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REVIEW

Optimal management of Alzheimer's disease patients: Clinical guidelines and family advice

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Abstract: Family members provide most of the patient care and administer most of the treatments to patients with Alzheimer's disease (AD). Family caregivers have an important impact on clinical outcomes, such as quality of life (QoL). As a consequence of this service, family caregivers suffer high rates of psychological and physical illness as well as social and financial burdens. Hence, it is important to involve family caregivers in multimodal treatment settings and provide interventions that are both suitable and specifically tailored to their needs. In recent years, several clinical guidelines have been presented worldwide for evidence-based treatment of AD and other forms of dementia. Most of these guidelines have considered family advice as integral to the optimal clinical management of AD. This article reviews current and internationally relevant guidelines with emphasis on recommendations concerning family advice.

Keywords: caregivers, management, quality of life, treatment

Introduction

Alzheimer's disease (AD) is the most prevalent cause of dementia encountered in older patients.[1] Late-stage clinical AD can result in substantial clinical burden and a reduction of quality of life (QoL) for the patients and family caregivers.[2] There are a number of effective nonpharmacological and symptomatic pharmacological approaches to treat AD. All of those approaches, however, cannot prevent, cure or stop the progression of the disease.[1,3] Therefore, the specific goals of current treatments are to preserve cognitive and functional ability, minimize behavioral disturbances, slow disease progression, ease the burdens on the patient and family, and maintain their QoL through clinical management. In optimal management of AD patients, both pharmacological and nonpharmacological treatments must be considered necessary and adapted to meet the individual needs of each AD patient and their family caregivers.[3,4] In this review, we focus on nonpharmacological approaches that address family advice as part of an optimal clinical management of AD.

Family caregivers provide most of the patient care and administer most of the treatments used for patients with AD.[3] They have an important impact on the QoL of dementia patients.[5,6] Further, they suffer high rates of psychological and physical illness, as well as carrying many of the social and financial consequences.[7] Hence, it is important to involve family caregivers in multimodal treatment settings and provide interventions that are directly addressed to the family caregivers (eg, education programs, support groups, and counseling).

In recent years, several clinical guidelines for evidence-based treatment of AD and other forms of dementia have been published worldwide. Here, we review current and internationally relevant guidelines with respect to the given recommendations concerning family advice.

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Method

Clinical guidelines were identified via a MEDLINE search using MeSH headings, *Alzheimer disease* AND *clinical guidelines*. The alternative terms, *practice guidelines, treatment guidelines, consensus guidelines, consensus statement, practice parameter, and practice recommendation* were also searched in conjunction with the MeSH term, *Alzheimer disease*. Additionally, MEDLINE was searched using the term *dementia* AND *clinical guidelines* or *practice guidelines*. All searches were limited to articles published in English within the last five years. The reference lists of articles thus identified were searched manually to identify additional articles of interest. A total of 125 unique articles were identified. Based on these articles, four internationally relevant clinical guidelines for the treatment of patients with AD were identified (see Table 1). For this review, we defined clinical guidelines as statements that have been systematically developed and which aim to assist clinicians in making decisions about treatment for specific conditions. Clinical guidelines are linked to evidence and are meant to facilitate good medical practice.[8]

Clinical guidelines for the treatment of patients with AD

The principal benefit of guidelines is to improve the quality of clinical care by providing a robust management strategy for patients.[9] Guidelines represent an option for improving the overall quality of clinical care; nevertheless, they need to be interpreted and applied in a way that is clinically appropriate.[8] Below, we analyze and discuss four recently published and internationally accepted dementia guidelines with respect to the given recommendations concerning family advice.

American Psychiatric Association (APA)

Purpose

According to the authors, the purpose of this guideline was to assist the psychiatrist in caring for a dementia patient. In particular, the authors sought to summarize data in order to inform the care of patients with AD and other forms of dementia, including vascular dementia, dementia with Parkinson's disease, dementia with Lewy bodies, and the frontotemporal dementia spectrum disorders.[10]

Contents

The APA practice guideline covered the pharmacological and nonpharmacological treatment of dementia patients as well as the support for family members and other caregivers.

Synopsis of treatment recommendations

The guideline summarized treatment recommendations for cognitive symptoms, psychosis and agitation, depression, and sleep disturbances. The authors discussed psychiatric management, specific psychotherapies and other psychosocial treatments and provided corresponding recommendations. In addition, the authors critically considered special concerns such as somatic treatments for elderly patients and dementia patients, as well as special issues for long-term care. In addition, the authors proposed an extensive guide to develop and implement a stage-specific treatment plan for the individual patient and discussed how specific clinical features influence the treatment plan in great detail.

Table 1 Internationally relevant guidelines

Reference	Country of origin	Editor	Target group	Contents	Recommendation of family advice
10	USA	American Psychiatric Association (APA)	Psychiatrists	Treatment of people with dementia; Support for Caregivers	Yes
11	UK	NICE and SCIE	General Practitioners, Nurses, Geriatricians, Psychiatrists, Social Workers, Care Home Managers and Care Staff, Commissioners, Managers and Coordinators of Health and Social Care	Identification, Treatment and Care of people with dementia; Support for Caregivers	Yes
12	USA	American Academy of Neurology (AAN)	Neurologists; Other Clinicians who manage Patients with Dementia	Treatment of people with dementia; Support for Caregivers	Yes
13	EU	European Federation of Neurological Societies (EFNS)	Clinical Neurologists; Geriatricians; Psychiatrists; Other specialist Physicians responsible for the care of Patients with Dementia	Identification, Treatment and Care of people with dementia; Support for Caregivers	Yes

The authors of the APA practice guideline[10] declared that the guideline is intended to be inclusive and to cover the range of necessary treatments that might be used by a physician or consultant who provides or coordinates the overall care of the dementia patient. They indicated that the psychiatrist caring for a dementia patient should consider, but need not be limited to, the treatments recommended in the practice guideline.

Recommendations concerning family advice

Throughout the entire guideline, the authors emphasized the relevance of providing critical support for family members and other caregivers and making referrals to social, legal, and other community resources. The guideline also notably highlighted the role of family advice in optimal psychiatric management. The recommended interventions include educating patients and families about the illness, the course of treatment, and sources of additional care and support (eg, support groups, respite care, nursing homes, and other long-term care facilities). Other tasks pertaining to the recommended interventions included advising patients and their families of the need for financial and legal planning due to the patient's eventual incapacity (eg, power of attorney for medical and financial decisions, an up-to-date will, and the cost of long-term care), and addressing the imminent or eventual need for driving cessation with patients and their families due to the increased risk of vehicular accidents even in mild dementia. Additionally, the guideline denoted the necessity of monitoring the signs of caregiver distress, and the need to support families during decisions about institutionalization.

National Institute for Clinical Excellence (NICE) – Social Care Institute for Excellence (SCIE)

Purpose

The NICE-SCIE guideline's specific aims were firstly to evaluate the role of specific pharmacological agents, psychological and psychosocial interventions in the treatment and management of dementia, and secondarily to evaluate the role of specific services and systems for providing those services in the treatment and management of dementia. The guideline recommended the integration of both of these goals to provide best practice advice on the care of individuals with a diagnosis of dementia through the different phases of illness, including the initiation of treatment, the treatment of acute episodes and the promotion of well-being. In addition, the authors considered the economic implications of various interventions for dementia.[11]

Contents

The NICE-SCIE guideline covered the assessment and diagnosis of dementia, as well as pharmacological and nonpharmacological treatment and care of dementia patients. The guideline also indicated that support should be provided for family caregivers within primary and secondary healthcare, and social care.

Synopsis of treatment recommendations

The guideline presented a range of recommendations on pharmacological and nonpharmacological treatments for cognitive symptoms and maintenance of functioning, as well as recommendations regarding treatments for noncognitive dementia symptoms. Some recommendations were given for educational interventions in dementia patients. The authors critically discussed the role of dementia care mapping (DCM); and recommended that further systematic research be conducted using outcome measures of quality of life other than DCM, in order to adequately evaluate its impact as a vehicle of change. The authors highlighted the impact of staff training and interventions on caregivers of dementia patients and the guideline proposed requirements for review and evaluation of care plans, adherence to ethical principles and assessment of capacity to make decisions. The authors provided recommendations regarding how to recognize and respond to suspected abuse and neglect, how to approach the topic of workforce development, and how to design the environment to be supportive and therapeutic. Also identified was the need for acute inpatient hospital services to address the specific problems of dementia patients.

The guideline also emphasized the need for care to be person-centered and the authors recommended a coordinated and integrated approach between health and social care services to treat and care for dementia patients and their caregivers.

Family advice

The guideline emphasized the imperative in dementia care to consider the needs of caregivers, and to consider ways of supporting and enhancing the efforts of caregivers on behalf of the dementia patient. The authors emphasized that dementia patients are enabled to live longer in their own communities when caregivers are well supported and well informed.[11]

Specifically, the guideline recommended educating the family caregivers with written information about the signs and symptoms of dementia, the course and prognosis of the condition, treatment options, local care and support services, and the types of support groups available. It also clarified the

value of helping the family know where sources of financial and legal advice are located, how they may benefit from advocacy, what the relevant medico-legal issues are (ie, such as driving cessation), and where other local information sources, including libraries and voluntary organizations, are located. The authors recommended that there be continuous assessment of family caregivers´ needs in parallel to the design of a care plan for family caregivers of dementia patients. This may consist of multiple components including: individual or group psychoeducation, peer-support groups with other caregivers, support and information by telephone and through the internet, training courses about dementia, services, communication and problem solving skills in the care of dementia patients, as well as involvement of other family members and the primary caregiver in family meetings. Additionally, the authors proposed some recommendations for practical support and services such as, day care, day- and night-sitting, adult placement, short-term and/or overnight residential care, and transport services.

American Academy of Neurology (AAN)

Purpose

The objective of this guideline was to define and investigate key issues in the management of dementia and to make literature based treatment recommendations. Pharmacologic and nonpharmacologic treatments for dementia management were addressed in terms of scientifically sound, clinically relevant practice parameters to aid in the practice of neurology.[12]

Contents

The AAN practice parameter "Management of dementia" covered the treatment of dementia patients and the support that should be provided for family members and other caregivers.

Synopsis of treatment recommendations

The AAN practice parameter addressed four clinically relevant questions regarding the management of dementia: Does pharmacotherapy for cognitive symptoms improve outcomes in dementia patients compared with no therapy? Does pharmacotherapy for noncognitive symptoms improve outcomes in dementia patients compared with no therapy? Do educational interventions improve outcomes in patients and/or caregivers of dementia patients compared with no such interventions? Do nonpharmacologic interventions other than education improve outcomes in patients and/or caregivers of dementia patients compared with no such interventions?

The authors presented analysis of evidence and practice recommendations for all named issues. Very briefly, the guideline put forth three additional issues that were evaluated to be important: cooperation amongst neurologists, other clinicians, and community care providers; the impact of different economic models of care; and assessments for predicting decision-making capacity for dementia patients. With respect to these issues, the guideline stated more research is needed to derive more specific recommendations.

Family advice

The guideline recommended that specific nonpharmacological interventions should be offered to family caregivers to improve caregiver satisfaction and to delay the time to nursing home placement for the patient with AD. The recommended interventions included education (eg, comprehensive, psychoeducational caregiver training, short-term programs directed toward educating family caregivers about AD, and intensive long-term education), support (eg, such as support groups, telephone support, and other support services when available), and respite care (eg, such as adult day care for patients and other respite services). Additionally, the guideline suggested the use of computer networks to provide education and support to caregivers. Moreover, the authors stressed that more research is recommended to develop ways to match family caregiver interventions to the specific needs of family caregivers.

European Federation of Neurological Societies (EFNS)

Purpose

The international EFNS guideline on dementia aimed to present a peer-reviewed evidence-based statement to guide the practice of clinical neurologists, geriatricians, psychiatrists, and other specialist physicians responsible for the care of dementia patients.[13]

Contents

The EFNS guideline covered the identification and pharmacological treatment of dementia patients and briefly addressed the support that is necessary to be provided for family members and other caregivers.

Synopsis of treatment recommendations

The main emphasis of this guideline was on recommendations for pharmacological treatment. It offered recommendations on pharmacological treatments for cognitive symptoms and maintenance of functioning, as well as recommended

treatments for noncognitive symptoms. The authors purposely limited their guideline to pharmacological treatments, and so many other important aspects of the care for dementia patients were intentionally not covered. Nevertheless, a few recommendations were given with respect to counseling and support for family caregivers, relevant legal issues, problems with driving, and the collaboration of specialist physicians with other health care professionals.

Family advice

The authors emphasized the relevance of providing counseling and support for family members and other caregivers; however, they did not offer explicit or specific recommendations for treatment or other forms of intervention. The authors indicated that education and information, along with support groups for both patients and family caregivers, are all helpful with regard to the treatment of behavioral and psychological symptoms in dementia. They also suggested that specialist physicians assess family caregiver distress and needs at regular intervals throughout the course of the disease.

Additional guidelines

In the last five years, some additional guidelines have been published (see Table 2). Some of those guidelines have a priori been developed as national guidelines and others focus only on pharmacological treatments of dementia and are therefore not relevant for this article. Nevertheless, these guidelines are valuable for the further enhancement of international guidelines, and in particular, for the improvement of national clinical management of AD. These other guidelines are also statements that have been systematically developed, linked to evidence, and that were meant to facilitate good medical practice. Therefore, they can be classified as clinical guidelines.

Link to evidence

All the guidelines considered in this review prove to be linked to empirical evidence. Regarding the four guidelines considered relevant to this article, we find that the guideline development process was traceable and that certain levels of evidence for the given recommendations have been defined. However, we also note that several guidelines specifically reviewed herein did not consistently correlate each of the provided recommendations with a statement of the strength of the underlying evidence.

Table 2 Additional guidelines selected

Reference	Country of origin	Editor
35	Canada	Canadian Medical Association (CMA)
14		
15	Germany	DGPPN and DGN
16	USA	ACP and AAFP
17	Brazil	Brazilian Academy of Neurology
18	Italy	Italian Association of Psychogeriatrics

For the AAN and EFNS guidelines, the level of evidence is readily identifiable since it is always mentioned in combination with the given recommendation.

In particular, the AAN guideline defined three levels of evidence:

Standard Principle for patient management that reflects a high degree of clinical certainty,

Guideline Recommendation for patient management that reflects moderate clinical certainty,

Practice Option Strategy for patient management for which the clinical utility is uncertain.[12]

The EFNS guideline graded the recommendations according to the strength of evidence, using the definitions given in the EFNS guidance:

Level A rating established as useful/predictive or not useful/predictive,

Level B rating established as probably useful/predictive or not useful/predictive,

Level C rating established as possibly useful/predictive or not useful/predictive.[19]

The APA guideline began with an executive summary in which treatment recommendations were coded according to three levels of degree of clinical evidence:

[I] Recommended with substantial clinical confidence,
[II] Recommended with moderate clinical confidence,
[III] May be recommended on the basis of individual circumstances.[10]

To identify the strength of the underlying evidence of a recommendation given in the associated sections of the APA guideline, one can examine the listing of cited references. Each reference was followed by a letter code in brackets that indicated the nature of the supporting evidence. The guideline allows the reader to appreciate the evidence base behind the guideline recommendations and the weight that should be given to each recommendation. The initial executive summary provided a clear overview about the levels of evidence.

The NICE-SCIE guideline used four components (study, design/quality, consistency and directness) to produce an

overall quality of evidence grade. The following definitions were used:

High Further research is very unlikely to change our confidence in the estimate of the effect,
Moderate Further research is likely to have an important impact on our confidence in the estimate of the effect, and may change the estimate,
Low Further research is very likely to have an important impact on our confidence in the estimate of the effect, and is likely to change the estimate,
Very low Any estimate of effect is very uncertain.[11,20]

In this guideline, each recommendation was followed by a referencing note; for example, 'for the evidence, see section 6.3'. In this section, the reader finds a factual, well-supported rationale for the recommendation. To prove the underlying evidence of a citation, the reader can further search for the respective profile table in an appendix, which is published as a substantive volume with accompanying CD-ROM. This CD-ROM includes the full results of evidence assembly and synthesis, including search details, pharmacological interventions, and evidence tables based on meta-analyses and narrative summaries for psychological interventions (eg, cognitive stimulation, life review, light therapy). However, there is no such information given for recommendations concerning family advice. Hence, the strength of the underlying evidence for most of the recommendations relevant for this article cannot be derived out of the NICE-SCIE guideline.

Family advice in the context of optimal clinical management

All of the reviewed guidelines presented the consistent demand for interventions that include family advice. Further, at least three of the four guidelines underscored that family advice has potential to ease the burdens on the patient and family and to increase their QoL.[10–12] In contrast to the other guidelines, the EFNS guidelines scarcely mentioned family advice, mainly due to the scope and limitations described therein. Family advice was considered more or less comprehensively in the AAN guideline and was given high attention in the APA and NICE-SCIE guidelines.

The various guidelines recommended similar interventions as part of an optimal clinical management of AD; however, they did not agree on the specific strategies of advising families. This difference makes some sense in light of the fact that the guidelines target diverse professional groups. Besides the problem of different target groups, another explanation for this difference is that family advice research has limited randomized controlled trial evidence for the specific effects of interventions. For example, the authors of the guidelines had to extrapolate many recommendations from controlled or even uncontrolled clinical trials with small samples. Therefore, we see that the authors of the guidelines often have had to work with uncertain data; and even when the data are certain, recommendations for or against interventions will involve subjective value judgments.[9] There appears to be susceptibility to bias in the guidelines that is based on the nature of evidence, subjective clinical opinion, and level or nature of clinical experience in the composition of the guideline development group. This susceptibility for bias may confound the validity of guidelines.[8,9,21] Although the methodological quality, design and implementation of family caregiver intervention studies continues to improve over time, drawing comparisons between studies and making practical applications remains difficult due to the use of a wide range of different outcome domains and measures.[7,11,22] For example, it is often difficult to discern whether two intervention programs share common features or if different outcomes are comparable.[11] The problems mentioned above are not to suggest the guidelines are ungrounded, but rather provide impetus for further high quality research. For example, there is a critical need for well designed, randomized, controlled trials of potential interventions that examine family advice specifically, and that standardize the use of outcome domains and measures.

In order to provide a systematic basis for research on those interventions, the following sections survey the recommended interventions that include family advice with respect to their current level of evidence. We derived five types of interventions: Education, counseling, assessment of family caregiver distress and needs, practical support and services, and psychosocial interventions for dementia patients. If available, the levels of evidence documented in each guideline, are integrated into the listed recommendations. In terms of the NICE-SCIE guideline, only the levels of evidence for the recommendations concerning psychological interventions can be considered. Further recommendations of the NICE-SCIE guideline will be listed even though no information about the levels of evidence has been provided.

As mentioned above, the four guidelines have used different definitions for the levels of evidence. To simplify matters, we suggest the following descriptors for levels of evidence, which are integrated into three levels (see Table 3):

Level 1 substantial clinical certainty,
Level 2 moderate clinical certainty,
Level 3 uncertain clinical utility.

Table 3 Integrated levels of evidence

Integrated for this article	APA	NICE	EFNS	AAN
Level 1: substantial clinical certainty	Level [I]	Evidence grade [High]	[Level A rating]	Level [Standard]
Level 2: moderate clinical certainty	Level [II]	Evidence grade [Moderate]	[Level B rating]	Level [Guideline]
Level 3: uncertain clinical utility	Level [III]	Evidence grade [Low] and Evidence grade [Very low]	[Level C rating]	Level [Practice option]

The original classifications of the guidelines for the five types of interventions that include family advice can be found in Table 4. We do not perform a meta-analysis, but present the recommendations and the classified levels of evidence, if available, in a narrative way for particular types of interventions that include family advice.

Education

All guidelines recommended educational interventions for families that can be conducted for individuals or groups. The classified levels of evidence differ from level 1 to level 2.[10,12,13]

According to the APA (2007) and NICE-SCIE (2007) guideline, the following contents should be included in educational interventions: information about the illness, available treatments and medication management, local care and support services, basic principles of care, communication and problem solving in the care of dementia patients.

Education can be provided via psychoeducation or skills training support groups, in which caregivers may learn from one another; or conjunctively via written information and telephone and internet-based systems for additional provision of information and support.[10–13] Furthermore, it may be useful to take into account basic cultural and gender differences in approaches to caring when designing educational interventions for family caregivers.[10,11] However, it is worth noting that when educational interventions are introduced at an early stage after establishment of the diagnosis, those who provide treatment for family caregivers of dementia patients should be aware of the possibility that education about dementia may sometimes have an adverse effect on a caregiver's anxiety.[11] The AAN guideline differentiated the effects of short- and long-term programs. Short-term programs directed toward educating family caregivers about AD should be offered to improve caregiver satisfaction; whereas, intensive long-term education and support services should be offered to caregivers of patients with AD to delay time to nursing home placement.[12]

The NICE-SCIE guideline highlighted that information is the most useful when dementia patients were involved in the educational process. Therefore, the authors recommended that care providers consider involving dementia patients in psychoeducation, support, and other meetings for family caregivers.[11]

Table 4 Levels of evidence for interventions that include family advice

Intervention	APA	NICE	EFNS	AAN
Education	Level [I]	Recommended; no access to evidence rating	[Level B rating]	Level [Guideline]
Counseling	Level [II]	Recommended; no access to evidence rating	[Level B rating]	Level [Guideline]
Assessment of caregiver distress and Needs	Recommended; no access to evidence rating	Recommended; no access to evidence rating	[Level C rating]	No recommendation; Call for research
Practical support and services	Recommended; no access to evidence rating	Recommended; no access to evidence rating		Level [Practice options]
Psychosocial interventions for dementia patients				
• Behavioral approaches	Level [II]	Recommended; no access to evidence rating		Level [Guideline]
• Stimulation-oriented treatments	Level [II]	Evidence grade [Moderate]		Level [Guideline]
• Reminiscence and validation therapy	Level [III]	Evidence grade [Moderate]		No Recommendation

Counseling

All guidelines recommended counseling interventions for families. The APA guideline classified the evidence for those interventions as level 1; the EFNS classified it as level 2.[10,13] The AAN guideline combined recommendations pertaining to counseling interventions and educative interventions; and although these constructs seem related and can overlap, it is more tedious to distinguish the recommendations that are unique to counseling due to the lack of separation of the different types of interventions. As mentioned above, the evidence for education, which again includes counseling, is classified as level 2.

Although counseling includes the provision of information, it is more than education alone. Counseling also serves to provide emotional support and to help people make their own decisions and plan their future actions. Another important aspect to counseling as part of optimal clinical management pertains to referrals for financial and legal advice due to the patient's eventual incapacity (eg, power of attorney for medical and financial decisions, an up-to-date will, and financial planning for the cost of long-term care).[10,11] Furthermore, patients and families need to be informed about the potential and inevitable safety issues. For example, it is not uncommon for accidents to occur due to forgetfulness, such as fires during the cooking of meals; and there is increased risk of vehicular accidents, even in mild dementia. As such, driving cessation is an inevitable event for which patients with AD and their family caregivers must be prepared.[10,11] In addition, the APA guideline recommended counseling for families during decisions about institutionalization. The EFNS guideline provided recommendations pertaining to legal issues and driving, but did not specify legal and safety issues as essential information for counseling. The AAN guideline mentioned neither financial and legal issues nor driving and safety issues; and it did not offer recommendations with regard to what the specific tasks of counseling should be. The American Academy of Neurology published a specific guideline concerning the risk of driving in patients with AD.[23] However, the need to advise the family about the safety issues related to driving was also not clearly covered in this specific guideline.

Assessment of caregiver distress and needs

The NICE-SCIE, APA and EFNS guidelines identified the necessity of assessing caregiver distress and needs at regular intervals throughout the course of the disease. The EFNS guideline was the only guideline that we found documented a level of evidence for this recommendation at level 3.

Additionally, the NICE-SCIE guideline recommended that assessing distress and identifying needs of family caregivers are important to the design of a care plan for family caregivers of dementia patients.

The APA guideline further recommended some interventions that have been developed to ease the distress associated with long-term care-giving. These interventions include psychoeducational programs for improved emotional coping with frustration or depression, psychotherapy focused on alleviating symptoms of depression and anxiety, exercise interventions for caregivers, workshops in stress management techniques, and support groups that combine education with support. We did not find any level of evidence documented for those recommendations, but the cited studies imply an evidence level of 2.

The AAN guideline did not explicitly recommend the assessment of caregivers' distress and needs, but called for research to develop ways to match caregiver interventions to the specific needs of caregivers.[12]

Practical support and services

An additional component of family advice is the information about sources of practical support and services. All guidelines recommended various services to be introduced to families, such as respite services, nursing homes, other long-term care facilities, day care, day- and night-sitting services, and short-term and/or overnight residential care. The AAN guideline classified the evidence for practical support and respite services as level 3.[12] Based on the statements of the APA guideline, there is mixed evidence for practical support and services aside from a clear Level 1 evidence statement for the recommendation that care should be organized to meet the needs of patients.[13]

Psychosocial interventions for dementia patients

Three of the four considered guidelines recommended some psychosocial interventions that are tangent to family advice, as the organization or implementation of these interventions often falls on the family caregivers.[10–12] All of the reviewed guidelines concluded that there is limited evidence (from randomized controlled trials) regarding the specific effects of psychosocial interventions on dementia patients. Nevertheless, the reviewed guidelines have provided recommendations for interventions. Behavioral approaches, and stimulation-oriented treatments (eg, recreational activity, art therapy, music therapy, and pet therapy) are recommended with

level 2 evidence.[10–12] Furthermore, supportive psychotherapy is recommended to address issues of loss in the early stages (level 2 evidence).[10] Cognition-oriented treatments, such as reality orientation, cognitive retraining, and skills training focused on specific cognitive deficits, are not recommended since they are unlikely to have a persistent benefit and have been associated with frustration in some patients.[10,11] The levels of evidence for reminiscence and validation therapy are not consistently classified in the guidelines (NICE-SCIE: level 2 evidence; APA: level 3 evidence).[10,11]

Potential benefits and limitations of clinical guidelines

The principal benefit of guidelines is to provide a robust management strategy for patients, and thus improve the quality and consistency of care received by patients.[8] With evidence-based guidelines, the quality of clinical decisions can be improved, and authoritative recommendations can reassure practitioners about the appropriateness of their treatment policies.[9] However, guidelines need to be interpreted and applied in a way that is clinically appropriate.[8] Awareness of a treatment's effectiveness does not confer knowledge about how to use that treatment.[24] Good evidence can lead to bad practice if it is applied without clinical acumen or without therapeutic empathy.[25] All of the guidelines presented herein concluded that the care of every dementia patient must be individualized to meet the unique needs of that patient and his or her family caregivers.[10–13]

Multidisciplinary cooperation

Although it can be assumed that clinical practice guidelines should improve the quality of care, it is less clear whether they actually achieve this goal in daily practice.[9,26] The majority of interventions that include family advice require special and diverse competencies that cannot be assumed for all users of a guideline. Multidisciplinary cooperation is needed in order to effectively apply the evidence-based interventions recommended in these guidelines in the context of clinical practice. Accordingly, the APA, EFNS, and NICE-SCIE guidelines recommended a multidisciplinary approach in the treatment of dementia, and assumed this as a matter of course for optimal clinical management.[10,11,13] However, there is a lack of evidence-based articles concerning this issue. As such, the AAN guideline formulated recommendations for future research. According to the AAN guideline, more research is needed to define the roles of various types of practitioners (eg, neurologists, psychiatrists, geriatricians, primary care physicians) in the care of dementia patients. The AAN guideline suggested that the benefits of an interactive care approach involving multiple practitioners, including cost-benefit assessments, must be studied.[12] Furthermore, the AAN guideline postulated that research leading to guidelines for the cooperation between clinicians is needed because AD is a chronic illness requiring coordinated management that can adapt over the course of the illness.[12]

The NICE-SCIE guideline explicitly recommended strategies to improve coordination and integration of health and social care. It recommended that health and social care managers should coordinate and integrate work efforts across all agencies involved in the treatment and care of people with dementia and their family caregivers, including common agreement of written policies and procedures.[11] Furthermore, the NICE-SCIE guideline postulated that joint planning should include local service users and family caregivers in order to highlight and address problems specific to each locality.[11]

The assignments of "care managers" and "care coordinators" are promising approaches to ensure the coordinated delivery of health and social care services for dementia patients. Future research is needed to show how multidisciplinary cooperation is best achieved and whether multidisciplinary cooperative approaches to intervention will lead to the intended improvements in treatment outcomes for patients with AD and their family caregivers.

The problem of treatment implementation

In published dementia caregiver intervention research, there has been a widespread failure to measure whether the implementation of treatment has been effective because there is a lack of empirical research regarding implementation strategies and outcomes.[27] The same appears to be true of the clinical guidelines. The effect of clinical guidelines on medical practice and their impact on patient care is often limited.[28,29] Hence, guideline development needs to be complemented by evidence-based implementation.[30]

All considered guidelines have given evidence based recommendations, which allows for better practice than recommendations not based on scientific evidence.[31] The NICE-SCIE and APA guidelines provided precise definitions of recommended performance, which can improve the use of guidelines according to Grol and colleagues.[31]

Although the NICE-SCIE guideline formulated precise recommendations for local implementations as well as details about how the implementation can be audited, it also recommended the development of a more broadly

based implementation strategy.[11] None of the other research guidelines considered relevant to this article gave recommendations for local or national implementations and auditing of the guidelines. The APA guideline formulated recommendations for the implementation of a treatment plan, which is necessary, but not sufficient for local or national implementations.

Conclusion

Evidence-based clinical guidelines have become a major feature in health care. Researchers and clinicians in many countries have established programs to summarize the evidence for managing AD and other dementias. According to current evidence, interventions that include family advice are an essential part of an optimal clinical management of AD. All of the considered guidelines agree on the potentially positive effects of family advice on dementia patients and their family caregivers with medium range levels of evidence.

However, guideline recommendations are frequently not applied in practice.[32] As such, many patients do not profit from evidence-based insights.[33] Practitioners need special skills in order to apply the interventions recommended in the guidelines concerning family advice. For example, skills such as leading a psychoeducational training group cannot be assumed for all types of practitioners. Hence, it seems important to provide education for practitioners about how to change their clinical practice in order to take into account the recommendations given in the clinical guidelines (eg, how to successfully realize the recommendations of the guidelines in a multidisciplinary team setting). In order to address the needs of the end user of a guideline, caregiver education materials and practical tools to manage family advice in practice should be provided to practitioners.[34]

Research that addresses the clinical problem of how to apply the clinical guidelines and evidence-based interventions practically is clearly needed to increase the use of the guidelines in clinical practice and to improve the management of patients with AD and their family caregivers.

Disclosure

The author reports no conflicts of interest in this work.

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