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Running Head: AD Education

Providing education about Alzheimer's disease.

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Abstract

Improving carers' knowledge of Alzheimer's disease (AD) has been associated with benefits for carer well being (Dieckmann, Zarit, Zarit, & Gatz, 1988; Graham, Ballard, & Sham, 1997b). This has lead to recognition of the need to systematically evaluate dementia education tools (Graham, Ballard, & Sham, 1997a; Moniz-Cook & Woods, 1997; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999). In this study dementia knowledge was measured pre- and post- interventions designed to improve knowledge in a sample of 100 undergraduate students. Dementia education materials were selected from existing resources that are readily accessible and are recommended for use in clinical settings (American Psychiatric Association (APA), 1997; Boise, Morgan, Kaye, & Camicolli, 1999). Subjects were allocated to one of four conditions including a control group. Subjects allocated to education conditions were asked to view a video on AD, read written information about the disease, or do both. Results showed that education improved knowledge of AD, as measured by increased scores on a dementia knowledge questionnaire. This study has important implications for public education about dementia and resource allocation for service providers.

Estimates of the prevalence of Alzheimer's disease (AD) have ranged from less than 1% of the population under 65 years of age to more than 40% of those aged 85 and older (Brodaty, Griffin, & Hadzi-Pavlovic, 1990; Dukoff & Sunderland, 1997; Ott et al., 1995; Roberto, 1994; Schofield, 1999; Welkenhuysen, Evers-Kiebooms, & Van den Berghe, 1997; Woodward, 1999). In Australia, it has been estimated that between 70,000 and 100,000 people currently have AD, and this figure is expected to double by the year 2011 (Woodward, 1999). Clearly, the treatment and management of those with AD will become an increasing public health concern as the population ages and prevalence rates increase (Brookmeyer, Gray, & Kawas, 1998). Given that appropriate treatment and management relies heavily on diagnosis and carer education, it is important to consider how this process is managed.

Previous research has shown that carer knowledge of dementia has important implications for the wellbeing of those who care for AD patients, and indirectly for patients themselves (Cahill & Shapiro, 1997; Graham et al., 1997a, 1997b).

However, few published studies have investigated the most effective way of educating carers about AD (Boise et al., 1999). To fill this gap, this study examined the effectiveness of selected educational materials as a means of informing individuals about AD.

Particularly in the early stages of dementia, it has been noted that carers and families of people with AD have "education needs" (Moniz-Cook & Woods, 1997). Information about diagnosis, prognosis, treatment, planning for the future, and managing behaviour may need to be conveyed. How the education process occurs however, may be partly determined by where clients and carers go to seek treatment (service characteristics), how assertive clients and carers are (client characteristics),

and the characteristics of individuals who manage the education process. These issues will be discussed in the following sections.

Service characteristics may impact on how information is conveyed to clients and carers. For example, diagnoses may be provided in a team setting, such as a memory clinic or psychogeriatic assessment unit, by psychiatrists in private practice, or by general practitioners or family physicians. Factors such as access to funding, time, and whether the service is a specialist diagnostic service or a general health service, are likely to have resource implications that may impact on the nature of education materials produced or disseminated to carers by service providers. In addition, there is on-going debate regarding the role of specialist services such as memory clinics, and whether this should be broadly defined to include psychosocial and psychoeducational services (Moniz-Cook & Woods, 1997; Wright & Lindesay, 1995). Given that there is no explicitly agreed upon model for memory clinics, this may impact on carer education at these services (Wright & Lindesay, 1995).

In a recent survey examining resource use in 20 memory clinics in England, Scotland and Eire, results showed that just over three quarters of this sample (81%) reported having written information about dementia available for carers (Gilliard & Gwilliam, 1996). Less than half of these clinics (38%) had information available in "other forms" such as audiocassettes (Gilliard & Gwilliam, 1996). In another study conducted at two old age psychiatric services in the United Kingdom, it was noted that information was largely disseminated verbally and no educational packages were used (Graham et al., 1997a). Even where material resources exist at specialist services, it has been suggested that the actual dissemination of material may rely on individual health care professionals (Graham et al., 1997a).

The situation in Australian memory clinics has not been documented, nor has the resource base of other potential service providers (e.g., privately practicing psychiatrists or general practitioners). However, it seems reasonable to expect that specialist tertiary referral centres such as memory clinics and psychogeriatric assessment services are more likely to produce or provide direct access to education resources than less specialised services. In practice however there appears to be wide variation in the use of educational resources at specialist services.

Carer characteristics may also partly determine the nature and extent of AD information conveyed as part of the education process. For example, current practice guidelines for the treatment of patients with dementia produced by the American Psychiatric Association explicitly state that the nature of information conveyed to family members must be "adapted to the concerns and abilities of the patient and their family" (APA, 1997, p.12). The guidelines do not state how an assessment of the family's concerns and abilities should be made, and this presumably varies across clinicians. Although this approach may allow for maximum flexibility in disseminating information to clients it may not be as effective as intended given that some carers report being dissatisfied with AD information they received (Cahill & Shapiro, 1997).

In addition, carers themselves report some reluctance to ask questions when they are unsure, and they may not know how to ensure their education needs are adequately met (Boise et al., 1999). Patient assertiveness has been implicated in some studies as a factor that may be taken into consideration when determining the nature and type of information that should be disclosed to carers (Benson & Britten, 1996).

The third factor that may determine the nature and extent of AD information conveyed to carers is the characteristics of the educator. There are at least two reasons for this. First, the qualifications and training of those providing information may differ and this may impact on their ability to provide education, and second, there may be differences in the beliefs or behaviours of members within a profession with responsibility for dementia education.

For example, if families seek help from psychiatrists, whether in private practice or as part of a psychogeriatric assessment team, their experience may partly be determined by practice recommendations for the treatment of people with dementia set out for psychiatrists (APA, 1997). Although there is some debate about how useful the dissemination of guidelines is as a means of changing clinical practice in relation to dementia management (Cheok, Cohen, & Zucchero, 1997), practice guidelines should at least represent a model for best practice. These guidelines for psychiatrists recommend the use of the information materials provided by the Alzheimer's Association as one means of providing AD education (APA, 1997). However, the guidelines do not specify how this information should be disseminated and there has been no systematic evaluation of the effectiveness these education materials published to date. In addition, seeking help from members of other professions may result in a different experience for carers given that different guidelines may govern their practice, if guidelines exist at all.

The proposition that members within a profession may vary in the way they provide AD information to carers is also borne out by research by Cahill and Shapiro (1997) amongst others (Rice, Warner, Tye, & Bayer, 1997). For example, families seeking help from their physician or general practitioner have reported that the amount of information provided by their doctors varied from no advice whatsoever to

advice "about the incurable nature of the illness" or "hints" about the clients' diagnosis or prognosis (Cahill & Shapiro, 1997, p. 21). It should be noted that the study by Cahill and Shapiro (1997) is unlikely to be representative of information giving practices of all general practitioners for methodological reasons. For example, their conclusions were based on interviews with a convenience sample of 39 carers of spouses with dementia (Cahill & Shapiro, 1997). However, it remains important to note that some carers report being dissatisfied with the way doctors manage the education process. This variation may be due to differences in the training or skills of general practitioners, and the time required to provide educational services which may be limited in primary care settings (Brown et al., 1998; Fortinsky, Leighton & Wasson, 1995; Woolford, 1998b).

In addition to behaving differently, members within a profession may have beliefs about a disease that may impact on how information is communicated. For example, there is a growing body of literature documenting variation in relation to disclosing AD diagnoses which suggests that some doctors consider there may be more harm than good in being direct about diagnosis (e.g., Boise et al., 1999; Markle, 1993; Woolford, 1998b), that euphemisms should be used in preference to terms such as Alzheimer's disease (e.g., Rice & Warner, 1994), and that the perceived uncertainty inherent in AD diagnosis may impact on disclosure practices (Drickamer & Lachs, 1992; Vassilas & Donaldson, 1998). Given the extent of variation in relation to disclosure practices in relation to AD, and it is probably not unreasonable to expect that this generalises to educational information that may be conveyed in the context of a "diagnosis" (Fortinsky et al., 1995).

It is clear that there may be several factors that determine whether adequate information is provided to carers, however it is also necessary to consider why carer

education is important and there are a number of reasons. First, providing information to carers appears to have beneficial effects on carer expectations and carer well being. For example, there is a positive correlation between carers' knowledge of dementia and their reported sense of competency (Graham et al., 1997a, 1997b). In addition, carers who know more about dementia tend to have lower expectations of the dementia patient and are more positive toward them (Graham et al., 1997a, 1997b). Finally, levels of depression have been found to be lower in carers with more knowledge of AD (Graham et al., 1997a, 1997b).

There has been one anomalous finding reported in the literature with regard to the putative benefits of education on carer well being. This study showed that carers with more knowledge of AD had higher levels of anxiety (Graham et al., 1997b). However, this result has yet to be replicated and appears to be inconsistent with the weight of evidence in this area. Therefore this finding but does not appear to detract substantially from the argument that in general educating carers appears to have beneficial effects on their well being although educators may need to monitor carer anxiety levels.

Second, there may be a relationship between how informed carers are and the way they care for those with AD. For example, more than one third of the sample (n = 15) interviewed by Cahill and Shapiro (1997) reported that they would have managed their spouse or relative differently had they been better informed.

Although these results do not indicate whether actual behaviour change occurs as a function of carer education, it is interesting to note that carers reported this was likely to be the case. This does not seem unreasonable, given that carers who fail to associate behavioural problems with AD for example, may misinterpret behaviour and

attempt to resolve difficulties in a manner that is ineffective for all parties (Dieckmann et al., 1988).

Third, providing information to carers is recognized as good practice, and where this does not occur problems with consumer satisfaction may arise. For example, as indicated previously, the current APA practice guidelines for the treatment of people with AD support disclosure of information to carers (APA, 1997). When insufficient or inappropriate information is provided carers may respond by reporting being dissatisfied with the services received (Cahill & Shapiro, 1997; Hill, O'Brien, Morant, & Levy, 1995).

Fourth, providing information to carers may impact on their attitudes towards the disease in general, such as whether a diagnosis should be disclosed to the person with dementia and attitudes towards predictive AD tests (O'Conor, 1999; Welkenhuysen et al., 1997). A small number of studies have attempted to explore these relationships however, at this stage, results are inconclusive. Nonetheless, if AD knowledge is related to willingness to take a predictive AD test, or attitudes towards diagnosis disclosure, it is clearly important to know the best method of educating those for whom this may be indicated. Further, if we can determine how to effectively educate carers and relatives of people with AD, this may have implications for education of the general population. Currently, the general public's knowledge of AD appears to be poor. More specifically, studies have shown that knowledge of the disease amongst the elderly (Price, Price, Shanahan & Desmond, 1986) and medical students (Welkenhuysen et al., 1997) is limited. Given the magnitude of the AD public health problem and the number of individuals who will be affected directly or indirectly by this disease, devising good public health

strategies may prevent delays in seeking treatment that have been partly attributed to a lack of knowledge about AD (Boise et al., 1999).

Finally, it may be that whilst service providers and clinicians recognise the need to provide information, they are unsure how this can be achieved most effectively, and may feel the need to provide information indirectly by providing hints or using euphemisms (Boise et al., 1999; Cahill & Shapiro, 1997; Gilliard & Gwilliam, 1996; Rice & Warner, 1994). If this is the case, testing the effectiveness of various methods of educating carers about AD may assist service providers in making these decisions about how AD carers can be educated most effectively.

It is clear from this review of the literature that at present, methods for providing carers with information about AD appear to vary widely. This variation may be partly due to factors such as service characteristics, client characteristics, and the characteristics of the educator. Despite this variation however, there are a number of important reasons to provide education to dementia carers and their families. In addition, there appears to be a growing consensus that information provided by the Alzheimer's Association (AA) should be incorporated in the education process (e.g., APA, 1997; Cahill & Shapiro, 1997; Graham et al., 1997a). The AA education tools are particularly valuable because they are widely available, address a range of important topics and are provided in a number of mediums (e.g., written information sheets and educational videos). Therefore, given the importance of determining how we can most effectively educate carers, the aim of this study was to investigate which AA education tools improve AD knowledge. Specifically, written and video education materials, and the combination of these, were tested relative to controls to determine the most effective way of improving participants' knowledge of AD. Therefore, it was predicted that participants in education

conditions would show improved knowledge of AD, as measured by increased scores on an Alzheimer's disease knowledge questionnaire, compared to controls. In addition, it was expected that participants exposed to video and written information about AD would have better knowledge of the disease than those exposed to one source of information.

Method

Participants

Seventy-five first year undergraduate psychology students from Queensland University of Technology (QUT) and twenty-five first year undergraduate psychology students from James Cook University (JCU) participated in this study (females = 79; males = 21). Age of participants ranged from 17 to 56 (\underline{M} = 26.83, \underline{SD} = 10.17). Participants in this study received course credit points in return for participation.

QUT students were randomly allocated to one of three education conditions. JCU students were allocated to the control condition. No significant differences were found between groups on age ($\underline{M} = 26.83$; $\underline{SD} = 10.87$; $\underline{F}(3,96) = 1.47$; $\underline{p} = .227$), gender ($\chi 2$ (3) = 4.521, $\underline{p} = .210$), or the number of people with an AD relative ($\chi 2$ (3) = 3.125, $\underline{p} = .373$).

Materials

A number of studies documenting existing measures of AD knowledge were consulted prior to selecting a measure for this study (Brown, Mutran, Sloane, & Long, 1998; Dieckmann et al., 1988; Graham et al, 1997a, 1997b; Karlin & Dalley, 1998; Price et al., 1986; Welkenhuysen et al., 1997). The Alzheimer's Disease Knowledge Test (ADK) was selected for this study, because it is an established measure of AD knowledge with known psychometric properties elsewhere (Dieckmann et al., 1988), and follows sound scale development procedures (Karlin & Dalley, 1998). In its original format, the ADK is a twenty-item instrument with alpha coefficients ranging from .71 to .92 giving it acceptable internal consistency. Recently, independent investigators have described the ADK as having satisfactory validity and reliability (Karlin & Dalley, 1998). Items are in the form of multiple choice questions.

Figure 1 shows an example of one item on the ADK. Option (e) is provided for each item in order to discourage guessing of answers (Dieckmann et al., 1988).

Insert Figure 1 about here

Three ADK items were modified for this study following recommendations from the scale's authors that items should be updated as new information becomes available. For example, to reflect current estimates of the prevalence of AD, the correct answer to item 1 was changed from 5% to 10% (Alzheimer's Association of Queensland, 1995). Item 11, which makes reference to the use of lecithin as a treatment for AD, was deleted because this avenue of treatment is no longer considered a treatment of choice (Brickman et al., 1982; Gray, 1989; Higgins & Flicker, 1999; Pomara et al., 1983; Vatassery & Maletta, 1983). Item 19 referred to medical insurance, however this item was deleted due to differences in the North American and Australian health care systems. Copies of the modified version of the ADK used in this study are available from the first author on request.

A second purpose-built questionnaire assessing attitudes towards a diagnosis of AD was administered following the ADK. This test, called the Reasons for Wanting to Know Questionnaire (RWK), was based on similar scales used in previous studies of this issue (Erde, Evan, Nadal, & Scholl, 1988; Holroyd, Snustad, & Chalifoux, 1996; Maguire et al., 1996). The RWK was intended to measure whether an individual would want to be told a diagnosis of AD and whether individuals would approve of a close relative being told a diagnosis of AD. A number of reasons for and against diagnosis disclosure were included on this test and participants were

asked to rate their importance on a five-point Likert scale (very important to very unimportant). Results from the RWK will be reported separately.

<u>Procedure</u>

Participants were tested over two sessions held one week apart. In session one, participants were told about the study, invited to ask questions and requested to sign a consent form. Each participant filled out a copy of the ADK and the RWK.

Immediately prior to a repeat administration of the ADK during session two, participants in education conditions were shown an educational video about AD, given a written information sheet about AD, or shown the video and asked to read the information sheet. Educational materials used in this study were selected from the Alzheimer's Association catalogue and obtained from the Alzheimer's Association of Australia, Queensland branch. These materials were selected because they are currently recommended for carer education purposes (e.g., APA, 1997). The written information presented was an information sheet entitled, "Alzheimer's disease - What is it?" (Alzheimer's Association of Queensland, 1995). The information sheet was three pages long and included sections on managing AD symptoms, epidemiology, differential diagnosis and specific diagnostic tests, as well as descriptions of cognitive and behavioural changes that can occur in mild, moderate and severe stages of the The AD education video was called "You must remember this: Inside Alzheimer's disease" (Film Australia, 1990). This video contained similar information to that covered in the written information sheet, but used a case study approach to convey details. Specifically, the video depicted individuals' subjective experiences of living with AD or caring for someone with AD, and in the process conveyed information regarding aetiology, symptomatology, disease progression, epidemiology, diagnosis and treatment of AD. To help maintain viewer interest,

avoid repetition, and minimise fatigue effects, only the first 28 minutes of the video were shown.

Three independent raters determined the number of ADK items that could be answered correctly from video and written information sources to assess content equivalence. Independent raters were given an assessment form for each medium and asked to indicate via a check mark those questions they believed could be answered after exposure to education materials. At least two out of three raters agreed that 33% (6/18) of ADK items could be answered after having watched the video, 50% (9/18) of items could be answered after reading the information sheet, and 61% (11/18) of items could be answered after exposure to both sources of information. Raters agreed that answers to the same four ADK items (22%) could be obtained from either source. Control group participants were not exposed to educational materials prior to reassessment.

Results

Before analyses, the data were screened for outliers, normality, linearity and homogeneity of variance. No violations of assumptions were found. One participant failed to answer the last page of questions on the ADK (four items). The mode for each of these items was substituted in order to calculate a final ADK score for this participant following procedures suggested by Tabachnick and Fidell (1996).

There were significant differences between mean ADK scores across testing sessions for education groups, but not controls. Table 1 shows mean ADK scores and standard deviations for participants in all groups across both testing sessions. On average, participants in the written education group and the written/video group answered correctly four more items on the ADK. Members of the video group

answered on average two more items correctly. Participants in the control group on average scored one point less on the ADK at session two than at session one.

Insert Table 1 about here

To assess whether there were differences on ADK scores, a repeated measures Analysis of Variance was conducted, with one within-subjects variable (occasion) and one between-subjects variable (groups). With alpha set at .05, significant effects for groups ($\underline{F}(3,96) = 19.34$, $\underline{p}<.05$), occasions ($\underline{F}(1,96) = 113.66$, $\underline{p}<.05$) and the interaction between these variables ($\underline{F}(3,96) = 26.76$, $\underline{p}<.05$) were found. Power was 1.00 for all significant effects. Figure 2 illustrates these results.

Insert Figure 2 about here

To further investigate the interaction between sessions and groups on the ADK, difference scores were calculated. For each group, the mean ADK score at session two was subtracted from the mean ADK scores at session one. A one-way ANOVA with one between-groups factor (group) and alpha set at 0.05 was then conducted on total ADK scores. A significant overall F-value for this analysis was found (F (3,96) = 26.76, p<.05). Post hoc tests were performed using the Scheffé method, which is considered the most conservative test of complex comparisons (Hinkle, Wiersma, & Jurs, 1994). Significant differences between all education groups and the control group were found (see Table 1). Within education groups, no significant differences were found between the written- and the video-group or the written- and the written/video-group. However, significant differences were found

between the video-only group and the written/video group, with the video-only group learning less than the combined education group.

An item analysis was conducted to determine the items on which responses post-education improved. A one-way ANOVA on difference scores for each of the 18 ADK items showed gains in knowledge on 5/18 ADK items. All of the items on which learning occurred were assessed as answerable by independent raters described previously, indicating that improvements in knowledge were found on items specifically addressed in educational materials.

Discussion

The aim of this study was to evaluate selected AD education materials to determine the best means of increasing individuals' knowledge of AD. This study demonstrated that knowledge of Alzheimer's disease could be improved using education tools that are readily available from the Alzheimer's Association. Given that higher levels of AD knowledge are associated with lower levels of depression in dementia carers (Graham et al., 1997b), this is an important finding. In addition, given that carers report their management of those with AD depends on how informed they are (Cahill & Shapiro, 1997), this finding may have implications for the management of AD patients.

It was predicted that participants who underwent AD education would have better knowledge of AD than those who received no education. This hypothesis was supported given that groups who received AD education showed a significant improvement in their knowledge of AD relative to controls.

The second hypothesis for this study predicted that participants exposed to both the written and video methods of AD education would have better knowledge of AD than those exposed to only one source of information. Partial support for this hypothesis was found. That is, a combination of written and video material was found to improve the effectiveness of the AD education above that of a video only. However, the combination approach did not significantly improve AD knowledge based on written information alone. This finding provides support for current practice at many memory clinics the British Isles, where written AD information is available for carers (Gilliard & Gwilliam, 1996).

In addition, although video-only was shown to be effective in increasing AD knowledge, gains were relatively small in this condition. By comparison, gains in knowledge in the dual education (written and video) and written-only conditions were substantial, given that on average participants in these conditions showed a 22% increase in ADK scores. Compared to the number of items covered in written- and written/video-information conditions as judged by our raters, an increase of four points on the ADK represents correct recall of approximately 50% of available information in the written education condition, and approximately 36% of available information in the dual education condition.

These results may have implications for AD education resource allocation. Clearly if resources allow, it is recommended that a multimedia approach to AD education is undertaken to accommodate different learning styles of individuals. However, limits to public health funding may prohibit implementation of this strategy. Where funding limitations impact on acquisition of multimedia education tools, written education materials are recommended above educational videos.

In addition to financial considerations however, there are a number of other practical factors that suggest that resources may be best spent on written information. First, video education tools require access to hardware that older adults may not have.

This may be less of a problem for younger carers or if services provide viewing facilities. If this study is replicated with older adults it may be helpful to assess hardware access issues to determine the viability of take home education videos.

Second, carers themselves have called for the provision of written information to follow the diagnostic process (Connell & Gallant, 1996). Providing written take home AD information may therefore have the additional benefit of increasing consumer satisfaction.

Third, the dual education approach, whilst effective, may take too long to be useful in practice, depending on where education occurs. If video and written education tools are being used as take home measures, presumably clients can learn at their leisure. Whether carers would feel able to set aside the time required to watch a video and read an information sheet will probably vary, however carers often comment that the demands on their time may impact on help-seeking behaviour (e.g., Connell & Gallant, 1996). The amount of time that carers are prepared to devote to take home education could be assessed in future research.

If dual education occurs within a clinic setting however, there may be the added advantage that staff may be on hand to answer questions that are raised, although the time demands on staff and carers may be prohibitive. One possible solution might be to schedule education sessions separately. However, in this study the benefits of dual education were assessed using serial exposure to sources of information, and the effect of gradual exposure methods remains unknown.

At this stage, it may be prudent to continue collecting information in both formats if this is financially viable until the generalisability of these results can be thoroughly tested. For example, in this study educational gains were found in a sample of undergraduate university students using written information, however these

participants may be more comfortable with this type of information than members of the general public, or those with declining cognitive function or failing eyesight. Until these results are replicated in a sample of older adults cautious interpretation of these results is warranted.

Merely acquiring or maintaining education resources for carer education purposes does not ensure materials are appropriately disseminated however (Graham et al., 1997a). For example, it has been noted that distribution of information may not be effective if this process relies on *individual* health professionals within tertiary referral settings (Graham et al., 1997a). Whilst it is clear that there is an element of uniqueness in each case, and managing the process of education optimally requires a degree of clinical judgement, there are a number of possible strategies that could be trialed to minimise dissemination problems.

For example, strategies for minimising difficulties with dissemination appropriate for tertiary referral settings could include devising a policy on managing dementia education that could be used to guide practice, creating a specialist position for dementia education within treating teams, specifying a role for case managers in dementia education, or implementing a model for providing information to families, such as the Psychoeducational Family Conference Model proposed by Woolford (1998a) or the Minnesota Family Workshop proposed by Ostwald and colleagues (Ostwald et al., 1999). These options could allow for developing interventions that include providing support and eduction (rather than support or education alone). This is important given that comprehensive interventions have been shown to be more effective in reducing carer depression or caregiver burden than single approaches (Ostwald et al., 1999).

Referral to the Alzheimer's Association is a dissemination strategy that may be used to outsource education services in both primary and tertiary care settings (Brown et al., 1998; Cheok et al., 1997; Gilliard & Gwilliam, 1996; Fortinsky et al., 1995). However, the actual referral rate amongst general practitioners may be as low as 1 in 20 (Cheok et al., 1997), and in tertiary referral settings it has been noted that the takeup rate of AA referrals may be problematic (Gilliard & Gwilliam, 1996).

Finally, in primary care settings, out-reach education has been proposed to ensure that family physicians have the requisite skills to manage AD education independently (Brown et al., 1998; Connell & Gallant, 1996). This discussion clearly illustrates that service providers are attempting to address this issue, and future research could examine the effectiveness of strategies designed to minimise dissemination problems. In the meantime, this study may serve to prompt further discussion about how the dissemination of AD educational materials is currently managed in both primary and tertiary care settings.

The need for further research in this area is clear and there are a number of exciting avenues this could take. Future studies could look at comparing other AA education materials to determine whether the results from this study represent an effect of mode of education, or whether these effects are specific to the materials used for this project. In addition, it may be possible to introduce a classification system for written and video materials that reflects their educational content. Broadening the range of educational materials that is included in future comparisons of effectiveness may also be of interest. For example, are "talking books" or information provided in this medium as effective as information provided in video or written formats?

It would also be interesting to conduct further analysis of the scale properties of the modified version of the ADK used in this study. Although the modifications made to this test for the purposes of this project were relatively minor, and the original scale was selected because of its good psychometric properties (Dieckmann et al., 1988), the psychometric properties of the modified scale should be reassessed. In addition, validity issues need to be explored further, possibly by determining the extent to which ADK scores correlate with specific carer behaviours.

To further our understanding of how dementia education is most effectively conducted, future studies could also include a range of additional measures. For example, it may be useful to include a measure of participants' learning styles to determine whether this predicts the most effective medium for educating individuals. In addition, if this research is replicated with carers, a measure of carer anxiety could be included to help determine whether carer education is in fact related to anxiety. An attitudes-to-education scale could also be developed to assess hardware access issues as mentioned previously, and responses to items such as: how much time would you spend reading an information sheet/watching a video on AD?

Finally, it may be useful to determine the nature and type of information held in Australian memory clinics. This would be useful for comparative purposes with world standards (e.g., Gilliard & Gwilliam, 1996), but perhaps most importantly, to inform the selection of materials used in future studies of this type.

Providing information about AD is clearly an important part of managing the diagnostic process and meeting the education needs of carers (APA, 1997; Graham et al., 1997b; Moniz-Cook & Woods, 1997). In addition to being "good practice", it has demonstrable effects on carer well being and improvements on current practice in this area could probably be made (e.g., Boise et al., 1999). Systematic evaluation of

selected Alzheimer's Association educational materials showed that providing written information about AD may be the most cost-effective and practical means of improving carer's knowledge of the disease.

Finally, as noted previously, current APA practice guidelines for the treatment of patients with dementia endorse carer education but do not provide guidance as to how this information can be disseminated most effectively (APA, 1997). With further research in this area, it may be possible to generate the evidence-base required to formulate a recommendation on this matter for inclusion in future best practice guidelines.

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The Queensland University of Technology Human Research Ethics

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Figure Caption

<u>Figure 1</u>. Example of one of the items on the Alzheimer's Disease Knowledge Test (ADK).

- 10. Although the rate of progression of Alzheimer's disease is variable, the average life expectancy after onset is:
- a. 6 months 1 year
- b. 1-5 years
- c. 6-12 years
- d. 15-20 years
- e. I don't know

Table 1.

Mean ADK scores and standard deviations pre- and post-education for all groups (n = 25).

	Pre-education		Post-education	
Group	M	SD	M	SD
Written information only	7.16	2.94	10.64	3.45
Video information only	7.84	3.12	9.88	3.19
Video & Written information	8.80	3.15	12.36	2.29
Control	5.76	2.47	4.96	2.78

Note. Higher scores represent greater knowledge of AD. Maximum ADK score is 18.

All education groups were significantly different from controls on post-hoc tests.

<u>Figure 2.</u> Mean ADK scores on two testing occasions (pre- and post-education) for all groups.

