Current knowledge and future directions about the disclosure of dementia: A systematic review of the first decade of the 21st century

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Abstract

**Background:** The disclosure of Alzheimer’s disease presents a great challenge because it entails emotionally charged communication about a life-threatening, incurable, and stigmatized disease. Although a broad consensus has evolved regarding the potential benefits of early disclosure of the diagnosis, little is known about how these recommendations are actually implemented, and there is limited published research about the process issues of the disclosure.

**Purpose:** (1) To systematically obtain and evaluate the relevant literature on disclosing a diagnosis of dementia, with special attention to process issues, and (2) to summarize current research findings and draw conclusions for future research and clinical care in this area.

**Methods:** A systematic review of the literature on disclosure of dementia during the first decade of the 21st century was conducted.

**Results:** From 265 articles retrieved, 47 were included in the review. Although the studies published in the first years of the decade were concerned with assessing attitudes and preferences of those involved in the process of disclosing the diagnosis, those of the last years have focused more on communication and other process issues.

**Conclusions:** A conceptual development over time in the area is observed in which in the first years, thought processes begin as an ethical debate among clinicians and researchers about the topic of “truth telling” and dementia, continue as a search of the opinions of those involved in the process of disclosing truth telling, and evolve (observed more recently) into an examination of how this truth telling is delivered.

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**Keywords:** Alzheimer’s disease; Dementia; Disclosure; Diagnosis

1. Introduction

As a result of the aging Western populations, dementia and particularly Alzheimer’s disease (AD) are becoming progressively a more serious public health problem. Projections of the incidence and prevalence of AD in the United States suggest that over a 50-year period (2000–2050), the prevalence of AD is expected to quadruple and its incidence, to triple [1]. Similar rates are predicted in other Western countries [2]. In light of these challenging statistics, an increasing number of elderly persons, their family caregivers, and physicians will be involved in the process of the diagnosis of AD and the need to disclose it. The disclosure of AD presents a great challenge because it entails emotionally charged communication about a life-threatening, incurable, and stigmatized disease that is associated with enormous societal, familial, and personal costs [3–5].

Currently, a broad consensus has evolved regarding the potential benefits of early disclosure of the diagnosis [6,7] as a basis for needed treatment and management decisions. Indeed, in the Third Canadian Consensus Conference [8], the issue of disclosing the diagnosis was included as one of the main topics addressed [9]. Sensitive and individually tailored transmission of information to patients and caregivers is recommended [10,11] as a moral and legal obligation, allowing the individual to play an active role in their life...
and maximize their quality of life [12–14]. However, little is known about how these recommendations are actually implemented in clinical practice [15], and there is limited published research about the process issues of the disclosure, such as what is said and done within the encounter, who is present, are partnerships and coalitions created, and what is the flow of the communication. Research and guidelines for disclosure published by scholars and professional organizations lack details regarding the participants’ expectations and needs of the process and the way of dealing with them [16–18]. The efficiency of the methods that have been recommended, such as “patient-led” discussions intended to minimize adverse emotional consequences [19], as well as stepwise disclosure emphasizing the assessment of needs and expectations, and adjustment to the patient’s pace [20], are not supported by empirical data. Although some guidelines and articles do mention the need to provide and discuss the diagnosis with patients, enhancing autonomy, they allow variation based on medical ethics and the fear of causing harm [9,21,22]. The possibility for variation is exhibited by using terminology such as “if at all possible,” after the suggestions to share information with patients [17].

One of the ways to advance understanding in a specific area is to scrutinize and summarize existing knowledge to identify key characteristics of research that will guide future directions and efforts. Therefore, the aims of this review are to examine the published literature in the area of disclosing the diagnosis of dementia during the past decade. Our specific objectives were as follows:

1. To systematically obtain and evaluate the relevant literature on disclosing a diagnosis of dementia, with special attention to process issues, and
2. To summarize current research findings and draw conclusions for future research and clinical care in this area.

Several reviews have been published during the last years of the decade in the area of disclosing a diagnosis of dementia, although they were limited to previous years and to partial aspects of the overall topic. For example, Gordon and Goldstein’s [23] evaluation of the available literature focused on the reasons for telling or not telling patients about a diagnosis of AD. Twelve articles published between 1966 and 1999 were included in their review, and most of them were considered to conform to level II (case-controlled or cross-sectional studies) or level III evidence (experts’ opinions, descriptive studies, or reports from expert committees). Carpenter and Dave [24] conducted a review of the literature from 1972 to 2002 on opinions and practices regarding the diagnostic disclosure of dementia. Although the exact number of sources included was not specified, the authors concluded that there is a gap between experts’ recommendations and practices in actual clinical settings and encouraged the design and performance of further research, most specifically regarding process issues. Bamford et al [16] published a thorough systematic review covering an extensive period of time (1966–2003) that included 59 articles that conformed to the inclusion criteria defined by the authors. As in the case of Carpenter and Dave’s [24] findings, these researchers found serious discrepancies between actual practice and clinical guidelines, questionable methodologies, and a relative neglect of the patient in the disclosing process.

Finally, in the last 2 years, two systematic reviews were published. Bradford et al [25] examined the literature published between 1980 and 2008 to establish the prevalence of and factors that contribute to the delayed diagnosis of dementia and concluded that the main factors were related to prevailing attitudes among patients and physicians, deficits in education, and limited resources. Koch and Iliffe [10] conducted a review covering up to August 2009 to assess the barriers to the early detection of dementia and classified, as did Bradford et al [25], the factors affecting a delayed diagnosis of dementia as being related to patient factors, physician factors, and system characteristics.

The present review adds to this body of knowledge by focusing on the literature of the past decade and by emphasizing process issues.

2. Methods

2.1. Search strategy

A computer-based literature search was performed to identify publications on the topic of disclosing the diagnosis of dementia, published between January 2000 and December 2010. MEDLINE and PsycINFO databases were chosen for the search because both contain publications that cater to a wide range of health professions related to dementia care. The following keyword search terms were used: diagnose* AND (dementia OR Alzheimer*) AND disclos*.

The search was restricted to publications in the English language on human subjects and was supplemented by manual searching of reference lists. Two researchers independently reviewed the titles and abstracts of the articles identified. Articles that appeared to meet the inclusion criteria were read in full.

2.2. Inclusion and exclusion criteria

Studies that identified the key terms in the title, abstract, article, or MeSH heading were retained. Excluded were the studies published as abstracts, conference proceedings, or pilot results published in non–peer-reviewed journals. Books, book chapters, comments on publications, and dissertations were also excluded.

3. Results

3.1. Publication search and exclusion

Two hundred sixty-five publications were identified—174 in PubMed and 91 in PsycINFO. Two hundred eighteen were classified as not relevant because they were duplicates,
book chapters, dissertations, or contained non-dementia-specific data. Four publications were review articles [2,6,24,26], which were excluded from the systematic review but are still detailed in Table 1 and included in the background and discussion sections. The remaining 47 studies were read in full, and the information is summarized in Tables 1–4. Articles that examine more than one topic are included in the relevant table only.

3.2. Background of studies reviewed

Studies were from the United Kingdom (13), the United States (10), Canada (5), the Netherlands (5), Belgium (2), Finland (2), Israel (1), Brazil (1), Ireland (1), France (1), Italy (1), Germany (1), Taiwan (1), Japan (1), Australia (1), and Europe (1). The number of studies increased in the last years of the decade. Between 2000 and 2003, 10 studies; between 2004 and 2006, 17; between 2007 and 2009, 15; and in 2010, five studies were published.

The studies included were categorized under the following general topics: patients’ and caregivers’ attitudes and preferences toward the disclosure, professionals’ knowledge and attitudes toward the diagnosis, and process issues in the diagnosis of dementia.

3.3. Patients’ and caregivers’ attitudes and preferences toward the disclosure of dementia

Most of the articles (73%) in this topic were published in the first 6 years of the decade (Table 1). None was published in 2010. Methodologically, 10 were qualitative studies, and the rest used quantitative methodologies, although only two used random sampling. Most of the studies examined ethnically homogeneous samples. Eight examined dyads of patients with dementia and their family caregivers, eight examined only caregivers, and three studies examined the attitudes and preferences of persons with dementia. Three studies assessed the preferences of healthy elderly persons concerning the disclosure of a diagnosis of dementia as presented in vignettes or hypothetical cases.

The majority of the studies found that family caregivers wanted to be informed of the diagnosis of dementia. In fact, in most cases, family members reported that after the initial shock and embarrassment of hearing the diagnosis, they actually felt relieved and their fears were somewhat alleviated [31,46,47]; their quality of life and relationship with the patient was improved [31,33]; and the diagnosis disclosure had provided them with an opportunity to prepare for the future [34]. However, some negative reactions were also reported and were associated mainly with a feeling that the information and emotional support provided to them were inadequate [31,38,41,42,46]. The main information desired by the caregivers was related to the treatments and services for the disease, the management of behavioral and psychiatric symptoms, and financial and legal issues [52]. Indeed, one of the few studies that examined the experience of receiving a diagnosis of dementia over time demonstrated that 3 months after the diagnosis was disclosed, family caregivers started to organize themselves and get practical help to deal with the difficulties of caregiving [50]. Similar findings were reported by Byszewski et al [29] who conducted a focus group with caregivers of persons with dementia, a month subsequent to the diagnostic disclosure.

Also, studies assessing the attitudes of persons with dementia consistently found that the majority favored the disclosure of the diagnosis [22,29,39,45]. Although several studies reported that the disclosure of the diagnosis was accompanied by feelings of uncertainty and a desire to know more about the disease and about the future [22,46], no catastrophic emotional reactions were reported; in fact, in some cases, anxiety levels were actually reduced after the disclosure [30].

Studies that examined preferences for the disclosure of dementia in hypothetical situations also found that the majority of the participants favored the disclosure to the caregivers and to the patients. No clear associations were found between the desire to be informed about the diagnosis and previous familiarity with AD. Lin et al [43] in their study of 150 persons aged 23 to 89 years found that knowing a person with AD increased participants’ willingness to be told about a diagnosis of AD, whereas Ouimet et al [44] in a study 204 subjects aged ≥65 years and Turnbull et al [48] in a study of 200 persons in the same age range found that familiarity decreased the willingness to be told. Umegaki et al [49] in a study assessing attitudes toward the disclosure of dementia among healthy elderly persons found that increased age was associated with decreased preferences to be told about the diagnosis.

3.4. Professionals’ knowledge and attitudes toward the diagnosis

Except one, all the studies in this section were published between 2004 and 2008 (Table 2), and the majority were quantitative and used mail surveys and samples of general practitioners (GPs). Only one study was based on a random sample of 1000 GPs [55], whereas in the others, the sample size ranged between 40 and 631 participants. The findings in these studies showed consistently that the majority of the GPs reported an awareness of the benefits of disclosing the diagnosis of dementia, but only a minority actually did so in their practice with the patients. Feelings of stigma, futility, and difficulties to handle the disclosure were among the main barriers to the disclosure of the diagnosis [58,60,62]. One qualitative study based on interviews with neurologists as well as observations of 14 diagnostic disclosure encounters showed that the existence of barriers such as fear of withdrawing hope and eliciting negative emotions, including shame and anxiety, as well as respect for the patient’s right “not to know,” have led to the development of a variety of strategies aimed at disguising
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<tr>
<th>Reference</th>
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<th>Participants</th>
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<tbody>
<tr>
<td>Aminzadeh et al [27]</td>
<td>Canada</td>
<td>30 patient–caregiver dyads</td>
<td>Qualitative study at three points in time: at the disclosure meeting, one week after the disclosure, and a focus group held with caregivers one month after the disclosure</td>
<td>Three types of emotional reactions were observed: lack of insight, grief reactions, and positive coping responses</td>
</tr>
<tr>
<td>Bachman et al [28]</td>
<td>USA</td>
<td>35 caregivers of persons with AD</td>
<td>Phone interviews with structured questionnaire</td>
<td>The majority agreed that it was correct to tell the patient about the diagnosis and that the disclosure was not very upsetting</td>
</tr>
<tr>
<td>Byszewski et al [29]</td>
<td>Canada</td>
<td>30 patient–caregiver dyads</td>
<td>Qualitative study at three points in time: at the disclosure meeting, one week after the disclosure, and a focus group held with caregivers one month after the disclosure</td>
<td>Most participants (caregivers and patients) preferred a full disclosure</td>
</tr>
<tr>
<td>Carpenter et al [30]</td>
<td>USA</td>
<td>90 dyads of elderly persons (mean age, 73 years) and their companions participating in a longitudinal study of healthy aging and mild dementia</td>
<td>Structured instruments assessing depression and anxiety</td>
<td>69% were diagnosed with dementia</td>
</tr>
<tr>
<td>Connell et al [31]</td>
<td>USA</td>
<td>52 caregivers (mean age, 63 years) and 39 physicians (family and internal medicine and general practice)</td>
<td>Focus groups</td>
<td>Caregivers and physicians differed in their perceptions regarding the emotional reaction of the caregivers, in the description of the process, and in the amount and quality of the information provided, especially with regard to treatment</td>
</tr>
<tr>
<td>Connell et al [32]</td>
<td>USA</td>
<td>178 family members of persons with AD</td>
<td>Structured questionnaire</td>
<td>Participants strongly endorsed obtaining a diagnosis</td>
</tr>
<tr>
<td>Derksen et al [33]</td>
<td>The Netherlands</td>
<td>Case study</td>
<td>Grounded theory including a semistructured interview guide and videotaping</td>
<td>The impact of the disclosure affected three areas: awareness of dementia, interpersonal relationship, and social relationships</td>
</tr>
<tr>
<td>Derksen et al [34]</td>
<td>The Netherlands</td>
<td>18 dyads of patients and caregivers</td>
<td>Grounded theory including a semistructured interview guide and videotaping</td>
<td>The disclosure of the diagnosis did not usually introduce stress for patients and caregivers: 86% wanted to know the cause of their problem, and 69% wanted to be told if diagnosed with AD</td>
</tr>
<tr>
<td>Elson [35]</td>
<td>UK</td>
<td>95 patients aged ≥65 years suffering from memory complaints</td>
<td>Face-to-face semistructured interviews</td>
<td>54% of the participants wanted to be told about the diagnosis</td>
</tr>
<tr>
<td>Faby et al [36]</td>
<td>UK</td>
<td>100 caregivers recruited from semirural memory clinics and inner-city community mental health teams</td>
<td>Interviews</td>
<td>Lower MMSE scores (&lt;17) were associated with not wanting a disclosure of diagnosis</td>
</tr>
<tr>
<td>Hinton et al [37]</td>
<td>USA</td>
<td>39 family caregivers from a variety of sources</td>
<td>Semistructured qualitative interviews</td>
<td>Pathways of dementia diagnosis as reflected in help-seeking behaviors vary according to ethnic group</td>
</tr>
<tr>
<td>Holroyd et al [38]</td>
<td>USA</td>
<td>57 family members attending support groups</td>
<td>Structured questionnaire</td>
<td>The majority of the participants advocated telling patients about the diagnosis</td>
</tr>
<tr>
<td>Jha et al [39]</td>
<td>UK</td>
<td>53 patients with dementia from outpatient clinics</td>
<td>A self-administered quantitative questionnaire to be returned by postal service</td>
<td>Most participants welcomed the idea of knowing their diagnosis and were not upset by it</td>
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Table 1
Summary of articles examining patients’ and caregivers’ attitudes and experiences toward the disclosure of the diagnosis (Continued)

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<tr>
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<tbody>
<tr>
<td>Keightley and Mitchell [40]</td>
<td>UK</td>
<td>Seven health care professionals—two clinical psychologists and five psychiatric nurses</td>
<td>Grounded theory</td>
<td>Concerns about the patient’s reaction and willingness to know and feeling of hopelessness and helplessness were the main reason for not disclosing the diagnosis</td>
</tr>
<tr>
<td>Laakkonen et al [41,42]</td>
<td>Finland</td>
<td>1943 caregivers of persons with AD Mean age, 78 years</td>
<td>Random sampling and structured interview</td>
<td>The majority were in favor of disclosing the diagnosis to patients and spouses 59% reported willing to discuss advance care planning</td>
</tr>
<tr>
<td>Lin et al [43]</td>
<td>Taiwan</td>
<td>150 family members attending an outpatient neurological clinic Mean age, 55 years 60% children of AD person</td>
<td>Self-administered structured questionnaire presenting hypothetical scenario of AD</td>
<td>The majority (93%) reported being in favor of disclosure if they had AD, but only 76% wanted it for their relatives</td>
</tr>
<tr>
<td>Marzanski [22]</td>
<td>UK</td>
<td>30 consecutive patients with dementia Mean age, 81 years</td>
<td>Open-ended questionnaire</td>
<td>The majority reported not receiving good information nor opportunity to discuss the diagnosis</td>
</tr>
<tr>
<td>Ouimet et al [44]</td>
<td>Canada</td>
<td>204 persons aged ≥65 years attending outpatient clinics 40% with ≥13 years of education 49% born in Canada</td>
<td>Vignette study with structured face-to-face interview</td>
<td>The majority reported wanting a diagnosis of dementia to be disclosed to them When medication was said to be available, the percentage of persons wanting a diagnosis for themselves and for their spouses increased</td>
</tr>
<tr>
<td>Pinner and Bouman [45]</td>
<td>UK</td>
<td>50 patients and their caregivers recruited from a memory clinic Mean age, 79 years</td>
<td>Semistructured quantitative questionnaire</td>
<td>The majority of the patients and the caregivers wanted to be informed about the diagnosis</td>
</tr>
<tr>
<td>Robinson et al [46]</td>
<td>UK</td>
<td>Nine dyads of persons with dementia and their spouse recruited from memory clinics</td>
<td>Qualitative interviews</td>
<td>Receiving a diagnosis of dementia was described as having both positive and negative effects The couples reported looking for ways to make sense of the situation</td>
</tr>
<tr>
<td>Smith and Beattie [47]</td>
<td>Canada</td>
<td>14 patients and their family-accompanying members (40 persons)</td>
<td>Observations of the assessment process and the family conference and in-depth interviews after 6–8 weeks from the disclosure</td>
<td>The disclosure of the diagnosis was generally beneficial</td>
</tr>
<tr>
<td>Turnbull et al [48]</td>
<td>USA</td>
<td>200 nondemented persons aged ≥65 years attending a University clinic Mean age, 73 years Mean years of education, 9 50% Caucasian; 50% African American</td>
<td>Vignette study with structured questionnaire</td>
<td>Most participants wanted to be told if they had AD Familiarity with the disease was associated with less willingness to be told</td>
</tr>
<tr>
<td>Umegaki et al [49]</td>
<td>Japan</td>
<td>Study 1: 1200 residents aged 40–64 years and 5000 residents aged ≥65 years Study 2: 3949 residents aged ≥45 years, with a family member needing long-term care</td>
<td>Study 1: Random sampling and mail survey using a structured questionnaire Study 2: Random sampling and face-to-face interviews using a structured questionnaire</td>
<td>Approximately three-quarters of the younger and older participants preferred being disclosed a hypothetical diagnosis of dementia Percentages were lower in study 2 but still relatively high</td>
</tr>
<tr>
<td>Vernooij-Dassen et al [50]</td>
<td>The Netherlands</td>
<td>18 dyads of persons with dementia and a family caregiver</td>
<td>Qualitative case series study two weeks after the disclosure and 10 weeks later using semistructured interviews and videotaping</td>
<td>The disclosure of the diagnosis is seen as a process and is not inevitably associated with negative feelings</td>
</tr>
<tr>
<td>Wackerbarth and Johnson [51]</td>
<td>USA</td>
<td>528 family caregivers (response rate, 72%)</td>
<td>Mail survey and structured questionnaire</td>
<td>Benefits included medical confirmation and access to treatment Barriers included a variety of emotional and pragmatic reasons</td>
</tr>
<tr>
<td>Wald et al [52]</td>
<td>UK</td>
<td>100 caregivers 58% White</td>
<td>Semistructured interview</td>
<td>Caregivers wanted to receive as much information as possible at the time of the disclosure, especially what is dementia, its treatment, and knowledge about behavioral and psychological symptoms of dementia</td>
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Abbreviations: USA, the United States; UK, the United Kingdom; AD, Alzheimer’s disease; MMSE, Mini-Mental State Examination.
and veiling the information, especially the specific name and explanation of the disease and its prognosis [15].

3.5. Process issues of the diagnosis of dementia

Process issues refer to the “where,” the “who,” and the “how” of the encounter. They include details such as the physical location, the key participants (patient, caregiver, physician, other health care professionals), and the manner in which the encounter is conducted (e.g., communication processes and styles, formation of coalitions).

Only 10 articles were found in this area, with six of them published during the last 2 years (Table 3). These studies address the question regarding how the diagnostic disclosure is delivered (or should be delivered) rather than whether it should be delivered. Two types of studies are included in this section: interventional studies aimed at training professionals and caregivers in the best practices for the process of breaking bad news and studies that assess the communication processes embedded in the disclosure of the diagnosis of dementia.

Five intervention studies are reviewed in this section, although only three deal with the results of the efficacy of the intervention, and only two [65,66] involved randomized clinical trials. One of the interventions was geared toward caregivers and included a psychoeducational program to deal with the consequences of the disclosure [64]. The goal of the other four interventional programs was to train professionals in the appropriate methods of disclosure of the diagnosis of dementia, although no empirical data are presented. The same group of researchers in an article

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<tbody>
<tr>
<td>Cahill et al [53]</td>
<td>Ireland</td>
<td>300 GPs (50% response rate)</td>
<td>Representative national postal survey</td>
<td>Only a minority reported disclosing the diagnosis</td>
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<td></td>
<td></td>
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<td></td>
<td>Concerns about the impact of the diagnosis on the patient was one of the main barriers to the disclosure</td>
</tr>
<tr>
<td>Cantegreil-Kallen et al [54]</td>
<td>France</td>
<td>631 GPs</td>
<td>Mail survey of a structured survey asking to relate to the last patient with AD (39% response rate)</td>
<td>Although 88% considered their role to provide the diagnosis, only 28% reported disclosing it Few topics are discussed directly with the patient</td>
</tr>
<tr>
<td>De Lepeleire et al [55]</td>
<td>Belgium</td>
<td>Random sample of 1000 GPs</td>
<td>Mail survey of a structured questionnaire (60% response rate)</td>
<td>Although 75% reported seeing benefits in disclosure, only 36% reported disclosing the diagnosis always or usually</td>
</tr>
<tr>
<td>Johnson et al [56]</td>
<td>UK</td>
<td>40 physicians (geriatricians and psychogeriatricians)</td>
<td>Mail survey and structured questionnaire (73% response rate)</td>
<td>Only 40% of the participants reported telling the diagnosis to patients</td>
</tr>
<tr>
<td>Kaduszkiewicz et al [57]</td>
<td>Germany</td>
<td>30 GPs, 389 GPs and 239 neurologists</td>
<td>Qualitative in-depth interviews Mail survey with structured questionnaire (40% and 84% response rate, respectively)</td>
<td>The majority of the participants (GPs and neurologists) agreed that patients should be informed about the diagnosis</td>
</tr>
<tr>
<td>Raicher et al [17]</td>
<td>Brazil</td>
<td>181 physicians, including geriatricians, neurologists, and psychiatrists</td>
<td>Electronic survey (19% response rate)</td>
<td>Only 45% reported revealing the diagnosis</td>
</tr>
<tr>
<td>Robinson et al [58]</td>
<td>Australia</td>
<td>100 participants (family caregivers, health care professionals)</td>
<td>Focus groups</td>
<td>Feelings of stigma and futility emerged accompanied by differences between professionals and caregivers</td>
</tr>
<tr>
<td>Tarek et al [59]</td>
<td>Belgium</td>
<td>252 neurologists and neuropsychiatrists</td>
<td>Mail survey with structured questionnaire (44% response rate)</td>
<td>68% reported disclosing the diagnosis</td>
</tr>
<tr>
<td>Turner et al [60]</td>
<td>UK</td>
<td>127 GPs</td>
<td>Self-administered structured questionnaire</td>
<td>Overall good knowledge was found, although lower in epidemiological topics Participants reported difficulties talking with patients about the diagnosis Physicians disclose the diagnosis to the majority of the caregivers but to a minority of the patients Specific advice was provided in &lt;50% of the cases</td>
</tr>
<tr>
<td>Van Hout et al [61]</td>
<td>The Netherlands</td>
<td>64 GPs</td>
<td>Prospective observational study</td>
<td></td>
</tr>
<tr>
<td>Vernooij-Dassen et al [62]</td>
<td>Europe</td>
<td>23 experts in dementia</td>
<td>Modified focus groups</td>
<td>Stigma on aging and dementia and the feeling that there is nothing to do were the main barriers to a timely diagnosis</td>
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</table>
published in 2008 [67] provide a list of “best practice” behaviors in the disclosure of dementia as they emerged from the literature and from the experience of patients with dementia, their caregivers, and professionals. A high level of agreement between these sources was found, with the main behavioral elements mentioned being preparing for disclosure, integrating family members, exploring the patient’s perspective, disclosing the diagnosis, responding to patient’s reactions, focusing on quality of life and well-being, planning for the future, and communicating effectively.

Studies aimed at describing communication techniques and processes were mostly based on the analysis of videotapes and were performed by the same group of researchers in the United States [70,72]. The third article in this group used quantitative interviews to characterize and compare the perceptions of caregivers, patients, and physicians regarding the communication style developed during the disclosure encounter [71]. Results of these studies showed that physicians tend to dominate the communication process and that they differ from each other in the topics they find important to discuss with the caregiver compared with the patient [15,71].

4. Discussion

The aim of this article was to conduct a comprehensive review of published studies assessing the topic of disclosure
of dementia in the current century. To discuss our findings in light of those of the previous decade as well, we included in the Appendix tables summarizing studies published on the topic up to 1999.

Our survey reveals a relative abundance of the reports published during the past decade that deal with the topic of the disclosure of the diagnosis of AD, especially compared with other reviews covering much larger time periods [10,25]. Indeed, almost half of the studies included in our review (n = 21) have been published in the last 4 years.

More interestingly, the studies reveal a conceptual development over time in the area. Studies published in the first years of the decade continued the line of research of the previous century and were concerned with assessing attitudes and preferences of those involved in the process of disclosing the diagnosis of dementia. Studies published during the last years of the decade have focused more on communication and other process issues related to the disclosure. In other words, the review of the past decade starting with the close of the previous century highlights the development of the thought processes that begin as an ethical debate among clinicians and researchers about the topic of “truth telling” and dementia, continue as a search of the opinions of those involved in the process of disclosing the truth, and evolve (observed more recently) into an examination of how this truth telling is delivered. This pattern resembles the process observed in the area of breaking bad news in terminal cancer, which began 50 years ago [74,75]. This time lag might be a result of the different characteristics of the diseases. As in other mental illnesses [76], the diagnosis of AD is characterized by a higher degree of uncertainty [26] and stigma [5,77].

However, the most important question is whether the findings of the studies of the first decade of the 21st century broaden and deepen the evidence base and enhance our understanding of the area to provide insights into how this happens (and should happen). The following discussion will focus on the three sections presented earlier in the text.

### 4.1. Studies assessing patients’ and caregivers’ attitudes and preferences regarding the diagnosis of dementia

Although publications during the previous century were characterized by controversies regarding the benefits and harms of telling the truth about the diagnosis of dementia [78,79], the examination of the literature in the past decade showed consistently that patients and caregivers are willing and prepared to receive and cope with the diagnosis. However, most of the studies reviewed were descriptive, and the ethnic composition of the samples was mostly homogeneous. This is worrisome because two studies that examined the topic in different ethnic and age groups demonstrated differences between the groups regarding perceptions, experiences, and help-seeking patterns [32,37]. These findings warrant the examination of the feasibility and effectiveness of more individualized and tailored approaches to the disclosure of dementia. Heterogeneous sampling should broaden the exploration of the demographic factors that may influence the impact of the disclosure on receiving, perceiving, and ultimately coping with it [49].

### 4.2. Studies assessing physicians’ preferences and practices regarding the diagnosis of dementia

These studies showed that although declaring their support for disclosure, the majority of the physicians do not implement it in their practices. Voorhees et al [80] noted that this is true also in the case of cancer, where disclosure of the diagnosis is a difficult task for the physician, especially when transmitted to noncompetent patients. They also demonstrated that the training of physicians in communication and delivering of bad news was associated with heightened desire and willingness on the part of the physician to discuss diagnosis and prognosis [80]. These findings stimulate the development of future studies aimed at designing and evaluating such educational and training programs for physicians in the area of AD. These programs should emphasize elements of self-awareness of personal difficulties with these tasks [81,82] as well as the enhancement and updating of

<table>
<thead>
<tr>
<th>Reference</th>
<th>Country</th>
<th>Aims</th>
<th>Findings and recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carpenter and Dave [24]</td>
<td>USA</td>
<td>To review and report on previous opinions and practices regarding the diagnosis of dementia</td>
<td>A wide variety of opinions in favor against the disclosure were found. Increased research regarding process issues of the disclosure is encouraged.</td>
</tr>
<tr>
<td>Cornett and Hall [6]</td>
<td>USA</td>
<td>To discuss issues affecting the decision to disclose the diagnosis</td>
<td>Supports the disclosure of the diagnosis but discusses ethical issues related to it and stresses the importance to relate to patient’s feelings. Provides suggestion for best practice strategies for the disclosure.</td>
</tr>
<tr>
<td>Iliffe et al [2]</td>
<td>UK</td>
<td>To review the role of primary care practitioners in the diagnosis of dementia</td>
<td>The diagnosis of dementia is a shared responsibility between primary care physicians and specialists.</td>
</tr>
<tr>
<td>Monaghan and Begley [26]</td>
<td>UK</td>
<td>To review and discuss the ethical dilemmas involved in the disclosure</td>
<td>Truth telling is based on ethical principles and should be done using multidisciplinary teams</td>
</tr>
</tbody>
</table>
specific skills and protocols for breaking bad news [83], especially those related to breaking bad news in a multiparti-
cipant conversation with varying needs and capabilities.

With the exception of the study by De Lepeleire et al [55],
which was based on a random sample of Flemish physicians,
most of the studies in this area were performed using conve-
ience samples of GPs and mail surveys, leading to relatively
low response rates. To strengthen the understanding and
representativeness of the findings, additional studies using
larger more representative samples and more rigorous
designs are needed. Moreover, in view of increased recogni-
tion of the need of a multidisciplinary approach in this area
[58], the perceptions, experiences, attitudes, and practices of
other specialists (such as neurologists, psychiatrists, geriatri-
cians, psychologists, nurses, and social workers) should also
be examined.

4.3. Studies assessing process issues

Our review shows that in the last years of the decade, an
increasing, although still limited, number of studies concen-
trate on the process aspects of the disclosure and on interven-
tions aimed at improving its outcomes. However, only one
random controlled trial [65] and two unblinded trials
[63,66] were conducted (although results are not yet avail-
able for one of them [66]). To promote evidence-
based practice in the area of disclosure of dementia, more
rigorous interventional studies, which will improve the de-
livery of information and standard care and will lead to the
development of practice guidelines, need to be developed.
Therefore, the current availability of strategies for facilitat-
ing the relationship and transmission of information and in
medical encounters [84–86] mandates the development of
well-designed interventions that will enable rigorous assess-
ment of different strategies with regard to their relative effec-
tiveness in the disclosure of the diagnosis of dementia.

Because the majority of the encounters involving elderly
persons are threesomes [87,88], there is an urge for addi-
tional studies assessing the triadic interaction between
cognitively impaired patients, family caregivers, and
health professionals. We located only three studies
[70–72] that have addressed communication processes in
trias (patients–caregivers–physicians). This is surprising
because the guidelines of professional associations, such as
the American Medical Association [89], do mention
the need to understand the caregivers’ role, be wary of the
complexities, and address their needs [89,90]. However,
these are mentioned in general rules and without specific
suggestions about handling these conversations (e.g., with
or without the patient present).

4.4. Limitations of the review

Despite making every effort to unearth the relevant lit-
erature, we cannot disregard the possibility that some studies
may not have been identified. This is an inherent limitation
of systematic reviews, which in an effort to be specific are
prone to miss articles of importance [91]. Furthermore, in-
f ormation was synthesized and reported in summary tables,
and no statistical techniques were used to assess methodo-
 logical issues such as sample size and more. However, it
should be noted that only a few of the studies reviewed
were randomized trials that would have been appropriate
for the application of these techniques.

5. Conclusions and future directions

Based on this review, the last 10 years have been notable
for an increasing degree of interest and greater numbers of
publications in the area of disclosing the diagnosis of de-
mentia, with a gradual transition from mostly descriptive
studies assessing attitudes and preferences to studies assess-
ing process aspects of the disclosure. However, several gaps
in our understanding of the disclosure of dementia can still
be identified in our fundamental understanding of the pro-
cess of the disclosure of the diagnosis of dementia, and these
need to be addressed.

5.1. Research suggestions

Undoubtedly, the current body of knowledge has pro-
vided with a clear identification of the barriers to the dis-
closure of dementia. However, empirically rigorous research is still needed in the development and assessment of
interventions to minimize these barriers. One of the
ways to attain this goal might be developing clear protocols
for the disclosure of the diagnosis. Available generic proto-
cols for conveying bad news, such as the SPIKES [83] and
the ABCDE mnemonics [92], can possibly be tested and
subsequently adapted for the specific disclosure of demen-
tia. Modifications will need to be instituted to deal with the
challenge of handling a multiparticipant conversation and
dealing with the disease characteristics. Another research
area in need of expansion is the assessment of the structural
characteristics of the disclosure of dementia, with special
attention to the communication and interactive processes
within the triad. Finally, special research attention should
be paid to the ethical consequences that might emerge in
light of the past developments in the identification of AD
and the recently proposed revised diagnostic criteria en-
 couraging increased use of biomarkers for identifying
“asymptomatic” persons with increased risk for developing
dementia [93].

5.2. Clinical suggestions

The transmission of bad news in general and specifically in
the case of dementia requires special attention and sensitivity
from clinicians. The move between truth telling and being hon-
est while being sensitive and showing concern to patients’ abil-
ities and needs and fear of doing harm is a continuing struggle
[15] that no simple guideline can resolve. However, diagnosis
disclosure communication should never choose sides in this
dilemma/challenge. Recent guidelines warn against the reliance on professionals’ fear or family members’ concerns for psychological harm and increase the reliance on patient’s wishes [9]. This suggestion emphasizes the need to discuss, early on in the relationship, patient’s preferences for information and involvement in their care. This ongoing assessment (as preferences may change over time) can help better guide the actual decision of what to share, when, to whom and how, or, as Fisk et al [9] suggest, it may help in finding the individualized approach best suited to that patient and family. This is further emphasized by Alzheimer Europe guidelines [13].

To deal with these difficulties, training including specific strategies for appropriate communication within the constraints of a triadic relationship should be provided throughout the continuum of medical education and the education of allied health professionals; for example, how and when caregivers should be asked questions and what information should they be given? What information can be given when both the patient and the caregiver are present and which should be discussed separately? Whose right and responsibility is it to know?

As in other diagnosis disclosure conversations, it seems that there is a great need to understand that it is not about a diagnosis disclosure encounter, but rather about a diagnosis disclosure process. Within this process, various types of information should be given (e.g., prognosis, advance planning, treatment options) [21], and the importance of the need to process the information and come back with more questions and needs—the wish for a follow-up meeting and continuation of care—should be conveyed [9,12]. These needs can be, at least partially, addressed by different professionals in the clinic (nurse, social worker) and should preferably include written material as well [12,52].

In summary, this review indicates that despite important advances, gaps in the knowledge and practice of disclosing a diagnosis of dementia remain. We tried to identify these gaps and provide with suggestions for advancing this area. Obviously, the implementation of these suggestions will require changes and increases in funding strategies.

Acknowledgment

This research was supported by a grant from the Israel Science Foundation (P.W. and O.K.M.).

References

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[68] Perry M, Draskovic I, van Achtenberg T, Borm GF, van Eijken MI, Lucassen PL, Olde Rikkert MG. Can an easy care based dementia training programme improve diagnostic assessment and management of dementia by general practitioners and primary care nurses? The
design of a randomised controlled trial. BMC Health Serv Res 2008; 8:71–80.


Appendix

A search was conducted for articles published between January 1950 and December 1999. One hundred forty-six publications were identified—123 in MEDLINE and 23 in PsycINFO. One hundred thirty-six studies were classified as not relevant because they were duplicates, letters, book chapters, dissertations, or contained non–dementia-specific data. One publication was a review article (Downs, 1997) and was excluded from the tables, leaving 10 studies in our computer-based literature search. In addition, we further manually searched the reference lists of five review articles (Bamford et al., 2004; Bradford et al., 2009; Carpenter and Dave, 2004; Gordon and Goldstein, 2001; Koch and Iliffe, 2010) and obtained an additional 14 articles for inclusion. The total search yielded 24 original studies, which were read in full, and the information is summarized in Tables A1 and A2.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Country</th>
<th>Participants</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bass et al [1]</td>
<td>USA</td>
<td>576 primary caregivers</td>
<td>Semistructured interviews</td>
<td>Caregivers for the individuals who had received a formal diagnosis reported more relationship strain and reduced activities compared with caregivers for those who had no official diagnosis, independent of the level of patient impairment</td>
</tr>
<tr>
<td>Boise et al [2]</td>
<td>USA</td>
<td>38 families and 53 family caregivers</td>
<td>Focus groups and subsequently mailed questionnaire</td>
<td>The average time between initial symptom recognition and diagnosis was 30 months. Factors delaying the diagnosis included caregiver’s lack of knowledge and factors related to family, patient, and physician</td>
</tr>
<tr>
<td>Brodaty et al [3]</td>
<td>USA</td>
<td>188 caregivers</td>
<td>Postal questionnaire</td>
<td>The diagnosis was always told to the caregivers, but only 35% of the patients were told the diagnosis</td>
</tr>
<tr>
<td>Chenoweth and Spencer [4]</td>
<td>USA</td>
<td>289 caregivers</td>
<td>Postal questionnaire</td>
<td>20% of the caregivers were unable to recall any explanation being given at the time of diagnosis</td>
</tr>
<tr>
<td>Connell and Gallant [5]</td>
<td>USA</td>
<td>233 spouse caregivers</td>
<td>Mail survey questionnaire</td>
<td>The benefits of disclosure were to find out what was wrong. Disadvantages included the lack of effective treatments, the time required to obtain a diagnosis, its cost, and the lack of access to physicians trained to diagnose dementing illnesses</td>
</tr>
<tr>
<td>Erde et al [6]</td>
<td>USA</td>
<td>224 adult patients who were waiting to see their physicians</td>
<td>Self-report questionnaire</td>
<td>92% would want to be told the diagnosis. The same proportion thought patients should be told</td>
</tr>
<tr>
<td>Heal and Husband [7]</td>
<td>UK</td>
<td>71 caregivers</td>
<td>Postal self-report questionnaire with forced and open-ended questions</td>
<td>48% of the patients were told the diagnosis, mainly by their caregivers than their doctors. Only 21% of the caregivers were given an opportunity to discuss the issues involved</td>
</tr>
<tr>
<td>Holroyd et al [8]</td>
<td>USA</td>
<td>156 older people living in a retirement community</td>
<td>Postal self-report structured questionnaire assessing responses to vignettes</td>
<td>80% would want to know if they had AD, married subjects significantly less than singles. 66% would want their spouse to be informed if their spouse had AD</td>
</tr>
<tr>
<td>Husband [9]</td>
<td>UK</td>
<td>42 caregivers</td>
<td>Standardized interview</td>
<td>98% of the caregivers were given the diagnosis alone. 10% were given an opportunity to discuss whether to tell the patient. 5% of the patients were told by a professional, 21% by their caregiver</td>
</tr>
<tr>
<td>Husband [10]</td>
<td>UK</td>
<td>Three newly diagnosed people with dementia</td>
<td>Case study described the psychological impact of learning of a dementia diagnosis and the issues arising from psychotherapeutic work with them</td>
<td>After disclosure, the patients were all preoccupied with and anxious about the diagnosis. There was evidence of self-stigmatization and negative effects on self-esteem and personhood. These difficulties resolved considerably over the course of the sessions</td>
</tr>
<tr>
<td>Maguire et al [11]</td>
<td>Ireland</td>
<td>100 caregivers</td>
<td>Standardized interviews with memory clinic physicians</td>
<td>Only 17 caregivers thought the patient should be told, but 71 would want to be told if they developed AD</td>
</tr>
<tr>
<td>McWilliams [12]</td>
<td>England</td>
<td>Five patients Five caregivers Five geriatric psychiatrists</td>
<td>Qualitative interview</td>
<td>Patients were distressed at the lack of information they were given and wanted practical help</td>
</tr>
<tr>
<td>Newens et al [13]</td>
<td>UK</td>
<td>73 caregivers</td>
<td>Hospital case notes of patients reviews and follow-up interviews</td>
<td>In 63% of cases, diagnosis was made by a neurologist; in 27%, by a psychiatrist. At initial contact with GPs, 48% of the patients were unaware that they had any problem. 15% of the caregivers were not given a diagnosis after the completion of the assessment. 45% of the initial diagnoses were made by GPs and 47% by a psychiatrist. More than 50% of the patients were not told the diagnosis. Diagnosis of AD supported the patient’s sense of identity. The patient was able to trust the results, but remained concerned about the future. Nondiagnosis resulted in feelings of mistrust about the accuracy of the results, and failed to reassure them about the future.</td>
</tr>
<tr>
<td>Robinson et al [15]</td>
<td>Sweden</td>
<td>Eight patients attending in-patient investigation unit</td>
<td>Qualitative interview</td>
<td></td>
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</tbody>
</table>

(Continued)
### Table A1
Summary of articles examining patients’ and caregivers’ attitudes and experiences toward the disclosure of the diagnosis, 1950 to 1999 (Continued)

<table>
<thead>
<tr>
<th>Reference</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Smith et al [16]</td>
<td>UK</td>
<td>90 main caregivers</td>
<td>Postal quantitative and qualitative questionnaires</td>
<td>85% of the caregivers were given a diagnosis, and 85% wanted to know. Caregivers rated the helpfulness of the diagnosis as 8.6 for themselves and 7.0 for the person with dementia (10 = good or helpful)</td>
</tr>
<tr>
<td>Boise et al [17]</td>
<td>USA</td>
<td>78 primary care physicians</td>
<td>Focus groups</td>
<td>Most physicians thought that neither the patient nor the family would want them to uncover dementia. Difficulties in discussing the diagnosis were attributed to stigma and reflected the perceived lack of effectiveness of treatments.</td>
</tr>
<tr>
<td>Brodaty et al [18]</td>
<td>Australia</td>
<td>1473 GPs</td>
<td>Postal questionnaire</td>
<td>20% of GPs regarded disclosure as more harmful than helpful. 13% thought that patients and families may deny the diagnosis initially. Severity of dementia was unrelated to forecasted behavior—90% of physicians would disclose the diagnosis to the caregiver independent of severity. Around one-third of the physicians would separate the patient and caregiver for disclosure.</td>
</tr>
<tr>
<td>Fortinsky et al [19]</td>
<td>USA</td>
<td>498 office-based primary care physicians</td>
<td>Postal self-report questionnaire assessing response to case study or clinical vignettes</td>
<td>37.5% of the clinics reported having guidelines for sharing the diagnosis with the patient and family, but only 6% had written guidelines. Whereas all the caregivers were told the diagnosis, only 56% of the patients were told the same. The diagnosis was given together or separately to caregivers, never to the patient only.</td>
</tr>
<tr>
<td>Gilliard and Gwilliam [20]</td>
<td>UK</td>
<td>16 staff members working in memory clinics</td>
<td>Postal questionnaire</td>
<td>Difficulty in disclosing the diagnosis was common in all professional groups, but all groups felt more able to tell the relatives the diagnosis.</td>
</tr>
<tr>
<td>Iliffe et al [21]</td>
<td>UK</td>
<td>558 primary health care: GPs, community nurses, community psychiatric nurses, practice nurses</td>
<td>Postal questionnaire</td>
<td>Although caregivers almost invariably were told the diagnosis, patients were almost never told, and their disclosure was related to severity of dementia. Psychiatrists were more likely to tell patients with mild dementia than to those with severe dementia. GPs were significantly less likely to disclose a diagnosis of dementia than of terminal cancer. The three most important factors influencing the decision to disclose were diagnostic certainty, the patient’s desire to be told, and the patient’s emotional stability.</td>
</tr>
<tr>
<td>Rice and Warner [22]</td>
<td>UK</td>
<td>244 geriatric psychiatrists</td>
<td>Postal self-report questionnaire</td>
<td>GPs were significantly less likely to disclose a diagnosis of dementia than of terminal cancer. The three most important factors influencing the decision to disclose were diagnostic certainty, the patient’s desire to be told, and the patient’s emotional stability.</td>
</tr>
<tr>
<td>Vassilas and Donaldson [23]</td>
<td>England</td>
<td>281 GPs</td>
<td>Postal self-report questionnaire</td>
<td>Geriatric psychiatrists were less likely to report avoiding the term “dementia,” but no significant differences were found in the professionals’ attitudes toward disclosure; however, they were unsure of telling the patient.</td>
</tr>
</tbody>
</table>

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### Table A2
Professionals’ knowledge and attitudes toward the diagnosis of dementia, 1950 to 1999*

<table>
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<td>16 staff members working in memory clinics</td>
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<td>Difficulty in disclosing the diagnosis was common in all professional groups, but all groups felt more able to tell the relatives the diagnosis.</td>
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</table>

Abbreviations: USA, the United States; UK, the United Kingdom.
References


