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Health-Care Delivery for Older People with Dementia in Primary Care

Conceição Balsinha, Manuel Gonçalves-Pereira,
Steve Iliffe, José Alexandre Freitas,
and Joana Grave

Abstract

Dementia is a disabling, highly prevalent condition in older age. Complexities related to dementia care challenge the existing models of health and social services. Although for most people in Western Europe the first contact point for health-related concerns is a general practitioner, the role of primary care physicians and primary care teams regarding older people with dementia needs clarification. Primary care has much to offer to older people with dementia and their informal, family carers, but several challenges still need to be addressed. Given that the perspectives of people with dementia, their carers and staff regarding the role of primary care in dementia may share several points, it seems possible to define priority areas for intervention. Despite a growing number of studies on dementia care delivery in primary care, interventions addressing a wide range of important outcomes in dementia (e.g. falls, frailty) are overlooked in the research agenda; this probably hinders the quality of health care provided. At the end of the chapter, we finally discuss how current knowledge on dementia care fits into the Portuguese health and social care systems, as a case study example.

Abbreviations

BPSD	Behavioural and psychological symptoms of dementia
PCP	Primary care physicians
PwD	People with dementia, or person with dementia

Key Points

- The role of primary care physicians and primary care teams regarding older people with dementia still needs clarification.

C. Balsinha (✉) · J. A. Freitas
CEDOC, Chronic Diseases Research Centre, NOVA Medical School/Faculdade de Ciências Médicas, Universidade Nova de Lisboa, Lisboa, Portugal

Unidade de Saúde Familiar Marginal,
São João do Estoril, Portugal
e-mail: maria.balsinha@nms.unl.pt

M. Gonçalves-Pereira · J. Grave
CEDOC, Chronic Diseases Research Centre, NOVA Medical School/Faculdade de Ciências Médicas, Universidade Nova de Lisboa, Lisboa, Portugal
e-mail: gpereira@nms.unl.pt; joanagrave@ua.pt

S. Iliffe
Primary Care and Population Health, University College London, London, UK

Centre of Expertise in Longevity and Long-Term Care, Charles University, Prague, Czech Republic
e-mail: s.iliffe@ucl.ac.uk

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- There are several challenges related to dementia care delivery for older people in primary care.
- The perspectives of people with dementia, their carers and staff regarding dementia care in primary care may have several common points.
- Interventions that could improve the quality of care for older people with dementia in primary care are overlooked in research.
- Primary care has much to offer to older people with dementia and their carers.
- How current knowledge on dementia care fits into the Portuguese health and social care systems.

23.1 Introduction

Our world faces continuous growth in ageing populations. In 2015, the population aged 65 years or older represented 7% or more of the total in many countries [1] and 18.9% of the population in the European Union [2]. These demographic changes are leading to a number of challenges for health and social care systems.

A great number of these challenges depend to a large extent on the health profile of the older population, but gaining knowledge of these health profiles has proved challenging, and evidence regarding future health trends is conflicting [3]. According to the OECD publication 'Health at a Glance 2017' [4], 51% of all over-65s on average across 26 European countries in 2015 reported that they were limited either to some extent or severely in their usual daily activities because of a health problem. Predicting the future prevalence of disability in the older population is the cornerstone of this debate. Population ageing and the greater longevity of individuals will lead to increasing numbers of people at older ages with disability and in need of long-term care [5]. On the other hand, a compression of morbidity (a shorter period of illness before death) in the future [6] will probably lead to a greater proportion of years lived without disability in older age.

One of the disabling conditions with a high prevalence in older age is dementia, broadly defined as loss of memory and problems in other cognitive functions causing impairment in everyday activities. Among chronic diseases, dementia is the fourth leading cause of burden of disease (DALYs) in high-income countries and is one of the major causes of disability and dependency among older people worldwide and therefore considered a public health priority [7]. It has extensive health consequences for the patients and their carers and a high financial impact on the patient, his family and society [8]. Although the incidence of dementia may be declining in some countries due to cardiovascular risk reduction and improved brain health [9, 10], dementia remains only partially preventable and is not a reversible condition in the great majority of cases. This puts pressure on health and social services to find solutions in order to deal with an increasing number of related challenges.

For most people in Western Europe, the first point of contact for health-related concerns is a primary care provider, most often a primary care physician (PCP). As a result, the quality of dementia health care that is delivered in primary care has been under scrutiny for decades. In 1996, Downs [11] wrote an editorial review in which she described the role that PCPs and primary care teams could play in dementia care and the difficulties they were facing and provided suggestions for supporting PCPs and primary care teams in dementia care delivery. Surprisingly, or not, those are the same issues that we are still debating today. It seems that primary care has been struggling to fulfil the expectations of health-care systems regarding dementia care in several countries for more than 25 years. It is not possible to discuss dementia care delivery in primary care without trying to frame it within a wider context that considers the interfaces between society and health care and health-care policies and health-care delivery (Fig. 23.1).

In this chapter, we will first review the role of primary care physicians and primary care teams in managing dementia. Secondly, we will explore the main challenges related to dementia care delivery for older people in primary care. Thirdly,

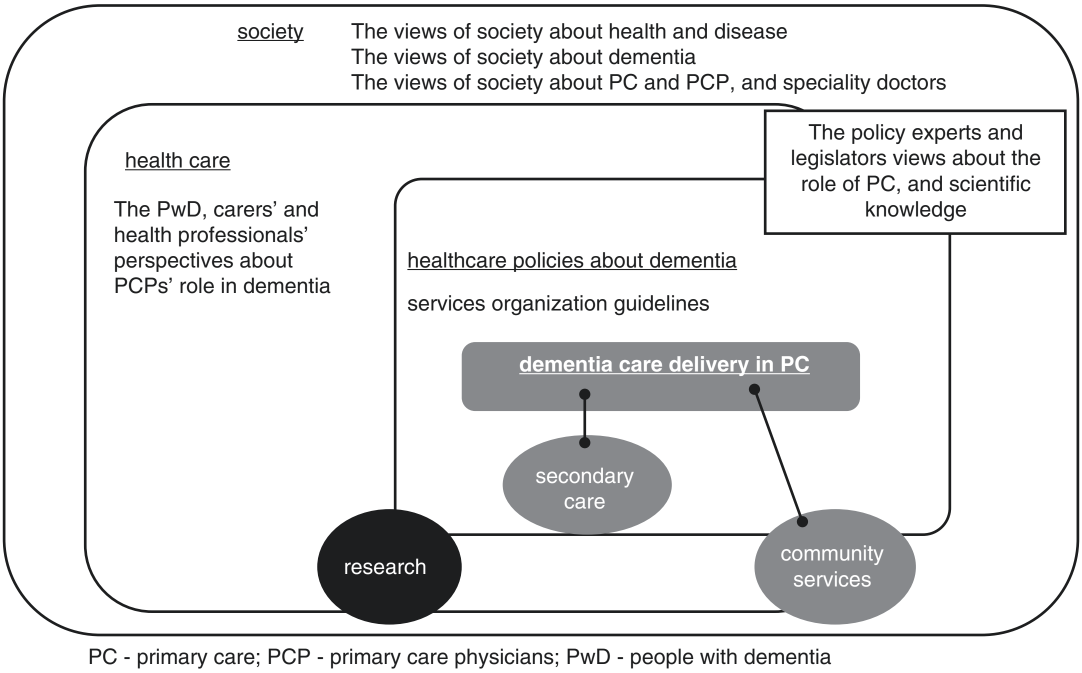

Fig. 23.1 Integrative model of interfaces that condition dementia care delivery in primary care. *PC* primary care, *PCP* primary care physicians, *PwD* people with dementia

we will explore the perspectives of people with dementia, their carers and health professionals on dementia care in primary care. Here we will try to define common ground and discrepancies, trying to pave the way for any possible interventions. Fourthly, we will review interventions that have been tested to improve the quality of care for older people with dementia in primary care. Fifthly, we will discuss what primary care has to offer to older people with dementia and their carers, considering the salience of specialist[1] services and prevailing ways of thinking about illness. Finally, we will discuss how current knowledge on dementia care fits into the Portuguese health and social care systems.

23.2 What Is the Role of Primary Care Physicians and the Primary Care Team in Managing Dementia?

The role of PCPs in health care, as defined by the World Organization of Family Doctors [12], is clear: to 'care for the individual within the context of the family, for the family within the context of the community, and for the community in the context of public health (…) for providing comprehensive and continuing, person-centred care (…), and in helping coordinate and integrate care' (p. 42). In addition, PCPs and other primary care professionals provide first contact to every person seeking health care and advice. Although this role applies to dementia care delivery, the roles and responsibilities of primary care providers with respect to dementia care have generally not been explicitly defined [13].

Despite the lack of definition of the PCP role in dementia care, it is expected that these care providers assume a wide range of respon-

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[1] In some countries (e.g. Germany, the UK), PCPs are not considered specialists. Therefore, in this chapter we will refer to 'specialists' meaning neurologists and psychiatrists (and geriatricians, in some countries) in charge of people with dementia, regardless of setting (public or private practice, hospital settings or not).

sibilities, such as ensuring early detection of dementia and diagnosis [14–18], initiating and managing pharmacological treatment [16, 19], providing ongoing support to the patients and their carers through the different stages of the disease [16–18], being able to assist in difficult decisions (e.g. medico-legal issues, driving) [16, 20–22] and having a central and coordinating role in collaborative care models [16, 17].

In each of the national dementia strategies of 14 European countries (UK, Norway, Finland, Netherlands, Denmark, Italy, Greece, Spain, Croatia, Bulgaria, Slovenia, Czech Republic, Switzerland, Belgium), the role of PCPs with respect to dementia is also mentioned [23]. The most well-established task is detecting new cases of dementia and maintaining the general health and safety of the patient, while the role in diagnosing dementia, initiating anti-dementia drugs and providing social support is more controversial. A recent EU-JPND study involving eight countries (Actifcare, i.e. ACcess to TImely Formal Care, www.actifcare.eu) focused on the access to and use of community care services for home-dwelling people with dementia (PwD) and their carers and issued best practice recommendations that also concerned the role of PCPs [24]. These professionals should have more knowledge and provide information about available community care services, have specific training to make timely diagnoses of dementia and to recognize the need of advanced diagnostic assessments (e.g. dementia subtypes) and have a comprehensive overview of the situation of the PwD. These recommendations also highlight the need for a well-defined pathway for PCPs' referrals regarding treatment of urgent cases and the need for PwD and their carers having a named contact person (e.g. PCP, case manager). These Actifcare best practice recommendations have been discussed taking into account each country's particular circumstances. The definition and roles of this 'contact person', along with implementation issues, are motivating an ongoing debate and generating further research questions within the consortium.

23.3 What Are the Main Challenges Related to Dementia Care Delivery for Older People in Primary Care?

The numerous challenges related to dementia care delivery for older people in primary care can be attributed to difficulties in drawing the line between the effects of ageing and those of the disease, as well as to the wide scope of action of primary care.

23.3.1 Primary Care Physicians Find It Difficult to Recognise Dementia

Underdiagnosis of dementia by PCPs has been identified as an important shortcoming in several countries [25–28]. A systematic review [29] of studies assessing the ability of PCPs to recognize dementia found that PCPs typically identify three out of four PwD but have more difficulties in the early stages (one out of two people with mild dementia) and record the correct diagnosis in medical notes infrequently.

A systematic review [30] of quantitative and qualitative studies on barriers to the recognition of dementia in primary care found factors related to physicians (diagnostic uncertainty or insufficient knowledge or experience disclosing the diagnosis, stigma attached to dementia and therapeutic nihilism), factors related to the patient or society (stigma and delayed presentation) and factors related to the health system (time constraints, lack of support and financial or remuneration issues). Dodd et al. [31] argued that PCPs' lack of confidence in making independent dementia diagnoses seems to be a major barrier to dementia diagnosis in primary care. In order to avoid inappropriate diagnoses, PCPs reported a modal average of four consultations with patients and their relatives before they make a conclusion.

It is important to acknowledge that there are different factors shaping PCPs' ability to diagnose dementia. The process of diagnosis and decision-making is not a linear one; instead it has been described in primary care as a three-step process [32]: (1) generating a list of diagnostic hypotheses, given the problem presented by the patient; (2) imposing a hierarchy on the list, based on the likelihood of each hypothesis; and (3) establishing a definite diagnostic conclusion, after excluding the hypotheses one by one. Dementia (as an overall condition) is not a disease but a syndrome (a group of symptoms that consistently occur together). However, subtypes of dementia such as Alzheimer's disease are associated with biomarkers that allow for a disease diagnosis [10]. Even if a diagnosis of subtype is not feasible in primary care, generally speaking, different factors pose specific challenges to PCPs regarding the dementia syndrome recognition. Cognitive performance at a defined moment of assessment is affected not only by normal ageing and education but also by, for example, depressive symptoms or stressful circumstances (like the death of a spouse). Moreover, the ability to live independently is also affected by physical conditions as well as by social expectations and not always easily ascertained as fulfilling the criterion for a diagnosis of dementia.

Another widely debated issue is the necessity of an early diagnosis [33–35]. The benefits of an early recognition of dementia include ending uncertainty regarding the cause of symptoms and behaviour change, giving access to appropriate support, promoting positive coping strategies, facilitating planning and developing the process of adaptation to the carer role [33, 36, 37]. On the other hand, negative consequences of unsupported diagnostic disclosure for PwD and their carers have also been identified: risk of causing emotional distress, inability of the person with dementia to understand and/or retain diagnosis, anxiety about increasing disability, negative effects on self-esteem and restricted activities [36]. In addition, attributing a range of behaviours or cognitive changes to dementia may lead to under-treatment of other conditions like depression [34]. It is important to consider that the drawbacks of an early diagnosis may outweigh the benefits if people are left with a diagnosis but are offered little support [33].

In fact, the focus on 'early diagnosis' is being overridden by a different emphasis on 'timely diagnosis', which means 'communicating a diagnosis at a time when the person with dementia and their carers will benefit from interventions and support' [38].

23.3.2 Multimorbidity and Frailty Are Highly Prevalent in Older People with Dementia

Throughout the discussions on the PCPs' role in managing PwD, there is surprisingly little focus on the integrated care of physical, mental and cognitive co-morbidities, given that most PwD have several co-morbidities [39, 40].

Effective provision of chronic health condition management may be compromised by prevailing views that the chronic disease burden is made up of individual diseases that are best managed independently (e.g. establishing a national diabetes or dementia strategy). Research [41] on co-occurrence of chronic diseases in older adults and geriatric syndromes highlighted the importance of providing comprehensive care to address multimorbidity. Given that the prevalence of chronic diseases increases in old age as does dementia [42], older PwD will also face the challenges of multimorbidity and most probably of geriatric syndromes (e.g. falls, urinary incontinence) [39, 40]. In addition, the co-existence of dementia and other conditions in older people increases the risk of disability and frailty and consequently of dependence; thus there will be a great diversity of care needs in an aged population with dementia [40]. Koroukian et al. [40] examined the prevalence of chronic conditions, functional limitations and geriatric syndromes across gradients of cognitive impairment in a representative sample of the US population aged 50 years or older. These authors have also defined a complex variable consisting of the co-occurrence of chronic conditions (minimum one), functional limitations and geriatric syndromes. Their findings showed an increased prevalence of multimorbidity in individuals with higher levels of cognitive impairment, but more interesting the same happened with the prevalence of the complex variable.

A recent systematic review [43] on the prevalence of frailty identified five studies including 543 patients with Alzheimer's disease and provided a pooled prevalence estimate of 31.9%.

The need to consider and optimize physical health in PwD (e.g. nutritional status, risks of falls) highlights the importance of a greater involvement of primary care in the delivery of dementia care [13]. On the other hand, the co-morbidities of dementia and their association with frailty increase the risk of dependence, which leads in turn to the wide variety and complexity of needs for care of PwD.

23.3.3 Older People with Dementia Often Have a Large Number of Highly Complex Needs

Previous research [44–48] on unmet needs (i.e. when a person is not receiving an appropriate support in a particular area of their life) have shown that they seem to predict important outcome measures, such as decreased quality of life, psychological and behavioural symptoms, institutionalization and mortality.

The comprehensive interview-based Camberwell Assessment of Needs for the Elderly [49, 50] has been used to map the needs and amount of help (received and needed) of PwD living in the community [46, 51]. Miranda-Castillo et al. [46] interviewed 125 PwD, with mild/moderate cognitive impairment, and their carers. The most frequent unmet needs identified by the carers (regarding PwD needs) were daytime activities (41.1%), company (29.8%), psychological distress (26.6%) and eyesight/hearing (20.2%). The most frequently met needs identified by the carers were memory (94.4%), looking after home (87.1%), food (86.2%) and money (81.5%). The European Actifcare cohort study [51] recruited 451 dyads of PwD and their carers. Most of these PwD (78%) had mild dementia and exclusion criteria included relying on significant amounts of formal care; thus the focus was on the intermediate stages of dementia. The most frequently unmet needs identified by the carers were daytime activities and company, and the most frequently met needs were looking after home, food, memory and money.

A recent systematic mixed studies review [52] of studies that identified needs of patient-carer dyads found that the most frequently reported need was an earlier disclosure of dementia diagnosis, followed by needs related to education and counselling on the disease. Carers also pointed out the need for home support, and patients mentioned needs for meaningful activities where they could participate in and be assisted in daily activities.

Identifying unmet needs could help to identify who is at risk of an adverse outcome and to provide the care needed through tailored interventions. On the other hand, identifying the most frequently met needs, and the way they are met, could help policymakers to better design appropriate responses to support PwD and their carers. Evidence [46, 51] suggests that most needs are related to social support, highlighting the importance of the social model.

Sociology has much to tell us about health and illness and especially about chronic conditions, such as dementia. Sociology tends to be undervalued in medical training; therefore understanding about the experience and meaning of an illness eventually escapes physicians through the rush of consultations. Since medical sociology concerns the patient, their family and society as a whole, it has special relevance for PCPs providing dementia care.

Traditional views of illness put its investigation and treatment in the domain of medicine and the professions allied to medicine. The task of helping people to manage the personal and social consequences of illness is the domain of the social care professions [53]. Therefore, when we look at dementia mainly as a medical problem, we feel hopeless because it cannot be contained or cured; but if we see it as a disability, it can be accommodated into daily life [54]. However, in order to foster PwD's and their carers' wellbeing, we have to frame disability within the social model. The social model sees the problem experienced by people with disabilities as being the direct product of the physical, social and attitudinal environments. In the social perspective, the problem is a failure of the environment to adjust to the needs and desires of people with disabilities. In comparison, the medical model sees disability as a deviation from biomedical norms of structure and function, putting the solution in medical intervention to help the person adjust to their limitations.

The application of medical science cannot be ignored, but in the case of PwD, it is necessary to bring both the clinical and social perspectives together. By doing this, the lack of post-diagnostic support will be ameliorated, and many of the unmet needs currently identified by PwD and carers will be eventually met.

23.3.4 Informal Carers Are Not Only a Resource in Dementia Care

People with dementia most often need support from informal carers. Many older PwD are cared for at home, primarily by spouses and adult children [51, 55, 56]. These informal carers are frequently more actively involved in the caregiving process than their counterparts caring for patients with other illnesses, acting as care coordinators, information sources and front-line communicators for their relatives [57] and often being involved in medical encounters [58].

The negative consequences of informal caregiving in dementia have been widely studied, and the associated burden, in physical, emotional, social or financial terms, is uncontentious [55, 59, 60]. Cuijpers [61] reviewed the prevalence of depressive disorders in dementia caregivers and found a range of 15–32% prevalence rates and relative risks 2.8–38. A recent meta-analysis [62] found that carers of persons with Alzheimer's disease have a higher prevalence of mental health disorders, particularly depression and anxiety, as compared with the general population and with carers of patients with other health conditions. In sum, there is a consensus that about 40% of dementia caregivers may suffer from clinically significant anxiety or depression, while others present significant psychological symptoms [63]. It has also been acknowledged that taking care of an older relative with dementia places a heavy burden on the general health of older carers [64]. Carers' somatic problems overall include cardiovascular issues and compromised immune function, with difficulties engaging in health behaviours and a higher mortality [55, 59, 60].

It is well established that neuropsychiatric, behavioural and psychological symptoms are particularly linked to carer burden in dementia [55, 65]. PCPs need better training in assessing and managing these behavioural and psychological symptoms of dementia (BPSD), but these professionals also should have better access to back up speciality services (e.g. geropsychiatry, occupational therapy) and be reimbursed for time spent on its prevention, assessment and management [66]. In conclusion, there is a rationale for the involvement of family members in clinical assessments of PwD. As informants, relatives are helpful, often decisive in the patient's evaluation. As informal carers, they may deserve to be assessed in their own right (concerning, e.g. psychological distress, ongoing ability to provide care). Finally, family dynamics must sometimes be evaluated or addressed; noteworthy, the family is seldom considered as a whole system in dementia caregiving research. Secondary carers may also be at risk and ought to be assessed in many situations [65]. The National Institute for Health and Care Excellence (NICE) clinical guidelines acknowledge that the diagnosis does not affect just one person but the whole family system [67].

In countries where PCPs are accountable for the whole family system, they are in a privileged position for a more comprehensive approach to PwD and their carer(s). This enables PCPs to 'think family' by empathically assessing and mobilizing family members, facilitating brief and simple family interventions [68].

23.3.5 Comprehensive and Coordinated Health-Care Systems Are Needed for Better Provision of Care in Dementia

The need for a continued management of such a complex condition as dementia in the community stresses the importance of a comprehensive and coordinated primary care system. It follows that primary care service organization must be adapted to the provision of dementia care and that primary care professionals must have a good enough knowledge about dementia.

In 1998, Starfield identified the four pillars of primary care practice, which are still used today as a measure of good primary care systems [69, 70]: first-contact care, continuity over time, comprehensiveness and coordination with other parts of the health system. First-contact care means that primary care is the point of entry into the health-care system. Continuity means that patients/families have a regular source of care over a significant period of time. However, this can be extended to incorporate a more comprehensive definition of continuity of care, as provided by the World Health Organization [70]: cross-sectional continuity (coherent interventions over the short term both within and among teams) and longitudinal continuity (uninterrupted series of contacts over the long term). Comprehensiveness is the extent to which different types of health services are provided (e.g. preventive, chronic, palliative). Finally, coordination involves the integration of all care, making it coherent for the individual patient.

More recently, other attributes (e.g. population-focused accountabilities for care, active patient engagement in care and team-based care) have been added to the aforementioned four pillars and together characterize high-performing primary care [69, 71].

These attributes sound promising in addressing the needs of PwD and their carers, although there are suggestions that primary care is struggling to keep up with these attributes of high-performing care. An integrative review [71] that included a broad range of published and grey literature between 2000 and 2013 identified three models of primary care for dementia:

- Carved-out models—they respond to the complexity of dementia care by referring patients and their carers to resources outside the practice (and focus exclusively on dementia care). It assumes that most of the needs of carers and patients are beyond the capacity of normal primary care and that the majority of needs need care plans built around dementia.
- Co-managed models—they respond to the complexity of dementia care by meshing external resources into primary care. This assumes that the patients require specialized attention but acknowledges the centrality of the primary care relationship. A robust electronic communication strategy is vital to ensure informational continuity in this model.
- Integrative-hub models—they respond to the complexity of dementia care by building capacity in primary care teams and incorporating resources to sustain the continuity of the primary care relationship.

The authors concluded that there has been a slow penetration of the high-performing primary care attributes into primary care delivery in the case of dementia. They note that the studies classified in the integrative-hub category were most consistent with providing comprehensive, relational and whole person-centred care. Nevertheless, most approaches described in the review still favour the dementia-specific care plans and interventions that focus on the coordination of disease-specific supports and services (with varying degrees of connection back to the primary care context), placing the disease in the foreground and fragmenting dementia care such that it fits within the constraints and time-compressed nature of primary care.

To our knowledge there has been little research on evaluating primary care comprehensiveness of dementia care, and the results have been limited by the small number of participants [20, 21, 72] and by audits to medical records [20, 22]. These studies showed an underuse of functional assessment tools and of community support [21], lack of home safety assessments [20], lack of attention to wandering, driving and medicolegal issues [20–22], unavailability of dementia-specific services [20, 72], lack of attention to carers' issues [21] and lack of registered information about signs and symptoms of dementia and treatment options [22]. The positive findings were general health assessments (vision, hearing, nutritional, continence and sleep) being done in 70% of cases

[20] and the presence or absence of BPSD and cognitive tests' results being documented in 30–40% of records [22].

A German national database analysis of pharmacological prescription showed that PCPs prescribe fewer anti-dementia drugs and more neuroleptics when compared with specialists [73].

23.4 Do People with Dementia, Their Informal Carers and Health Professionals Have Different Perspectives on Dementia Care Delivery in Primary Care?

To better understand the challenges of primary care regarding older PwD and their carers, it is important to know what their perspectives on dementia care delivered in primary care are.

Considering the early stages of the dementia diagnosis process, research [31, 74] suggests that carers were satisfied with primary care services. Nonetheless, some carers found the PCP reluctant to give a diagnosis, and many felt that their first concerns were not always addressed [31]. In addition, an association between perceived quality and the interpersonal skills of professionals was found (e.g. showing concern, being thorough) [74]. By contrast, when considering the care provided after the diagnosis, the carers and older PwD were found to be less satisfied with primary care services. The lack of support following the dementia diagnosis was identified by carers and older PwD alike [31, 75, 76]. The lack of information on available services provided by primary care professionals [31, 76] as well as on how to deal with carer burden and on how to manage dementia [75] has also been presented as negative aspects from the carer's perspective.

Regarding the perspective of PCPs, there is a growing body of evidence on constraints of dementia care delivery in primary care. The main barriers include:

- Structural and system-related factors: [77–79] insufficient consultation time, difficulty in accessing and communicating with specialists, low reimbursement, poor connections with community social service agencies and lack of interdisciplinary teams
- Family-related factors: [79] carers' fatigue/exhaustion/anger and planning for the patient's institution placement
- Medical-related factors: [30, 31, 77–79] inadequate clinician time, length of time needed to administer screening tools and limited treatment options
- Health-related factors: [30, 79] behavioural and psychological symptoms of dementia (e.g. aggressiveness, restlessness/agitation) and co-morbidities (e.g. falls, delirium, adverse reactions to medication, urinary incontinence)

The difficulties in coordinating with specialists seem to compromise the care for PwD and influence aspects of medical practice and may be due to three key factors [77]:

- Structural and system-related factors: managing care, carve outs (e.g. an approach to managing care that separates psychological and psychiatric services from medical care services, in order to reduce health costs), insurance/entitlements, poor geographical distribution, lack of trained providers and reimbursement policies.
- Patient/family and societal factors: ambivalence about treatment, frailty, neuropsychological symptoms, stigma, financial difficulties, cultural values and logistical problems.
- PCP/specialist factors: a lack of geriatric and psychiatric training for PCPs (increasing their need for referrals for complex diagnosis and treatment decisions), poor communication, lack of feedback from specialists and lack of coordinated care. PCPs preferred to use mental health specialists for consultations only and continue overall care management themselves in order to care for the co-morbid medical illness.

The attitudes and behaviours of primary care professionals towards informal carers have also been explored [80]. In general, the professionals perceive the informal carer as a resource and co-worker in dementia care; however, they fail to attend to carers' responses and attitudes to the caregiver role.

In our understanding, PwD and primary care professionals other than PCPs are underrepresented in research, particularly concerning the perceived role of primary care and primary care professionals regarding the provision of dementia care.

It is interesting to notice that PwD and carers identify some critical points that are related to the professionals' perspectives: lack of support following the diagnosis (PwD/carers) relates to lack of PCPs' geriatric/psychiatric training, lack of feedback from specialists and lack of coordinated care (PCPs); lack of information on available services (carers) relates to poor connections with community social service agencies and lack of interdisciplinary teams (PCPs); and lack of information on how to deal with carer burden (carers) relates to the professionals' perceptions of the informal carers as a resource and a co-worker in dementia care.

23.5 What Interventions Have Been Tested to Improve the Quality of Care for Older People with Dementia in Primary Care?

A systematic scoping review [13] to identify strategies for improving the quality and outcomes of primary healthcare regarding dementia may be found in the World Alzheimer Report 2016.

In this section, we would like to introduce our own review of intervention studies, identified by restricting the search scope of dementia in primary care with specific search terms related to ageing. Through this approach, we aimed to identify studies that considered other aspects of the health of PwD besides dementia itself (e.g. falls, co-morbidities assessment).

We identified eight studies that, aside from some overlapping strategies, share several common goals: to improve guideline adherence, to improve collaborative work, to manage symptoms more appropriately and to provide better carer support. These studies can be divided into three broad groups:

- Case management (also described as collaborative care) [52, 81–86]
- Implementing/improving clinical decision support systems [85–87]
- Educational interventions for PCPs [84]

Improving care delivery using a case manager appears to be a sensible option. Taking care of PwD is complex and requires experience that a PCP cannot easily achieve due to the low number of cases in their panels [88]. In addition, in a 15–20 min visit, physicians often do not have time to counsel patients and carers, and many do not know how to assess needs outside the scope of traditional medical management [83, 88, 89]. To overcome these barriers, it has been proposed that nurse practitioners specialized in dementia care could play a role in improving the quality of care for PwD and their carers in primary care. Through being dedicated to this role, they potentially have the time and knowledge to address medical and social aspects of care (e.g. counselling for safety concerns, managing dementia-related medication, referral to community resources, coordinate care). However, one systematic review [90] demonstrated that case management had limited positive effect on behavioural symptoms of dementia and length of hospital stay for patients and on burden and depression for carers. These heterogeneous results as well as the minimal benefits may imply that only highly intense case management is effective, which entails a small caseload, regular proactive patient-carer follow-up, regular contact between case managers and PCPs and effective communication between all healthcare professionals [90].

One study [82] that focused solely on collaborative care between primary care and community-based organizations found disappointing results. It assessed the effect of 'dementia care consultants' provided by local Alzheimer's Association chapters on nursing home placement and carer outcomes. Patients whose carers were in the intervention group were less likely than their control group counterparts to be admitted to a nursing home (AOR 0.40, 95% CI 0.14–1.18), but no effect on carer self-efficacy, carer depression, or strain was found. However, a sub-analysis showed that carer satisfaction with the intervention played a role in self-efficacy in symptom control and in using support services.

A combined approach between case management and collaborative care with community-based organizations was also found [81, 83]. In one study [81], an advanced practice nurse was integrated in a primary care team and worked with family carers in a case management model to assess its effect on neuropsychiatric symptoms. The intervention group showed lower BPSD and lower carer strain. The study found there was no effect on carer depression. The use of cholinesterase inhibitors and antidepressants was enhanced without increasing the use of antipsychotics or sedatives/hypnotics. The intervention was found to have no effect on PwD's cognition, depression, activities of daily living, hospitalization, nursing home placement, or death.

This combined approach was also tested at the University of California at Los Angeles in an Alzheimer's disease quality improvement programme (UCLA-ADC) [83]. A co-management model was developed with nurse practitioner dementia care managers working with PCPs and community-based organizations, to enhance adherence to guidelines. They verified an improvement in guideline adherence, regarding the assessment and screening for cognitive decline, co-morbidities, complications of dementia and counselling on various domains, but adherence to treatment guidelines did not improve. Carers' satisfaction with the programme was also assessed and showed high carer satisfaction with the care manager (help on decisions and listening to concerns) and with the support for their role.

A different way of optimizing delivery of care by the case manager is to use clinical decision support systems. This approach was shown to be effective in two large trials [85, 86]. One trial [86] tested the effect of a disease-based management programme implemented by case managers on quality of care and outcomes. The intervention group of this trial showed a twofold increase in guideline adherence, with higher care quality on 21 out of 23 guidelines and a higher proportion of assistance received from community agencies. An increase was found in PwD's quality of life, quality of caregiving and social support in the intervention group; conversely unmet caregiving assistance needs decreased. No effect on carer's quality of life was found. The second trial [85] tested the effectiveness and safety of dementia care management in the treatment and care of PwD as well as the carer burden. This used a computer-assisted assessment to create personalized intervention modules and subsequent success monitoring. The intervention resulted in significantly decreased behavioural and psychological symptoms of dementia and carer burden compared with usual care. In the intervention group, there was an increase in the use of anti-dementia drugs and a significant increase in quality of life for patients not living alone, but quality of life was not increased overall. Another study [87] analysed the results of the implementation of a computerized intervention-management-system that has been developed to facilitate dementia care management. The analysis showed that 72% of the unmet needs identified by the computer system were not recognized by the case manager, and, as a result, this improved the provision of recommendations for the PCP.

Finally, one study [84] assessed if a practice redesign intervention coupled with referral to local Alzheimer's Association chapters could improve the quality of dementia care. Adherence to guidelines by PCPs was used to measure the quality of care provided. One of the quality indicators of care for older people that has been used is the "Assessing Care of Vulnerable Elders" (ACOVE). In this study, a modified version of this instrument was used to redesign practice in primary care by improving PCPs' skills (ACOVE-AD); however, the results fell short of the required value to be clinically significant [84].

To sum up, we did not find evidence of measures concerning other aspects of the health of PwD besides dementia itself. The reviewed studies [52, 81, 83, 84, 86] do not refer to any co-morbidities other than depression.

Additionally, collaborative work with community-based organizations or using case managers as a single intervention seems to be ineffective. On the other hand, comprehensive approaches that combine different strategies (e.g. case managing with clinical decision support systems) may be of interest regarding guideline adherence and should be further explored.

Designing and testing innovative approaches with new services (e.g. carer schools) have been overlooked.

23.6 What Does Primary Care Offer to Older People with Dementia and Their Carers, Considering the Salience of Specialist Services and Ways of Thinking About Illness?

It is widely accepted that the initial identification of likely cases of dementia is an important function of primary care [7, 8, 13, 31, 91, 92]. In most countries, PCPs see their patients in their own environment, over a long period, with an understanding of the medical and non-medical life history of their patients [93]. The capacity that PCPs and other professionals in primary care have to assess co-morbidity in combination with dementia, to manage geriatric syndromes and to promote measures of primary and secondary prevention ensuring relational and management continuities has been seen as one of the major arguments for the greater involvement of primary care in the delivery of dementia care [13]. Furthermore, PCPs frequently see themselves as a provider of social care in some way, where symptoms must be interpreted in the context of the patient's life as a whole (as is required by the patient-centred care model) and attention should be given to the interplay between clinical and social factors. In addition, in countries such as Portugal, PCPs deliver care to several members of the same family, which gives them the opportunity to work with families more effectively, as previously discussed in Sect. 23.3 [68].

Despite the potential that primary care has for providing good quality care to older PwD and their carers, dementia specialists and dementia specialized services still have a major role in providing care. It is possible that this partially results from ways of thinking about illness. Medicine often has relatively few interventions that make a real difference to the patient with a chronic disabling condition (e.g. dementia). Nonetheless, physicians (and patients) dominate the management of the disease. This notion may be rooted in the stereotypical disease form, dominated by the methods and principles of the biological sciences, which it is the function of medicine to treat [94]. Furthermore, these concepts are subject to social, cultural and economic influences, and in recent years there has been a growing tendency to classify states of being as diseases and to medicalization [95, 96]. In this sense, it would matter to know how dementia is conveyed by the social media. A qualitative study [97] of UK national newspaper articles identified a 'panic-blame' framework where dementia was represented in catastrophic terms. Therefore, catastrophizing dementia in an era with so many technological and scientific developments can lead to increasing the demand for specialized medical care.

Given this situation, primary care professionals are in a privileged position to understand the experience and meaning of their patient's dementia, considering its social and emotional consequences for both patients and their family members. All of which enables them to deliver the most proper care to the patient (as a person) and the family.

23.7 Fitting the Current Knowledge on Dementia Care into Portuguese Primary Care

Portugal is a southern European country where the National Health Service (including primary care systems) has attained high standards in several areas of care, despite problems that are yet to be resolved. Dementia stands as an important public health problem where primary care services face major difficulties in tackling the needs of patients and families and remain to a large extent ineffective at this purpose. This picture contrasts with the potential of primary care in Portuguese settings, a case worth exploration in this last section.

In Portugal, the proportion of older people is expected to rise considerably in the forthcoming years, and the prevalence of dementia was estimated higher than the OECD-35 mean rate in 2017 [4]. A recent survey [98] reported a dementia prevalence rate of 9.2% (95% CI 7.8–10.9), using the 10/66 Dementia Research Group algorithm in community-dwelling older people. Despite lack of incidence data, awareness is increasing of the societal burden of dementia.

23.7.1 Brief Overview of Health and Social Care Systems

Everyone in Portugal has access to the mainly tax-funded National Health Service (NHS). In recent years, there have been a number of reform initiatives, and groups of primary health-care centres were created in 2008, aiming at a better use of resources and management structures [99].

However, and regardless of the promising findings of small-scale studies on the potential of brief evaluations, older people's needs assessment in primary care is not routine [100]. In dementia, particular challenges arise, concerning, e.g. diagnosis, home care and general support.

23.7.1.1 Diagnostic and Therapeutic Settings

The role of PCPs regarding dementia management is not formally defined, but these professionals are considered to be the first point of contact for PwD and their families, and they usually provide an important gatekeeping function. PCPs are allowed to prescribe anti-dementia medication, although they do it infrequently and this is not reimbursed as with neurologists or psychiatrists' prescriptions. The prevalence of PwD in primary care has doubled in the last 5 years, from 0.4% to 0.8% of all users [101]. Access to specialized physicians (in the NHS) is limited by waiting time for consultations, mandatory referral, out-of-pocket payment and, in some cases, traveling long distances. There are disparities in GPs' dementia knowledge and skills, along with insufficient support from specialized care and non-medical staff. GPs' gatekeeping functions may actually contribute to diagnosis delay: when referred to neurology or psychiatry, most patients are already at moderate or severe stages [102].

Outpatient clinics specifically for cognitive impairment/dementia are available in public hospitals (mainly connected to neurology services and of the 'memory clinic' type), but access is conditioned by long waiting times and sometimes long traveling distances [103].

23.7.1.2 Home Care and Support for People with Dementia

There is no formal contact person for PwD and their families although the PCP is generally considered the main reference person for NHS users. Team-based community mental health care for older people is rarely available and is not dementia-specific. Most day centres deliver social care for older people in general, and the few dementia-specific day centres are only regionally available. The provision of care at home to meet PwD's basic needs or assist in basic activities of daily living is available nationwide, and in the area of home care, standards have increased significantly during the last decade, from a low level in 2005 [4]. Nursing homes for older people in general are available nationwide, while for PwD they are scarce and only available at regional level. Respite care is available nationwide through the National Network for Integrated Long-Term Care (RNCCI), but not in NHS hospitals [103].

23.7.1.3 Information and Counselling

Information structures aiming to provide information for PwD and their carers regarding dementia and support services are regionally available, mainly through Alzheimer Portugal [103].

On the whole, relationships between health and social care systems are complex, and boundaries overlap [103]. This represents a major problem, more so as case management does not exist in community dementia care, and there is no current official definition of professionals' roles or of standard pathways to health and social care. As a consequence, there are difficulties in timely access to community health/social formal services and insufficient support for carers and families [103].

There have been strong claims that primary care should be much more involved in early diagnosis of dementia and its appropriate disclosure, among other areas (e.g. treatment monitoring in collaboration with specialized care, counselling and support, monitoring carers' health) [102]. This could help meeting the complex biopsychosocial needs in dementia [104].

Nevertheless, opinions may differ on whether primary care services should be more proactive in dementia management or if current focus should be solely on optimizing referral systems and improving follow-up according to indications from highly specialized hospital centres.

23.7.2 A Portuguese Dementia Policy Is Urgently Needed

There is still no official dementia policy in Portugal (either as a strategy or a plan), although an initial proposal [105] was drafted in 2017 by a workgroup of experts in different health and social areas, nominated by the Health Ministry. These experts put forward examples of what should be done in primary care:

- To early identify cognitive impairment and consider referral for specialized assessment or follow-up when appropriate
- To foster collaborations between primary and secondary care, enabling integrated diagnoses (dementia subtype and functional assessment)
- To implement an Individual Care Plan (it is still to be defined if the care manager should be a PCP, nurse, or social assistant)
- To deliver more person-centred and tailored therapeutic interventions to PwD and their families, in coordination with health and social care community services

It must be recognized that this endeavour implies firm, two-way and continuing collaborations between primary, secondary and tertiary care, as well as between primary care and the social sector.

23.7.3 The Complexity of Practice Can Hinder the Implementation of Dementia Policy

The utilization of knowledge, be it a policy or research evidence, necessarily requires the active involvement and skills of health-care professionals, which means it must be adapted locally. In Table 23.1 we frame the current knowledge available and the generic goals advanced for the role of primary care in dementia, taking into account the complexity of primary care practice in Portugal.

In Portugal as elsewhere, as pointed out in major international reports [8, 13], primary care must take a more important role in the delivery and optimization of dementia care. Overall it has been internationally recognized that dementia (often occurring along with frailty and multiple somatic morbidities) calls for integrated, comprehensive, evidence-based and friendly person-centred approaches to prevent nutritional problems, falls, infection, or *delirium*. This calls for a major involvement of primary care, where staff are best acquainted with PwD and their families, while also implying better resourced services, and a serious discussion of task-shifting versus task-sharing approaches [13, 60].

The wide scope of action of primary care is, perhaps, the main challenge for primary care professionals to ensure quality of care for PwD and their carers. The literature concerning dementia care delivery in primary care has evolved so far around the core notion of enhancing primary care professionals' (namely, PCPs') education and of better service coordination regarding dementia (including case management programmes). Unfortunately, approaches focusing on comprehensive, whole-person primary care have been overlooked. In fact, attributing specific roles to PCPs without better understanding PwD's, carers' and professionals' expectations of the roles and responsibilities of PCPs can lead to policy failure.

In order to understand the limited success of primary care in struggling to fulfil the expectations of health-care systems in the last decades,

Table 23.1 Policy aspirations and theoretical expectations and the complexity of practice in Portuguese primary care

	Policy aspirations/theoretical expectations	Complexity of practice in primary care
Under-recognition of dementia in primary care	PCPs should early identify cognitive impairment	Diagnosis processes in primary care do not fit the complexities of ageing
		Lack of education in geriatrics and cognitive impairment in particular
		Lack of non-medical staff in primary care teams (e.g. neuropsychologists)
Coordination/collaboration between primary and secondary care	To accomplish an integrated diagnosis and follow-up	Feedback information from specialists is not mandatory
		Access to patients' health hospital records depends on faulty informatics
		Conflicting relationships between primary and secondary care
		Patients' and professionals' views may compromise policy's aspirations
Case management	To implement an Individual Care Plan Coordination/collaboration with social care (and with secondary/tertiary care)	Large increase in complexity and intensity of clinical and bureaucratical work in the recent years
		Non-clinical activity is undervalued by administration
		Possible funding limitations
		Lack of community resources specific for dementia
Therapeutic interventions	To deliver more person-centred and tailored care (PwD and families) Reframing dementia according to the social model of disability or the biopsychosocial model	Available 'skill mix' is insufficient in primary care
		Lack of community resources specific for dementia

PCP primary care physicians, *PwD* people with dementia

we seriously need to address these concerns through high-quality mixed method health services research.

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