of disclosure, and their views on this matter may be less likely to be confounded with experience of the process of disclosure itself, which has noted to be lacking in a number of studies (e.g., Chenoweth and Spencer, 1986; Connell and Gallant, 1996). Only one of the studies of non-AD carer preferences was conducted relatively recently (Sullivan and O’Conor, 2001b). However, that study did not use older adults, and further studies of older non-AD carers’ views on AD diagnostic disclosure are clearly needed.

Details of the 12 papers dealing with disclosure preferences plus two additional papers that were not included in the Bamford review are shown in Table 1. These papers are presented in chronological order to facilitate assessment of change over time in disclosure preferences<sup>2</sup>. The data in Table 1 suggests that *at least some* AD-disclosure attitudes may have changed over time. Specifically, there appears to be a trend towards a growing preference for disclosure at least for oneself. For example, the percentage of people supporting disclosure for themselves tends to increase over time, with some minor exceptions (e.g., Marzanski, 2000; Jha *et al.*, 2001) and in some recent cases is extremely high (i.e., above 90% support for disclosure; see Pinner and Bouman, 2003 for example). Trends in the data in relation to whether a relative should be told their diagnosis (disclosure to others) are less consistent. For example, in those studies where preferences for disclosure to self versus others are compared (i.e., five studies), early studies suggested lower rates of preference for disclosure to others versus self (e.g., Erde *et al.*, 1988; Holroyd *et al.*, 1996), whereas more recent studies on this topic have not supported this distinction (Dautzenberg *et al.*, 2003; Sullivan and O’Conor, 2001b, but see Pinner and Bouman, 2003). The reason put forward to explain these early differences between self- and other preferences was that peoples’ views about disclosure to others were largely “paternalistic” (Brodaty, Griffin, Hadzi-Pavlovic, 1990, Deber, 1994). Whether this is still the case is an issue that needs further investigation.

---

Insert Table 1 about here

---

In terms of understanding what underlies people’s diagnostic preferences in relation to AD, there have been relatively few detailed investigations of this issue (six

---

<sup>1</sup> Including the study by McWilliams (1998) which reported on data from a mixed sample, of carers, patients, and professionals and was largely focussed on the experiences of all three groups in the disclosure process.

<sup>2</sup> Note: Bamford and colleagues presented their review of the literature in order of author name.

of the 59 papers described by Bamford *et al.*, 2004). In those studies where reasons for diagnostic preferences have been sought, these have typically been assessed using open-ended questions (e.g., Pinner and Bouman, 2003). This has made it difficult to make comparisons either between groups within a study or over time, since responses to the same items have not necessarily been collected. In 2001, Sullivan and O'Connor (2001b) developed a questionnaire for collecting such information, but used it in a sample of young adults only. In this study, we used the same questionnaire to assess the reasons behind disclosure preferences in a sample of older adults.

Finally, though there have been relatively few studies of the determinants of people's AD diagnosis disclosure preferences, a relatively recent study has shown that the level of carer education is correlated with disclosure preference (Bachman *et al.*, 2000). This finding is contrary to early research suggesting that predictors of who would and who would not want to be told an AD diagnosis could not be identified (Holroyd *et al.*, 1996). In Australia, there has been one published study investigating the relationship between knowledge of AD and diagnosis disclosure (Sullivan and O'Connor, 2001b). This study showed that knowledge was not significantly related to diagnostic preference. However this finding was limited by two, possibly related factors. First, this study used an undergraduate student sample and as such results from this study may not generalise to older adults. Thus the disclosure preferences and level of AD knowledge among older Australian adults, as well as the possible relationship between these variables, remains unknown. Second, the high rate of endorsement of disclosure reported in this sample (over 90% of the sample wanted to be told the diagnosis) prohibited exploration of the relationship between knowledge and disclosure preferences (Sullivan and O'Connor, 2001b). This may have been due in part to the use of a younger sample, given that younger people may subscribe to a more autonomous model of health care than older adults (e.g., Benbassat *et al.*, 1998). Alternately this finding may suggest that disclosure preferences in Australia, as elsewhere, are tending to favour disclosure irrespective of participants' age.

Overall, this review of the literature suggests the need for further studies of the attitudes of non-AD adults towards AD diagnostic disclosure, the relationship between disclosure preferences and AD knowledge, and the relationship between disclosure preferences for self versus others. This aim of this study was to address this need.

## Method

### *Participants*

Twenty healthy elderly adults (16 females) were recruited from senior citizen clubs in metropolitan Brisbane. These participants were a subgroup of those who participated in a larger study of AD misconceptions reported elsewhere (Sullivan, Muscat and Mulgrew, submitted). Participants were recruited after group activities held at Senior Citizens clubs. The average age of participants was 78 years ( $SD = 6.15$ , age range 60 to 88 years). Most participants in this group were educated to primary school or junior high school level. All participants were free from a diagnosis of dementia, free from severe cognitive impairment (defined as a Mini-Mental Status Examination score (Folstein, Folstein and McHugh, 1975) of greater than 23;  $M = 26.85$ ;  $SD = 2.13$ ), free from depression (defined as a Geriatric Depression Scale (GDS) score of less than 11 (Burns, Lawler and Craig, 2002),  $M = 5.32$ ,  $SD = 4.9$ ), and were generally healthy as indicated by an SF-36 physical functioning score in the upper

range of the 100 point scale (Ware and Kosinski, 2001), where 100 represents optimal functioning,  $M = 73.94$ ,  $SD = 19.04$ ).

A convenience sample of sixteen carers of people with AD (15 females) participated in this study. Fourteen of these participants were recruited from the Alzheimer's Association of Queensland (AAQ), with the remaining two participants identified as part of recruitment at Senior Citizens clubs. Participants need to reside in metropolitan Brisbane and the majority were invited to volunteer after being approached by a member of the AAQ during routine contact. Carers were defined broadly as someone with primary responsibility for caring for someone with AD, and were predominantly the spouse or partner of a person with AD. These participants were similar to those recruited from senior citizen's clubs in terms of education (the highest level of education reported by 50% of the sample was junior high school), cognitive status (all MMSE scores above 23,  $M = 27.5$ ,  $SD = 2.06$ ;  $t(33) = -9.21$ ,  $p = .364$ ), mood (GDS  $M = 5.92$ ,  $SD = 3.947$ ,  $t(33) = -.378$ ,  $p = .708$ ), and physical functioning (SF-36  $M = 85.13$ ,  $SD = 11.11$ ,  $t(33) = -1.927$ ,  $p = .063$ ). Unlike participants recruited from senior citizens' clubs all participants in this group had previously undergone the AAQ's Living with Memory Loss program, and on average, carers were significantly younger than non-caring participants ( $M = 67.06$ ;  $SD = 9.06$ ;  $t(34) = 4.31$ ,  $p = .000$ ).

### *Materials*

The Alzheimer's Disease Knowledge Test (ADK) was originally developed by Dieckmann, Zarit, Zarit, and Gatz (1988). The purpose of this test was "assess the level of knowledge of AD of caregivers, mental health professionals, nursing home staff, and other individuals who interact with dementia patients, and to establish educational objectives, stimulate group discussion, clarify common misconceptions, and evaluate support groups and other educational programs" (Dieckmann *et al.*, 1988, p.402). More recently, this test was modified by Sullivan and O'Conor (2001a) to produce an item 18 version of this test for use in an Australian population, which was used for this study. Items were presented with five response options for each question, including an "I don't know" option. Responses on the ADK were scored 1 (correct) or 0 (incorrect), with higher scores reflecting greater knowledge of Alzheimer's disease.

The RWK is relatively new tool that aims to assess people's attitudes towards being told a diagnosis of AD (Sullivan and O'Conor, 2001a, b). This test begins with a yes/no question about disclosure preference for self and others, (i.e. imagining a relative of yours had developed AD, would you want them to be told the diagnosis?). The remaining items are presented on a five-point Likert scale ranging from very important to very unimportant. These items assess participants' reasons for and against disclosure and also allow for the addition of reasons nominated by the participant. Separate sections assess reasons for and against disclosure for self and others.

In previous studies data from the RWK has been analysed descriptively (Sullivan and O'Conor, 2001b). In this study a total score on the RWK was generated using Likert data responses for fixed categories<sup>3</sup>, with separate figures being calculated for self and others. Scores in response to reasons for disclosure were reversed for this analysis. Therefore RWK-self and -others scores could range from 2

---

<sup>3</sup> Fixed category responses excluded responses to open-ended questions.

to 60, with higher scores reflecting greater preference for disclosure and less agreement with statements against disclosure.

#### *Procedure*

Participants recruited from Senior citizens clubs were individually interviewed in a private space at their club. Carers of people with AD were interviewed in their own home. Questionnaires used in this study were formatted so that they could be presented using flipcharts, such that each page showed one question and the response options for that question. Questions and the response options were then read to participants who were asked to respond verbally. Verbal responses were then recorded by the interviewer. Participants were invited to respond to a suite of questionnaires (including the MMSE and GDS and SF-36) which were used for screening purposes). The order of administration of questionnaires was counterbalanced to minimise fatigue and order effects. Note that this study reports primarily on data from the two core measures (RWK and ADK).

#### Results

##### *ADK results*

Descriptive statistics for the ADK are shown in Table 2. This table shows that, on average, healthy older adults got five out of 18 ADK items correct, and the highest score obtained on the ADK was 7 out of 18. This level of performance is similar to the mean level of performance on the ADK reported by Sullivan and O'Connor (2001) for each of the four groups of 25 young, healthy adults they tested prior to education about Alzheimer's disease (mean ADK scores for these groups ranged from 5.76 to 8.8). Carers of people with AD scored approximately 11 out of 18 items correct, on average. This level of performance is similar to that reported by Sullivan and O'Connor (2001a) for three groups of 25 healthy younger adults after they had undertaken various types of AD education (e.g., mean ADK scores for these groups ranged from 9.88 to 12.36). To test for group differences in knowledge about AD in the current sample, an independent samples *t*-test was conducted. With alpha set at .05, the results of this test suggest that carers know significantly more about AD than the healthy older adults used in this sample,  $t(34) = -6.16, p = .000$ .

Insert Table 2 about here

##### *Results on disclosure*

###### *Disclosure preference*

The analysis of data from the RWK examines responses from the yes/no portion of this questionnaire (prefer disclosure yes or no), followed by responses to Likert scale items that assessed the reasons for and against disclosure. Carer's unanimously opted for disclosure when they imagined it was them who had developed the disease ( $n = 16$ ; 100% of this group), and only one carer opted for non-disclosure when they imagined their relative had been affected (93% of this group). The pattern of results for non-carers was similar, in that the same percentage of non-carers (85% of this group) indicated they would prefer disclosure for themselves or a relative, despite less support for disclosure among non-carers overall. These results are depicted in Table 3.

Insert Table 3 about here

The pattern of responses to the yes/no disclosure question from the RWK was further investigated using McNemar's test. This non-parametric test for related samples was used to perform a comparison of disclosure preferences for self- and others, irrespective of group. Perhaps unsurprisingly given the proportions reported above, the result of this comparison was non-significant ( $p = 1$ ), suggesting that

disclosure ratings for self- and other did not differ significantly. Two further comparisons were performed factoring in group status. For these comparisons a 2 X 2 chi-squared test of independence was calculated, and Fisher's Exact statistic reported because of small cell sizes. The first of these analyses revealed a non-significant difference between disclosure preference for self as a function of group membership ( $p = .238$ ), such that carers did not support disclosure more than non-carers. Similarly, when ratings for relatives were used non-significant group differences emerged ( $p = .613$ ), indicating a similar level of support for disclosure among carers and non-carers. Overall, these figures suggest disclosure preferences are not affected by who it is that one imagines has developed the disease, since similar results obtain when ratings are sought for self and others. In addition group membership does not appear to significantly influence disclosure preference.

*Prediction of disclosure preference by AD-knowledge*

The high rate of endorsement of disclosure in this study, combined with a small sample size, did not permit exploration of the relationship between disclosure preference and AD-knowledge.

*Reasons for and against disclosure*

In terms of the reasons for or against disclosure of a diagnosis of AD, the data were collapsed across the self- and other- dimension to yield an overall preference for disclosure score, and an overall preference not-to-disclose score<sup>4</sup>. To compare differences between carers' and non-carers' ratings of the reasons for and against disclosure, two independent samples *t*-tests were performed. For the first analysis preference for disclosure scores were used. The results of this comparison suggested no significant difference between preference for disclosure among carers ( $M = 66.06$ ,  $SD = 13.04$ ) and non-carers ( $M = 67.40$ ,  $SD = 10.26$ ),  $t(34) = .345$ ,  $p = .732$ . The second analysis used preference not-to-disclose scores. The result of this analysis was also non-significant,  $t(34) = -1.358$ ,  $p = .183$ , suggesting similar preference for non-disclosure among carers ( $M = 46.62$ ,  $SD = 11.75$ ) and non-carers ( $M = 41.40$ ,  $SD = 11.24$ ).

Further inspection of responses to specific RWK items was undertaken for descriptive purposes. Interestingly, the lowest rate of agreement recorded among the reasons for disclosure for self related to being able to "plan my suicide". The modal rating for this item was 5 ("very unimportant") whereas the modal rating for all other possible reasons for disclosure (e.g., to explore treatment options") was one ("very important"). The mode for all items relating to *non*-disclosure for self was five, indicating that most participants felt the reasons listed against non-disclosure (such as the potential for being depressed or agitated by the diagnosis) were "very unimportant". Similarly, the modal rating for potential reasons for disclosure to a relative (such as their "right to know") was one, suggesting participants mostly considered these "very important". Whilst the general trend for endorsement of reasons that have been suggested against disclosure for relatives (including the possibility that the relative may commit suicide) suggested participants thought these reasons were mostly "very unimportant" (modal rating of five) there were two exceptions to this pattern. These were when it was known the relative did not want to be told, and where there were concerns that telling the relative would upset them (modal rating for these items was 1 ("very important") respectively. These results are shown in Table 4.

---

<sup>4</sup> Higher scores on composite scores represented greater agreement with pro-disclosure ideas, and less agreement with reasons that have been suggested as mitigating against disclosure.

## Discussion

The aim of this study was twofold. First, to investigate the level of AD knowledge in a community dwelling sample of older adults and carers of people with Alzheimer's disease, and to explore the relationship between knowledge and disclosure preference. The knowledge data generated in this study was also sought to provide some preliminary Australian normative data for a modified version of the ADK for older people, since previous studies using this tool included young adults only. Second, this study aimed to examine contemporary attitudes towards diagnosis disclosure among healthy older Australians and their AD-carer counterparts.

In terms of AD knowledge, the results of this study showed a dramatic difference in the level of knowledge of AD carers, and their non-carer peers. Specifically AD carers were significantly more knowledgeable about AD than non-carer older adults. In real terms this finding suggests that AD carers were twice as knowledgeable about AD as their non-carer peers. Interestingly the level of performance of non-carer and carer groups was similar to that reported previously for participants prior to training about AD and participants following AD education respectively (Sullivan and O'Connor, 2001a) which, in absolute terms, suggests there is continued room for improving knowledge.

The finding that AD carers, or more specifically AD carers associated with the AAQ, are more knowledgeable about AD than their non-caring peers is perhaps not surprising, since providing educational services is part of the AAQ's charter. Nonetheless, it is heartening to note that service users appear to retain this information and, given higher levels of knowledge among carers has generally been associated with better carers outcomes (e.g., lower levels of depression and higher levels of carer competence; Graham *et al.*, 1997a; 1997b but see Kuhn and Mendes de Leon, 2000), this finding is significant. Whilst it is important to acknowledge the limitations of this data, in particular the use of a small convenience sample of AD carers who were receiving AAQ support, future studies using more representative sampling techniques will help determine the generalisability of these results.

In terms of attitudes towards AD diagnosis, two aspects of this data deserve particular comment. First, in terms of within-group comparisons the data from this study do not suggest that disclosure preferences change significantly depending on whether participants are asked to think about disclosure for themselves or others. This finding is consistent with that of Sullivan and O'Connor (2001b) who also used Australian data to show that disclosure preferences were similar for self- and others-among young, healthy adults, but also that a slight non-significant trend towards higher rates for disclosure for self over others continues to be apparent.

Second, taking the finding in relation to carer data alone (that carers in this study support disclosure (for self and others) to a similar extent), this pattern of results is partly inconsistent with some of the previous research that has shown carers tend *not* to support disclosure to others (e.g., Rice *et al.*, 1997; Maguire *et al.*, 1996), and offer moderate (and variable) support for disclosure to self. However, these early studies were conducted almost 10 years ago, and it may be that carers attitudes towards disclosure have changed over time to favour disclosure, or that cultural factors contribute to disclosure preferences yielding sample specific trends. Recent findings from a Dutch study reported by Dautzenberg and colleagues (2003) are consistent with both possible explanations, since their study showed high rates of relatives' support for disclosure to patients (over 94% of their sample of 50 relatives



rated disclosure as important or very important). Thus, findings in Holland and Australia may differ from results in the settings studied by early researchers (i.e. UK and Ireland respectively), or it may be that these two recent studies are among the first to reflect a change in attitudes that more accurately reflect contemporary beliefs about such matters.

Further exploration of this data also revealed that preferences for disclosure are not affected by group membership (i.e., whether the person is currently caring for someone with AD or not). However, it should also be noted that small cell sizes in this study due to insufficient numbers opting against disclosure in this sample may have limited the robustness of these analyses, and future researchers may wish to replicate these comparisons if greater endorsement of non-disclosure is found in other samples. Notwithstanding the limitation of small cell sizes, the finding of no-significant difference in disclosure preferences between carers and non-carers is important because this study is the first of its type to include both carer and non-carer participants using a structured questionnaire, and as such, permit comparisons of the responses of both groups in a single study. These results suggest that people's attitudes towards disclosure may not change once in the role of AD-carer or, once they understand what the diagnostic process involves, compared to the preferences they held before this. Whether this is in fact the case is an empirical question that could be investigated through a longitudinal study of attitudes towards disclosure. An alternate explanation of these results is that data from the carer group in this study over-estimates pro-disclosure attitudes because of the use of carers who are users of Alzheimer's Association services. Similar views may not be held by AD carers who are not actively involved with such organisations. We recommend future studies include a group of AD carers without such involvement to determine the robustness of findings in relation to disclosure preferences among AD carers and non-carers.

The second aspect of the RWK that deserves comment is the overall disclosure preference rate for carers and non-carers, relative to what we know about younger people's preferences from earlier studies. Whilst such comparisons must be made tentatively because of methodological differences between studies, including differences in sample characteristics and the timing of data collection, these considerations suggest that disclosure preferences may be related to age. That is, excluding carers from this comparison given the high rate of endorsement of disclosure among this group, older non AD-carer Australians reported a slightly lower rate of preferences for disclosure than younger adults. Again, whilst the reason for this must remain a matter for speculation, it seems possible this is partly due to differences in the medical model subscribed to younger and older adults could partly account for this finding. However, a fully controlled study, with matched samples, is needed to investigate this issue further.

In terms of the reasons for and against disclosure offered by AD-carer and non-AD carer groups, similar ratings of the importance of reasons for disclosure and non-disclosure were reported by both groups. On the important issue of suicide, findings from this study suggest that participants view this issue as a relatively unimportant part of their decision making in relation to diagnostic preferences, though it should be noted that suicide in AD patients is not unknown (Rohde, Peskind and Raskind, 1995). Rather participants RWK responses suggest that disclosure preferences are more likely to be influenced by views about the potential for future planning that disclosure might allow, as well as the expressed wishes of individuals in this regard.

Overall, the results of this study suggest the continuing need for public education about AD, given that the level of knowledge of AD in this sample of healthy older adults (and to a lesser extent, AD-carers) could be improved. To the extent that early detection and diagnosis of AD is associated with awareness of the signs and symptoms of AD, this would seem important. In terms of disclosure practices in relation to AD diagnoses, the findings from this study seem to support the contention that community attitudes towards AD disclosure show an increasing trend towards preference for disclosure. However, such preferences are not universal. So what do we do when we know that most, but not all people want to be told a diagnosis of AD? One answer is to continue studies of the predictors of such preferences, where this is possible. For instance, we know that in some populations study of such predictors is limited by high rates of endorsement of disclosure (e.g., Dautzenberg *et al.*, 2003; Sullivan and O'Connor, 2001b), but investigations using a larger sample of non-AD carer older adults may prove useful and would seem particularly important since it is the attitudes of these people that are arguably the most important to understand as they are the ones most likely to face the prospect of disclosure. In the meantime, it is important to consider recommendations for practice based on these results and consideration of the wider literature reviewed in this paper, especially if the gap between patient-preference and practice is to be minimised. To this end, it seems reasonable to suggest that a possible way forward is to encourage discussion of this topic between clients and caregivers, and to continue to monitor this apparent changing of attitudes towards AD diagnosis.

#### Key Points

- Participants in this study overwhelmingly supported disclosure of AD diagnoses
- Pro-disclosure attitudes were recorded by individuals with- and without experience of current disclosure processes.
- Similar reasons for disclosure were given by carers and non-carers, and included factors such as an individual's right to know their diagnosis.
- Carers of people with Alzheimer's disease are more informed about Alzheimer's disease than non-AD carers, though the relationship between knowledge of Alzheimer's disease and disclosure preferences requires further investigation.

#### References

- Alzheimer's Association of Queensland, Inc (undated). The Alzheimer's Association of Queensland Inc. [brochure]. Brisbane, Australia: Alzheimer's Association of Queensland.
- Bachman, DL, Wagner, MT, DePalma, M. (2000). Caregiver attitudes about patients told they have Alzheimer's disease after truth disclosure. *J Clin Geropsychol* 6: 309-313.
- Bamford, C, Lamont, S., Eccles, M., Robinson, L., May, C., & Bond, J. (2004). Disclosing a diagnosis of dementia: a systematic review. *Int J Geriatr Psychiatry*, 19: 151-169.
- Benbassat, J., Pilpel, D., & Tidhar, M. (1998). Patients' preferences for participation in clinical decision making: A review of published surveys. *Behav Med* 24: 81-88.
- Brodsky, H., Griffin, D., Hadzi-Pavlovic, D. (1990). A survey of dementia carers: doctors' communication problem behaviours and institutional care. *Aust New Zealand J of Psychiatr*, 24: 362-370.
- Burns, A., Lawlor, B., & Craig, S. (2002). Rating scales in old age psychiatry. *Br J Psychiatr*, 180: 161-167.

- Chenoweth B, Spencer B. 1986. Dementia: the experience of family caregivers. *Gerontologist* 26: 267-272.
- Connell, CM, Gallant, MP. 1996. Spouse caregivers' attitudes toward obtaining a diagnosis of a dementing illness. *Aging Ment Health* 44: 1003-1009.
- Dautzenberg, P. L. J., van Marum, R. J., van der Hammen, R., & Paling, H. A. (2003). Patients and families desire a patient to be told the diagnosis of dementia: A survey by questionnaire on a Dutch memory clinic. *Int J Geriatr Psychiatry* 18: 777-779.
- Deber, R. (1994). Physicians in health care management: 7. The patient-physician partnership: changing roles and the desire for information. *Can Med Assoc J*, 151: 171-176.
- Dieckmann, L., Zarit, S., Zarit, J., & Gatz, M. (1988). The Alzheimer's Disease Knowledge test. *Gerontologist* 28: 402-407.
- Erde, E., Evan, C., Nadal, D., & Scholl, T. (1988). On truth telling and the diagnosis of Alzheimer's disease. *J Fam Pract* 26: 401-406.
- Fahy M, Wald, C, Walker, Z, Livingston, G. 2003. Secrets and lies: the dilemma of disclosing the diagnosis to an adult with dementia. *Age Ageing* 32: 439-441.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 12: 189-198.
- Graham, C., Ballard, C., & Sham, P. (1997a). Carers' knowledge of dementia and their expressed concerns. *Int J Geriatr Psychiatry* 12: 470-473.
- Graham, C., Ballard, C., & Sham, P. (1997b). Carers' knowledge of dementia, their coping strategies and morbidity. *Int J Geriatr Psychiatry* 12: 931-936.
- Holroyd, S., Snustad, D., & Chalifoux, Z. (1996). Attitudes of older adults' on being told the diagnosis of Alzheimer's disease. *J Am Geriatr Soc* 44: 400-403.
- Jha, A., Tabet, N., & Orrell, M. (2001). To tell or not to tell - comparison of older patients' reaction to their diagnosis of dementia and depression. *Int J Geriatr Psychiatry* 16: 879-885.
- Kuhn, D. R., Mendes de Leon, C. F., (2001). Evaluating an educational intervention with relatives of persons in the early stages of Alzheimer's disease, *Res Soc Work Pract* 11: 531-549.
- Maguire, C., Kirby, M., Coen, R., Coakley, D., Lawlor, B., & O'Neill, D. (1996). Family members' attitudes toward telling the patient with Alzheimer's disease their diagnosis. *Br Med J* 313: 529-530.
- Marzanski M 2000. Would you like to know what is wrong with you? On telling the truth to patients with dementia. *J Med Ethics* 26: 108-113.
- McWilliams, E. 1998. The process of giving and receiving of a diagnosis of dementia: an in-depth study of sufferers', carers' and consultants' experiences. *PSIGE Newsletter*, 64: 18-25.
- Pinner, G. (2000). Truth-telling and the diagnosis of dementia. *Br J Psychiatry* 176: 514-515.
- Pinner, G., & Bouman, P. (2003). Attitudes of patients with mild dementia and their carers towards disclosure of the diagnosis. *Int Psychogeriatr* 15: 279-288.
- Price, J. A., Price, J. H., Shanahan, P. M., Desmond, S. M. (1986). Elderly persons' perceptions and knowledge of Alzheimer's disease. *Psychol Rep* 58: 419-424.
- Pucci, E, Belardinelli, N, Borsetti, G, Giuliani, G. 2003. Relatives' attitudes towards informing patients about the diagnosis of Alzheimer's disease. *J Med Ethics* 29: 51-54.
- Rice, K., Warner, N., Tye, T., & Bayer, A. (1997). Geriatricians' and psychiatrists' practice differs [Letter to the Editor]. *Br Med J* 314: 375-376.
- Rohde, K., Peskind, E. R., & Raskind, M. A (1995). Suicide in two patients with Alzheimer's disease. *J Am Geriatr Soc* 43: 187-189.
- Sullivan, K. A., & O'Connor, F. (2001a). Providing education about Alzheimer's disease. *Aging Ment Health* 5: 5-13.
- Sullivan, K. & O'Connor, F. (2001b). Should a diagnosis of Alzheimer's disease be disclosed? *Aging Ment Health* 5: 340-348.

- Sullivan, K, Muscat, T, Mulgrew, K. (submitted). Knowledge of Alzheimer's disease amongst patients, carers, and non-carer adults: Misconceptions, knowledge gaps, and correct beliefs. *Aging Ment Health*
- Turnbull, Q, Wolf, AM, Holroyd, S. 2003. Attitudes of elderly subjects towards "truth telling" for the diagnosis of Alzheimer's disease. *J Geriatr Psychiatry Neurol* 16: 90-93.
- Ware, J.E., & Kosinski, M. (2001). *SF-36 Physical & Mental Health Summary Scales: A Manual for Users of Version 1 (2nd Edition)*. Lincoln, RI: QualityMetric.
- Werner, (2001) Correlates of family caregivers' knowledge about Alzheimer's disease., *Int. J. Geriatr Psychiatry* 16: 32-38.

### Acknowledgements

The authors would like to thank Jody Thompson and Jasmine Gygis from the Alzheimer's Association of Queensland Inc. (AAQ) for their help in recruiting carer participants. We would also like to thank the administration and staff from the Queensland metropolitan senior citizens clubs for help with recruiting non-carer participants. We would like to thank those AAQ and senior citizens club members who volunteered to participate in this study.

Data for this project was collected by Tracey Muscat for her Honours thesis. Karen Sullivan was the primary supervisor of this thesis. This thesis was part of a larger program of research being conducted by Karen Sullivan.

The Queensland University of Technology Human Research Ethics committee granted ethical clearance for this project.

Assistance with the preparation of this manuscript was provided by Dr Julie Hansen (statistical advice) and Mrs Debra Waugh (production of parts of this manuscript).

NOTE: Tables in separate file

---