

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

Perla Werner^{a,*}, Orit Karnieli-Miller^b, Shmuel Eidelman^c

^aDepartment of Gerontology, University of Haifa, Mount Carmel, Haifa, Israel

^bDepartment of Community Mental Health, University of Haifa, Mount Carmel, Haifa, Israel

^cSchool of Public Health, University of Haifa, Mount Carmel, Haifa, Israel

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 disclosure about truth telling, and evolve (observed more recently) into an examination of how this truth telling is delivered.

© 2013 The Alzheimer's Association. All rights reserved.

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

*Corresponding author. Tel.: 972-4-8249950; Fax: 972-4-8249946.
E-mail address: werner@research.haifa.ac.il

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 exam-

ined 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 of 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

Table 1
Summary of articles examining patients' and caregivers' attitudes and experiences toward the disclosure of the diagnosis

Reference	Country	Participants	Methods	Results
Aminzadeh et al [27]	Canada	30 patient–caregiver dyads	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	Three types of emotional reactions were observed: lack of insight, grief reactions, and positive coping responses
Bachman et al [28]	USA	35 caregivers of persons with AD	Phone interviews with structured questionnaire	The majority agreed that it was correct to tell the patient about the diagnosis and that the disclosure was not very upsetting
Byszewski et al [29]	Canada	30 patient–caregiver dyads	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	Most participants (caregivers and patients) preferred a full disclosure
Carpenter et al [30]	USA	90 dyads of elderly persons (mean age, 73 years) and their companions participating in a longitudinal study of healthy aging and mild dementia	Structured instruments assessing depression and anxiety	69% were diagnosed with dementia No changes in depression scores were observed after the disclosure; anxiety decreased
Connell et al [31]	USA	52 caregivers (mean age, 63 years) and 39 physicians (family and internal medicine and general practice)	Focus groups	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
Connell et al [32]	USA	178 family members of persons with AD 58% Caucasian; 42% African American	Structured questionnaire	Participants strongly endorsed obtaining a diagnosis Black participants endorsed benefits of the diagnosis more frequently than Caucasian participants
Derksen et al [33]	The Netherlands	Case study	Grounded theory including a semistructured interview guide and videotaping	The impact of the disclosure affected three areas: awareness of dementia, interpersonal relationship, and social relationships
Derksen et al [34]	The Netherlands	18 dyads of patients and caregivers	Grounded theory including a semistructured interview guide and videotaping	The disclosure of the diagnosis did not usually introduce stress for patients and caregivers
Elson [35]	UK	95 patients aged ≥ 65 years suffering from memory complaints	Face-to-face semistructured interviews	86% wanted to know the cause of their problem, and 69% wanted to be told if diagnosed with AD
Fahy et al [36]	UK	100 caregivers recruited from semirural memory clinics and inner-city community mental health teams	Interviews	54% of the participants wanted to be told about the diagnosis Lower MMSE scores (< 17) were associated with not wanting a disclosure of diagnosis
Hinton et al [37]	USA	39 family caregivers from a variety of sources 76% with ≥ 9 years of education 10 African American; 14 Chinese; 15 Caucasian	Semistructured qualitative interviews	Pathways of dementia diagnosis as reflected in help-seeking behaviors vary according to ethnic group
Holroyd et al [38]	USA	57 family members attending support groups Mean age, 63 years Mean years of education, 16 95% Caucasian	Structured questionnaire	The majority of the participants advocated telling patients about the diagnosis Half of the participants felt they were not given enough information
Jha et al [39]	UK	53 patients with dementia from outpatient clinics Mean age, 80 years	A self-administered quantitative questionnaire to be returned by postal service	Most participants welcomed the idea of knowing their diagnosis and were not upset by it

(Continued)

Table 1
Summary of articles examining patients' and caregivers' attitudes and experiences toward the disclosure of the diagnosis (*Continued*)

Reference	Country	Participants	Methods	Results
Keightley and Mitchell [40]	UK	Seven health care professionals—two clinical psychologists and five psychiatric nurses	Grounded theory	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
Laakkonen et al [41,42]	Finland	1943 caregivers of persons with AD Mean age, 78 years	Random sampling and structured interview	The majority were in favor of disclosing the diagnosis to patients and spouses 59% reported willing to discuss advance care planning
Lin et al [43]	Taiwan	150 family members attending an outpatient neurological clinic Mean age, 55 years 60% children of AD person	Self-administered structured questionnaire presenting hypothetical scenario of AD	The majority (93%) reported being in favor of disclosure if they had AD, but only 76% wanted it for their relatives
Marzanski [22]	UK	30 consecutive patients with dementia Mean age, 81 years	Open-ended questionnaire	The majority reported not receiving good information nor opportunity to discuss the diagnosis
Ouimet et al [44]	Canada	204 persons aged ≥ 65 years attending outpatient clinics 40% with ≥ 13 years of education 49% born in Canada	Vignette study with structured face-to-face interview	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
Pinner and Bouman [45]	UK	50 patients and their caregivers recruited from a memory clinic Mean age, 79 years	Semistructured quantitative questionnaire	The majority of the patients and the caregivers wanted to be informed about the diagnosis
Robinson et al [46]	UK	Nine dyads of persons with dementia and their spouse recruited from memory clinics	Qualitative interviews	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
Smith and Beattie [47]	Canada	14 patients and their family-accompanying members (40 persons)	Observations of the assessment process and the family conference and in-depth interviews after 6–8 weeks from the disclosure	The disclosure of the diagnosis was generally beneficial
Turnbull et al [48]	USA	200 nondemented persons aged ≥ 65 years attending a University clinic Mean age, 73 years Mean years of education, 9 50% Caucasian; 50% African American	Vignette study with structured questionnaire	Most participants wanted to be told if they had AD Familiarity with the disease was associated with less willingness to be told
Umegaki et al [49]	Japan	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	Study 1: Random sampling and mail survey using a structured questionnaire Study 2: Random sampling and face-to-face interviews using a structured questionnaire	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
Vernooij-Dassen et al [50]	The Netherlands	18 dyads of persons with dementia and a family caregiver	Qualitative case series study two weeks after the disclosure and 10 weeks later using semistructured interviews and videotaping	The disclosure of the diagnosis is seen as a process and is not inevitably associated with negative feelings
Wackerbarth and Johnson [51]	USA	528 family caregivers (response rate, 72%)	Mail survey and structured questionnaire	Benefits included medical confirmation and access to treatment Barriers included a variety of emotional and pragmatic reasons
Wald et al [52]	UK	100 caregivers 58% White	Semistructured interview	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

Abbreviations: USA, the United States; UK, the United Kingdom; AD, Alzheimer's disease; MMSE, Mini-Mental State Examination.

Table 2
Professionals' knowledge and attitudes toward the diagnosis of dementia

Reference	Country	Participants	Methods	Results
Cahill et al [53]	Ireland	300 GPs (50% response rate)	Representative national postal survey	Only a minority reported disclosing the diagnosis Concerns about the impact of the diagnosis on the patient was one of the main barriers to the disclosure
Cantegreil-Kallen et al [54]	France	631 GPs	Mail survey of a structured survey asking to relate to the last patient with AD (39% response rate)	Although 88% considered their role to provide the diagnosis, only 28% reported disclosing it Few topics are discussed directly with the patient Stress is discussed with the majority of the caregivers
De Lepeleire et al [55]	Belgium	Random sample of 1000 GPs	Mail survey of a structured questionnaire (60% response rate)	Although 75% reported seeing benefits in disclosure, only 36% reported disclosing the diagnosis always or usually
Johnson et al [56]	UK	40 physicians (geriatricians and psychogeriatricians)	Mail survey and structured questionnaire (73% response rate)	Only 40% of the participants reported telling the diagnosis to patients
Kaduszkiewicz et al [57]	Germany	30 GPs 389 GPs and 239 neurologists	Qualitative in-depth interviews Mail survey with structured questionnaire (40% and 84% response rate, respectively)	The majority of the participants (GPs and neurologists) agreed that patients should be informed about the diagnosis
Raicher et al [17]	Brazil	181 physicians, including geriatricians, neurologists, and psychiatrists	Electronic survey (19% response rate)	Only 45% reported revealing the diagnosis
Robinson et al [58]	Australia	100 participants (family caregivers, health care professionals)	Focus groups	Feelings of stigma and futility emerged accompanied by differences between professionals and caregivers
Tarek et al [59]	Belgium	252 neurologists and neuropsychiatrists	Mail survey with structured questionnaire (44% response rate)	68% reported disclosing the diagnosis
Turner et al [60]	UK	127 GPs	Self-administered structured questionnaire	Overall good knowledge was found, although lower in epidemiological topics Participants reported difficulties talking with patients about the diagnosis
Van Hout et al [61]	The Netherlands	64 GPs	Prospective observational study	Physicians disclose the diagnosis to the majority of the caregivers but to a minority of the patients Specific advice was provided in <50% of the cases
Vernooij-Dassen et al [62]	Europe	23 experts in dementia	Modified focus groups	Stigma on aging and dementia and the feeling that there is nothing to do were the main barriers to a timely diagnosis

Abbreviation: GP, general practitioner.

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 profes-

sionals 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 [63,65,66,68]. Foy et al [73] in a manuscript published in 2007 describe the principles of developing a theoretically based intervention to promote adequate disclosure of a diagnosis of dementia, although no empirical data are presented. The same group of researchers in an article

Table 3
Studies dealing with process issues

Reference	Country	Participants	Methods	Results
Downs et al [63]	UK	36 general practices in London and central Scotland, including a total of 450 medical records	Unblinded, cluster-randomized, before-and-after controlled trial of three educational interventions to increase detection rates and management of dementia	Decision support software and practice-based workshops were significantly better than standard care in detecting dementia
Ducharme et al [64]	Canada	13 primary caregivers of persons with dementia who have received the diagnosis in the previous 6 months	Development and qualitative assessment of a psychoeducational intervention program for caregivers after the diagnosis	The feasibility, acceptability, and clinical utility of the intervention were shown in the qualitative evaluation
Eccles et al [65]	UK	644 health care professionals	Randomized controlled trial (using a postal survey) of three interventions aimed at increasing diagnosing disclosure	No statistically significant differences were found between the interventions
Iliffe et al [66]	UK	20 primary care practices in London with an intention to include 200 dementia patients	Cluster-randomized controlled trial examining an educational intervention including workshops and electronic guidance	No results reported yet
Lecouturier et al [67]	UK	Four persons with dementia; six informal caregivers; eight health care professionals	Literature review; interviews with people with dementia and informal caregivers; consensus panel	Eight categories of “best practice” behaviors emerged: preparing for disclosure, integrating family members, exploring the patient’s perspectives, disclosing the diagnosis, responding to patient reactions, focusing on quality of life and well-being, planning for the future, and communicating effectively
Perry et al [68] (describes the principles of an intervention program to be developed)	The Netherlands	100 dyads of GPs and nurses will be included in the intervention	A multifaceted intervention aimed at increasing collaboration between nurses and GPs will be developed	
Portrei et al [69]	Italy	Two patients	Clinical cases	The physicians take into account the information from the patient
Sakai and Carpenter [70]	USA	86 physician–patient–companion triads attending disclosure sessions	Videotaping and examination of linguistic features	Physicians dominate the conversation Patients spoke more than companions
Werner et al [71]	Israel	12 triads of physician–patient–caregiver attending diagnostic encounters	Face-to-face interviews using structured questionnaire	Perceptive differences were found between the three members of the triads in all the aspects of the disclosure encounter
Zaleta and Carpenter [72]	USA	54 patients–companions–physicians during the diagnosis of dementia	Videotaping using the Roter Interaction Analysis System	Physicians used moderate amounts of positive rapport building, facilitation, and patient activation Physicians used low amounts of emotional rapport building

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

Table 4
Review articles

Reference	Country	Aims	Findings and recommendations
Carpenter and Dave [24]	USA	To review and report on previous opinions and practices regarding the disclosure of dementia	A wide variety of opinions in favor and against the disclosure were found. Increased research regarding process issues of the disclosure is encouraged.
Cornett and Hall [6]	USA	To discuss issues affecting the decision to disclose the diagnosis	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.
Iliffe et al [2]	UK	To review the role of primary care practitioners in the diagnosis of dementia	The diagnosis of dementia is a shared responsibility between primary care physicians and specialists.
Monaghan and Begley [26]	UK	To review and discuss the ethical dilemmas involved in the disclosure	Truth telling is based on ethical principles and should be done using multidisciplinary teams

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 previous 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 the disclosure about truth telling, 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

specific skills and protocols for breaking bad news [83], especially those related to breaking bad news in a multiparticipant 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 convenience 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 recognition of the need of a multidisciplinary approach in this area [58], the perceptions, experiences, attitudes, and practices of other specialists (such as neurologists, psychiatrists, geriatricians, 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 concentrate on the process aspects of the disclosure and on interventions 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 available 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 delivery 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 facilitating the relationship and transmission of information and in medical encounters [84–86] mandates the development of well-designed interventions that will enable rigorous assessment of different strategies with regard to their relative effectiveness 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 additional 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 triads (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 attempt to unearth the relevant literature, 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, information was synthesized and reported in summary tables, and no statistical techniques were used to assess methodological 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 dementia, with a gradual transition from mostly descriptive studies assessing attitudes and preferences to studies assessing 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 process 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 provided with a clear identification of the barriers to the disclosure 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 protocols 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 dementia. 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 encouraging 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 honest while being sensitive and showing concern to patients' abilities 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

- [1] Brookmeyer R, Johnson E, Ziegler-Graham K, Arrighi HM. Forecasting the global burden of Alzheimer's disease. *Alzheimers Dement* 2007;3:186–91.
- [2] Iliffe S, Robinson L, Brayne C, Goodman C, Rait G, Manthorpe J, The Dendron Primary Care Clinical Studies Group. Primary care and dementia: 1. Diagnosis, screening and disclosure. *Int J Geriatr Psychiatry* 2009;24:895–901.
- [3] Eters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Acad Nurse Pract* 2008;20:423–8.
- [4] Werner P, Heinik J. Stigma by association and Alzheimer's disease. *Aging Ment Health* 2008;12:92–9.
- [5] Werner P, Goldstein D, Buchbinder E. Subjective experience of family stigma as reported by children of Alzheimer's disease patients. *Qual Health Res* 2010;20:159–69.
- [6] Cornett PF, Hall JR. Issues in disclosing a diagnosis of dementia. *Arch Clin Neuropsychol* 2008;23:251–6.
- [7] Hort J, O'Brien JT, Gainotti G, Pirttila T, Popescu BO, Rektorova I, Scheltens P. EFNS guidelines for the diagnosis and management of Alzheimer's disease. *Eur J Neurol* 2010;17:1236–48.
- [8] Chertkow H. Introduction: the Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia. *Alzheimers Dement* 2006;2007(3):262–5.
- [9] Fisk JD, Beattie BL, Donnelly M, Byszewski A, Molnare FJ. Disclosure of the diagnosis of dementia. *Alzheimer Dement* 2007;3:404–10.
- [10] Koch T, Iliffe S. Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review. *BMC Fam Pract* 2010;11:54–9.
- [11] Lee L, Weston WW. Disclosing a diagnosis: helping learners to break bad news. *Can Fam Physician* 2011;57:851–2.
- [12] Alzheimer's Association. Telling the truth in diagnosis; 2012. Available at: <http://www.alz.org/>. Accessed February 12, 2012.
- [13] Alzheimer's Europe. The importance of informing the person about the diagnosis; 2012. Available at: <http://alzheimer-europe.org/>. Accessed February 12, 2012.
- [14] American Psychiatric Association. Practice guidelines for the treatment of patients with Alzheimer's disease and other dementia of late life. *Am J Psychiatry* 1997;154:1–39.
- [15] Karnieli-Miller O, Werner P, Adler A, Eidelman S. Dilemmas in the (un)veiling of the diagnosis of Alzheimer's disease: walking an ethical and professional tight rope. *Patient Educ Couns* 2007;67:307–14.
- [16] Bamford C, Lamont S, Eccles M, Robinson L, May C, Bond J. Disclosing a diagnosis of dementia: a systematic review. *Int J Geriatr Psychiatry* 2004;19:151–69.
- [17] Raicher I, Shimizu MM, Takahashi DY, Nitrini R, Carmelli P. Alzheimer's disease diagnosis disclosure in Brazil: a survey of specialized physicians' current practice and attitudes. *Int Psychogeriatr* 2008;20:471–81.
- [18] Prince M, Bryce R, Ferri C. World Alzheimer's report: the benefits of early diagnosis and intervention. London: Alzheimer's Disease International; 2011.
- [19] Meyers BS. Telling patients they have Alzheimer's disease (Editorials). *BMJ* 1997;314:921–2.
- [20] Samuels SC. Sharing the diagnosis of Alzheimer's disease: methods and expectations. Breaking news to patients requires patience and sensitivity to their needs. *Geriatrics* 2004;59:38–42.
- [21] Patterson CJS, Gauthier S, Bergman H, Cohen CA, Feightner JW, Feldman H, et al. The recognition, assessment and management of dementing disorders: conclusions from the Canadian Consensus Conference on Dementia. *Can Med Assoc J* 1999;160:S1–15.
- [22] Marzanski M. Would you like to know what is wrong with you? On telling the truth to patients with dementia. *J Med Ethics* 2000;26:108–13.
- [23] Gordon M, Goldstein D. Alzheimer's disease. To tell or not to tell. *Can Fam Physician* 2001;47:1803–9.
- [24] Carpenter B, Dave J. Disclosing a dementia diagnosis: a review of opinion and practice, and a proposed research agenda. *Gerontologist* 2004;44:149–58.
- [25] Bradford A, Kunik ME, Schulz P, Williams SP, Singh H. Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. *Alzheimer Dis Assoc Disord* 2009;23:306–14.
- [26] Monaghan C, Begley A. Dementia diagnosis and disclosure: a dilemma in practice. *J Clin Nurs* 2004;13:22–9.
- [27] Aminzadeh F, Byszewski A, Molnar FJ, Eisner M. Emotional impact of dementia diagnosis: exploring persons with dementia and caregivers' perspectives. *Aging Ment Health* 2007;11:281–90.
- [28] Bachman DL, Wagner MT, DePalma M, Spangenberg KB, Hendrix SA, Perlman DJ. Caregiver attitudes about patients told

- they have Alzheimer's disease after truth disclosure. *J Clin Geropsychol* 2000;6:309–13.
- [29] Byszewski AM, Molnar FJ, Aminzadeh F, Eisner M, Gardezi F, Bassett R. Dementia diagnosis disclosure: a study of patient and caregiver perspectives. *Alzheimer Dis Assoc Disord* 2007;21:107–14.
- [30] Carpenter BD, Xiong C, Porensky EK, Lee MM, Brown PJ, Coats M, Morris J. Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment. *J Am Geriatr Soc* 2008;56:405–12.
- [31] Connell CM, Boise L, Stuckey JC, Holmes SB, Hudson ML. Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *Gerontologist* 2004;44:500–7.
- [32] Connell CM, Roberts JS, McLaughlin SJ, Carpenter BD. Black and white adult family members' attitudes towards a dementia diagnosis. *J Am Geriatr Soc* 2009;57:1562–8.
- [33] Derksen E, Vernooij-Dassen M, Gillisen F, Olde-Rikkert M, Scheltens P. The impact of diagnostic disclosure in dementia: a qualitative case analysis. *Int Psychogeriatr* 2005;17:319–26.
- [34] Derksen E, Vernooij-Dassen M, Gillisen F, Olde-Rikkert M, Scheltens P. Impact of diagnostic disclosure in dementia on patients and carers: qualitative case series analysis. *Aging Ment Health* 2006;10:525–31.
- [35] Elson P. Do older adults presenting with memory complaints wish to be told if later diagnosed with Alzheimer's disease? *Int J Geriatr Psychiatry* 2006;21:419–25.
- [36] Fahy M, Wald C, Walker Z, Livingston G. Secrets and lies: the dilemma of disclosing the diagnosis to an adult with dementia. *Age Ageing* 2003;32:439–41.
- [37] Hinton L, Franz C, Friend J. Pathways to dementia diagnosis: evidence for cross-ethnic differences. *Alzheimer Dis Assoc Disord* 2004;18:134–44.
- [38] Holroyd S, Turnbull Q, Wolf AM. What are patients and their families told about the diagnosis of dementia? Results of a family survey. *Int J Geriatr Psychiatry* 2002;17:218–21.
- [39] Jha A, Tabet N, Orrell M. To tell or not to tell—comparison of older patients' reactions to their diagnosis of dementia and depression. *Int J Geriatr Psychiatry* 2001;16:879–85.
- [40] Keithley J, Mitchel A. What factors influence mental health professionals when deciding whether or not to share a diagnosis of dementia with the person? *Aging Ment Health* 2004;8:13–20.
- [41] Laakkonen ML, Raivio MM, Eloniemi-Sulvaka U, Saarenheimo M, Pietila M, Tilvis RS, Pitkala KH. How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care? *J Med Ethics* 2008;34:427–30.
- [42] Laakkonen ML, Raivio MM, Eloniemi-Sulvaka U, Tilvis RS, Pitkala KH, Pitkala KH. Disclosure of dementia diagnosis and the need for advance care planning in individuals with Alzheimer's disease. *J Am Geriatr Soc* 2008;56:2156–7.
- [43] Lin K, Liao Y, Wang P, Liu H. Family members favor disclosing the diagnosis of Alzheimer's disease. *Int Psychogeriatr* 2005;17:679–88.
- [44] Ouimet M, Dion D, Elie M, Dendukuri N, Belzile E. Disclosure of Alzheimer's disease. Senior citizen's opinions. *Can Fam Physician* 2004;50:1671–7.
- [45] Pinner G, Bouman WP. Attitudes of patients with mild dementia and their carers towards disclosure of the diagnosis. *Int Psychogeriatr* 2003;15:279–88.
- [46] Robinson L, Clare L, Evans K. Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples. *Aging Ment Health* 2005;9:337–47.
- [47] Smith AP, Beattie BL. Disclosing a diagnosis of Alzheimer's disease: patient and family experiences. *Can J Neurol Sci* 2001;28:S67–71.
- [48] Turnbull Q, Wolf AM, Holroyd S. Attitudes of elderly subjects towards "truth telling" for the diagnosis of Alzheimer's disease. *J Geriatr Psychiatry Neurol* 2003;16:90–3.
- [49] Umegaki H, Onishi J, Suzuki Y, Endo H, Iguchi A. Attitudes toward disclosing the diagnosis of dementia in Japan. *Int Psychogeriatr* 2007;19:253–65.
- [50] Vernooij-Dassen M, Derksen E, Scheltens P, Moniz-Cook E. Receiving a diagnosis of dementia: the experience over time. *Dementia* 2006;5:397–410.
- [51] Wackerbarth SB, Johnson MMS. The carrot and the stick: benefits and barriers in getting a diagnosis. *Alzheimer Dis Assoc Disord* 2002;16:213–20.
- [52] Wald C, Fahy M, Walker Z, Livingston G. What to tell dementia caregivers—the rules of threes. *Int J Geriatr Psychiatry* 2003;18:313–7.
- [53] Cahill S, Clark M, Walsh C, O'Connell H, Lawlor B. Dementia in primary care: the first survey of Irish general practitioners. *Int J Geriatr Psychiatry* 2006;21:319–24.
- [54] Cantegreil-Kallen I, Turbelin C, Olaya E, Blanchon T, Moulin F, Rigaud AS, Flahault A. Disclosure of diagnosis of Alzheimer's disease in French general practice. *Am J Alzheimers Dis Other Demen* 2005;20:228–32.
- [55] De Lepeleire J, Buntinx F, Aertgeerts B. Disclosing the diagnosis of dementia: the performance of Flemish general practitioners. *Int Psychogeriatr* 2004;16:421–8.
- [56] Johnson H, Bouman WP, Pinner G. On telling the truth in Alzheimer's disease: a pilot study of current practice and attitudes. *Int Psychogeriatr* 2000;12:221–9.
- [57] Kaduszkiewicz H, Bachmann C, van den Bussche H. Telling "the truth" in dementia—do attitudes and approach of general practitioners and specialists differ? *Patient Educ Couns* 2008;70:220–6.
- [58] Robinson AL, Emden CG, Elder JA, Lea EJ, Vickers JC, Turner PA. Multiple views reveal the complexity of dementia diagnosis. *Australas J Ageing* 2008;27:183–8.
- [59] Tarek ME, Segers K, Van Nechel C. What Belgian neurologists and neuropsychiatrists tell their patients with Alzheimer disease and why: a national survey. *Alzheimer Dis Assoc Disord* 2009;23:33–7.
- [60] Turner S, Iliffe S, Downs M, Wilcock J, Bryans M, Kevin E, O'Carroll R. General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. *Age Ageing* 2004;33:461–7.
- [61] van Hout HP, Vernooij-Dassen MJ, Jansen DA, Stalman WA. Do general practitioners disclose correct information to their patients suspected of dementia and their caregivers? A prospective observational study. *Aging Ment Health* 2006;10:151–5.
- [62] Vernooij-Dassen MJF, Moniz-Cook ED, Woods RT, De Lepeleire J, the Interdem group. Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma. *Int J Geriatr Psychiatry* 2005;20:377–86.
- [63] Downs M, Turner S, Bryans M, Wilcock J, Keady J, Levin E, Iliffe S. Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomized controlled study. *BMJ* 2006;332:692–6.
- [64] Ducharme F, Beaudet L, Legault A, Kergoat M, Levesque L, Caron C. Development of an intervention program for Alzheimer's family caregivers following diagnostic disclosure. *Clin Nurs Res* 2009;18:44–67.
- [65] Eccles MP, Francis J, Foy R, Johnston M, Bamford C, Grinshaw JM, Whitty PM. Improving professional practice in the disclosure of a diagnosis of dementia: a modeling experiment to evaluate a theory-based intervention. *Int J Behav Med* 2009;16:377–87.
- [66] Iliffe S, Wilcock J, Griffin M, Jain P, Thune-Boyle I, Koch T, Lefford F. Evidence-based interventions in dementia: a pragmatic cluster-randomised trial of an educational intervention to promote earlier recognition and response to dementia in primary care (EVIDEM-ED). *Trials* 2010;11:13–22.
- [67] Lecouturier J, Bamford C, Hughes JC, Francis JJ, Foy R, Johnston M, Eccles MP. Appropriate disclosure of a diagnosis of dementia: identifying the key behaviors of "best practice". *BMC Health Serv Res* 2008;8:95–104.
- [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.
- [69] Porteri C, Galluzzi S, Geroldi C, Frisoni GB. Diagnosis disclosure of prodromal Alzheimer disease—ethical analysis of two cases. *Can J Neurol Sci* 2010;37:67–75.
- [70] Sakai EY, Carpenter BD. Linguistic features of power dynamics in triadic dementia diagnostic conversations. *Patient Educ Couns* 2011; 85:295–8.
- [71] Werner P, Karnieli-Miller O, Adler A, Eidelman S. How neurologists tell their patients with Alzheimer disease about their diagnosis: another side to Tare et al's study. *Alzheimer Dis Assoc Disord* 2010; 24:115–7.
- [72] Zaleta A, Carpenter BD. Patient-centered communication during the disclosure of dementia diagnosis. *Am J Alzheimer Dis Other Dement* 2010;25:513–20.
- [73] Foy R, Fracis JJ, Johnston M, Eccles M, Lecouturier J, Bamford C, Grimshaw J. The development of a theory-based intervention to promote appropriate disclosure of a diagnosis of dementia. *BMC Health Serv Res* 2007;7:207–15.
- [74] Novack DH, Plumer R, Smith RL, Ochitill H, Morrow GR, Bennett JM. Changes in physicians' attitudes toward telling the cancer patient. *J Am Med Assoc* 1979;241:897–900.
- [75] Oken D. What to tell cancer patients: a study of medical attitudes. *JAMA* 1961;175:1120–8.
- [76] Seeman MV. Breaking bad news: schizophrenia. *J Psychiatr Pract* 2010;16:629–76.
- [77] Blay SL, Peluso TP. Public stigma: the community's tolerance of Alzheimer disease. *Am J Geriatr Psychiatry* 2010;18:163–71.
- [78] Husband H. The psychological consequences of learning a diagnosis of dementia: three case examples. *Aging Ment Health* 1999;3: 179–83.
- [79] Markle GB. Telling the diagnosis of Alzheimer's disease (Correspondence). *N Engl J Med* 1993;328:736.
- [80] Voorhees J, Rietjens J, Onwuteaka-Philipsen B, Deliens L, Cartwright C, Faisst K, Van der Heide A. Discussing prognosis with terminally ill patients and relatives: a survey of physicians' intentions in seven countries. *Patient Educ Couns* 2009;77:430–6.
- [81] Meitar D, Karnieli-Miller O, Eidelman S. Personal difficulties with breaking bad news and their influence on patterns of communication. *Acad Med* 2009;84:1582–94.
- [82] Novack DH, Suchman AL, Clark W, Epstein RM, Najberg E, Kaplan C. Calibrating the physician. Personal awareness and effective patient care. *JAMA* 1997;278:502–9.
- [83] Baile WF, Buckman R, Lenzi R, Globler G, Beale EA, Kudelka AP. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000;5:302–11.
- [84] Britt E, Hudson SM, Blampied NM. Motivational interviewing in health settings: a review. *Patient Educ Couns* 2004;53:147–55.
- [85] Frankel RM, Stein T. Getting the most out of the clinical encounter: the four habits model. *Perm J* 2001;3:79–88.
- [86] Miller WR, Rollnick S. Motivational interviewing: preparing people to change addictive behavior. New York: Guilford Press; 1991.
- [87] Adelman R, Greene MG, Ory MG. Communication between older patients and their physicians. *Clin Geriatr Med* 2000;16:1–24.
- [88] Fortinsky RH. Health care triads and dementia care: integrative and future directions. *Aging Ment Health* 2001;5:S35–48.
- [89] American Medical Association (AMA). Differentiating normal aging and dementia; 2012. Available at: http://www.ama-assn.org/resources/doc/public-health/aging_vs_dementia.pdf. Accessed February 12, 2012.
- [90] American Medical Association (AMA). Family caregiving topics; 2012. Available at: <http://www.ama-assn.org/ama/pub/physician-resources/public-health/promoting-healthy-lifestyles/geriatric-health/caregiver-health/family-caregiving-topics.page?> Accessed February 12, 2012.
- [91] Crowther MA, Cook DJ. Trials and tribulations of systematic reviews and meta-analyses. *Hematology* 2007;1:493–7.
- [92] Rabow MW, McPhee SJ. Beyond breaking bad news: how to help patients who suffer. *West J Med* 1999;171:260–3.
- [93] Furiak NM, Kahke-Wroblewski K, Callahan C, Klein TM, Klein RW, Siemers ER. Screening and treatment for Alzheimer's disease: predicting population-level outcomes. *Alzheimers Dement* 2012; 8:31–8.

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 A1
Summary of articles examining patients' and caregivers' attitudes and experiences toward the disclosure of the diagnosis, 1950 to 1999

Reference	Country	Participants	Methods	Results
Bass et al [1]	USA	576 primary caregivers	Semistructured interviews	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
Boise et al [2]	USA	38 families and 53 family caregivers 191 family caregivers	Focus groups and subsequently mailed questionnaire	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
Brody et al [3]	USA	188 caregivers	Postal questionnaire	The diagnosis was always told to the caregivers, but only 35% of the patients were told the diagnosis
Chenoweth and Spencer [4]	USA	289 caregivers	Postal questionnaire	20% of the caregivers were unable to recall any explanation being given at the time of diagnosis 28% said they felt they had received adequate explanations
Connell and Gallant [5]	USA	233 spouse caregivers	Mail survey questionnaire	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
Erde et al [6]	USA	224 adult patients who were waiting to see their physicians	Self-report questionnaire	92% would want to be told the diagnosis The same proportion thought patients should be told
Heal and Husband [7]	UK	71 caregivers	Postal self-report questionnaire with forced and open-ended questions	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
Holroyd et al [8]	USA	156 older people living in a retirement community	Postal self-report structured questionnaire assessing responses to vignettes	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
Husband [9]	UK	42 caregivers	Standardized interview	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
Husband [10]	UK	Three newly diagnosed people with dementia	Case study described the psychological impact of learning of a dementia diagnosis and the issues arising from psychotherapeutic work with them	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
Maguire et al [11]	Ireland	100 caregivers	Standardized interviews with memory clinic physicians	Only 17 caregivers thought the patient should be told, but 71 would want to be told if they developed AD
McWilliams [12]	England	Five patients Five caregivers Five geriatric psychiatrists	Qualitative interview	Patients were distressed at the lack of information they were given and wanted practical help
Newens et al [13]	UK	73 caregivers	Hospital case notes of patients reviews and follow-up interviews	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
Rao [14]	England	49 caregivers	Postal questionnaire	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
Robinson et al [15]	Sweden	Eight patients attending in-patient investigation unit	Qualitative interview	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

(Continued)

Table A1

Summary of articles examining patients' and caregivers' attitudes and experiences toward the disclosure of the diagnosis, 1950 to 1999 (*Continued*)

Reference	Country	Participants	Methods	Results
Smith et al [16]	UK	90 main caregivers	Postal quantitative and qualitative questionnaires	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)

Table A2

Professionals' knowledge and attitudes toward the diagnosis of dementia, 1950 to 1999*

Reference	Country	Participants	Methods	Results
Boise et al [17]	USA	78 primary care physicians	Focus groups	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
Brodady et al [18]	Australia	1473 GPs	Postal questionnaire	20% of GPs regarded disclosure as more harmful than helpful 13% thought that patients and families may deny the diagnosis initially
Fortinsky et al [19]	USA	498 office-based primary care physicians	Postal self-report questionnaire assessing response to case study or clinical vignettes	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
Gilliard and Gwilliam [20]	UK	16 staff members working in memory clinics	Postal questionnaire	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
Iliffe et al [21]	UK	558 primary health care: GPs, community nurses, community psychiatric nurses, practice nurses	Postal questionnaire	Difficulty in disclosing the diagnosis was common in all professional groups, but all groups felt more able to tell the relatives the diagnosis
Rice and Warner [22]	UK	244 geriatric psychiatrists	Postal self-report questionnaire	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
Vassilas and Donaldson [23]	England	281 GPs	Postal self-report questionnaire	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
Wolff et al [24]	Scotland	35 consultants in geriatric psychiatrists 35 GPs	Postal questionnaire Standardized interview	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

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

References

- [1] Bass DM, McClendon MJ, Deimling GT, Mukherjee S. The influence of a diagnosed mental impairment on family caregiver strain. *J Gerontol* 1994;49:S146–55.
- [2] Boise L, Morgan D, Kaye J, Camicioli R. Delays in the diagnosis of dementia: perspectives of family caregivers. *Am J Alzheimer Dis* 1999;14:20–6.
- [3] Brodaty H, Griffin D, Hadzi-Pavlovic D. A survey of dementia carers: doctors' communications, problem behaviors, and institutional care. *Aust N Z J Psychiatry* 1990;24:362–70.
- [4] Chenoweth B, Spencer B. Dementia: the experience of family caregivers. *Gerontologist* 1986;26:267–72.
- [5] Connell CM, Gallant MP. Spouse caregivers' attitudes toward obtaining a diagnosis of a dementing illness. *J Am Geriatr Soc* 1996;44:1003–9.
- [6] Erde EL, Nadal EC, Scholl TO. On truth telling and the diagnosis of Alzheimer's disease. *J Fam Pract* 1988;26:401–6.
- [7] Heal HC, Husband HJ. Disclosing a diagnosis of dementia: is age a factor? *Aging Ment Health* 1998;2:144–50.
- [8] Holroyd S, Snustad DG, Chalifoux ZL. Attitudes of older adults' on being told the diagnosis of Alzheimer's disease. *J Am Geriatr Soc* 1996;44:400–3.
- [9] Husband HJ. Sharing the diagnosis—how do carers feel? *J Dement Care* 1996;4:18–20.
- [10] Husband HJ. The psychological consequences of learning a diagnosis of dementia: three case examples. *Aging Ment Health* 1999;3:179–83.
- [11] Maguire CP, Kirby M, Coen R, Coakley D, Lawlor BA, O'Neill D. Family members' attitudes toward telling the patient with Alzheimer's disease their diagnosis. *BMJ* 1996;313:529–30.
- [12] McWilliams E. The process of giving and receiving of a diagnosis of dementia: an in-depth study of sufferers', carers' and consultants' experiences. *PSIGE Newsl* 1998;64:18–25.
- [13] Newens AJ, Forster DP, Kay DW. Referral patterns and diagnosis in presenile Alzheimer's disease: implications for general practice. *Br J Gen Pract* 1994;44:405–7.
- [14] Rao R. The role of carers in the information process in dementia. *Psychiatr Bull* 1997;21:264–6.
- [15] Robinson P, Ekman SL, Wahlund LO. Unsettled, uncertain and striving to understand: towards an understanding of the situation of persons with suspected dementia. *Int J Aging Hum Dev* 1998;47:143–61.
- [16] Smith A, King E, Hindley N, Barnetson L, Barton J, Jobst KA. The experience of research participation and the value of diagnosis in dementia: implications for practice. *J Ment Health* 1998;7:309–21.
- [17] Boise L, Camicioli R, Morgan DL, Rose JH, Congleton L. Diagnosing dementia: perspectives of primary care physicians. *Gerontologist* 1999;39:457–64.
- [18] Brodaty H, Howarth GC, Mant A, Kurrle SE. General practice and dementia: a national survey of Australian GPs. *Med J Aust* 1994;160:10–4.
- [19] Fortinsky RH, Leighton A, Wasson JH. Primary care physicians' diagnostic, management, and referral practices for older persons and families affected by dementia. *Res Aging* 1995;17:124–48.
- [20] Gilliard J, Gwilliam C. Sharing the diagnosis: a survey of dementia and their families, and the support they offer. *Int J Geriatr Psychiatry* 1996;11:1001–3.
- [21] Iliffe S, Eden A, Downs M, Rae C. The diagnosis and management of dementia in primary care: development, implementation and evaluation of a national training programme. *Aging Ment Health* 1999;3:129–35.
- [22] Rice K, Warner N. Breaking the bad news: what do psychiatrists tell patients with dementia about their illness? *Int J Geriatr Psychiatry* 1994;9:467–71.
- [23] Vassilas CA, Donaldson J. Telling the truth: what do practitioners say to patients with dementia or terminal cancer? *Br J Gen Pract* 1998;48:1081–2.
- [24] Wolff LE, Woods JP, Reid J. Do general practitioners and old age psychiatrists differ in their attitudes to dementia? *Int J Geriatr Psychiatry* 1995;10:63–9.