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Informal caregivers and psychosocial support: Analysis of European Dementia Policy documents

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Significance for public health

This study has important public health impacts on informal caregivers in a European context. The study reveals that the European countries of Alzheimer Europe - especially policymakers, social and healthcare providers and non-government organizations - should update or prepare the necessary

national dementia strategies, promote benchlearning, improve international collaboration and systematically manage those who provide psychosocial support.

ABSTRACT

Various countries in Europe have different strategies for promoting care solutions for dementia challenges. The different approaches of Austria, Belgium, Czechia, Denmark, Finland, Germany, Gibraltar, Ireland, Israel, Malta, Nederland, Norway, Sweden and the United Kingdom (Scotland and Wales) were investigated. Dementia has a significant social, psychological and economic impact on the individual, family and society. As the disease progresses dementia sufferers become increasingly dependent. As many dementia sufferers are at home during the initial stages, the physical, emotional, and social demands of the dementia sufferers are often covered by informal caregivers. This study, therefore, aims to investigate the integration of psychosocial interventions for comprehensive care pertaining to informal caregivers of people with dementia in Europe. Furthermore, the study will highlight how implementation of technologies might enable psychosocial support of informal caregivers. The data is based on 15 national dementia strategies from various European countries. Data was based on preexisting coding systems with the predefined keywords and analyzed by qualitative content analysis by four of the authors. Our results show that psychosocial support is provided in various modalities and that informal caregivers need to be supported by a psychosocial approach. Due to this need the national dementia strategies should include measures to reduce the emotional burden of informal caregivers. Psychosocial support provided to informal caregivers in a comprehensive and systematic way is likely to enable informal caregivers to handle the emotional, cognitive, and behavioral consequences of the disease and its treatment, while helping to maintain their work-life balance.

INTRODUCTION

With an aging society in Europe, the incidence of dementia is increasing in every European country. Dementia as a clinical syndrome is characterized by global cognitive impairment, representing a decline from the previous level of functioning, and is associated with impairment in functional abilities and, in many cases, behavioral and psychiatric disturbances (1). Dementia is associated with considerable physical, psychological, social, and economic burdens on the individual, their caregivers and families, and society at large (2). With time, the affected individual gradually loses both mental function and autonomous capacity, becoming more dependent on others for personal care. Dementia

constitutes an increasingly important issue in policy and practice and demands national plans and strategies.

In Europe, most dementia care is provided in the community by informal caregivers. Research shows that those informal caregivers often suffer from distress. This stress might be hazardous to the caregiver's health (3-5). The major burden of support for individuals with dementia usually falls on one person (commonly the spouse) who takes on the role of the main domestic caregiver and, as a result, often experiences considerable hardship in terms of the physical and emotional burden, for up to 10 hours a day (6).

For the purpose of this study we base our definition for informal caregiving on the main caregiver. This could be a spouse, partner or an adult descendant providing care without payment (7-9). Informal caregivers often provide caring family relations including social support (e.g., providing love, advice and care). However, having a personal relationship can lead to an increased caregiver burden. More arguments, unnecessary criticism, and unrealistic expectations and demands are likely to negatively influence the patient's well-being (10).

An aging population and the consequent increased demand for formal long-term care services have led to public services being restricted towards those with the highest levels of caring needs. The gap in care supply is made up through the provision of informal supply by family and friends (11). The economic contribution of unpaid altruistic and often family-based support has been estimated as being up to 36.8% of European GDP (12).

Alzheimer Europe, a non-government organization, is highlighting dementia as a European priority by promoting a rights-based approach, supporting research and strengthening the European dementia movement. In 2014, the Glasgow Declaration called for the creation of a combined European Dementia Strategy and national strategies in every country in Europe. The number of countries recognizing dementia as a public health priority and developing national strategies continues to grow (13). This organization presented online National Dementia Strategies from 40 countries. The National Strategy for Dementia acts as a national voice for dementia sufferers, their caregivers and family members.

Psychosocial intervention is an umbrella term for initiatives aimed at supporting, developing and retaining the psychological, cognitive, functional and social resources of dementia sufferers and/or their relatives. The term 'psychosocial interventions' is sometimes used synonymously with the term 'non-pharmacological intervention'. Support groups as a psychosocial intervention are considered an especially effective and economical way to relieve informal caregiver's stress and burden, although it is unclear if participating in group meetings produces a meaningful outcome for the informal caregiver (14, 15). Social support is also one of the important functions of social relationships and is commonly

categorized into four types of behaviors: i) Emotional, ii) Instrumental, iii) Informational and iv) Appraisal (16, 17). Recent studies show that psychosocial interventions had a positive impact on carers outcomes (18). These interventions included setting exercises along with group-based and individual health-promoting interventions.

Objective

The objective of this study was to investigate the integration of various psychosocial interventions for comprehensive care pertaining to informal caregivers of dementia sufferers in the political national dementia strategies or plans available from the websites of Alzheimer Europe. Specifically, it sought to investigate what kind of psychosocial support modalities for informal caregivers exist and how implementation of technologies enables psychosocial support for informal caregivers.

The main research question of this study is: *How is psychosocial support for the informal caregivers of dementia sufferers integrated into the 15 National Dementia Strategies of the member states of the Alzheimer Europe organization?*

Methods

This was a descriptive qualitative exploratory study conducted through document analysis of national dementia strategies. These were focused on integration of various psychosocial interventions for comprehensive care pertaining to the informal caregivers of dementia sufferers.

Document analysis is a systematic research technique that uses both printed and electronic materials as its source, analyzing them in-depth to extract information and indications relative to the study objective (19). It is important to note that document analysis is a process involving skimming (superficial examination), reading (thorough examination) and interpretation of content to provide answers to research questions (20).

The national dementia strategies/plans serve as a “roadmap” for the next stage of the journey towards a future where dementia and informal caregivers are public health challenges. These plans set out the goals, vision and established landmarks in the form of specific measurable objectives. Web pages connected to dementia associations are an excellent reference for current information and a compilation of all dementia websites by key players. All information from selected web pages was as a supplement to national dementia strategies/plans.

Based on the agreement all the European states endorsed we focus on fifteen countries: Austria, Belgium, Czechia, Denmark, Finland, Germany, Gibraltar, Ireland, Israel, Malta, Nederland, Norway, Sweden, the United Kingdom (Scotland and Wales) and illuminate:

1. The kind of psychosocial support modalities for the informal caregivers that exist in selected national dementia strategies.
2. How implementation of technologies enables psychosocial support for informal caregivers.

Data collection

Documents were sourced and collected from a web-based literature search on an information platform - Alzheimer Europe - of 40 National Dementia Strategies in Europe between November 2020 and March 2021.

These publicly available strategic documents were considered external communication and included national dementia plans with policy strategies and websites. Key search terms identified were:

- A) support and synonyms such as: social support, support group, caregivers support, self-help group, psychoeducational group, psychosocial support, supporting family members, family intervention, psychosocial intervention, psychosocial measures, peer support, respite service, community services.
- B) technologies and synonyms such as: online help, technical support, digital technology, assistive technology, telemedicine, welfare technology.
- C) informal caregivers and synonyms such as: spousal care, family caregivers, relatives, families, main health carers, caregiver, family carers.

Documents relating to these topics found on the dementia organization websites were noted and selected. Search records with document identification were kept for each country, forms and relevant information were electronically saved, printed, allocated an identification code and sequentially organized into files per selected country.

The following inclusion and exclusion criteria were applied. Inclusion criteria:

1. National dementia strategies/plans from 2012 until 2030. All had to be the latest plan, available online and the full text.
2. The national dementia strategies/plans were published in all languages the authors can speak (Czech, Danish, English, German, Norwegian, Slovak and Swedish).
3. National dementia strategies/plans and websites include a description of psychosocial support or interventions for informal caregivers.

From 40 published national dementia strategies/plans 25 were excluded for the reasons highlighted in Table 1.

Data analysis

Considering the methodological advantages and limitations of document analysis (19), data analysis was determined by both the research objectives (deductive) and multiple readings and interpretations of the data from the documents (inductive). The publicly available documents and the informal responses to formal policies by various stakeholders were analyzed in a complementary fashion in this study (21).

Given the multitude and variety of documents, thorough reviews were the first step in the analysis. Some documents, although originally selected given their content, title, or possible link, were not deemed appropriate to the inquiry. Content of documents in relation to the research objectives was highlighted and recorded into tables. The data was organized according to the alphabetical order of selected countries and objective one: psychosocial support modalities for informal caregivers, and objective two: psychosocial support and technology.

RESULTS

According to a brief overview of the state of national dementia strategies across Europe, the number of countries in Europe recognizing dementia as a priority, and the implementation of national strategies, continues to grow. Presentation of the included countries is arranged alphabetically.

Austria

The aim of the Austrian Strategic Plan for Dementia *Living Well with Dementia* is to create a system in which dementia sufferers and their carers: live in a community that promotes participation and autonomy as much as possible; get the information they need as soon as possible; know where to look for help and what services are available; obtain quality care regardless of their place of residence, and to actively participate in decisions about their care (22).

The strategy is to help everyone in the community to better understand dementia and overcome the stigma associated with it. The forms of psychosocial support for informal carers are volunteers, who help with the disabled person's recreational activities and provide carers with relief, and self-help groups, including the so-called "Alzheimer's cafes." In this space, caregiver-relevant information can be exchanged by the caregivers themselves, and reflection of one's own mood is stimulated. PsychoSocial Information (PSI) provides an essential service; In cooperation with the Social Psychiatric Emergency Service, 24-hour availability of PSD (Psychosoziale Dienste) (Psychosocial Services in Vienna PSD) is guaranteed ("immediate assistance"). The Council and the applicants for assistance thus have a contact person who is available 24 hours a day. The main tasks of PsychoSocial Information are telephone and personal information service, counseling and help interviews and

organization and coordination of the PSD Family Forum. The group offers the opportunity to communicate with other relatives, learn more about the disease and its treatment options, and help with emerging issues.

Belgium

The updated *Dementia Plan for Flanders (2016-2019)* provides a broad vision for care involving all of society, with policy-makers' support through voluntary and informal care and professional support where necessary. To increase the informal caregiver's capacity and quality of life, the plan draws up tailored psychoeducation to be a point for attention in the overall informal care plan. The psychoeducation package "Dementia, Now What?" is continually monitored and updated whenever necessary.

For on-going care and support, the plan stimulates cooperation between the caregivers to ensure adequate support for the person living with dementia and their informal caregiver through the dementia coordination platforms. The platform includes psychoeducation, buddy assistance, contacts with fellow sufferers (e.g. through the 'Young-onset' dementia family groups), meetings for people in relation to dementia, home care and residential care facilities (daycare, short stay etc.) The suggested integrated care and support plan is tailored to each client and their informal caregiver. The importance of contact with other sufferers or self-help groups is explained.

Dementia experts are on hand to assist other caregivers in the region. The Dementia Plan adopted the "Forget dementia. Remember the person" campaign and promoted the platform to support the campaign's mission and be a portal for people living with dementia and their informal caregivers, professionals and the media (23).

Czechia

The purpose of the latest *Czech National Action Plan 2016-2019* is to formulate, implement and coordinate interdependent tasks to achieve the following objectives: improving the quality of life for both patients with Alzheimer's and similar diseases, and their caregivers; raising awareness in the provision of health and social services within the general public; to support and develop education for caregivers; and to support research activities focused on dementia.

One of the main aims of the strategy is to support the creation of a structured network of workplaces with defined care provided at individual levels. Psychological support groups such as "Tea at Five" for informal caregivers provide a professional assistant (nurse, social worker); other groups, such as "Wanderings of Memories and Souls" are peer self-help groups for the dementia sufferers. These

groups offer opportunities for consultations and advice. Education courses for informal caregivers are also described as an important task of the strategy (24).

The plan states that early diagnosis of dementia, proper cognitive treatment and adequate psychosocial intervention can significantly slow the progression of the disease and delay its advanced stages. Prolonging the self-sufficiency of a patient with dementia and keeping family carers economically active in the early detection of the disease can subsequently lead to savings on the part of the health and social sectors.

Denmark

The Danish plan is published with the title *A Safe and Valuable Life with Dementia - National Action Plan for Dementia 2025*. One of the most important tasks is the early diagnosis, treatment, assistance and support of dementia sufferers and their relatives. Creating a Danish dementia-friendly society and hospitals are priorities for the next period, as well as assistance for sufferers and their families in the form of support groups and educational programs. The goal of education is to manage the disease and the challenges the disease brings to the whole family. Counseling and activity centers for dementia sufferers and their relatives, including younger dementia sufferers, is another form of social support. The centers focus on involving and offering users supportive interviews, counseling, social and physical activities, as well as opportunities for belonging with equals. The centers additionally offer educational courses and focus on the use of social care.

This plan also specifically describes the situation of younger dementia sufferers and their support groups. Respite and daily services for relatives are offered to dementia sufferers, which allows relatives a much-needed rest. Flexibility in daily care and respite offers need to support and provide services in the evenings and at weekends (25).

Finland

Finland launched a national dementia plan called the *National Memory Programme 2012-2020* aiming to use 'case management' as the method. Case management involves carrying out a comprehensive assessment of each patient's circumstances and his or her need for assistance, support and care, using this information to produce a personalized care and service plan.

'Case management' ensures that patients and their families have access to as much information as possible about the services available from the public sector, the private sector and the third sector. This creates conditions for making choices and pooling the support services available to build a personalized package that is better able to meet the needs of the individual. Case management is an important tool

for guaranteeing patients' equality; this involves an assessment of the opportunities of the patient's family and friends to form a support network to help the patient cope with daily life (26).

Germany

The *German National Dementia Strategy* focuses on four fields of action: 1. Developing and establishing dementia-inclusive communities to enable people with dementia to participate in society; 2. Supporting people with dementia and their relatives; 3. Advancing health and long-term care services for people with dementia and 4. Promoting excellent research on dementia (27).

This National Dementia Strategy encourages and supports local networks to provide advice and support people living with dementia and their informal caregivers. It also reflects on the challenges informal caregivers experience and highlights the importance of networks, health and prevention programs for carers, establishes coordinated procedures in care between the primary, secondary and tertiary health care system, ascertains dementia-inclusive hospitals and active strategies which all are supported at government level. Additionally, Germany's Dementia Friends program aims to increase involvement in, and focus on, the area of dementia via a nationwide campaign.

Gibraltar

The priority of *Gibraltar's Dementia Plan 2015 (2020)* is the development of more integrated services; more comprehensive care programs; and greater awareness and understanding of the needs of people with dementia and their loved ones, such as their families, friends and carers. One of the main emphasis is on reforms aimed at greater integration and cooperation between health and social services. This will create the conditions under which the dementia coordinator and the connected person can significantly change the management of the family and service users through the dementia care process. The long-term vision is to create a "Dementia Supportive Community". The strategy describes the development of respite services, the simplification of the processes via which help can be obtained, and opportunities for psychological help among other possible supportive mechanisms.

Support for carers is focused on the moral appreciation of society, as well as educating and training relatives with the social skills they will need, such as coping with behavioral changes in a person with dementia. Through exercise and education, the right conditions are created for dementia sufferers with disabilities to be treated as individuals, with all the rights and considerations they deserve.

The support also includes innovative services in line with the latest best practice, which ensures the creation of a framework which is fully inclusive of patients and their carers in all aspects of treatment. The aim of the support is for dementia sufferers to live as long as possible at home or in their local community (28).

Ireland

The *Irish National Dementia Strategy* sets out to improve the lives of people with dementia, especially reducing stigmatization of those with dementia and increasing the understanding of the general public. A key message of the strategy is that, with the right support, a person with dementia can live well, often for quite a long time. The emphasis is therefore on ability rather than on how a person is restricted (29). The focus is to integrate services, support and care for people with dementia and their carers. The plan describes communities as the key to ensuring that staying at home with dementia is a feasible option. Examples of community support currently available for people with dementia include Alzheimer Cafés, social clubs, arts-based activities, family carer training and peer-led support groups. The Irish Age Friendly Cities & Counties Programme is a national initiative aimed at improving quality of life for older people at local level. The important objective is an integrated and multi-disciplinary response by community services, primary care and secondary care to support people with dementia and their carers. Services such as day care, home help and – particularly - home care packages can clearly assist family caregivers.

Israel

The formulation of the *National Strategic Plan to Address Alzheimer's and Other Types of Dementia* offer a holistic perspective and emphasize collaboration among all relevant agencies. The vision of the plan is to enable people with dementia and their families - through a broad array of easily accessible, high-standard supports and services - to live full, independent, and dignified lives as much as possible. The plan recognizes the need to address dementia from the stages of prevention of risk factors and early detection to diagnosis and patient care, and through assurance of the quality of end of life. The strategic plan relates to a number of areas that the interdisciplinary group of experts identified as central: raising public awareness of dementia and dispelling the associated stigma; developing responses to support family caregivers directly; and adapting the array of long-term institutional services in view of the changing needs (30). Developing information and consultation centers accessible by telephone, around the clock, for families to receive help in navigating the service system, and to provide a response in crisis situations are very important goals for Israel; expanding the development of responses to support families socially and emotionally - such as support groups, family therapy, and individual support – are also priorities. These services will provide information on the disease and existing services, imparting the skills and competencies required to care for the patient and provide emotional support.

Malta

Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing developed a strategy document: *Empowering Change - A National Strategy for Dementia in the Maltese Islands 2015-2023*. This strategy aims to implement a number of measures in the various areas of dementia management and care with the overarching aim of enhancing the quality of life for individuals with dementia, their caregivers and family members. The key objectives presented in this strategy include increasing awareness and understanding of dementia (31). One fundamental aspect of this strategy is that of increasing awareness and understanding of dementia among the general public and healthcare professionals in order to reduce stigma and misconceptions about the condition. The goal is to promote an ethical approach to dementia management and care, and to provide individuals with dementia and their caregivers with the necessary psychological support needed in making important decisions regarding their health and welfare.

The Netherlands

The Netherlands is preparing a new National Strategy for Dementia for 2021-2030 (32). The strategy's chief concern is to tailor support for people living with dementia. The starting point in this strategy is the mission statement: 'People with dementia and their loved ones can function as valuable members of our society and receive good support and care'. Person-centered care is part of this plan, as is family support. Young people with dementia are a significant and special group in this plan given that they often have different forms of dementia than people above 65 years of age. Young people with dementia often still have a family with children living at home, are physically stronger and participate in the labor process, and they have different requirements for support and care than their older fellow sufferers (32).

Support for informal carers is described in the form of contact with fellow sufferers, housing, exercise, food, sleep, security, finances and using technology that helps patients retain their independence for as long as possible. Integrated care (functional, medical, psychological and social) covering the entire knowledge chain and case management are important modalities of psychosocial support in the Netherlands.

Norway

The Norwegian Dementia plan 2025 - *Demensplan 2025* emphasizes the importance of identifying dementia sufferers and their relatives at the right time and providing quality personalized services. Ensuring dementia sufferers and their relatives can live an active and meaningful life with physical,

social and cultural activities tailored to individual interests, desires and needs are important parts of plan.

The Norwegian government has prepared an online knowledge and training program for relatives of people with dementia developed by WHO iSupport. The purpose of iSupport is to prevent physical and mental stress for people who are in close contact with dementia sufferers, as well as increase the quality of life of people with dementia. During the planning period the Norwegian Directorate of Health will provide translation and adaptation of the program to Norwegians and make it available for relatives (33). Additionally, a permanent contact person and ‘dementia team’ in the municipality with broad dementia competence will be proactive and make the first contact, develop an individual plan and provide individual support, and have a good overview of assistance available. The Norwegian government will continue its efforts to educate people with dementia and their relatives, such as schools for relatives and support groups. The Norwegian Dementia Plan also addresses the issue of people with dementia of immigrant origin; this new target group will require linguistic and cultural adaptation of help and support. Equally important are the indigenous people of Norway (Sámi) and their families, who need adapted support for culture, social and linguistic conditions (33). Welfare technology solutions and services are an important contribution for dementia sufferers and provide relief for relatives and caregivers (33).

Sweden

The Swedish national dementia strategy for care for people with dementia 2018-2022 identifies key areas: collaboration between health and social care; family and friends; society; and, digital and assistive technologies (34). The challenges that dementia sufferers and their relatives face require long-term and purposeful work. The national dementia strategy describes a model for a standardized course of action after diagnosis of dementia. It can contribute to continuity in care and support, meaning that a person with a dementia disease is offered the right support and measures at the appropriate time during the entirety of the disease. The model can also lead to increased security for the person with dementia, and security and relief for their relatives – commonly, daughters take great responsibility - and other informal caregivers. To support the person-centered and multi-professional teamwork, many municipalities have created so-called dementia teams. Sweden’s various support measures are provided accordant with a person-centered approach, and they are offered in a good psychosocial environment with a focus on the individual. The support should be based on the person's own wishes and remaining abilities.

United Kingdom (Scotland)

Scotland's National Dementia Strategy 2017-2020 focuses on improving the quality of care for dementia sufferers and their families through work on diagnosis, including post-diagnostic support and care coordination. This strategy recognizes the importance of a flexible, people-centered approach to providing support at all stages of the care journey.

Every person with a new diagnosis of dementia in Scotland is entitled to a minimum of one year of Post Diagnostic Support (PDS) from a named person who will work alongside the person and those close to them. The 5 Pillars Model provides a framework for dementia sufferers, their families and carers with the tools, connections, resources and plans to allow them to live as well as possible with dementia and prepare for the future. A range of interventions is implemented for carers of dementia sufferers: education, skills training, coping strategies and peer support. These interventions help carers consider their own general and mental health and wellbeing independently of the person they care for. The need for respite and right to their own social connections is also addressed (35). The first virtual resource center in the UK is a secure online space where people can enjoy all the of a dementia center from the comfort of their own home. It will provide "virtual hands" to people who need support anywhere, at any time. There will be access to groups and activities, such as Music Memories, a zone specifically for caregivers. There is also an opportunity to chat with a Dementia Link employee or Allied Health Professional (35).

Providing support after diagnosis and throughout the illness is constantly provided using a flexible, person-centered approach considering individual needs and circumstances (35).

United Kingdom (Wales)

The Welsh Assembly ratified their last Dementia Plan in February 2011 and a Dementia Friendly Nation outlining in 2015. In 2018 the Health Secretary launched the *National Dementia Action Plan for Wales*. Its aims are 1. Individuals will understand the steps they can take to reduce their risk, or delay the onset, of dementia; 2. The wider population understands the challenges faced by people living with dementia and are aware of the actions they can take to support them; 3. People are aware of the early signs of dementia; 4. People know the importance of a timely diagnosis, and where to get help; 5. More people are diagnosed earlier, enabling them to plan for the future and access early support and care if needed; 6. Those diagnosed with dementia and their carers and families are able to receive flexible person-centered care and support 7. Staff have the skills to identify people with dementia and feel confident and competent in supporting an individual's needs post-diagnosis. Furthermore, research is supported to help better understand the causes and management of dementia and enable people living with dementia, including families and carers, to be co-researchers (36).

SUMMARY OF THE FINDINGS

The strategies are intrinsically proactive. It points towards the importance of a multi-disciplinary approach that can improve knowledge, diagnosis, treatment, prevention, and social research into the welfare of individuals with dementia and their families and carers. Increasing awareness and timely diagnosis, together with support services delivered by a workforce trained specifically to work with dementia sufferers and their carers, have a positive and profound effect on their quality of life.

Overall, European countries provide a variety of psychosocial interventions, support services and educational programs for informal carers of people with dementia using traditional approaches (physical encounters with informal carers) and technological (online space). This study has revealed both support programs offered by community or non-government associations and hybrid programs based upon cooperation between non-government organizations and local communities.

The modalities of psychosocial support in the care of dementia sufferers are targeted to the specific psychosocial support needs of the patient and their informal caregivers. The national strategic plans described several modalities: individual, group meetings, and support through telecommunication or online-based support. The psychosocial support provided depends on the preferences of the individual carers (see Table 3). Table 3 presents the findings and a brief description of the modality.

DISCUSSION

This document investigates the integration of psychosocial support for the informal caregivers of dementia sufferers appertaining to national plans/strategies for dementia in Europe. We can state that the individual countries agree in their national plans that the condition for providing support and good care for dementia sufferers is that a person undergoes an early examination to establish a diagnosis that includes an assessment of the type and stage of the disease.

Increasing public awareness and fostering a more accepting society are prerequisites for improving prevention, early detection, treatment and services effectiveness. Most of the countries surveyed focused on changing citizens' attitudes towards people with dementia through a vision of a society friendly to dementia. Only two out of 15 countries - Austria and Czechia - do not report interventions to support informal carers through public campaigns. In 2017, increasing public awareness of dementia was identified as a priority by WHO. Campaigns provide information, including measures that aid referral for individuals with dementia and their caregivers and help to provide the most appropriate support according to the family's needs. Interestingly, some countries organized campaigns to change the perception of dementia by using destigmatizing counter frames, or different ways of looking at

dementia which better reflect reality e.g. Belgium used the slogan: "Forget dementia. Remember the person". The concept of the dementia-friendly municipality or society as a specialization of an age-friendly policy has been implemented in several countries (Belgium, Denmark, Finland, Germany, Gibraltar, Ireland, Israel, Nederland, Norway, Malta, Sweden, Scotland, and Wales). These tools contribute to raising awareness of the need to help people affected by dementia. Several countries such as Croatia, Estonia, Jersey, Hungary, Montenegro, North Macedonia, Poland, Romania, Slovakia, and Turkey haven't produced a national strategic plan for dementia. For example, Slovakia has developed support groups and intervention programs in the last 20 years (37, 38) but still has no national dementia strategy.

There are many forms of psychosocial support for informal caregivers in selected nations' strategies. Research points to the importance of psychosocial support for the quality of life and health for both relatives and people with dementia; additionally, some interventions can reduce informal caregivers' psychological morbidity (39-41). Programs that involve the patients and their families and are more intensive and modified to caregiver's needs may be more successful (42, 43). The studies of Donnellan et al. 2017 and Ringer et al. 2020 describe psychosocial support as having both a buffering effect and a direct influence on a better quality of life, health and participation in society through recognition, relationship development and belonging, and increased resilience, knowledge and mastery. Informal caregivers require increasing support to accept and adapt to the changes as the person with dementia impacts on their life (44). Several studies have demonstrated significant effects in reducing caregiver burden, lowering caregiver depression, and delaying institutionalization of care recipients through either targeted interventions that treat a specific caregiver problem, such as depression, or broad-based multi-component interventions, including counseling, case management, and phone or online support (45). When younger people in middle age suffer from dementia, there is often a need for support due to the illness' effect on the patient's relationships - the spouse, siblings, parents, children, colleagues and friends. The support for close relatives is very important; people who get dementia stay with support from the family for as long as possible. Challenges associated with supporting informal caregivers for young-onset dementia persons (before the age of 60) are described in relatively few countries (Belgian, Ireland, Norway, Malta and Wales).

Psychosocial intervention using technology can help informal caregivers for dementia sufferers develop targeted programs that combine aspects of several psychosocial interventional strategies. Since the advent of the covid-19 pandemic, digital technologies have become even more important and have a significant and positive role to play on the provision of psychosocial help and support. The helpline telecommunication offers emotional support to anyone, of any age, who is caring for someone with dementia as well as other family members or friends. Only some countries (Belgium - online

support groups, Denmark - online meetings, Finland - online forum, Ireland - online training, virtual dementia nurse, Norway - iSupport and Scotland - The Virtual Resource Centre online space for groups and activities) have flexibly moved psychosocial support to the online space and created new opportunities for safe and continuous support for informal carers. Measures aimed at protecting the health of vulnerable groups - people with dementia - have deepened the social isolation of informal carers and have therefore helped to adapt quickly to the conditions of society, especially in these countries. From the perspective of family carers, online support is an attractive option because it can be used at a convenient time (46).

Support groups create social capital in the sense of creating a safe space for sharing feelings and experiences. The day care centers for people with dementia give family caregivers support and relief and have a positive impact on the relationship between the family caregiver and the person with dementia (47).

More and more people with intellectual disabilities are living for a longer period of time than in the past, often reaching retirement age and above. This means that they have the same risk of suffering from other health problems as the rest of the population when it comes to aging and dementia. About 50–60 percent of people with developmental disabilities suffer from dementia (48, 49). Several updated national dementia strategies (Germany, Norway and Sweden) point to new challenges associated not only with care but also with the support of informal carers. There are two major challenges: firstly, the number of aging people with mental disabilities and dementia is increasing; secondly, providing tailored support for migrants whose mother tongue is not the language of the country in which they live. The loss of the most recently learned language creates a great challenge for the setting up of care and support for both people with dementia and informal carers, who require respect for cultural differences in the provision of care and support.

The Danish plan just refers to dementia sufferers as citizens with dementia, which we perceive as a change in the paradigm of providing help from the passive reception of patient assistance to the active attitude of a full-fledged citizen with dementia. The Dementia Practice Coordinator or dementia team is a form of psychosocial intervention in several countries. His or her important role is to identify the person with dementia and their family's specific needs and link them with the appropriate practitioner or service.

Psychosocial support should be available and recommended to all individuals affected by a crisis, or who have needs, from their primary contact with health services. This type of support can reduce the cost of treatment for informal carers in long-term care.

Strengths and limitation

The strength of this study is an international team that speaks several languages and were able to include studies published in national scientific journals. The topic is relevant, current, and points to a new direction in various modalities of psychosocial support for informal caregivers. Related to this is further research and the direction of public health policies and the strengthening of education for healthcare and social workers.

One limitation of this study is that we selected national plans/strategies from some but not all countries in Europe. It is suggested that more sources from different countries of the world be investigated in future studies. Also, we excluded plans and strategies for dementia that were not completely published. In addition, our dataset contains only past publications available online.

Regarding the analysis of documents, we only used articles from publicly available data sources from the Alzheimer's Europe Organization, which lead to a certain inaccuracy of the results. However, the benefits of this study outweigh the several disadvantages.

Recommendation for future research

Strategic plans of dementia in Europe will instigate a process of transformation of care across all sectors in the expectation of a growing number of persons with dementia; related to this is further research focusing on the methods and quality of psychosocial support provided to informal caregivers. Furthermore, such national dementia strategies will stimulate discussion on what constitutes integrated and inclusive psychosocial support, good and ethical practice in dementia management, alternative care practices ranging from novel welfare services to innovative assistive technologies, purposeful training and research programs in the dementia field.

Conclusion

We conclude that various national strategies are intrinsically proactive, as it points towards the importance of a multidisciplinary approach which can improve knowledge, diagnosis, treatment, prevention, and social research into the welfare of individuals with dementia and their families and carers.

The 15 included national dementia strategies/plans show that the European countries have a good understanding of psychosocial support for relatives and their people suffering from dementia. These countries are ready to extend health promotion work through combinations of interventions. The study has given a more complete picture of psychosocial support as health promotion. This knowledge can function as a basis for countries outside Europe when they develop their dementia strategies/plans.

Promoting the health of dementia sufferer's relatives requires mutual interaction between the community and individually oriented support. The interconnection of lay and professional help, support and assistance create the development of social work opportunities in a specific locality on the principle of social networking and the development of community social services as a complement to public services around Europe. Benchmarking and future research can help several countries in Europe to improve timely support and dissemination across Europe.

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Table 1 Overview of four main exclusion criteria

	Exclusion criteria	Countries	Number of excluded plans
1.	The National Dementia Strategy was ratified 10 years ago or longer	Belgium - Wallonia 2010 United Kingdom (England) 2009 United Kingdom (Northern Ireland) 2011	3 plans
2.	Language researchers did not understand or speak	Bosnia and Herzegovina, Bulgaria, Cyprus, Iceland, Italy, France, Luxembourg, Portugal, Switzerland, Spain, Slovenia	11 plans
3.	Currently does not have national dementia strategies	Croatia, Estonia, Jersey, Hungary, Montenegro, North Macedonia, Poland, Romania, Slovakia, Turkey	10 plans
4.	Plan prepared in the form of a budget	Greece	1 plan

Table 2. Psychosocial support and technology offered for informal caregivers in selected European countries

	Country and title of national plan	Objective 1 Psychosocial support modalities for informal caregivers	Objective 2 Psychosocial support and technology
1.	<p>Austria Dementia Strategy - Living Well with Dementia (Original title: <i>Demenzstrategie - Gut leben mit Demenz</i>)</p> <p>59 pages</p>	<ul style="list-style-type: none"> - Alzheimer's Cafe - Education and training for informal caregivers through support groups - Consultations - Peer-to-peer consultations - Discussion for partners - Discussion for daughters and sons - Self-help meetings "Coming over the mountain" - Exchange of experiences with dementia 	<ul style="list-style-type: none"> - PSI -The PsychoSocial Information (access to near-to-home contact points and drop-in centers) – Emergency call 24/7 - Promote Alzheimer's self-help platform https://www.alzheimer-selbsthilfe.at/
2.	<p>Belgium Continuing to Build a Dementia-Friendly Flanders Together Updated Dementia Plan for Flanders</p> <p>28 pages</p>	<ul style="list-style-type: none"> - 'Forget dementia. Remember the person' - campaign - Psych-Education pack - "Dementia, now what?" - Self-help groups in Alzheimer cafe - A dementia expert to assist and meet other caregivers in the region - The Group "The Fighters" for young-onset dementia persons (before the age of 60) - Daycare centers, short stay centers (respite services) 	<ul style="list-style-type: none"> - Promote Alzheimer League ASBL platform www.alzheimer.be - Online support group - Alzheimer Café "Chez Nous" - Phone - advisor Monday-Friday 08.00 to 18.00
3.	<p>Czechia National Action Plan for Alzheimer's Disease and Related Diseases 2016-2019</p> <p>(Original title: <i>Národní akční plán pro Alzheimerovu nemoc a obdobná onemocnění 2016-2019</i>)</p> <p>23 pages</p>	<ul style="list-style-type: none"> - Respite care - Support groups "Tea at Five" (for informal caregivers) - Peer groups "Wanderings of memories and souls" (for dementia sufferers) - Education and counseling 	<ul style="list-style-type: none"> - Promote The Czech Alzheimer's Society (ČALS) for family caregivers platform www.alzheimer.cz - Online support groups for informal caregivers - Online peer group for dementia sufferers
4.	<p>Denmark "A Safe and Valuable Life with Dementia - National Action Plan for Dementia 2025"</p>	<ul style="list-style-type: none"> - Dementia-friendly society and hospitals - Flexible daily and respite services (24/7) - Support groups 	<ul style="list-style-type: none"> - Promote Alzheimer's Association platform www.alzheimer.dk

	<p>(Original title: <i>Nasjonal Demenshandlingsplan 2025 - Et trygt og værdigt liv med demens</i>)</p> <p>48 pages</p>	<ul style="list-style-type: none"> - Counseling and activity centers. - Education programs and courses 	<ul style="list-style-type: none"> - Alzheimer's Association promotion on Social Media (FB, T, YT, I) - Digital platform (aktivi.dk) for online meetings - Phone-advisor (Demenslinien)
5.	<p>Finland National Memory Programme 2012-2020 Creating a „Memory Friendly Finland”</p> <p>21 pages</p>	<ul style="list-style-type: none"> - A memory friendly country - Case management - Counseling (also crisis counseling) - Support groups - Respite care and nursing - Daily rehabilitation and daycare services 	<ul style="list-style-type: none"> - Promote Memory Association's platform www.muistiliitto.fi - Online Forum on Memory and Memory Diseases (www.tukinet.net) - Peer support Line online (vertaislinja) - Social media (FB) - Helpline “The Memory Line”
6.	<p>Germany National Dementia Strategy (Original title: <i>Nationale Demenzstrategie</i>)</p> <p>146 pages</p>	<ul style="list-style-type: none"> - Dementia Awareness Campaign - Support groups - Integrated services - Dementia coordination - Family therapy, and individual support - Developing and establishing dementia-inclusive communities 	<ul style="list-style-type: none"> - Promoting excellent research on dementia - Alzheimer Organisation //www.alz.org/de/ - Self-help groups and counseling https://www.deutsche-alzheimer.de - Information and advice for migrants https://www.demenz-und-migration.de
7.	<p>Gibraltar Gibraltar’s National Dementia Strategy (2018 – 2021) Working to Become Dementia Friendly</p> <p>36 pages</p>	<ul style="list-style-type: none"> - Dementia Supportive Community and Dementia Friend Gibraltar - Integrated services - Education and training of social skills - Daycare centers - Palliative and end of life care - Dementia training - Individualized person-centered care - The Dementia Coordinator 	<ul style="list-style-type: none"> - Promote Dementia Friends Gibraltar platform http://www.dementiafriends.gi/ - 24/7 Helpline telephone - Gibraltar Alzheimer's & Dementia Society promotion on Social media (FB)
8.	<p>Ireland The Irish National Dementia Strategy</p> <p>40 pages</p>	<ul style="list-style-type: none"> - Dementia Friendly Communities - Integrated care - Case Manager to help to coordinate individual care plans - Alzheimer Cafe/Social club - Dementia Adviser - Daycare services - Respite services - Meals-on-wheels - Home care packages 	<ul style="list-style-type: none"> - The Alzheimer Society of Ireland platform - www.alzheimer.ie - www.dementiathways.ie - Social media FB, in, T, - National Helpline - Online Family Carer Training - Virtual Dementia Nurse - Online Family Carer Supports - Mobile Information Service travels through towns

9.	<p>Israel Addressing Alzheimer's and Other Types of Dementia: Israeli National Strategy 12 pages</p>	<ul style="list-style-type: none"> - Dementia Awareness Campaign - Dementia-friendly communities - Integrative care - Self-help and support groups - Family therapy, and individual support - Dementia Friends - volunteers program 	<ul style="list-style-type: none"> - The Alzheimer's Association of Israel - AMDA association - Promote website https://emda.org.il/ - Promotion on Social Media (FB) - Hotline service (information and consultation centers accessible by telephone, around the clock) - Online groups
10.	<p>Malta EMPOWERING CHANGE A National Strategy for Dementia in the Maltese Islands 2015-2023 132 pages</p>	<ul style="list-style-type: none"> - Dementia-friendly communities - Patient-centered dementia management and care - The Dementia Intervention Team managed by a Dementia Coordinator - Educational seminars and training programmes - Psychological counseling using a person-centered approach - Respite care as part of integrative care - Support networks: volunteers - Personal support/social groups and peer support 	<ul style="list-style-type: none"> - Promote Malta Dementia Society (www.maltadementiasociety.org.mt) - Social media (FB) - Dementia Helpline - Public activities: "Walk for Dementia" or "Memory Walk" - Online Newsletter - Online guide and training to dementia caregivers and family members - Publishing information booklets
11.	<p>Nederland National Strategy for Dementia for 2021-2030 (Original title: <i>Nationale Dementiestrategie 2021-2030</i>) 24 pages</p>	<ul style="list-style-type: none"> - More dementia-friendly society - Education and advising - Care coordination (provided by an assigned expert/independent guidance worker) 	<ul style="list-style-type: none"> - Promote Dutch national platform https://www.deltaplاندementie.nl - Online interventions for informal caregivers - The programme 'Dementiezorg voor elkaar'- A special database about improving the living environment
12.	<p>Norway Plan of Dementia 2025 (Original title: <i>Demensplan 2025</i>) 52 pages</p>	<ul style="list-style-type: none"> - "More Dementia-Friendly Society" & "Active and Healthy Aging - Age-Friendly Society." - Family school - education and support groups - User's school with focus on education and information and knowledge about dementia - Dementia Friend (Respite care) especially for young-onset dementia persons (before the age of 60) 	<ul style="list-style-type: none"> - Promote National Association for Public Health platform https://nasjonalforeningen.no/demens/ - National Association for Public Health promotion on Social Media (FB, T) - Adaptation of the WHO online knowledge and training program (iSupport) - Hotline/Demenslinje - National Welfare technology program

		<ul style="list-style-type: none"> - A permanent contact person in the community - Dementia team in the local/regional community 	<ul style="list-style-type: none"> - Personal guidance and advice via email
13.	<p>Sweden National Care Strategy for People with Dementia (Original title: <i>Nationell strategi för omsorg om personer med demenssjukdom 2018-2022</i>) 32 pages</p>	<ul style="list-style-type: none"> - Dementia-friendly society - Education (online,too) - Advising - Various support groups - Coordinated care plan for family - Facilitating the coordination of care and nursing interventions - Individually adapted support for young relatives - Dementia team in the local/regional community 	<ul style="list-style-type: none"> - Promote Demenscentrum on Dementia platform: https://demenscentrum.se/ - Stiftelsen Svenskt Demenscentrum on Social Media (FB, T) - The Swedish Dementia Center
14.	<p>United Kingdom (Scotland) Scotland's National Dementia Strategy 2017-2020 29 pages</p>	<ul style="list-style-type: none"> - Dementia-friendly society - Education and skills training focusing on coping strategies - Peer support - Post diagnostic support (PDS) with 5 elements - Information and advice - Personalized support services (including day centers, activities or groups in the community) - Dementia Friends (volunteers) 	<ul style="list-style-type: none"> - Promote Alzheimer Scotland Action on Dementia platform: https://www.alzscot.org/ - Alzheimer Scotland promotion on Social Media (FB, T) - The Virtual Resource Centre, online space for groups and activities - 24-hour freephone Dementia Helpline - The Dementia Dog - fun online support resources (virtual bingo games)
15.	<p>United Kingdom (Wales) Dementia Action Plan for Wales 2018-2022 43 pages</p>	<ul style="list-style-type: none"> - Dementia-friendly communities - Information, advice and advocacy; - Dementia support workers: Dementia Advisors or Dementia Navigators; - Person-centered care - Support: individual and family resilience; clubs, peer support groups, day treatment centers; - Community Care assessment - Activities: befriending services, Memory Cafes, Wellbeing Centres 	<ul style="list-style-type: none"> - Promote dementia platform: https://www.alzheimers.org.uk - Dementia Roadmap Wales - Social Media - Helpline Wales/Freephone

Table 3. Modalities of psychosocial support informal caregivers for persons with dementia.

Modality	Brief description of modality
Individual specialist	Face to face meeting to promote opportunities to meet professionals such as a medical doctor, nurse, social worker, lawyer, social educator, e.g., individual advice for informal caregivers (next of kin)
Individual layman	Face to face meeting with another informal caregiver with the same challenges (without professional assistance); peer advice
Group specialist	Meeting in a support group of informal caregivers with a specialist based on problem-solving, solution-focused, narrative or informal caregivers-centered counseling. Often combines the education courses with skill training activities to enhance communications skills, or cope with stressful situations e.g. 'Family schools'. Meeting in a support group for persons with dementia with a specialist includes knowledge about dementia and social-recreational counseling e.g. Memory café / 'User's schools'
Group layman	Meeting in a self-help /peer group of informal caregivers, or former caregivers for deceased persons, to promote emotional support to those who care for people with the same type of dementia, for example 'Dementia or Alzheimer's Cafe'
Telecommunication	The intervention provided by phone or chat conversation, for example, emergency call or chat for dementia 24/7 helpline
Online based	Promote websites of Alzheimer's Societies, online groups, online advising (FAQ), online activities (e.g., The Dementia Dog), social media promotions