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Should a Diagnosis of Alzheimer's Disease be Disclosed?

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Abstract

There is evidence that some health practitioners may be reluctant to disclose a diagnosis of Alzheimer's disease (AD) to patients (Clafferty, Brown, & McCabe, 1998; Drickamer & Lachs, 1992; Fortinsky, Leighton, & Wasson, 1995; Kirby & Maguire, 1998; Maguire et al., 1996; Rice & Warner, 1994; Rice, Warner, Tye & Bayer, 1997). However, this reluctance towards disclosure may not be in accordance with patient expectation (Erde, Evan, Nadal, & Scholl, 1988; Holroyd, Snustad, & Chalifoux, 1996; Kirby & Maguire, 1998; Maguire et al., 1996; Vassilas & Donaldson, 1998). This study examined the attitudes of 100 undergraduate psychology students towards disclosure practices in relation to AD, before and after exposure to AD education. After AD education, 93% of participants indicated a desire to be informed of a diagnosis of AD, and 95% of participants were in favour of telling a close relative a diagnosis of AD. Results are discussed in terms of the relationship between age and attitudes towards AD diagnosis. It is concluded that the high rate of support for disclosure of AD diagnoses to patients among younger adults may reflect a change in the information preferences of patients brought about by a shift away from a patriarchal medical model, toward a more autonomous model of health.

Estimates of the prevalence of Alzheimer's disease (AD) in developed countries suggest that at least 3.7 million people may be affected (Alzheimer's Disease International, 1999). In Australia, AD affects between 55,000 and 144,000 individuals, however the number of cases of AD is expected to double by the year 2011 (Woodward, 1999). As the world's population ages and the incidence of AD increases, the treatment and management of those with AD will become an increasing public health concern (Brookmeyer, Gray, & Kawas, 1998).

An important aspect of the effective care of people with AD is the manner in which the diagnosis of the disease is managed. A particularly important part of this process, is how this information is conveyed to patients and their families. Whilst some practice guidelines for the management of people with AD include sections on disclosure (e.g., American Psychiatric Association, 1997; American Psychological Association, 1998), the information provided may be too general and non-specific, if the issue is dealt with at all. The need for guidance on this matter is apparent from previous research on the issue of disclosing diagnoses of AD, which suggests significant variation in practice, and also current debate in the literature on what constitutes best practice in this area (e.g., Rice et al., 1997). For example, some practitioners advocate telling the patient his or her diagnosis, whereas other practitioners are reluctant to disclose this information to patients (Drickamer & Lachs, 1992; Kirby & Maguire, 1998; Maguire et al., 1996; Rice & Warner, 1994; Rice et al., 1997; Vassilas & Donaldson, 1998).

To account for the reluctance of some practitioners to disclose AD diagnoses, some researchers have drawn parallels between attitudes towards disclosure of AD and cancer diagnoses (Buckman, 1996; Drickamer & Lachs, 1992; Green & Gantt, 1987; Noritoshi, 1998; Thomsen, Wulff, Martin, & Singer, 1993). For example, an investigation by Oken of cancer surgeons in the United States in 1961, found that 90% of those questioned did not routinely

tell patients their diagnosis (as cited in Buckman, 1996). Over time however, attitudes towards cancer diagnosis have changed considerably. A replication of Oken's study in 1977 found a complete reversal of attitude, with 97% of those surveyed indicating a willingness to disclose a diagnosis of cancer to their patients (Holroyd et al., 1996).

It has been argued that many health professionals currently treating AD patients have the same reservations about disclosing an AD diagnosis to patients as those treating cancer patients in the 1960s (Drickamer & Lachs, 1992; Kirby & Maguire, 1998; Maguire et al., 1996; Rice & Warner, 1994; Rice et al., 1997; Vassilas & Donaldson, 1998). For example, a survey conducted by Vassilas and Donaldson (1998) showed that 95% of general practitioners would tell patients, always or often, a diagnosis of terminal cancer, but only 39% of this group would always or often tell patients a diagnosis of dementia.

Some of the reasons given for the reluctance to tell AD patients their diagnosis are the same as those that have been advanced for not telling a patient they have cancer (Drickamer & Lachs, 1992). For some practitioners there is the fear that delivering bad news may result in long-term harm to the patient's emotional well being. For others, there is the concern about the certainty of the diagnosis of AD, and the belief that since there is no cure for the disease, a definitive diagnosis of AD is unimportant. Other practitioners cite opposition by relatives to informing the patient of a diagnosis of AD as influential in their disclosure practice (Drickamer & Lachs, 1992; Kirby & Maguire, 1998; Miller et al., 1992).

The shift in the disclosure practices of professionals treating cancer patients may be partially explained by improved cancer treatments and changes to legal liability laws (Holroyd et al., 1996). Drickamer and Lachs (1992) have also argued that the empirical demonstration that patients do want to know their diagnosis has been influential in the change of attitude

towards truth disclosure with cancer. However, it has been suggested that greater societal support for individual autonomy and a lesser acceptance of paternalistic medical practices may have exerted an even greater influence on changes to disclosure practices (Holroyd et al., 1996).

Most of the studies that have looked at the issue of disclosure of AD diagnoses have done so from the perspective of the health professional (Clafferty et al., 1998; Fortinsky et al., 1995; Gilliard & Gwilliam, 1996; Holroyd et al., 1996; Rice & Warner, 1994; Rice et al., 1997; Vassilas & Donaldson, 1998). The few studies that have examined this issue from the viewpoint of the potential patient have suggested that attitudes held by some health professionals to the disclosure of a diagnosis of AD may differ significantly from the general public.

For example, Erde and colleagues (1988) surveyed 224 individuals on the question of whether or not they would want to be told a diagnosis of AD. Over 90% of respondents answered in the affirmative. In another study with older adults ($M = 79.7$, $SD = 6.9$), results showed that 79.5% of participants would want to know a diagnosis of AD (Holroyd et al., 1996). Finally, a study of people with a first-degree relative with AD showed that 71% would want to be told their diagnosis (Maguire et al., 1996). Reasons given for wanting to know a diagnosis of AD have included the right to know, to make provisions for the future, to explore treatment options, to commit suicide, to get a second opinion, to settle family matters, to travel or go on a vacation, to understand what is happening, to prepare spiritually, and to find out as much as possible about the disease (Erde et al., 1988; Holroyd et al., 1996; Maguire et al., 1996).

An interesting contradictory result was found when researchers asked individuals whether they believed that a close relative with AD should be told his or her diagnosis. Holroyd and colleagues (1996) found that only 65.7% of respondents would want their spouse told a diagnosis of AD; a lower percentage than the 79.5% who expressed a desire to be told their own diagnosis of the disease. In excess of 80% of the 100 participants in the study by Maguire and colleagues (1996) did not believe it was appropriate for a family member be told a diagnosis of AD. This is in marked contrast to the 71% who indicated that they themselves would want to be told a diagnosis of AD. In a letter to the editor, Rice and colleagues (1997) reported the results of an unpublished survey of 40 carers of people with AD. Ninety percent of these participants said that they did not believe the patient should be told a diagnosis of AD. Included in the reasons provided for not wanting to disclose a diagnosis of AD to a close family member was that the diagnosis would depress or agitate the relative, the relative would not understand the diagnosis, that there is no benefit in knowing, the relative would not want to be told, and the fear that the relative may commit suicide (Holroyd et al., 1996; Kirby & Maguire, 1998; Maguire et al., 1996; Vassilas & Donaldson, 1998).

In contrast to the findings of the majority of studies on this issue however, Barnes (1997) found that the majority of first-degree relatives of patients with AD were in favour of telling the relative a diagnosis of AD. It should be noted that Barnes' (1997) study was described in a letter to the editor, thus it is difficult to comment on potential differences in methodology that could account for this discrepancy. Nonetheless, this inconsistency in results suggests there may be a need for further research to clarify how people feel about disclosing AD diagnoses to relatives, and whether there is a difference between people's attitudes when thinking about disclosure in relation to themselves or to others.

Previous studies have attempted to identify demographic markers of those with differing preferences for medical information (Benbassat, Pilpel, & Tidhar, 1998; Deber, 1994; Petrisek, Laliberte, Allen, & Mohr, 1997; Walsh, Girgis, & Sanson-Fisher, 1998). These studies have suggested that at least two factors may influence individuals' information preferences. These are: patient age and knowledge of the disease in question (Benbassat et al., 1998, Meredith et al., 1996; Petrisek et al., 1997, Welkenhuysen, Evers-Kieboom, & Van den Berghe, 1997). For instance, age has been found to influence the patient-doctor relationship, such that older individuals (60 years of age and above) adopt a more passive role in the consultation process with their doctors than younger individuals (Benbassat et al., 1998). The paternalistic medical model, widespread in the 1950s, may have instilled in older individuals an expectation that the patient should be a passive receiver of medical treatment with the doctor taking control of the consultation process (Benbassat et al., 1998). Younger individuals may be influenced by a more egalitarian medical model in which patients are encouraged to take greater responsibility for their health care (Petrisek et al., 1997). Given that age may influence the degree to which an individual participates in the medical decision-making process, it seems reasonable to expect that the desire to be told a diagnosis, or to give permission to tell a diagnosis, may differ with the age of the person making this decision.

Research on the relationship between age and attitudes to the disclosure of an AD diagnosis has been limited and in some cases poorly designed. For example, Erde and associates (1988) concluded from their study that no demographic marker could predict an individual's attitude to AD diagnosis disclosure. However, the mean age and lower- and upper-limits of the age range of participants in their study were not reported. Thus, it is difficult to comment on attitudes to diagnosis disclosure at specific age periods.

In addition, although Holroyd and associates (1996) have stated that they were unable to find a demographic marker, including age, which would be useful for distinguishing between those individuals in favour and those against diagnosis disclosure, their study only older individuals ($M = 79.7$, $SD = 6.9$). This would seem to limit extensive comments on disclosure attitudes as a function of age.

Nonetheless, the study by Erde and colleagues has arguably made the most comprehensive attempt to explore the relationship between age and attitudes towards diagnosis to date. For example, Erde and colleagues (1988) endeavoured to gauge attitude changes to diagnosis disclosure as a function of age, using an age projection technique. This technique involved asking participants to imagine how they would feel about the disclosure of a diagnosis of AD at ages ranging from 40 to 90 years old. As has been noted however, an individual's cohort may influence his or her preference for medical information (Benbassat et al., 1998; Petrisek et al., 1997), thus age projection techniques may not be the most effective means of assessing age differences in attitudes to diagnosis disclosure.

Another means of determining whether there is a relationship between age and attitudes towards disclosure of AD diagnoses, is to compare results across cross-sectional studies with "older" and "younger" samples. For example, in the study conducted by Holroyd and colleagues (1996), which involved "older" subjects (participants mean age was 79.7), a lower percentage (79.5%) of the sample was in favour of diagnosis disclosure than the "younger" subjects tested by Erde and associates (1988; 80% of the sample were described as under the age of 65). There are at least two limitations associated with making this type of comparison that need to be acknowledged however, before accepting this comparison as evidence of a trend in the data. First, as noted above, the age of the sample included in the

study by Erde and colleagues is difficult to estimate, thus the extent to which this comparison provides a reasonable test of the proposition that age is related to disclosure preferences is difficult to determine. Second, direct comparison of percentages across studies can at best provide a weak test of this proposition, given that differences may be due to a range of variables that were not equally controlled. Nonetheless, when considered in light of relevant theoretical models, this pattern of results may suggest a trend in the data. That is, if older people are more reluctant to want to be told their diagnosis than younger people, this would be consistent with the age/autonomy model of health-seeking behaviour, which posits that older individuals are less likely than younger people to explicitly seek information about their medical condition.

Lack of AD knowledge has also been implicated in a reduction of the information seeking behaviour of some older individuals (Boise, Morgan, Kaye, & Canicolli, 1999). For instance, when quizzed on the possible reasons for the delay in obtaining a diagnosis of AD for a family member, 72% of caregivers surveyed by Boise and associates (1999) indicated that it was because they did not know very much about AD. Since lack of AD knowledge has been shown to affect an individual's information seeking behaviour, attitudes towards diagnosis disclosure may also be affected by a lack of AD knowledge.

This review of the literature on attitudes towards AD diagnosis for self and others illustrates a number of important points. First, contrary to the opinions and practice of some health professionals, which suggests there may be a reluctance to disclose a diagnosis of AD to some patients, the general consensus in the literature appears to be that most people would want to be told a diagnosis of AD if they were to develop the disease (Barnes, 1997; Erde et al., 1988; Holroyd et al., 1996; Maguire et al., 1996; Rice & Warner, 1994). Second, there

may be a discrepancy in people's attitudes towards diagnosis when they consider this issue in relation to themselves and to others, at least for older adults (Barnes, 1997; Holroyd et al., 1996; Maguire et al., 1996; Rice & Warner, 1994). Whether this pattern of results reflects the attitudes of younger people remains unknown however. Third, although there are clearly people who, do not want to be told a diagnosis of AD (Girgis & Sanson-Fisher, 1998), however the reasons for this may vary and could include a lack of knowledge about the disease. Fourth, although attempts have been made to discover a means of predicting those who favour the disclosure of an AD diagnosis and those who oppose it, based on the available literature, it appears that we can not tell in advance who will and who will not want to be told their diagnosis. However, as noted previously, there may be a need to further investigate the potential role of age as a possible predictor given restrictions on this variable in previous studies. Fifth, and perhaps most importantly, this review of the literature shows there are serious limits to our knowledge in relation to attitudes towards AD diagnoses. Although there may sound methodological reasons for studies to focus on older adults, given that the prospect of developing the disease may be perceived as a more serious risk for this age group (Welkenhuysen et al., 1997), thus there may be more concordance between older people's attitudes and behaviour in relation to AD, an understanding of younger adults' attitudes towards diagnosis is also clearly important.

The aims of this study were two-fold. The first aim of this study was to explore the attitudes of younger adults to the disclosure of a diagnosis of AD. Importantly, it was anticipated that mean age for the sample used in this study would be lower than that used in previous studies. Since younger individuals may be more heavily influenced by the current autonomy based model of health care than older individuals (Petrisek et al., 1997), it was

predicted that a large majority of individuals in this study would approve of the disclosure of a diagnosis of AD for themselves and for others. Although it is difficult to make comparisons across studies as noted previously, it was anticipated that the size of the "majority" supporting disclosure in this study would be greater than that found in previous studies with older adults.

The second aim of this study was to examine the relationship between knowledge of AD and attitudes to diagnosis disclosure. Given that a reduction in information seeking behaviour has been noted previously in those with a lack of AD knowledge (Boise et al., 1999), it was expected that individuals with a greater knowledge of AD would be more likely to support being told their diagnosis of AD than individuals with less knowledge of AD.

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 ($M = 26.83$, $SD = 10.17$). Participants in this study received course credit points in return for participation. No significant group differences in age were apparent, $F(3,96) = 1.47$, $p = .227$, nor were there significant gender differences between groups, $\chi^2(3) = 4.52$, $p = .210$.

Materials

The Reasons for Wanting to Know Questionnaire (RWK) was developed for this study to assess attitudes towards diagnosis disclosure and was based on scales used in previous

research (Erde et al., 1988; Holroyd et al., 1996; Maguire et al., 1996). The RWK was circulated to attendees at a meeting of the Australian Psychological Society's College of Clinical Neuropsychologists Queensland branch, prior to use in this study to ensure appropriate content and clarity. No changes to the scale content or format were made as a result of this process.

The RWK was intended to assess whether an individual would want to be told a diagnosis of AD should they develop the disease. It was also intended to assess whether an individual would approve of a close relative being told a diagnosis of AD, if they were to develop the disease. A number of reasons for and against diagnosis disclosure were listed on the RWK and participants were asked to rate their importance on a five-point Likert scale, ranging from very important to very unimportant. Participants were asked to circle the number that best represents the importance to them of the reason given. Figure 1 shows a sample RWK item. Copies of the RWK are available from the first author on request.

Insert Figure 1 about here

The Alzheimer's Disease Knowledge Test (ADK; Dieckmann, Zarit, Zarit, & Gatz, 1988) was also administered to participants in this study. The rationale for selecting the ADK, and the modifications made to this instrument for the purposes of this study have been described fully elsewhere (Sullivan & O'Connor, in press). Briefly the ADK is an established measure of knowledge of AD, that was designed to be used as an evaluative tool and continues to be used for this purpose (e.g., Karlin & Dalley, 1998). In its original format, the ADK is a twenty-item instrument that includes items presented as multiple choice questions,

each with a "don't know" option to discourage guessing of answers (Dieckmann et al., 1988). For this study, two items were dropped from the scale, and the response options for three items were changed in line with the scale authors recommendations that items be updated to reflect current knowledge.

Procedure

The full procedure for this study has been described previously (Sullivan & O'Connor, in press) but will be described here briefly. Participants were tested over two sessions held one week apart. Students from QUT were randomly assigned to one of three groups before the start of session one. Students from JCU were assigned to a control group. 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.

At session two, QUT students were exposed to education intervention depending upon group allocation. That is, some students were provided with written information about AD, others saw a video about AD, and the remainder were exposed to both types of information. The control group (JCU students) did not undergo any education. The written information was presented as an information sheet entitled, "Alzheimer's disease - What is it?" (Alzheimer's Association of Queensland, 1995) and participants in the video condition viewed a segment from a programme called "You must remember this: Inside Alzheimer's disease" (Film Australia, 1990). Education materials were obtained from the Alzheimer's Association of Australia (Queensland branch) because materials produced by this group have been shown to be effective in educating the public about AD (Boise et al., 1999). Administration of the ADK and the RWK was repeated at session two for all participants.

Results

Results for the analyses of the RWK are presented descriptively following a precedent set by other researchers (Erde et al., 1988; Holroyd et al., 1996; Maguire et al., 1996). Preference for being told a diagnosis of AD, or telling a close relative a diagnosis of AD, did not change significantly after education, $\chi^2(4) = 23.23$, $p = .000$, therefore results following education are reported only. However, it should be noted that detailed results from the ADK, addressing the most effective means of improving knowledge of AD, have been reported elsewhere (Sullivan & O'Connor, in press).

Ninety-three percent of participants responded in favour of being told a diagnosis of AD, and 95% of participants indicated in favour of telling a close relative a diagnosis of AD. Table 1 illustrates the results of the question of whether or not an individual supports the disclosure of a diagnosis of AD.

Insert Table 1 about here

The Likert scale data obtained from RWK was collapsed into two categories: (a) very or moderately important and (b) very or moderately unimportant to simplify data analysis. Table 2 presents the reasons that were considered important both for wanting to know a diagnosis of AD and for not wanting to know a diagnosis of AD. For example, Table 2 shows that 96% of those participants who said that they would want to know a diagnosis of AD indicated that an important reason for this was the belief they had a "right to know". For those participants against diagnosis disclosure ($n = 3$), the fact that they would not want to be

informed of any illness was nominated by all respondents as an important reason for their attitude against disclosure of an AD diagnosis.

Insert Table 2 about here

Table 3 shows the reasons that were considered important for telling or not telling a close relative a diagnosis of AD. For example, 94% of those participants in favour of disclosing a diagnosis of AD to a close relative, indicated that the patient's "right to know" was an important motive for disclosure. The fear of upsetting the relative by disclosing a diagnosis of AD was important for those participants who said they did not support telling a close relative a diagnosis of AD.

Insert Table 3 about here

Of those participants who indicated that they would want to know a diagnosis of AD (see Table 2), 96% indicated that an important reason for this was their right to know. To plan ahead, explore treatment options, to get a second opinion, and to settle family matters were also considered important to the majority of respondents (i.e., more than 87% of this group). Nine percent of participants indicated that being able to plan their suicide was also an important consideration. Of those participants who were in favour of telling a diagnosis of AD to a close relative (See Table 3), the relative's right to know was considered important by 94% of this group. Most respondents (92% of this group) also indicated that they believed the relative would cope better if he or she were told a diagnosis of AD.

Discussion

The aims of this study were two-fold. First, to explore the attitudes of younger adults to the disclosure of a diagnosis of AD; and second to examine the relationship between AD knowledge and attitudes to diagnosis disclosure in younger adults.

To achieve these aims, two hypotheses were proposed. First, the hypothesis, that a large majority of individuals in this study would approve of the disclosure of a diagnosis of AD for themselves and for others, was supported. Results pertaining to attitudes towards diagnosis for self are discussed first, followed by results pertaining to attitudes towards disclosure for others.

In this study, 93% of participants responded in favour of being told a diagnosis of AD. The high percentage of participants in this study who said that they would want to know a diagnosis of AD is in accordance with the study by Erde and colleagues (1988) whose participants were mostly younger than 65 years old. In addition, the percentage of the participants in this study indicating a desire to be told a diagnosis of AD (93%), is higher than that found in studies with older adults (i.e., 79.5%; Holroyd et al., 1996). This finding appears to provide further support for the proposition that there may be age differences in people's attitudes towards disclosure of AD diagnoses, given that studies with older adults suggest a lower percentage of participants are in favour of disclosure (Holroyd et al., 1996). However, these results need to be interpreted cautiously, since, as noted previously, comparisons of percentages derived from cross-sectional research can be problematic if sample characteristics are not equivalent. Therefore, to fully investigate the issue of the relationship between age and attitude towards the disclosure of a diagnosis of AD, a study that includes participants from a wide range of age groups may be warranted.

As noted previously, differences between younger individuals and older adults have been noted in relation to the patient-doctor relationship generally (Benbassat et al., 1998). This difference has been attributed to a changing medical model with younger individuals expecting to take a more active role in this relationship than older individuals (Benbassat et al., 1998). This influence may also extend to an individual's information seeking practices; with those influenced by the autonomous medical model expecting a more egalitarian exchange of information with their doctors. However, further exploration of the relationship between age and attitude towards diagnosis disclosure is needed, to determine whether apparent differences between the attitudes of younger and older adults can be attributed to an autonomous medical model, such as that proposed by Benbassat and associates (1998). For example, this could be done by including a questionnaire that assesses attitudes toward the doctor-patient relationship specifically.

Previous research has found that people tend to be more in favour of being told a diagnosis of AD themselves than of telling a close relative his or her diagnosis (Holroyd et al., 1996; Maguire et al., 1996). In accounting for this inconsistent finding, Maguire and colleagues (1996) have suggested that some individuals who endorse autonomous decision-making with regards to their own health, may take a more paternalistic view when considering the information needs of those close to them. That is, they may fail to deliver (or have delivered) bad news in an effort to protect loved ones. Contrary to this pattern of results, participants in this study were equally supportive of being told (93%) and telling a close relative a diagnosis of AD (95%). Again, this result may be a reflection of the profound influence of the autonomous medical model on younger people.

The second hypothesis for this study, that individuals with a greater knowledge of AD would be more likely support being told their diagnosis of AD than individuals with less knowledge of AD, could not be tested in this study. Examination of the relationship between knowledge of AD and attitudes towards the disclosure of a diagnosis of AD was made difficult due to the large numbers of individuals in favour of diagnosis disclosure. As has been noted, the heavy bias towards wanting to know a diagnosis of AD may illustrate the extent to which young people are influenced by the autonomous medical model.

However, this finding raises two important issues. First, the results of this study suggest that even when provided with information about AD, participants support for disclosure remained high. That is, support for disclosure did not decline after participants were provided with information about AD, even though their knowledge of the disease increased following education (see Sullivan & O'Connor, in press). This result may contradict some of reasons against disclosing diagnoses to patients that have been reported in the literature. For example, Markle (1993) has suggested that "...given the distressing facts [of diagnosis] many patients, while still able, would simply shoot themselves" (p. 736). While this perspective is probably not be representative of the views held by most doctors, the results of this study suggest that even when provided with "the distressing facts", such as the incurable nature of the disease, the likely level of dependency, and the serious and debilitating cognitive symptoms, younger adults continue to want to be told their diagnosis.

Secondly, it is important to note that this is the first time the relationship between education and attitudes towards disclosure of a diagnosis of AD has been investigated in young people, and the relationship between these variables has yet to be explored with older individuals. Considering that there may be more variation in older people's attitudes towards

disclosure, it may be possible to measure the effect of knowledge on attitudes with an older sample. That is, examination of the relationship between AD knowledge and disclosure attitudes of older individuals may provide some insight into the possible link between these variables. In addition, future studies could also look at using a non-university based sample of younger adults to further explore the potential relationship between education and attitudes towards diagnosis, given that the general public may demonstrate more variation in attitudes towards disclosure than the sample used in this study. Using both older and non-university based samples who may have less education than subjects used in this study may also permit further investigation of the relationship between education and disclosure preference.

The reasons given by individuals both in favour and against disclosure of AD diagnoses are interesting and may have important implications for the management of people with AD and their families. For example, individuals who supported the disclosure of a diagnosis of AD indicated that being able to get a second opinion about the diagnosis, to plan ahead, to explore treatment options, and to settle family matters, were important reasons for this. Having a right to know was considered important both by those who favoured being told a diagnosis of AD and those who supported telling a close relative a diagnosis of AD. This support for patient's rights lends further credence to the autonomy theory of individuals' information preferences in this sample.

A small number of individuals indicated that it was important for them to be told a diagnosis of AD in order to plan for their suicide. Recently, there have been two documented cases of suicide in patients with probable AD, however the risk of suicide amongst those with AD is generally considered low (Rohde, Peskind, & Raskind, 1995). Nonetheless, the results of the present study suggest that suicide is a real consideration for a small percentage of

individuals and as such, suicide risk management must be considered as part of the process of managing disclosure of AD diagnoses.

Apart from not wanting to distress clients (Markle, 1993), one of the other reasons cited by medicos for not disclosing diagnoses is inability to understand diagnoses. For example, it has been argued that in advanced cases, the client would not be able to understand the information (Rice & Warner, 1994), although others point out there may be other benefits for the patient in disclosing diagnostic information (Brodaty, Griffin, & Hadzi-Pavlovic, 1990). In response to concerns about the patients' ability to comprehend a diagnosis, some doctors have indicated they may be more likely to tell relatives than the patient themselves, especially in advanced cases. Further, the practice of telling relatives and not patients may also occur at specialist diagnostic services that take a team approach to assessment and diagnosis of people with AD (e.g., Gilliard & Gwilliam, 1995). Nonetheless, it is important to note that other health professionals have raised concerns about the legal and ethical implications of such practices (Barnes, 1997; Drickamer & Lachs, 1993; Meyers, 1997; Rice et al., 1997). For example, some of the concerns that have been documented in the literature relate to whether the disclosure of information about a patient to their relatives, and not to the patient themselves, can in fact be justified. Obviously, this is a difficult issue that medicos and other health professionals are currently attempting to grapple with.

The dissemination of the results from this study may assist health professionals to better understand individuals' information preferences with regard to AD diagnoses. If these results can be replicated, this may help begin a process of building up sufficient evidence to warrant the development of best practice guidelines on this issue. These could be incorporated in future best practice guidelines, as a means of supporting practitioners involved

in managing the disclosure process. In the meantime, this study has provided the first empirical demonstration that an overwhelming number of young people would want to know their diagnosis, should they developed AD, and indeed they consider it a right, even when after they have been provided with facts about the disease. Importantly, this demonstration may be sufficient to begin changing disclosure practices of AD health professionals, in the same way that the knowledge of attitudes to cancer diagnosis may have contributed to a revision of disclosure practices for cancer diagnoses.

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Table 1

Percentage of Participants in Favour and Against the Disclosure of a Diagnosis of Alzheimer's Disease (AD)^a.

| Group | Would want to be told a diagnosis of AD | | Would want to tell a close relative a diagnosis of AD | |
|---------------|---|----|---|----|
| | Yes | No | Yes | No |
| Written | 19 | 1 | 19 | 2 |
| Video | 20 | 2 | 20 | 1 |
| Written/Video | 20 | 1 | 20 | 0 |
| Control | 21 | 2 | 21 | 1 |
| Total | 80 | 6 | 80 | 4 |

^aMissing data is excluded from calculation therefore percentages do not total 100

Table 2

Reasons for and Against Being told a Diagnosis of Alzheimer's Disease (AD)

| Reasons to be told a Diagnosis of AD | % | <u>N</u> ^a | Reasons not to be told a Diagnosis of AD | % | <u>N</u> ^a |
|---|----|-----------------------|---|-----|-----------------------|
| Plan ahead for future | 95 | 72 | Don't want to know of any illness | 100 | 3 |
| Have a right to know | 96 | 74 | No benefit in knowing | 100 | 3 |
| Explore treatment options | 94 | 72 | Diagnosis would depress or agitate | 75 | 3 |
| Get a second opinion | 88 | 63 | Fear of committing suicide | 50 | 2 |
| Settle family matters | 91 | 68 | Stigma of the diagnosis | 0 | 0 |
| Go on holiday/travel | 73 | 44 | | | |
| Plan my suicide | 9 | 6 | | | |

^aMissing data and participants who were undecided are excluded from calculation therefore N does not total 100

Table3

Reasons for and Against Telling a Diagnosis of AD to a Close Relative

| Reasons to tell a Close Relative a Diagnosis of AD | % | <u>N</u> ^a | Reasons not to tell a Close Relative a Diagnosis of AD | % | <u>N</u> ^a |
|---|----|-----------------------|---|-----|-----------------------|
| Has a right to know | 94 | 79 | Don't want to upset him/her | 100 | 2 |
| Could try to keep mind working | 81 | 56 | Relative dreads the disease | 100 | 1 |
| Would be aware he/she was ill | 93 | 78 | Stigma of the diagnosis | 100 | 2 |
| Would cope better if he/she knew | 92 | 54 | Relative may commit suicide | 100 | 1 |
| Understand why he/she forgets things | 87 | 66 | Wouldn't understand diagnosis | 100 | 1 |
| To sort out legal affairs | 84 | 63 | No benefit in knowing | 0.0 | 0 |
| To give consent to drug trials | 69 | 50 | They wouldn't want to know | 100 | 1 |
| No use hiding it | 72 | 43 | | | |
| Could work it out for him/herself | 55 | 33 | | | |

^aMissing data and participants who were undecided are excluded from calculation therefore N does not total 100

Figure Caption

Figure 1. Example of an item on the Reasons for Wanting to Know Questionnaire (RWK)

| <u>Reason</u> | <u>Rating</u> |
|--------------------------------|---------------------------|
| a. I have a right to know | 1-----2-----3-----4-----5 |
| b. To plan ahead for my future | 1-----2-----3-----4-----5 |
| c. To get a second opinion | 1-----2-----3-----4-----5 |
| d. To settle family matters | 1-----2-----3-----4-----5 |

1 = Very important, 2 = Moderately important, 3 = Undecided,
 4 = Moderately unimportant, 5 = Very unimportant