USERS AND HEALTH PROFESSIONALS' PERSPECTIVES REGARDING PORTUGUESE PRIMARY CARE SERVICES: A FOCUS ON DEMENTIA

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Abstract

Dementia is one of the major causes of disability amongst older age people worldwide, challenging governments to integrate a part of dementia care into primary care. However, research suggests that dementia is under-managed in primary care. Multifactorial barriers to dementia management have been identified, and the role of GPs in dementia care is still somewhat controversial.

The goals for clinical care change over the course of dementia and the typical physician-patient dyad often expands to a triadic relationship (the person with dementia, the family carer and the GP) as cognition declines. Evidence about triadic interactions suggests that the quality of interactions in consultations about dementia is unsatisfactory from the perspectives of both carers and physicians.

In the Portuguese National Health Service, family doctors and practice nurses are the first contact point for the majority of persons with dementia and their family carers, but most of these professionals do not have specific training in the area. The Portuguese Dementia Strategy has not yet been implemented, there are no dementia care pathways in place in primary care, and social support for persons with dementia remains limited.

To our knowledge, only a few studies addressed the barriers to dementia care from different perspectives (i.e., patients, carers, GPs and other primary care professionals), and no studies were conducted involving primary care teams and the users of their services. Additionally, since consultation analysis has been used in primary care for a variety of purposes, but to our knowledge, not yet considering dementia triads.

The general aim of this thesis is to contribute to the understanding of how dementia care is delivered in primary care. Specific objectives are: 1) to describe the experiences and perspectives of GPs, persons with dementia and their family carers about the current role of GPs in providing dementia care and the issues that impact on this role; 2) to explore dementia care in the context of triadic consultations; and 3) to explore the obstacles and barriers to the implementation of the Portuguese Dementia Strategy by primary care teams, from the perspectives of service users and professionals.

Using a qualitative approach, this work includes three studies involving primary care centres within the Lisbon metropolitan area, in which purposive sampling was used to recruit the participants. An *ad-hoc* quality framework for dementia care delivery in primary care guided the three studies. In two of them, semi-structured face-to-face interviews were conducted with 10 GPs, 8 practice nurses, 4 social workers, 8 persons with dementia and 10 family carers. In the third study, triadic consultations involving the same GPs, persons with dementia and their family carers were recorded and analysed. The framework approach, the thematic analysis and data triangulation were components of the data analysis.

Our findings suggest that GPs were alone within primary care teams in providing dementia care. Moreover, liaison with dementia specialists (neurologists, psychiatrists) was poor. General practitioners' contribution to dementia management was very limited, mostly relying on specialists to manage clinical symptoms and specific medication. The GPs assessed the impact of dementia on daily life to some extent, but failed to notice the comorbidities related to dementia. The exception were patients with advanced stages of dementia, given that specialists no longer followed them up. Importantly, the GPs had to address different subjects in consultations, which may have conditioned their more specific engagement in dementia care, strictly speaking.

The patients seemed to also have a limited access to dementia services because of undefined roles and poor coordination of health professionals, the lack of social workers and the inadequacy of community services for persons with dementia. Their psychosocial needs seemed to be overlooked, since most professionals and carers had limited views on those needs. The patients may have had additional difficulties in expressing themselves, given the lack of person-centredness of GPs' enquiries and patterns of disabling communication within the triad.

Finally, carers tended to assume the role of informants in most consultations, and their needs were poorly assessed. Therefore, strategies for improving family carers' assessments are needed.

Overall, we need enhanced competence in dementia, nurse-led systematic care of persons with dementia and their carers, and more extensive community support.

The analysis of triadic consultations may provide potential process measures for assessing the quality of clinical practice and consultation training in general practice, but this requires further study.

Our findings strongly suggest that Portuguese primary care teams are not yet prepared to comply with policy expectations regarding the management of dementia.

Resumo

A demência é uma das principais causas de incapacidade nas pessoas idosas em todo o mundo. As autoridades de saúde governamentais enfrentam o desafio de integrar parte dos cuidados de saúde prestados na demência na ação dos Cuidados Primários. No entanto, a evidência actual mostra a existência de barreiras multifactoriais na prestação de cuidados na demência neste contexto, e sugere que o papel dos médicos de família na gestão da demência ainda não é consensual.

Os objetivos dos cuidados prestados na demência mudam ao longo do curso da doença e a díade 'médico-paciente' transforma-se numa relação triádica (a pessoa com demência, o familiar cuidador e o médico de família) à medida que o compromisso cognitivo progride. A evidência disponível sobre as interacções na relação triádica no contexto da demência sugere que a qualidade destas é insatisfatória do ponto de vista dos cuidadores e dos médicos.

Os médicos de família e os enfermeiros são o primeiro contacto para a maioria das pessoas com demência e seus cuidadores familiares no Serviço Nacional de Saúde Português; no entanto, a maioria destes profissionais não tem formação específica nesta área. A Estratégia Portuguesa para a Demência ainda não foi implementada, não existe um plano assistencial integrado para a demência e o apoio social para pessoas com demência continua a ser limitado.

Tanto quanto sabemos, apenas alguns estudos exploraram as barreiras para o tratamento da demência sob diferentes perspectivas (i.e., pacientes, cuidadores, médicos de família e outros profissionais dos cuidados primários), e nenhum estudo envolveu as equipas de cuidados primários e seus utilizadores. Além disso, apesar de a análise de consultas ser usada nos cuidados primários com objectivos diversos, as tríades no contexto da demência não são habitualmente consideradas.

A finalidade desta tese é contribuir para a compreensão de como são prestados os cuidados na demência em cuidados primários. Os objetivos específicos são: 1) descrever as experiências e as perspectivas dos médicos de família, das pessoas com demência e dos seus familiares cuidadores sobre o papel atual daqueles profissionais na prestação de cuidados na demência e as questões que influenciam este papel; 2) explorar os cuidados na demência no contexto de consultas envolvendo tríades; e 3) explorar as barreiras à implementação da Estratégia Portuguesa para a Demência nas equipas de cuidados de saúde primários, na perspectiva dos utilizadores e profissionais dos serviços.

Esta tese baseia-se em três estudos qualitativos, envolvendo unidades de cuidados primários da área metropolitana de Lisboa. O recrutamento dos participantes foi realizado por amostragem intencional. As dimensões da qualidade para a prestação de cuidados na demência nos cuidados primários foram definidas *ad hoc* para orientar os três estudos. Em dois deles, foram feitas entrevistas semiestruturadas face a face com dez médicos de família, oito enfermeiros, quatro

assistentes sociais, oito pessoas com demência e dez familiares cuidadores. No terceiro estudo, analisaram-se as consultas com as tríades envolvendo os mesmos médicos de família, pessoas com demência e seus familiares cuidadores. A análise de dados baseou-se na abordagem referencial, análise temática e triangulação de dados.

Os nossos resultados sugerem que o exercício da prática clínica dos médicos de família na prestação de cuidados na demência era feita de forma isolada nas equipas de cuidados primários. Além disso, a articulação com os médicos especialistas em demência (neurologistas, psiquiatras) era quase inexistente. A contribuição dos médicos de família para a gestão da demência foi muito limitada: contavam com os especialistas para o controlo dos sintomas e gestão da medicação anti-demencial, e apesar de avaliarem alguns dos impactos da demência na vida diária, ignoraram as suas comorbilidades. A exceção foram os pacientes com demência em estádio avançado, uma vez que já não eram acompanhados pelos médicos especialistas. Importa destacar que os médicos de família tiveram que abordar vários assuntos nas consultas, o que pode ter condicionado o seu envolvimento na avaliação da demência.

Os pacientes pareciam ter um acesso limitado aos cuidados e serviços relacionados com a demência devido a: indefinição de funções e má coordenação dos profissionais de saúde, falta de assistentes sociais, e inadequação dos serviços comunitários. As suas necessidades psicossociais pareceram ser negligenciadas, uma vez que a maioria dos profissionais e dos cuidadores tinha uma visão limitada sobre o âmbito destas necessidades. Os pacientes podem ter tido dificuldades adicionais para se expressarem nas consultas, pois verificaram-se estilos de comunicação dentro da tríade que dificultaram a sua participação, e a abordagem dos médicos de família foi pouco centrada na pessoa. Por fim, os cuidadores tenderam a assumir o papel de informadores na maioria das consultas e as suas necessidades foram avaliadas de forma muito limitada.

Em conclusão, os profissionais necessitam ter mais competências na área da demência, os cuidados a prestar pelos enfermeiros a estes pacientes e seus familiares cuidadores precisam ser mais bem definidos, e o apoio comunitário deve ser mais abrangente. São também necessárias estratégias para melhorar as avaliações de necessidades dos familiares cuidadores.

A análise das consultas com tríades pode fornecer potenciais medidas de processo para avaliar a qualidade da prática clínica e do treino de consulta em Medicina Geral e Familiar na área da demência, mas são necessários mais projectos de investigação nesta área.

Os nossos resultados sugerem fortemente que as equipas portuguesas de cuidados primários ainda não estão preparadas para cumprir os requisitos das políticas relativas ao tratamento da demência.

This thesis includes the following publications or submitted manuscripts:

Balsinha C, Gonçalves-Pereira M, Iliffe S, et al. Health-Care Delivery for Older People with Dementia in Primary Care. In: Lima CAdM, Ivbijaro G, editors. Primary Care Mental Health in Older People. Switzerland: Springer; 2019. p. 311-29. https://doi.org/10.1007/978-3-030-10814-4_23

Balsinha C, Iliffe S, Dias S, et al. What is the present role for general practitioners in dementia care? Experiences of general practitioners, patients and family carers in Portugal. Dementia (London). 2020:1471301220977710. https://doi.org/10.1177/1471301220977710

Balsinha, C., Gonçalves-Pereira, M., Dias S, et al. Consultation analysis of dementia triads in Portuguese General Practice: exploratory study. *Manuscript submitted for publication.* 2021.

Balsinha C, Iliffe S, Dias S, et al. Dementia and primary care teams: obstacles to the implementation of Portugal's Dementia Strategy. *Manuscript submitted for publication.* 2021.

Throughout the work presented in this thesis, I was responsible, together with my supervisors and co-authors for study design, data collection, data analysis and interpretation. I was also responsible for drafting the articles for publication and organising the final versions.

Other publications related with this thesis:

Balsinha, C., Gonçalves-Pereira, M. and Iliffe, S. Comment on: Family caregiver assessment in primary care: How to strengthen the healthcare triad?. J Am Geriatr Soc 2021; 69: 2361- 2362. https://doi.org/10.1111/jgs.17276

Gonçalves-Pereira M, Marques M, Balsinha C. Persons with Dementia: The Value of Social Health and Primary Health Care. Acta Med Port. 2021;34(2):169-70. http://dx.doi.org/10.20344/amp.15508

Gonçalves-Pereira M, Marques MJ, Balsinha C, Fernandes A, Machado AS, Verdelho A, et al. Needs for Care and Service Use in Dementia: Baseline Assessment of Portuguese Participants in the Actifcare Cohort Study. Acta Med Port. 2019;32(5): 355-67. http://dx.doi.org/10.20344/amp.11136

Stephan A, Bieber A, Hopper L, Joyce R, Irving K, Zanetti O, et al. Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. BMC Geriatrics. 2018;18(1):131. https://doi.org/10.1186/s12877-018-0816-1

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Contents

Preface

I am interested in what it is being old since I have realised that it might be significantly different from being young. I have learned this with my grandmother, by observing her. What it would to be like to be 80-, 90 years old?

Much later, as a family doctor, I realised that I needed to know more about ageing to be able to better understand the needs and difficulties of the older people that consulted me.

In 2014, I obtained a master's degree in 'Health and Ageing' (1). During this period, I acquired useful knowledge to my clinical practice, I met Professor Iliffe, and Professor Gonçalves Pereira encouraged me to pursue a PhD.

Introduction

Dementia is becoming a health and social problem due to population aging and is one of the major causes of disability for older people worldwide, challenging governments to integrate a part of dementia care into primary care (2).

In 2015, I was invited to join the Actifcare (ACcess to Timely Formal Care) project[1]. The project aimed to analyse the pathways to formal care for persons with dementia and their families across eight EU countries in an attempt to better understand the reasons for inequalities in access to community services (3). This project focused on the intermediate stages of dementia, persons with dementia not using formal community care, e.g. day centres, but relying on informal care. It had different components (e.g. cost-efficiency analysis, identification of best-practice strategies), including a longitudinal cohort observational study (six and twelve-month follow-up) analysing formal service access and utilisation, in addition to the participants' needs and quality of life (QoL) (3).

The primary care services were not the focus of any of the study's components, despite the role of general practitioners (GPs) being mentioned regarding the pathways for referral to formal dementia care (4, 5). In fact, these services coordinate with other parts of the health and social systems, but have other important characteristics regarding dementia care delivery: they are usually the first contact point, and use a comprehensive approach to patients and their families. Moreover, primary care services have several health professionals (e.g. nurses, social workers) other than GPs.

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1 Actifcare was a three year EU Joint Programme – Neurodegenerative Disease Research (JPND) project, launched in January 2014 (https://www.alzheimercentrumlimburg.nl/actifcare) Actifcare was funded under Grant Agreement No. JPND/2013/2, and in Portugal by FCT (FCT - JPND-HC/0001/2012). It was coordinated by Profs. Frans Verhey and Marjolein de Vugt (Univ. Maastricht, The Netherlands). In Portugal, Prof. Manuel Gonçalves Pereira (FCM-UNL) was the principal investigator.

Given that the availability, accessibility and utilisation of these services by the persons with dementia and their family carers are unknown among us, we explored them in the Portuguese Actifcare cohort at the twelve-month follow-up (n=54). The methodology of the cohort study in Portugal is described elsewhere (6).

For the purpose of our specific sub-study on primary care services use, we used two questionnaires focusing on primary care services:

(1) Scale of Patient Overall Satisfaction with Primary Care Physicians[2] (Hojat, 2011) (7). This scale was answered by patients and carers separately, but both regarding the patient's GP.

(2) An *ad-hoc* questionnaire, to explore the perspective of persons with dementia and their carers about the delivery of primary care services. It encompassed the four key characteristics of primary care services that are part of service delivery: access to services, continuity of care, comprehensiveness and coordination of care (8). Questions from the 'Primary Care Evaluation Tool' (8) (open-ended questions), and the 'Verona Service Satisfaction Scale' (9, 10) and '10/66-Dementia Research Group' (11) (Likert scale questions) were adapted. Whenever suitable, the same question had to versions, one focusing on care in general and another focusing on care related to 'memory problems'.

These questionnaires were applied in interview format and were filled out by the interviewers.

An additional tool of the Actifcare protocol (3) was also used: the 'Resource Utilisation in Dementia', which measures medical and informal care resources use. It was completed based on information provided by the carer.

Thirty seven (68,5%) out of the 54 participants had a GP assigned. Eleven persons with dementia were not able to answer the questionnaires. The sociodemographic and clinical characteristics of the participants are described in Table 1.

[2] Translated with permission of Professor M Hojat (personal communication)

Table 1. Sociodemographic and clinical characteristics of the patients with dementia with a registered GP and their family / informal carers at the twelve-month follow-up

	Persons with dementia at follow-up registered with a GP (n = 37)
Age, years, mean (SD)	76.7 (5.8)
Sex, female, *n* (%)	23 (62.2)
Education, years, mean (SD)	6.2 (5.9)
Living together with carer, *n* (%)	32 (86.5)
Dementia type, *n* (%)	
Alzheimer	11 (29.7)
Vascular	5 (13.5)
Mixed	5 (13.5)
Dementia with Lewy bodies	2 (5.4)
Other	4 (10.8)
Unspecified	10 (27.1)
Taking anti-dementia drugs, *n* (%)	34 (91.9)
CDR categories 1 / 2, *n* (%)	33 (89.2) / 4 +(10.8)
Comorbidity (Charlson), mean (SD)	2.8 (1.2)
IALD, median (IRQ)	2 (8)
PSMS, median (IRQ)	3 (3)
	Informal carers (n=37)
Age, years, mean (SD)	67.7 (13.9)
Sex, female, *n* (%)	24 (64.9)
Education, years, mean (SD)	8 (6.3)
Relationship with person with dementia, (spouse/child/other), *n* (%)	22 (59.5) / 13 (35.1) / 2 (5.4)

CDR: Clinical Dementia Rating Scale; IALD: Instrumental Activities of Daily Living; PSMS: Physical Self-Maintenance Scale

Most of the persons with dementia (76,6%) had had an appointment with a GP in the 30 days prior to the interview (Table 2).

Table 2. Resource Utilisation in Dementia (RUD) regarding health care professional visits (n=37)

During the last 30 days, how many times did you visit a healthcare professional?	**N° of patients with visits / N° of visits**
General practitioner	30 / 53
Geriatrician	37 / 0
Neurologist	20 / 20
Psychiatrist	10 / 11
Physiotherapist	3 / 103
Occupational therapist	37 / 0
Social worker	37 / 0
Psychologist	2 / 48

In general, both persons with dementia and their carers were satisfied with the GPs (Table 3).

Table 3 - Overall satisfaction with primary care physicians

	Persons with dementia (n = 26)	**Carers (n = 37)**
Total score[1] of the scale of patient overall satisfaction with primary care physicians mean (SD), median	58.0 (12.7), 61	62.4 (9.2), 66
Examples of specific items with the highest and lowest scores: mean (SD)		
Satisfaction with the current GP	6.2 (1.4)	6.5 (0.9)
Listens carefully	6.2 (1.4)	6.4 (0.9)
Shows respect	6.1 (1.5)	6.5 (0.9)
Explains the reasons for medical tests	5.2 (2.0)	6.3 (1.2)
Has sufficient time during consultations	5.7 (1.5)	5.7 (1.3)

[1] Total score between 10 and 70: 10 items scored in a Likert scale (1 - strongly disagree; 7 - strongly agree)

Most of the persons with dementia (28/37) waited less than two weeks for a routine consultation, and were able to contact their GP by phone (27/37).

Only four patients had received other services than consultations with the GPs, and less than a quarter of the carers had received information about support services at the health centre. This may suggest poor coordination within primary care teams or a lack of professionals with specific knowledge in dementia.

Most participants had limited expectations about what GPs could do in dementia, and lower satisfaction scores with these professionals when memory problems were concerned (Table 4). In fact, half of the persons with dementia (13/26) and most carers (22/37) were unable to rate their satisfaction in the items that were specific of memory problems. Perhaps this happened mostly because they did not consider it a condition to be managed by the GPs, but by specialists instead.

Only one patient had received anti-dementia drug prescriptions from the GP, which may be due to patients being only reimbursed with neurologists' or psychiatrists' prescriptions for this medication (12).

Most patients were followed by a neurologist or psychiatrist (35/37), but our results suggest poor care coordination with secondary care, as it was an item poorly rated by the carers. Some carers reported to the interviewers that there were no communication between the GPs and the specialists (n=7) or that it was them who conveyed the clinical information from the specialists to the GPs (n=14).

Table 4. Satisfaction with primary care services

	Persons with dementia		Carers	
	In general (n=26)	Related to memory problems (n=13)	In general (n=37)	Related to memory problems (n=22)
Satisfaction with access to services				
Appearance and facilities' functionality [1], median (min-max)	n.a.	n.a.	3.59 (1-5)	n.a.
Paying for services [1], median (min-max)	n.a.	n.a.	3.68 (1-5)	n.a.
Satisfaction with continuity of care				
Communication between health centre's professionals [1], median (min-max)	n.a.	n.a.	3.78 (2-5)	3.58 (2-5)
Receiving information [1], median (min-max)	n.a.	n.a.	3.68 (2-5)	3.21 (1-5)
Satisfaction with comprehensiveness				
GP's competence [1], median (min-max)	3.84 (2-5)	3.30 (1-5)	4.11 (1-5)	3.24 (1-5)
Satisfaction with coordination of care				
Collaboration GPs / specialists [2], median (min-max)	n.a.	n.a.	3.00 (1-4)	3.00 (1-4)
Type of care / services at health centre [1], median (min-max)	n.a.	n.a.	4.00 (2-5)	2.73 (1-4)
Overall Satisfaction				
Help received [1], median (min-max)	3.69 (3-5)	3.08 (1-5)	3.76 (1-5)	2.93 (1-5)
Services and healthcare available [1], median (min-max)	3.69 (2-5)	3.00 (1-5)	3.73 (1-5)	2.73 (1-5)

[1] Items adapted from the Portuguese version of the 'Verona Service Satisfaction Scale' (9, 10), Likert scale (1 - Terrible; 5 - Excellent); [2] Item adapted from '10/66-Dementia Research Group' (11), Likert scale (1 - Terrible; 5 - Excellent)

Most of these results were expected to some extent considering some of the characteristics of the Portuguese health system: a deficient coordination between primary and secondary care, the GPs' overload with bureaucratic tasks, the limited number of performance indicators with respect to older people's health, and the absence of performance indicators with respect to dementia care. Additionally, the Portuguese dementia strategy, published in 2018 (13), is not yet implemented. It was surprising to find so many users who had such limited expectations regarding the contribution of GPs in dementia care. General Practitioners need to understand the impact of dementia in the treatment of other chronic conditions, need to know and manage its comorbidities, and provide support to the families, in addition to being the first contact for most of these patients with the health care system.

Another important finding was that most of the patients only accessed GPs' consultations in primary care, without contacting other health professionals. This suggested poor care coordination within primary care teams.

Our reflections about these exploratory results and our direct experience of the context of our primary care services raised a few research questions:

- What is the role of GPs in dementia from different perspectives?
- Do primary care teams make a specific contribution to dementia care?
- What happens in consultations?
- How does our dementia strategy fit into Primary Care's current organisation?

To our knowledge, there are no studies in Portugal that have examined these questions. It is possible that the research findings from other countries also apply to the Portuguese population; however, healthcare needs and healthcare provision are determined by culture, socio-economic factors and national politics, among other factors. Thus a better understanding of how dementia care is delivered in Primary Care is required, considering the perspectives of persons with dementia, their carers and health professionals.

The general aim of this thesis is to better understand how dementia care is delivered in Portuguese Primary Care.

The thesis is organised in seven chapters:

In chapter one, a review of the healthcare delivery for older persons with dementia in Primary Care focuses on what is known about the role of primary care physicians and primary care teams, and its current challenges. Additionally, the chapter frames current knowledge on dementia care into the Portuguese health and social care systems.

Chapter two presents our objectives and chapter three the quality framework that guided the research.

Chapter four to six present three qualitative studies, each one designed and reported both to stand individually and to be part of a wider view on the thesis' subject.

Finally, in the last chapter, overall conclusions are drawn from the three studies, and their implications for practice and future research are highlighted.

1

Health care delivery for older people with dementia in primary care

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Balsinha C, Gonçalves-Pereira M, Iliffe S, et al. Health-Care Delivery for Older People with Dementia in Primary Care. In: Lima CAdM, Ivbijaro G, editors. Primary Care Mental Health in Older People. Switzerland: Springer; 2019. p. 311-29. https://doi.org/10.1007/978-3-030-10814-4_23

Key Points:

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

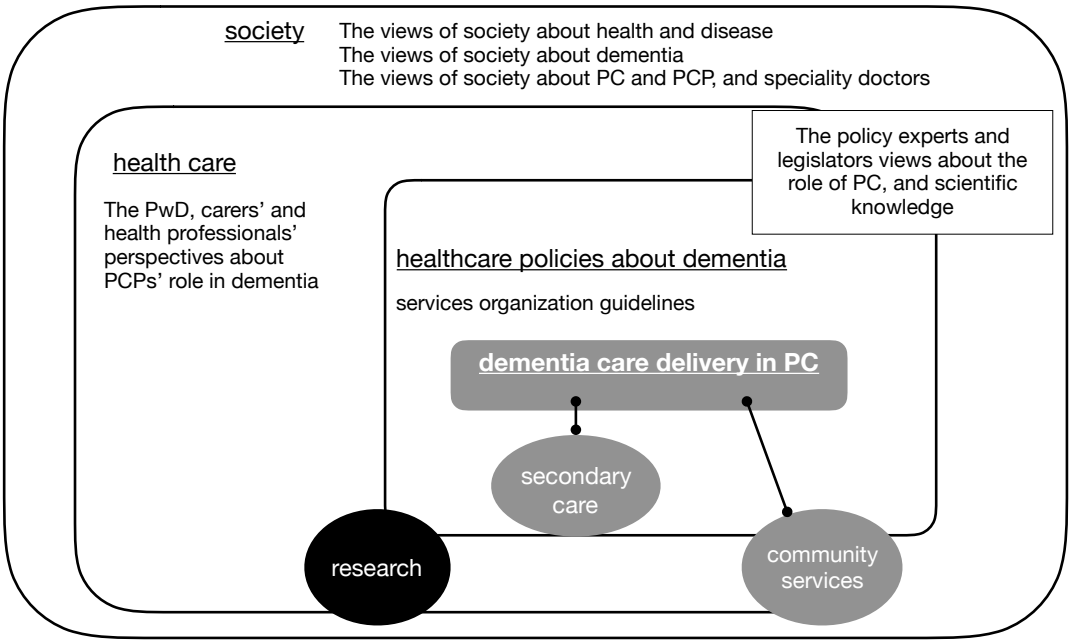
Our world faces continuous growth in ageing populations. In 2015, the population aged 65 years or older represented 7% or more of the total in many countries[1] and 18.9% of the population in the European Union.[2] These demographic changes are leading to a number of challenges for health and social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



PC - primary care; PCP - primary care physicians; PwD - people with dementia

Figure 1. Integrative model of interfaces that shape dementia care delivery in primary care

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, 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[3] 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.

1. 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 responsibilities, 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

[3]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).

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 and 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.

2. 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.

2.1. 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 recognise 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; (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 aging 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]

2.2. 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 optimise 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.

2.3. 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.[45, 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 frequent 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[52] 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 frequent unmet needs identified by the carers were daytime activities and company, and the most frequent 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 policy makers 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.

2.4. 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 backup 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 acquire a 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]

2.5. 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 services organisation 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 Organisation[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 characterise 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 involve 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 medico-legal 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]

3. 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] have 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 co-morbid medical illnesses.

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, 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); 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.

4. 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 to 20 minute 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 program (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 program 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 program 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[53, 81, 83, 84, 86] do not refer to any co-morbidities other than depression.

Additionally, collaborative work with community based organisations or using case managers as a single intervention seem 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.

5. 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 section 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, catastrophising 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.

6. 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), have 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.

6.1. 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 healthcare 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.

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 five 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 are of the 'memory clinic' type), but access is influenced by long waiting times and sometimes long traveling distances.[103]

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]

Information and counseling: 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, amongst other areas

(e.g. treatment monitoring in collaboration with specialized care, counseling and support, monitoring carers' health).[102] This could help meeting the complex bio-psycho-social 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.

6.2. 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 sub-type 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.

6.3.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 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.

Table 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	Feed-back 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 bio-psycho-social model	Available 'skill mix' is insufficient in primary care
		Lack of community resources specific for dementia

PCP - primary care physicians; PwD - people with dementia

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 recognised 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 programs). 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, we seriously need to address these concerns through high-quality mixed methods health services research.

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2

Objectives

The general aim of this thesis is to better understand how dementia care is delivered in Primary Care.

Specific Objectives

1. To describe the experiences and perspectives of GPs, persons with dementia and their family carers about the current role of GPs in providing dementia care and the issues that impact on this role
2. To explore dementia care in the context of triadic consultations (GP, person with dementia and their family carer)
3. To explore the obstacles and barriers to the implementation of the Portuguese Dementia Strategy by primary care teams, from the perspectives of service users and professionals

3

Quality framework

The interview guides and the analysis of consultations drew on a quality framework for dementia care delivery in Primary Care (table 5) defined by the authors according to the available literature (8, 14-16). The face validity of this framework for Portuguese settings was checked with the collaboration of two GPs and two carers.

Access to health services can be defined as 'the ease with which health care is obtained' (8).

Continuity generally means that 'patients/families have a regular source of care over a significant period of time' (8). In this research, we focused on two sub-types of continuity: longitudinal continuity (uninterrupted series of contacts over the long term, in a specific locus from an organised team of professionals), interpersonal continuity (an ongoing personal relationship between the patient and the care provider).

Comprehensiveness is the extent to which different types of health services are provided (e.g. preventive care, palliative care) (8), but for the purposes of this thesis, we focused on the extent to which the different corollaries of dementia were provided, accounting for the professional skills level of the primary health service provider.

Finally, **coordination** involves the integration of all care, making it coherent for the individual patient (8). For the purposes of this thesis, we considered the coordination within the primary care teams, and with other services.

Table 5 - Quality of dementia care delivered in Primary Care for older people (8, 14-16)

Accessibility	Organisational	Appointments (GP, Nurse, Social Worker) Duration of GP's consultation
Continuity	Longitudinal	Endurance of patient-provider relationship
	Interpersonal	Patient-provider relationship (e.g. shows interest, has time to listen, involves patients in decisions)
Comprehensiveness	Disease management	Dementia management (e.g. BPSD, medication management, advanced care planning, ethical and legal considerations) Multimorbidity assessment (e.g. continence, mobility and falls, depression, frailty, polypharmacy) Functionality assessment (e.g. self care, home care)
	Supporting carers	Psychoeducation (e.g. information, competence) Emotional distress Carer burden Carer-provider relationship
Coordination	Cohesion within health centre	Collaboration of GP with other primary care workers
	Coordination with other services	Referral system ,liaison support (with specialist, community services)

4

What is the present role for General Practitioners in dementia care? The experiences of GPs, patients and family carers

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Abstract

Background: Governments are being challenged to integrate at least part of dementia care into primary care. However, little is known about the current role of general practitioners (GPs) regarding dementia care, especially in countries that do not have dementia strategies in place. The aim of this study was to explore the experiences of GPs, persons with dementia and their family carers in Portuguese primary care settings, to better understand GPs' contribution to dementia care.
Methods: A qualitative interview study of participants recruited from six practices in different social contexts within the Lisbon metropolitan area. Purposive sampling was used to recruit GPs, persons with dementia and carers. Interviews with GPs explored dementia care comprehensiveness, including satisfactory and challenging aspects. Interviews with patients and carers explored the experience of talking to GPs about cognitive impairments and related difficulties, and the type of help received. Thematic analysis of interview transcripts was carried out using the Framework approach.
Results: Five major themes were identified: GPs have a limited contribution to dementia care; the case of advanced dementia; doctor-patient relationships; doctor-carer relationships; and management of chronic conditions other than dementia.
Conclusion: General practitioners seemed to contribute little to dementia care overall, particularly regarding symptom management. The exception were patients with advanced stages of dementia, given that specialists no longer followed them up. Remarkably, GPs seemed to be alone within primary care teams in providing dementia care. These findings strongly suggest that Portuguese primary care is not yet prepared to comply with policy expectations regarding the management of dementia.

Keywords: dementia, primary care, general practitioner, carer, family physician, caregiver, health services, health policy, qualitative methods, thematic analysis

Introduction

The increasing prevalence of dementia challenges governments to develop and improve services for persons with dementia, and especially to integrate dementia treatment and care into primary care (Alzheimer-Europe, 2017; WHO, 2017). There is consensus about the essential role of GPs, namely: recognising early manifestations of dementia, disclosing the diagnosis, monitoring and managing care needs, and coordinating care (Aminzadeh, Molnar, Dalziel, & Ayotte, 2012). Nevertheless,

evidence suggests that dementia is under recognised and under managed in primary care (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016).

The few studies assessing the quality of post-diagnosis services indicate primary care underperformance in several domains, for example: assessing signs and symptoms of dementia (Wilcock et al., 2016), managing antipsychotics (Connolly et al., 2012), managing depression (Connolly et al., 2012; Wilcock et al., 2016), and assessing social support and carers' needs (Connolly et al., 2012; Wilcock et al., 2016). Another study indicated that most carers had received insufficient information from GPs, but nonetheless expected their guidance (Peterson, Hahn, Lee, Madison, & Atri, 2016). Foley et al. (2017) explored GPs' dementia care educational needs and found that GPs mostly focused on neuropsychiatric symptoms, while patients and carers identified the need for GPs to engage in counselling and signposting of local services. A more recent study focused on carers' needs and barriers to dementia management in primary care (Wang et al., 2018). Carers seemed to be more in need of care guidance and psychological support, whereas GPs gave limited help because of their heavy workload. Previous research also suggests that persons with dementia may receive lower levels of care for cardiovascular comorbidity compared with those without dementia (Connolly et al., 2013).

Various barriers to the recognition and management of dementia in primary care have been identified and a growing body of evidence focuses on their complex and multifactorial characteristics (Balsinha, Gonçalves-Pereira, Iliffe, Freitas, & Grave, 2019). Three systematic reviews on this topic highlight the importance of patient factors (e.g. non-compliance with care and medication), GP factors (e.g. a general lack of knowledge regarding dementia, lack of training in communicating with the patients and their families) and, thirdly, system characteristics (e.g.limited availability of support services) (Aminzadeh et al., 2012; Koch & Iliffe, 2010; Mansfield, Noble, Sanson-Fisher, Mazza, & Bryant, 2018).

The Portuguese population has currently the third highest estimated prevalence of dementia in OECD countries (OECD, 2019). The Alzheimer Europe Yearbook 2019 estimated that 193,516 persons with dementia lived in the community in Portugal, where the population is over 10 million people (Statistics-National-Institute, 2018). Using the 10/66 Dementia Research Group algorithm, a prevalence rate of 9.2% (95% CI 7.8–10.9) was reported in a Portuguese sample of community-dwelling older people, the authors arguing that strict DSM-IV criteria may underestimate the real prevalence of dementia (Gonçalves-Pereira et al., 2017).

While this represents a public health challenge, everyone in Portugal has access to the National Health Service (NHS), in principle. General Practitioners are considered to be their first point of contact with the NHS, and provide a gatekeeping function (Gonçalves-Pereira & Leuschner, 2018). Portuguese GPs are allowed to prescribe anti-dementia medication, but this is not reimbursed in the way that neurologists' or psychiatrists' prescriptions are. Patient access to these

specialists in the NHS is mainly limited by waiting lists, mandatory referral by GPs, and, in some cases, traveling long distances (Balsinha et al., 2019). Although Portuguese GPs are 'specialists' strictly speaking, the use of this term is commonly applied to doctors other than GPs. Therefore, in this paper the term 'specialist' will refer to neurologists and/or psychiatrists.

A dementia strategy was published in Portugal in 2018 (Dispatch n° 5988/2018). The strategy assigns primary care the tasks of early screening for cognitive impairment, working with secondary care to enable integrated diagnosis and management of persons with dementia, and to coordinate person-centred care for both patients and families with health and social care community services. The implementation of this strategy through an official policy or plan was to follow, but has not taken place yet.

To our knowledge, most of the evidence available on how GPs provide dementia care comes from countries with some type of dementia strategy (Connolly et al., 2012; Peterson et al., 2016; Prince et al., 2016; Wilcock et al., 2016) and little is known about the countries that do not have dementia strategies in place, as is the case of Portugal. Gaining knowledge about the experience of dementia care of patients, carers and GPs could inform future strategies or policies in countries where they are still non-existent or scarcely implemented, but also in those countries where official guidance is more available.

The aim of this study was to explore the experiences and perspectives of GPs, persons with dementia and their family carers about the current role of GPs in providing dementia care and the issues that impact on this role.

Methods

A qualitative study, involving individual semi-structured interviews was performed. A purposive sampling was used to recruit participants (Ritchie, Lewis, & Elam, 2003). Primary care services in different social scenarios within the Lisbon metropolitan area were selected. A contact person in each practice recruited the GPs. The inclusion criterion was experience of providing care to persons with dementia. The GP sample included both genders and a range in years of clinical experience. The persons with dementia were recruited by their GPs, taking into account the inclusion criteria: having a dementia diagnosis according to ICD-10 DCR and being able to give informed consent. The patients with dementia comprised both genders, had different stages of dementia and different types of kinship with their carers. The inclusion criteria for carers were to be the primary carer and to chaperone the patient in consultations. All primary carers were family carers.

The sample size needed was estimated to be 10-12 participants using Guest et al's (2006) methods. Sampling led to an initial recruitment of 10 GPs and 10 dyads of

persons with dementia and their carers, across six general practices. Nine doctors were matched with 10 dyads, and a tenth doctor was recruited for sample saturation purposes. Data saturation criteria were based on an initial analysis sample of 10 interviews and on a stopping criterion of two interviews where no new ideas would emerge (Francis et al., 2009). These criteria were met at the sixth interview with persons with dementia and tenth interview with carers. In the case of GPs, only in the last interview did new ideas fail to emerge.

A total of 28 participants were interviewed: 10 GPs, 8 persons with dementia and 10 carers. Severity of dementia was assessed with the Clinical Dementia Rating (CDR) (Morris, 1993). Two of the ten persons with dementia had advanced dementia (Alzheimer and fronto-temporal sub-types) and were not able to be interviewed. The ability to recall what happened in GPs' consultations was limited by cognitive impairment in three participants. This led us to focus the interview on their subjective experiences, which is also a valid way to learn about the experiences of persons with dementia (Wilkinson, 2005). All interviews were conducted between March and December 2018. For the participants' convenience, the interviews with persons with dementia and their carers took place in their homes, and with GPs at their practices. The interviews were conducted one-to-one to enhance the in-depth approach.

The interview guides drew on a quality framework for dementia care delivery in primary care defined by the authors according to the available literature (Dreier-Wolfgramm et al., 2017; Fortinsky, 2001; Wensing, Mainz, & Grol, 2009; WHO, 2010). The face validity of this framework for Portuguese settings was checked with the collaboration of two GPs and two carers. The interview guides were adapted for the different sets of participants (see Table 1). The present paper reports only the findings related to the current role of GPs.

Six pilot interviews (two with each type of participants) were conducted to assure the length, detail and clarity of the interview guides and to identify gaps in the topics addressed. As a result, some questions were rephrased and sequentially aligned, and prompts were added to clarify the answers.

Interviews were informal in style, enabling specific issues to be explored as and when they arose (Creswell, 2014). Expressions such as 'memory problems' (for dementia) could be used initially when talking to persons with dementia or carers, unless or until they used the specific term 'dementia' or 'Alzheimer's'.

Interviews lasted around 40 minutes and were digitally recorded, transcribed, and anonymised. Transcriptions were always done before the next interview, allowing for new ideas to be explored and discussed by the interviewers (Creswell, 2014). The accuracy of the transcripts was checked by the primary author.

The codebook, designed by the primary author, was tested in coding nine interviews (three of each group of participants) by two of the authors independently. The coding consistency between the two sets was checked and the majority of the

codes were consistent. Inconsistencies were resolved by discussion between the two authors.

The framework approach (Ritchie, Spencer, & O'Connor, 2003), thematic analysis (Braun & Clarke, 2006) and data triangulation were core components of the data analysis. This approach enabled the transcripts to be handled in systematic stages, improving the transparency of results. Thematic analysis allowed inductive logic to be used for themes originally not anticipated to be included.

NVivo 12® was used to manage data analysis and simplify data retrieval.

Table 1. Interviews' Topic Guide

GPs' Interview Guide
Introductory questions Biographical information: personal and professional data, education in ageing and dementia Experience with persons with dementia: satisfactory and challenging aspects Comprehensiveness: dementia management (neuropsychiatric symptoms, anti-dementia drugs), managing comorbidities, carers' support Care coordination within primary care, with secondary care, and with community services (e.g. home care support)
Persons with Dementia Interview Guide
Introductory questions Biographical information: personal data Experience of talking to GPs about dementia/memory problems, and help received Quality of life related to dementia
Carers' Interview Guide
Introductory questions Biographical information: personal data, nature of caregiving relationship, sharing the same GP with the patient The role of GPs in providing care to patients and carers Experience of talking to GPs about dementia/memory problems, and help received Care coordination within primary care, with secondary care, and with community services (e.g. home care support) Quality of life related to caregiving

Findings

The characteristics of participants are summarised in Table 2.

Table 2. Group characteristics (N=28)

General practitioner (n=10)	
Age, years, median (min-max)	50 (31-64)
Sex, female, *n*	6
Specific postgraduate education in dementia /ageing, *n*	0 / 0
Years since medical school, median (min-max)	25 (7-41)
Number of persons with dementia *per* GP, median (min-max)	12 (5-18)
List size *per* GP, mean (SD)	1850 (98)
Person with dementia (n=8)	
Age, years, median (min-max)	77 (71-84)
Sex, female, *n*	5
Education, years, median (min-max)	4 (0-11)
Living together with carer, *n*	5
Years with dementia since the diagnosis, median (min-max)	2,5 (1-9)
Dementia type, *n*	
Alzheimer's disease	5
Vascular dementia	1
Mixed dementia	1
Lewy body dementia	1
CDR category 1/2, *n*	7/1
Charlson, median (min-max)	2 (1-5)
Diabetes diagnosis, *n*	4
Having specialist consultations (neurology, psychiatry) for dementia, *n*	7
Receiving support services on behalf of dementia, *n*	3
Time with current GP, years, median (min-max)	10 (1-14)
Time since last GP consultation, months, median (min-max)	0,5 (0-4)
Carer (n=10)	
Age, years, median (min-max)	61 (44-87)
Sex, female, *n*	7
Education, years, median (min-max)	8 (2-17)
Type of relationship with person with dementia (spouse/child), *n*	5 / 5
Dyad has the same GP, *n*	7
Time with current GP, years, median (min-max)	10 (1-20)
Time since last GP consultation, months, median (min-max)	2,3 (0,02-18)

Six out of the ten GPs were female. The median age of GPs was 50 years. None of them had had any specific training in dementia. The median number of patients with dementia in each of these GPs' register was 12.

Five of these eight patients were female. Their median age was 77 years and their median years of education was 4 years (corresponding to primary school education). Three of the patients lived alone. The median time since the diagnosis was 2.5 years. Seven patients had mild dementia (CDR=1) and seven were being followed in specialist outpatient services for dementia. The median length of registration with the current GP was 10 years. Finally, seven out of the ten carers were female. Their median age was 77 years. Half were spouses and the other half were adult children. Seven of the carers shared the same GP with their relatives.

Five major themes and four sub-themes were identified and are summarized in figure 1.

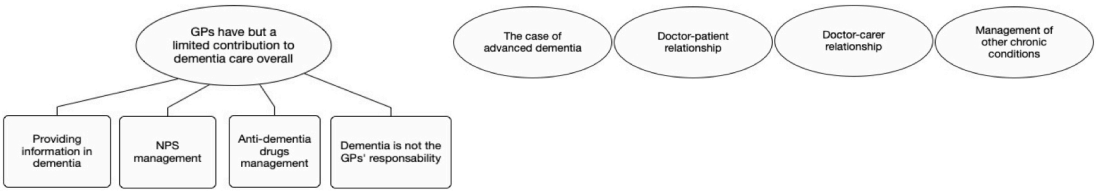

Figure 1. Thematic map

All GPs perceived their role in providing dementia care as a difficult and challenging one. This complexity was highlighted by many GPs and their overall attitude to dementia care tended to be pessimistic.

To better understand how relevant dementia care provision in primary care is, the relative importance of dementia among other patients' chronic conditions was specifically explored in patients' and carers' interviews. None of the patients talked about having dementia or Alzheimer's disease, and only a few identified their 'forgetfulness' as their most important health problem. However, from the perspective of all carers, their dementia was the most important health problem for their relatives.

GPs have but a limited contribution to dementia care overall

Although only a few GPs perceived themselves as very limited in providing dementia care to their patients, none of the patients remembered discussing memory problems with their GPs. Carers also found difficult to identify any meaningful situation where they had received assistance from GPs regarding dementia care specifically.

Providing information in dementia

Most participants reported that it was uncommon for GPs to provide information about dementia. None of the GPs had written information (e.g. a leaflet) available, but also neither carers nor the patients would usually ask for it. The few GPs taking a role on this area reported that providing information was challenging; the symptoms were difficult for families to understand and consequently were wrongly attributed to longstanding personality problems.

> *…understand that the patient is a victim that their behaviour is not just to upset the family, it is not their bad temper…GP7*

In addition, the uncertainty of dementia progression compromised communication, and increased difficulties in disclosing information that could raise further concerns.

> *…it's difficult to anticipate how it's going to be for that patient… and when they question us, it's difficult to give a defined prognosis (…) and to be assertive in addressing their concerns. GP9*

None of the patients mentioned having received information about their 'memory problems'. Furthermore, none of the carers recalled their relatives being informed about their condition either by the specialist or by the GP. Most of the carers themselves reported not having received much information about dementia from GPs or specialists (albeit to a lesser extent), particularly regarding neuropsychiatric symptoms (NPS) management.

> *Well, I don't think that any of them [GP and neurologist] had helped me that much. C6*

This led to reliance on problem-solving for example by searching for information in the internet.

> *…some things I know because I searched in the internet… for instance, I learned that I should avoid antagonising her… C2*

Nonetheless, some carers regarded practical experience as the most important way of understanding dementia and coping with it, perceiving the role of the doctors as irrelevant.

> *No one really helped me to understand this [dementia]… but I think that may not be relevant after all… days go by and will notice the changes, learn by our own … C10*

Neuropsychiatric symptoms management

For most GPs, neuropsychiatric symptoms (NPS) were one of the most challenging areas to manage in dementia and most relied on specialists to treat

these symptoms. Since NPS were essentially considered to be 'aggression' and 'agitation', GPs also perceived them as uncommon in their daily practice.

> *Some situations have to be managed with medication, but generally they are already medicated by the neurologist, so I don't need to do anything. GP8*

When GPs had to manage aggression and agitation symptoms, most of them reported using mainly anti-psychotics, as first-line treatment; however, a few had to use coping strategies to overcome their difficulties in managing the medication.

> *… as we do not prescribe these drugs every day, when I have to do it, I study or talk with my colleagues who have more experience instead. GP2*

Although a few GPs acknowledged the importance of non-pharmacological measures to manage NPS, none of them described helping carers to manage these symptoms.

Only a few GPs usually addressed depression, but only in the context of differential diagnosis in the early stages of dementia.

> *At the early stages is difficult to make the differential diagnosis with depression, especially in the elderly. GP6*

Most patients reported feeling sad or anxious too often without understanding the reasons for mood changes. Frequently, this was not considered a topic to be addressed by health professionals in general (including GPs) but to be accepted rather than confronted.

> *Sometimes I'm sad… but it's hard to say ... because now I'm feeling good, but tomorrow who knows?… That's how it is ... (...) but I have never talked about this with the GP, I never needed to … P1*

Some carers reported difficulties in understanding and managing their relatives' behaviour (particularly paranoid ideas about 'invented robberies'), describing them as being stubborn for not acknowledging their 'forgetfulness'

> *He says unimaginable things ... that everyone steals his things. Things disappear because he doesn't remember where he kept them, and he doesn't acknowledge that, he is very stubborn. C1*

Anti-dementia drugs management

Most of the GPs admitted having very limited knowledge about anti-dementia drugs, partially resulting from the lack of specific training in dementia. Moreover, some stated that the prevalence of patients with a diagnosis of dementia registered in their practices was low as compared with other conditions.

I've never had training in dementia (…) the prevalence of dementia is so much lower than of other conditions that I don't make an effort in studying it, and because I rely on the specialist to do it [anti-dementia drugs management] more effectively… GP2

Some of the GPs ended up delegating the management of these drugs to specialists because reimbursement was only possible with specialists' prescriptions. Consequently, none of the GPs were used to initiating or stopping these medications, identifying their side effects, or adjusting doses.

I don't even prescribe them because they are not reimbursed, so I usually leave it entirely to the specialist. GP8

There was variation in carers' experiences of GPs' management of these drugs. While a few carers reported that their GPs usually renew the prescriptions despite the reimbursement issues, a few others believed that GPs were actually forbidden from prescribing these drugs.

'The GP just cannot prescribe that medication, so we never talked about that.' C1

Dementia is not the GPs' responsibility

One GP referred that 'common sense' regards dementia as a condition to be managed by neurologists, consequently keeping the patients away from GPs.

…most people think that dementia is for neurologists and I think we (GPs) do too. (…) They end up having less contact with us than they should have. GP5

Accordingly, some patients took the view that 'memory problems' were not to be managed by their GPs.

It is not worth talking about that, because the consultation with the GP is not about brains, he is not familiar with that. P9

Other reported that their mood changes were a matter to be taken care of by other professionals.

I don't think it's for the GP, maybe for the psychologist or neurologist… P4

Most carers also believed that dementia was a condition to be managed by 'specialists', being sceptical regarding GPs' actual competence to help them regarding the difficulties they were facing.

I don't know... She is a GP... Maybe, if she had some medical specialty more focused on [dementia]… C2

In line with this, all carers recognised the role of GPs in managing their relatives' health problems in general terms, but most of them restated that this would not apply to dementia.

> *(…) (GP) is very useful for managing other conditions, but with respect to dementia itself I think he doesn't make much difference… he is not the specialist… C5*

The case of advanced dementia

Some GPs perceived themselves as responsible for delivering home care for patients with advanced dementia, although for a few this essentially meant managing intercurrent illnesses.

> *Sooner or later they end up needing home care and that fall upon on us. GP8*
>
> *…when they have intercurrent illnesses, I make home visits. GP3*

Most GPs reported that primary care nurses played a role in home care delivery but only regarding functional independence, since they did not have specific training in dementia.

> *To help in carers education, falls prevention, how to adapt the house, etc. as in any other dependent patient.GP8*

Carers of those patients in more advanced stages of dementia reported that their relatives had been discharged from the neurology clinic for more than one year; consequently, GPs and primary care nurses were the only healthcare professionals available to provide any type of care at home.

> *…the nurses came here a few times with the GP and told us how we should have our home adapted for this condition, I think they were great, very helpful. (…) Now, when we need something we call the GP. C9*

Doctor-patient relationships

The type and quality of doctor-patient relationship was very much influenced by its duration (particularly if it was established prior to the onset of dementia), the characteristics of the dementia condition and the presence of carers during consultations.

A few GPs reported that a longstanding doctor-patient relationship allowed the maintenance of fulfilling relationships even in advanced stages of dementia. Moreover, the knowledge of premorbid characteristics (personality, attitudes) of patients allowed for more person-centred approaches, allowing the doctor to combine a patients' previous wishes with their current needs.

… what satisfies me the most is when is possible to preserve their values, their will, based on what we know of these people and their families. GP4

On the other hand, a few GPs reported that their relationship with the patients could be compromised by pervasive cognitive impairment, which hampered clinical communication.

(…) this patient no longer has… well, he may hear what I say but later on he forgets, so I can't have that much influence on his life, right? GP1

In addition, a few GPs also had difficulties in sympathizing with patients' problems and establishing rapport.

I find difficult to relate to these patients, because we repeat the same things over and over ' watch out for the stairs' … things that families tell them all the time, things they don't agree on, so… I don't think it's easy to foster a trusting relationship with patients with dementia. GP7

In contrast with their attitude towards carers, none of the GPs expressed the need to be alone with the patients; nevertheless, a few did recognise that the presence of the carer during consultations could compromise a truly person-centred approach.

… sometimes I have this concern, I realize that that person no longer has their intimacy because there is always someone present, sometimes someone in control. GP6

Regardless, most patients reported trusting and close relationships with their GPs, describing them as being available, thoughtful, trustworthy, and 'a friend' to them.

I think he's an excellent man concerning talking with patients, he's thoughtful. P4

Exceptions to this were the two patients that had only met their current GP after their diagnosis of dementia and had not established any kind of meaningful relationship.

For a few patients it was difficult to recall what happened in consultations since the 'memory problems' began, so they described their overall impressions of the ongoing relationship with the GPs or gave 'near answers'.

- *How are things going with your GP's consultations?*
- *She is a very delicate lady, very attentive! The best doctor I have ever had, I like her very much. P2*

Doctor-carer relationships

The doctor-carer relationship seemed to be influenced by whether patient and carer were consulting the same GP, system characteristics, and GPs' attitudes to dementia.

Although most GPs expressed empathy about carers' burden, their ability to assess carers' needs depended upon the patient and carer consulting the same GP. This was seen as a necessary condition for GPs having time to assess carers' practical needs (e.g. difficulties bathing their relative), as well as their emotional needs, otherwise they have to advise them to consult with their own GP.

> *It is difficult to help carers who are not my patients. I usually suggest them to talk to their GP. GP8*

All GPs reported providing emotional support to carers, mainly through talking and listening, but only a few reported trying to identify carers' stress, depression or sleeping problems. Moreover, a few GPs acknowledged that carers needed privacy in consultations in order to express their needs and concerns.

> *They are anxious, depressed, with sleep problems; they are another patient.... If they are your patients, it is easier because we can make an appointment for them, namely without the patient with dementia present, right? GP2*

Most GPs identified carers as the key element of care coordination, which mostly consisted in assisting their relatives in daily living activities, ensuring GPs' liaison with specialists (e.g. by transmitting information) and finding support services in the community. This was seen sometimes as ethical obligation (assisting in daily living activities) and as something that could be easier for carers than for practitioners themselves (e.g. mobilising resources).

> *They have to understand that they have to help the patient with the medication, accompany them to consultations ...GP6*
>
> *It's much easier for them [carers] to talk to the neurologist than me (…) they are the liaison with the hospital.GP3*
>
> *… usually they can mobilize resources more easily than I can, and more quickly. GP8*

The few GPs who regarded dementia as subject for specialists, considered the carers to be their primary focus of attention.

> *These carers are almost my only focus of attention in this problem [dementia]. Because, as a doctor, I feel I can't do anything for the patient, I have to send them to the neurologist. GP7*

To some extent, this shift of focus was also the result of an insufficient knowledge about dementia.

… in fact, I feel more like I'm a doctor for the carer than for the patient, perhaps because I don't feel very comfortable in this area, I never had any specific training…GP3

Most of the carers who consulted their relatives' GPs felt supported regarding their own needs.

… although she was ill, there she was, listening to me, talking to me (…) And I felt good, felt supported. C1

On the other hand, one of the carers who had a different GP from their relative felt misunderstood regarding their difficulties as a carer, and that was taking its toll on their health. Other carers did not report any specific needs.

(…) for my sake it would be good that my GP would know the things I do for my mother, always running, sometimes I'm very anxious… if we both had the same GP, they would understand the reason for my complaints. C6

All the carers whose relatives were receiving home support services had to find these services on their own. One of them expressed that it would have been much better if there had been coordination between the health and social services.

But when we had to look for support services, we found no coordination between the practice and social services. C8

Management of other chronic conditions

General Practitioners were recognised by most participants as playing an important role in managing the patients' chronic conditions other than dementia. Nevertheless, none of the GPs reported assessing some specific conditions associated with dementia and with older age, such as frailty or the risk of falls. Polypharmacy was seen as an important issue to address by only one GP, who also highlighted the practical difficulties of the task.

[In this patient] drug management is, by far, the most difficult. I have already de-prescribed several drugs… GP9

Some patients and most carers recognised that GPs played an important role in monitoring chronic health conditions other than dementia, such as diabetes.

I go see the GP because of diabetes… just for that…P7

… (GP) always schedules routine appointments to check blood tests results. C6

Discussion

This study describes the experience of GPs, persons with dementia and their carers regarding dementia care in primary care settings, in a country without a dementia strategy in place. To the best of our knowledge, this is the first study examining the current role of GPs in providing dementia care - and the issues that impact on this - in which data has been triangulated and integrated from multiple sources. Perhaps the most important finding was that these GPs, patients and carers shared limited expectations of what GPs can do about dementia, and these expectations were confirmed by their practical experience; for most of the participants, dementia should be and is mostly managed by specialists. Generally, GPs regarded dementia as a complex and challenging area of care, and for a few of them its low prevalence in these primary care settings, as compared with other conditions such as diabetes, did not justify investment in dementia education. This last finding may reflect lower levels of knowledge about dementia prevention strategies or a pervasive stigma related with dementia, even in health professionals.

The first theme identified was that GPs have a small role in dementia care overall. The triangulation of data from patients, their carers and GPs revealed a stronger emphasis on GPs relying almost exclusively on specialists to manage dementia symptoms.

The general consensus of participants was that GPs rarely provide information about dementia, which is in line with previous research (Foley, Boyle, Jennings, & Smithson, 2017; Peterson et al., 2016; Wang et al., 2018). Surprisingly, this did not seem to be an issue to participants, given that GPs reported that carers did not usually ask them for information and most carers did not perceive it as a task for GPs. This was in contrast with studies suggesting that carers expect GPs to guide them through specific sources of information (Peterson et al., 2016) and provide care guidance (Wang et al., 2018). A possible explanation for these different attitudes is the lower educational background of the carers of this study.

In line with our findings, previous studies found a suboptimal management of NPS in primary care (Connolly et al., 2012; Wang et al., 2018; Wilcock et al., 2016). The triangulation of data in this study suggested that NPS misidentification along with little provision of information about dementia had important consequences for patients and carers alike. Most patients were experiencing emotional distress, regardless of being a symptom of dementia or an expression of emotional reactivity, which was being overlooked by themselves, carers and GPs. In fact, most carers attributed those changes to their character, including stubbornness. If not addressed NPS can have a negative impact on the quality of life of patients and their families. None of the GPs expressed to need training in managing NPS, contrary to the findings in other studies (Foley et al., 2017; Koch & Iliffe, 2010). This may result from GPs relying on specialists to manage NPS, but can also reflect a flaw in the interview

guide to address this topic. Remarkably, when specialists were unavailable, most GPs reported using antipsychotics despite their lack of experience with these drugs. This is in line with literature which suggests that antipsychotic drugs prescription is a common practice (Connolly et al., 2012; Wilcock et al., 2016), despite growing evidence that their use in dementia should be avoided (Directorate-General-of-Health, 2011).

There are different guidelines regarding anti-dementia prescription in Europe (Petrazzuoli et al., 2017); in Portugal, only neurologists' or psychiatrists' anti-dementia drugs prescriptions are reimbursed (Dispatch n° 13020/2011). Petrazzouli et al. (2017) suggested that GPs who were allowed to prescribe anti-dementia drugs claimed higher engagement in dementia work-up than GPs who were not allowed to do it. The study findings were consistent with this; despite Portuguese GPs being allowed to prescribe these drugs, the reimbursement issue seemed to affect their responsibility on their management. Consequently, most carers did not expect GPs to manage these drugs; in fact, a few actually believed that they were forbidden to prescribe them. Importantly, these findings suggest that this reimbursement issue can undermine GPs' image as physicians recognised to manage dementia.

A theme unique to this study was that the patients with advanced dementia were no longer followed up by the specialists. General Practitioners along with primary care nurses were, after all, the only health professionals making home visits to patients with advanced dementia. Nonetheless, the triangulation of data from carers and GPs suggested that the care they provided was mostly related to intercurrent problems (e.g. respiratory infection) and overall dependence, than to dementia itself. These findings might suggest that care needs in advanced dementia would be similar to those of palliative care, where these health professionals may have more training. Surprisingly, none of the participants reported any other participation of nurses than in advanced dementia and diabetes management.

This study findings suggest that a longstanding doctor-patient relationship enabled person-centred approaches from both patients' and GPs' perspectives. These findings extended those of previous research that an established doctor-patient relationship may facilitate the recognition of dementia (Adams, McIlvain, Geske, & Porter, 2005; Pentzek et al., 2019). On the other hand, the dementia process can negatively affect the relationship, impairing communication and the establishment of trusting relationships, which could result from lack of training in communicating with persons with dementia, identified as a barrier in previous studies (Aminzadeh et al., 2012; Mansfield et al., 2018). Moreover, the presence of carers in consultations was reported by only a few GPs as a limitation to a person-centred approach, despite their lack of emphasis on trying to ensure more privacy by interviewing the patient alone.

Being registered with the same GP as the person with dementia made support for carers easier to provide. This was consistent with a previous study that found that

having both carer and patient registered in the same practice would facilitate looking after carers (Parmar et al., 2020). In Portugal, GPs are accountable for the whole family, which facilitates a comprehensive approach to patients and their carers, and brief and simple family interventions (Gonçalves-Pereira, 2017). Despite their privileged position, the support provided by the GPs seemed to be mostly relational (i.e. emotional) rather than a formal psychoeducational approach. A theme unique to this study was carers being the primary concern of those GPs who held nihilistic views of dementia. This attitude poses potential ethical conflicts regarding the best interests of patients.

A consensus among participants was that GPs played a crucial role in managing chronic conditions. A particular example was diabetes. This may contradict previous suggestions that these patients may receive lower levels of diabetes care when compared with those without dementia (Connolly et al., 2013); however, the quality of diabetes follow up was not specifically assessed in the present study.

Importantly, this study findings seem to suggest that some comorbidities related to aging and dementia were overlooked. While none of the GPs mentioned assessing their patients for frailty, recent studies found frailty to be highly prevalent in older patients with dementia in the community, contributing to NPS and carer burden (Sugimoto et al., 2018).

Strengths and limitations

This qualitative study encouraged interviewees to fully express their views on the complex topic of dementia care. The codebook was carefully constructed to optimise the precision of definitions and clarity of themes. The triangulation of data enhanced the validity of findings. Additionally, to understand the current role of GPs in dementia care, it is important to capture the views of both patients and carers (Nolan, Ryan, Enderby, & Reid, 2002). The quality framework that guided the interviews was evidence-based and encompassed suggestions from carers and GPs. Its wide scope (e.g. multimorbidity assessment) ensured relevance to primary care contexts. Suggestions from persons with dementia should have been considered, but recruitment constraints applied.

There were other limitations. The study sample was small, so results are not necessarily transferable to other settings; however, primary care users were from different social settings. Purposive sampling may have introduced bias (e.g., patients nominated by their GPs may have better doctor-patient relationships). It is also possible that patients' and carers' discussions about their own GPs were influenced by the interviewers also being GPs, albeit not from their primary care practice. To address this potential interviewer bias the interviewees' anonymity was assured during the interviews and a teamwork approach was used (Barry, Britten, Barber, Bradley, & Stevenson, 1999). Furthermore, all interviews were conducted in the

participants' own homes. Similarly, GPs interviewed by a fellow GP may have been prone to social desirability bias. However, GP researchers have been shown to gain richer data than non-clinicians when interviewing their fellow GPs (Chew-Graham, May, & Perry, 2002). To address this issue, a teamwork approach was used when analysing and interpreting the data (Barry et al., 1999).

Implications for practice and research

Understanding the experiences of GPs, persons with dementia and their carers may help to plan a realistic role for primary care teams in dementia care. The study findings, particularly the themes not previously reported (e.g. the case of advanced dementia), have implications for clinical practice. For example, picking up the work with people with advanced dementia who are no longer seeing specialists could be the first step in shifting dementia care into general practice. To expand these study findings, future research should focus on the content of GPs' consultations in dementia, and on the characteristics of primary care teams and how they impact GPs' contribution to dementia care.

Conclusion

The findings of this study strongly suggest that primary care may not yet be prepared to comply with the national dementia strategy published in 2018. Future work will explore the barriers to dementia care from the perspective of users and primary care teams.

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5

Consultation analysis of dementia triads in Portuguese General Practice: exploratory study

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Abstract

Background As cognition declines in persons with dementia, medical care tends to be provided within triadic relationships (person with dementia, family carer and GP). However, it is not clear how triadic context affects the content of consultations in primary care.

Aim To explore dementia care in triadic consultations.

Design and Setting Analysis of ten digitally recorded consultations with dementia triads across six Portuguese practices from different social contexts.

Method Purposive sampling was used to recruit 9 GPs, 10 patients and 10 carers. Triadic consultations were recorded, transcribed and analysed. The analytical framework combined codes derived from the transcripts with codes from the available literature. Themes focused on the corollaries of dementia (e.g. need for information), and coordination of services.

Results Dementia-related content took up only 30% of consultations, despite their length (median 27 min). The GPs did not seem engaged in dementia management, their assessments lacked breadth and person-centredness, and interventions were limited. Carers facilitated GPs' assessment of dementia consequences, but their needs were poorly assessed. Patients' self-expression was limited by communication patterns within the triad.

Conclusion It is challenging for GPs to assess dementia among other conditions in a context of fragmented care. Strategies for improving family carers' assessments are needed. The analysis of triadic consultations may provide potential process measures for assessing the quality of clinical practice and consultation training in general practice, but this requires further study.

Keywords

primary health care, family practice, general practice, dementia triads, consultation, qualitative research, communication

Key message

- It is challenging for GPs to assess dementia in the context of fragmented care.
- Strategies for improving family carers' assessments are needed.
- Analysis of triadic consultations may help judging care quality, clinically and in research.

Background

There is a growing body of evidence that dementia is under-managed in primary care (1). General practitioners (GPs) seem to underperform in assessing signs and symptoms of dementia (2, 3), managing associated depression (2, 3), providing information about dementia (4, 5) and assessing social support and carers' needs (2, 3, 6). There are multiple barriers to the management of dementia in primary care, including challenges related to the complex biomedical and psychosocial nature of dementia itself; gaps in knowledge and skills of health professionals, and negative attitudes; and system characteristics (7, 8).

Biomedical models still dominate understanding and treatment of dementia. This leads dementia to be seen mostly as an invariably progressive condition where little is worthwhile beyond the limited pharmacological approaches currently available (9). This perspective conditions the help provided to persons with dementia and their families, and their ability to live better with dementia whilst struggling against its consequences. A complementary perspective that should be considered in primary care settings focusses on valuing 'social health': the ability of a person with dementia to preserve their autonomy and solve daily problems, to adapt to and cope with the practical and emotional consequences of dementia, and to participate in social activities (10).

Many characteristics of the Portuguese primary care system may impact on dementia care (11). General practitioners are gatekeepers within the National Health Service, controlling access to what in many countries are called 'specialists' (neurologists, psychiatrists). In primary care health centres, users are grouped into 'family files' and most nurses work closely with GPs, although current electronic clinical files do not allow sharing of information. General practitioners' consultations also tend to be brief (around the recommended 15 minutes) (12). Finally, Portuguese GPs are allowed to initiate and renew anti-dementia drug prescriptions, but patients pay for prescriptions and are only reimbursed if the prescription is given by a specialist. Unlike other European countries (e.g. UK, Netherlands) Portugal only published its dementia strategy in 2018 and it has yet to be implemented. The Portuguese strategy suggests that primary care should undertake early screening for cognitive impairment, foster integrated diagnosis and management of persons with dementia in coordination with secondary care, and promote person-centred care in coordination with community services. However, a recent study indicated that GPs seem to contribute little to current dementia care in Portugal, suggesting that primary care may not yet be prepared to comply with the national dementia strategy (5).

The concept of 'dementia care triads' has been used to depict systems including the person with dementia, the family carer and the GP, since the typical physician-patient dyad often expands to a triadic relationship as cognition declines (13). A

recent review about triadic interactions, based only on data from interviews, demonstrated their complexity, and highlighted the need to resolve mismatched expectations of individual roles, encourage patients' autonomy, and maintain continuity of care (14). Other studies based on survey methods suggest that persons with dementia are less likely to be actively involved in conversations and decision making as cognition deteriorates (13, 15), and coalitions between carers and doctors often occur (16). However, it is still not clear how triadic interactions with GPs may affect dementia care provision. Consultation analysis has been used in primary care for a variety of purposes (17, 18), but to our knowledge, not yet with dementia triads.

The aim of this study was to explore dementia care in the context of triadic consultations.

Methods

Design

A qualitative study was performed, involving the analysis of routine consultations with dementia triads (GP, person with dementia and their family carer).

Setting

As described in a previous studies (5), six practices within the Lisbon metropolitan area were selected to reflect different socio-economic characteristics.

Sampling

A contact person (GP) in each family health unit recruited the GPs. The GPs' inclusion criterion was that they provided regular care to persons with dementia. Purposive sampling was used to recruit participants (19). The GP sample comprised both genders and different durations of clinical experience. Persons with dementia were recruited by their GPs during routine appointments, regardless of their reason, according to the following criteria: 1) willingness to permit recording of their consultation, 2) dementia diagnosis according to ICD-10 DCR (20); 3) being accompanied by a consenting family carer in consultations. A purposive sample of persons with dementia included both genders, individuals at different stages of dementia and with different types of kinship with their carers. Mental capacity of the person with dementia was determined by the GPs, but lack of capacity was not an obstacle to involvement in the study provided a family member was willing to give proxy consent. All carers were family members.

The sample size needed was estimated to be 10-12 consultations using Guest et al.'s methods (21).

Data collection

All participants filled a brief *ad hoc* questionnaire on demographic data and dementia related information. Data saturation criteria were based on an initial analysis of 10 consultations and on a stopping criterion of two consultations where no new ideas would emerge (22). These criteria were met at the tenth consultation. The consultations were digitally recorded between January and November 2018; all recordings were uninterrupted and had good-sound quality. The place of consultation was either the practice or the patients' home. Consultations were transcribed and anonymised. The accuracy of the transcripts was checked by the primary author.

Data analysis

The framework method (23) allowed management of the transcripts in systematic stages, improving the transparency of results.

All transcripts were coded by two researchers using NVivo 12®. The initial analytical framework drew on available literature (13, 24-27) (see Table 1) and categories generated by the analysis of the first three transcripts, allowing for a combination of inductive and deductive analysis.

Table 1. Dementia quality-of-care in primary care for older people (13, 24-27).

Dementia care delivery	
Patient-doctor relationship	GP shows interest, involves patients in decisions, takes sides
Services Coordination	GP with other primary care workers, referral system / liaison support with secondary care and community services
Dementia management	Fostering cognitive stimulation, behavioural and psychological symptoms of dementia, anti-dementia drugs, advanced care planning
Multimorbidity assessment	Continence, mobility and falls
Functionality assessment	Self care, home care, social activities
Supporting carers	Carer burden, emotional distress, psychoeducation, carer-doctor relationship

An analytic framework with three themes was then developed and applied to each transcript, and differences were resolved by discussion. The transcripts and themes were translated to English by a bilingual speaker after data analysis.

General practitioners address a variety of health concerns in consultations (28); therefore, the length of these non-dementia discussions were quantified, guided by clinical judgement, as a proxy for the amount of time in the consultation focused on dementia (see Figure 1).

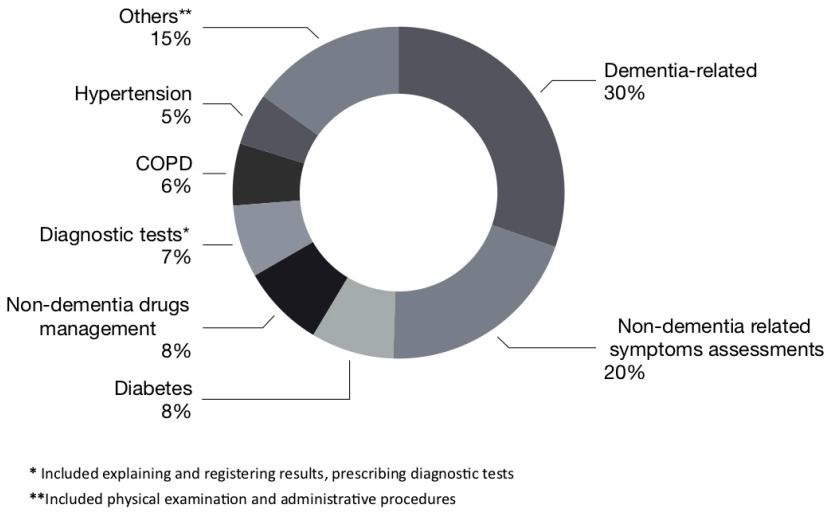

Figure 1. Proportion of topics addressed in consultations according to the transcripts

Consultation pattern was categorised as Doctor-Patient, Doctor-Carer, Doctor-Patient-Carer or Patient-Carer.

Ethics

Ethics approval was granted by the ARSLVT Research Ethics Committee n° 067/CES/INV/2017, and NOVA Medical School Ethics Committee n° 28/2017CEFCM, and written informed consent was obtained from each participant.

Findings

The characteristics of participants are summarised in Table 2.

Table 2. Participants' characteristics

General practitioner (n=9)	
Age, years, median (min-max)	49 (31-64)
Sex, female, *n*	6
Specific postgraduate education in dementia /ageing, *n*	0 / 0
Number of persons with dementia *per* GP's list, median (min-max)	12 (5-18)
List size *per* GP, mean (SD)	1850 (98)
Person with dementia (n=10)	
Age, years, median (min-max)	78 (71-84)
Sex, female, *n*	7
Education, years, median (min-max)	3.5 (0-11)
Living together with carer, *n*	7
Years with dementia since the diagnosis, median (min-max)	3 (1-9)
Dementia type, *n*	
Alzheimer's disease	6
Vascular dementia	1
Mixed dementia	1
Fronto-temporal dementia	1
Lewy body dementia	1
CDR category 1/2/3, *n*	7 / 1 / 2
Having specialist consultations (neurology, psychiatry) for dementia, *n*	7
Receiving support services on behalf of dementia, *n*	5
Time with current GP, years, median (min-max)	10 (1-20)
Carer (n=10)	
Age, years, median (min-max)	61 (44-87)
Sex, female, *n*	7
Education, years, median (min-max)	8 (2-17)
Type of relationship with person with dementia (spouse/child, *n*)	5 / 5
Person with dementia has the same GP, *n*	7

The characteristics of consultations are summarised in Table 3.

Table 3. Characteristics of consultations (n=10)

Characteristics of consultations	
Place (health centre/ home)	8 / 2
Duration, minutes, median (min-max)	26.5 (15-35)
Time since last GP consultation, months, median (min-max)	5 (1-8)
Person with dementia and carer always present, *n*	10
Other symptoms/conditions assessed, unrelated to dementia, median (min-max)	2 (1-4)

The proportion of doctor-patient-carer interactions are shown in Figure 2.

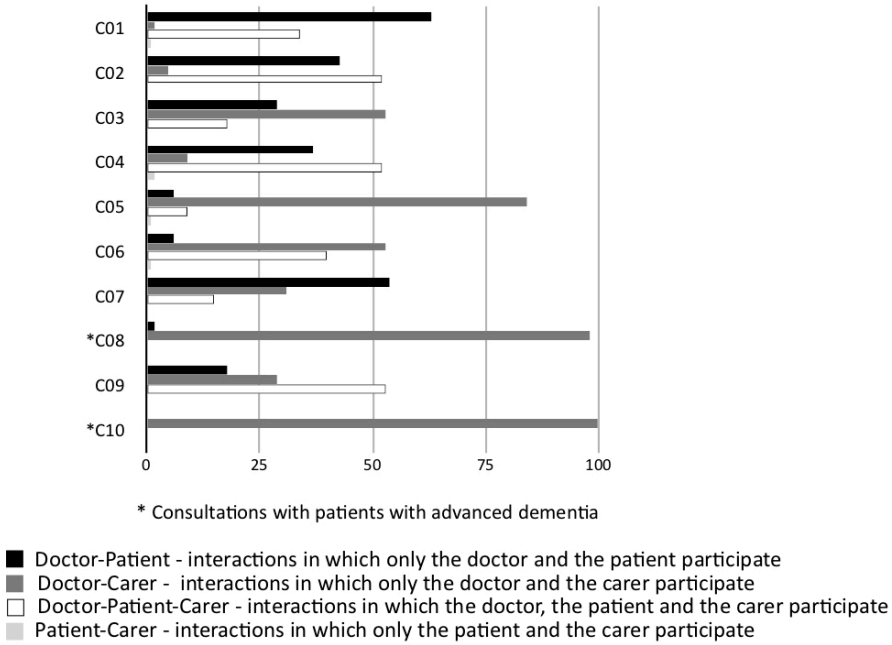

Figure 2. Percentage of text in the transcripts with coded utterances related to the interactions

Three major themes and five sub-themes were identified and are summarised in Table 4.

Table 4. Thematic table

Themes	Sub-themes
Assessment of the impact of dementia on daily life	Patients' needs / functional assessment Carers' needs
Management of the consequences of dementia	Information giving Medication management Providing emotional support: patient / carer
Coordination within primary care, with specialists and with social services	

Assessment of the impact of dementia on daily life

Half of the GPs enquired about sleep disturbances, agitation, and depression, from both patients and carers; although most of these assessments tended to be very brief, a few others were more extensive.

> *GP: And what about your sleeping? You used to sleep well, didn't you?*
>
> *Patient: Yes.*
>
> *GP: How are you doing now?*
>
> *Patient: Not very well since last week.*
>
> *GP: Really? What happened? Can you explain?*
>
> *C04*

Most GPs explored the consequences of dementia with patients and carers alike. They focused almost exclusively on patients' needs related to preparing meals and personal hygiene, disregarding their social relationships. Half of them also explored safety needs, such as medication errors and risk of falling, which seemed to be met.

> *GP: What about your medication? Do you take it on your own, or do they help you with that at the day centre?*
>
> *Patient: I have a pill box with the days of the week.*
>
> *GP: And you don't get it wrong?*
>
> *Patient: No.*
>
> *GP: Don't you get confused?*
>
> *Patient: No, no.*
>
> *Carer: They give her the medication at the day centre.*

GP: Ah! So the pill box is at the day centre!

C02

However, in these assessments, a few carers spoke on behalf of their relatives and sometimes GPs went along with this pattern, despite some GPs trying to involve the patient in the conversation.

GP: (…) She goes to the bathroom alone, doesn't she? [addresses the patient] Do you go to the bathroom on your own?

Patient: Luckily still- [carer interrupts]

Carer: She goes, yes.

GP: And do you need incontinence pants at night?

Patient: No- [carer interrupts]

Carer: No, no, but we have a few accidents because she doesn't always realise she needs to go to the bathroom, I think she doesn't realise (…)

GP: But she uses a little pad, right?

Carer: Yes, always!

C06

In general, the impact of dementia on carers was poorly assessed in these consultations. Most GPs did not actively explore carers' needs. A few carers spontaneously mentioned burden of care but GPs ignored this in half of the cases.

Carer: She really likes being at the day centre. It's a break for me. [laughs] Even better if she was there one more day in the week… Not Sundays, but Saturdays… would be great [laughs]

GP: So… what was the medication prescribed by the neurologist?

C06

In one case, the presence of the patient in consultation seemed to have prevented the carer from expressing their difficulties in addressing the patient's behavioural problems: a look of disapproval in the patient's face noticed by the GP made them change the subject.

GP: What's the most difficult thing for you?

Carer: When we tell her to do things and she won't do them.

GP: Mm-hmm

Carer: And she gets grumpy (…)

[GP assesses how the carer manages patient's behaviour]

GP: It might help distract her with another subject (…)

Carer: Yes, but she…

GP: [addressing the patient] You're making such a face…

Carer: Well, but she remains quite autonomous…

C05

Some GPs asked carers about their difficulties, but only when they lived together with patients. These difficulties were further explored in only one consultation, in which carer-GP interactions dominated.

GP: What's the most difficult thing for you?

Carer: When we tell her to do things and she won't do them

GP: Mm-hmm

Carer: Now she's a little better, but she has days…

C05

Management of the consequences of dementia

In general, GPs' dementia-related interventions were uncommon in these consultations. They did not regularly provide information about dementia. Only one GP briefly instructed the carer on managing behavioural and psychological symptoms of dementia (BPSD) and risk of falls.

Carer: Her stubbornness.... that's basically it, we tell her to do particular things and she decides not to do them (…)

GP: And what do you do then?

Carer: Letting her be, not making a fuss… In the beginning, we used to discuss a lot…

GP: Right..

Carer: But now, I know better…

GP: It might help distracting her with something else.

(…)

GP:…Then there's walking from the bed to the bathroom, when she needs to get up during the night … Do you have any rugs?

Carer: You're right, there's a rug, but I'm going to take it away from there.

GP: Good, either remove or secure it.

C05

Another GP tried to provide information about the diagnosis of dementia, but then abruptly changed the topic, preventing further questions.

Carer: What is sertraline for?

GP: It's for depression. Often, people … women in menopause and older people… the loss of cognitive abilities, memory, etc., is sometimes associated with depression, sometimes not…but we always try to help. You felt better with sertraline, but memory issues persisted. That's why, we did the CT scan and other tests (…) The scan suggested Alzheimer's, didn't it? But we will see what's going on, OK? Let's see… The CT scan showed this, didn't it? You also have anaemia, which got worse. Have you been eating well? Meat? Fish?

C07

While none of the patients questioned their GPs about dementia, a few carers did. One carer asked what caused their relative to have dementia but the GP was vague in their answers.

Carer: Uh ... there's another thing that I don't know whether it had any influence or not. She used to sleep an hour a night, this went on for years (…) She was always working hard ... and she used to drink lots of coffee to stay awake....

GP: Mm-hmm

Carer: Maybe all that influenced this...

GP: Hmm, not really, no ...

Carer: ... because she didn't have enough sleep, and this could have something to do with the situation, right? Couldn't it?

GP: Ah ... not necessarily.

Carer: Just trying to explain this to you, Doctor, just trying to help…

C09

On most occasions GPs did not provide explicit emotional support either to patients or carers. Some patients expressed their difficulties in accepting the consequences of dementia in daily living (e.g. driving ability), but most GPs did not validate their feelings.

Patient: My wife keeps forgetting that she had an accident, obviously not with me at the wheel…

GP: Do you think you are still fit to drive, is that it?

Patient: I think I am, I'll take full responsibility.

GP: So you don't get lost, contrary to what your wife says ...

Patient: Getting lost is different… Doctor, I haven't done thousands of kilometres, I have done millions of kilometers…

GP: You think you can drive just like you did before.

Patient: No, I do have one difficulty: road signs have been changed. But I do manage, I stop and ask for directions. I haven't done hundreds, but millions of kilometers!

C01

Only one GP explicitly explored the patient's psychological distress, by using prosody (changes in tone, stress and rhythm) to convey concern.

GP: OK, so when you talk about 'instability of thought' what do you mean?

Patient: Sometimes it takes me a long time to catch the thread of a conversation, that's it…

GP: Mm-hmm…

Patient: I don't know ...

GP: OK, I understand. Look, have you been feeling sad?

Patient: Yes ...

GP: Do you feel like crying or do you sometimes cry?

Patient: Before, I used to be moved by many things, but after I took sertraline ... it was the only thing that I felt was helping me ...

C04

Furthermore, carers were always present throughout these consultations, and in some cases, both GPs and carers prevented patients from expressing their thoughts and feelings ignoring their autonomy, as was the case of the GP who seemed to collude with the carer by adopting a paternalistic attitude.

Carer: (…) I put the breakfast on the table and it stays there for two hours, getting cold…

GP: But do you eat everything cold?

Patient: Sometimes yes, but I prefer to eat it cold rather than hot because I like to pray early in the morning.

GP: Well, but cold food is not good at all Mr X! [patronising tone]

Patient: But I have my religion…

GP: OK, but praying after eating is as valuable as praying before.

Patient: OK, but in my opinion...

GP: Yes ... it is true, but then after praying, you should warm it up a little bit, again, so that you're not eating things cold, OK?

C03

The few carers who received emotional support from GPs, participated in consultations where doctor-carer interactions dominated. Few GPs used active

listening techniques to facilitate the exploration of carers' concerns. However, one GP addressed fears regarding a patient's diabetes treatment plan by explicitly acknowledging nonverbal communication issues.

> *GP: Since you'll stop her corticosteroid within 6 days, I won't prescribe any insulin... Oh, I see you are staring at me…*
>
> *Carer: It's just…*
>
> *GP: You became quite distressed when…*
>
> *Carer: I'm… a little worried, because when her glycaemia goes up to 400 I get worried…*
>
> *GP: I know, I know ... but I'm tapering the dose of the corticosteroid, and that will lower the glycaemia, you know? So there is no reason for starting another medication and then stopping it, are you with me?*
>
> *C10*

Most patients were taking anti-dementia drugs, but most GPs did not manage them directly (renewing prescriptions or monitoring side effects). In fact, GPs and carers understood this medication to be 'the neurologist's medication'.

> *Carer: And the medication for memory… The one from the neurologist…*
>
> *GP: Exactly… It has to be prescribed by neurologists. (…)*
>
> *Carer: Since there were no great results, she [neurologist] increased the dose.*
>
> *GP: Donepezil? OK. So the present dose is 10 mg/day, is that it?*
>
> *Carer: Yes.*
>
> *GP: Very good. And regarding other medications, what prescriptions are you going to need?*
>
> *C08*

Coordination within primary care, with specialists, and with social services

There did not seem to be any liaison between GPs and specialists. The GPs had to ask carers for any information about the specialists' clinical assessments and patients' current medication.

> *GP: How did the Neurology consultation go? Were there any changes in the medication?*
>
> *Patient: No.*
>
> *Carer: … But they noticed a memory deficit. (…) She made a blood test ...*

GP: What test? Do you know?

Carer: As a matter of fact, no ...

GP: Must be related to the medication… But the medication wasn't changed… And can you tell me the name of the drug that was prescribed?

C02

No coordination with nurses regarding dementia was mentioned in these consultations; however, referrals to nurses were mentioned regarding diabetes. Although nurses were present in the two home visits, their contribution was limited to issues related to general dependency (e.g. carers' training on lifting). No coordination with social workers was mentioned and none of the GPs made referrals to any kind of social support services.

Discussion

Main findings

In a small purposive sample of triadic consultations in general practice involving a person with dementia, a family carer and their GP, consultations were almost twice the length of routine consultations in Portuguese general practice even though dementia-related content took up only 30% of the consultation. These GPs addressed a variety of subjects other than dementia (28). This might have limited dementia specific assessments, and dementia could have influenced, by itself, the assessment of other health concerns, sometimes extending the length of consultations.

Consultation analysis captured enquiries about the impact of dementia on everyday life, management of the corollaries of dementia (need for information, medication management, psychological support), and co-ordination of services. These enquiries lacked breadth and person-centredness, which is of potential concern for those patients and carers whose previous consultation had occurred more than five months previously.

The GPs overlooked dementia's consequences for social relationships and emotional wellbeing, even though most of doctor-patient and doctor-carer relationships were long lasting. This may reflect stereotyping of dementia amongst GPs (29) or their unawareness of the potential benefits of the social health approach (9, 10).

These GPs did not seem engaged in dementia management; providing very little information and emotional support, and mostly not managing anti-dementia drugs. The absence of formal training in dementia or geriatrics, combined with a small number of patients with dementia registered in their lists may compromise GPs'

confidence in addressing dementia. Moreover, the relationship between the patients and specialists may influence these triadic interactions (13), especially because these GPs are not allowed to prescribe anti-dementia drugs (14) which tends to lead to a lower engagement in dementia care (30). Our findings are consistent with the current predominant role of neurologists in Portuguese dementia care, contrary to other health system scenarios in Europe. The role of GPs was neglected and psychiatrists not even mentioned. It is possible that these persons with dementia did not have past psychiatric history nor striking BPSD, both frequently associated with psychiatric referral or follow-up.

Carers' assessments were, in general, poor, and sometimes limited by the presence of patients. In fact these assessments only occurred in consultations in which GP-carer interactions dominated, suggesting that there was insufficient time to assess both the carer and the patient. Furthermore, GPs might prefer to address carers needs in separate consultations given most carers consulted the same GP (5).

Our findings emerged, as expected, in various patterns of communication within the triad. The persons with dementia may have had difficulties to make decisions about their own care due to disabling dementia communication patterns within the triad (26). Both carers and GPs could have limited patients' expression of their thoughts and wishes; the former, by interrupting and speaking on behalf of them; the latter, by downplaying their concerns and colluding with carers (16). On the other hand, carers facilitated GPs' assessments of patients' activities of daily living and safety issues; and facilitated information exchange between the specialists and the GPs, in the absence of truly integrated care.

Notably, there were almost no references to nurses, psychologists or social workers.

Strengths and limitations

To the best of our knowledge this is the first study to use naturalistic data to examine triadic encounters in the presence of dementia in general practice. It did not rely on participants' recall of consultation content. The analysis was performed by two authors with experience in consultations with dementia dyads in primary care, and in clinical communication, which could influence their reflexivity. The analytical framework, allowed for a combination of inductive and deductive analysis.

There were some limitations. This was a qualitative exploration study in Portugal, so results are not necessarily transferable to other settings; however, GPs were recruited from different social settings. The participants were aware they were being tape recorded at the time of data collection, which could have altered their behaviour in consultations, particularly the GPs who could have prepared themselves for a better performance. However, recording consultations for research purposes does not seem to affect their content (31).

General practitioners deliver continuing care to their patients and this study reports findings from just one consultation with each triad; therefore, the quality of dementia care delivery may not be fully reflected in the study findings. However, information on the median time since last GP consultation was provided in order to add context to the findings.

Comparison with existing literature

Consistent with previous research (4, 6, 32), GPs did not seem to provide enough information about dementia. Frequently, neither the patients nor the carers asked GPs directly for this information, nor did the GPs offer them the opportunity to do so; this may indicate that for the patient and carer dementia is not a subject for discussion with the GP (5). Our study supports others suggesting that BPSD assessment is suboptimal in primary care (2, 3), which may result from GPs having unmet educational needs in this area (32). Importantly, this may lead to poor patient health outcomes and higher carer burden (33).

Our findings are also suggestive of 'fragmented care', affecting the GPs and both specialists and social services (e.g. home care, day centres). This is consistent with international experience (34) and with a European study that revealed great problems in accessing social services in Portugal (35). Previous research on the barriers to dementia management in primary care has been focused mostly on the GP factors (7), but potential benefits of involving other professionals in dementia care provision have been recently identified (36).

Finally, our study identified a few disabling communication patterns within the triad consistent with a previous study involving Admiral Nurses (dementia-dedicated nurses in the UK) (16). This may reflect study findings in which triadic encounters are complex, and that the dementia process can impair communication (13-15). However, it may also indicate a lack of training in general practice in communicating with persons with dementia (7, 8).

Implications for research and/or practice

This exploratory study has suggested areas for improvement in dementia care in general practice. Analysis of triadic consultations with persons with dementia might be useful in judging care quality and a larger study could yield different, and perhaps more typical findings, and strengthen their transferability.

Further research focusing on interactions within these triads is needed to identify GPs' needs in consultation training. These results would inform consultation training using scaffolding approaches. Another area for future research concerns the coordination of care taking into account the perspectives of all the stakeholders involved.

Strategies that promote family carers assessments may also improve the quality of care.

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6

Dementia and primary care teams: obstacles to the implementation of Portugal's Dementia Strategy

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Abstract

Background Portugal has a Dementia Strategy that endorses care co-ordination in the community, but the strategy is not implemented despite there being a network of multi-disciplinary primary care clinics that could support it. Recent research into barriers to dementia management in primary care has focused essentially on general practitioners' (GPs) factors and perspectives. A comprehensive triangulated view on the barriers to dementia management emphasising teamwork is missing. We aim to explore the barriers to the implementation of the Portuguese Dementia Strategy by primary care teams, from the perspectives of service users and professionals.

Methods Purposive sampling was used to recruit 10 GPs, 8 practice nurses, 4 social workers, 8 people with dementia and 10 family carers from six practices in different social contexts within the Lisbon metropolitan area. The analytical framework combined codes derived from the transcripts with codes from the available literature. Themes focused on the access to professionals/community services, care coordination within healthcare teams, and between health and community services.

Results Several system barriers were identified (undefined roles / coordination within teams, time constraints, insufficient signposting to community services) along with individual barriers (limited competence in dementia, unrecognised autonomy, limited views on social health and quality of life), hindering users access to dementia services.

Conclusion Enhanced competence in dementia, and nurse-led systematic care of people with dementia and their carers, are necessary. They can be effective in improving the quality of life in dementia, but only if associated with better community support.

Keywords: dementia, primary care, teamwork, general practitioner, carer, person with dementia, practice nurse, social worker, health services, qualitative methods

Background

As the numbers of people with dementia increase, it is unlikely that the current specialist care model will be able to meet their needs. This model is not affordable, and does not facilitate continuing care, holistic management of or care-coordination for complex multi-morbidities; these are core functions of primary healthcare (1).

Currently, there is no cure for dementia, and the goals for clinical care depend on the stage of the disease. Early on, they may focus on maximising function in daily activities and promoting social activities. At least this should be so, according to the recent focus on 'social health' in dementia (2). However, in later stages of dementia the goals may shift to addressing behavioural and psychological symptoms and reducing carer burden. As with other chronic diseases, assessing quality of life (QoL) in dementia is a core task. A metasynthesis of qualitative research identified four relevant determinants (relationships, agency in everyday life, a wellness perspective, and a sense of place); the experience of connectedness or disconnectedness within each factor influences the QoL of people with dementia (3).

Worldwide, dementia is under-managed in primary care (1). Three systematic reviews highlight the complex and multifactorial barriers to dementia management (4-6): people with dementia factors (e.g. non-compliance with care and medication), general practitioner (GP) factors (e.g. lack of knowledge about dementia, unfamiliarity with support services) and system factors (e.g. time constrains; limited availability of support services, and care coordination).

In Portugal, GPs control access to secondary care in the National Health Service. In recent years, a new organisation has been introduced in primary care: family health units consisting of multidisciplinary teams (GPs, practice nurses (PNs) and administrative staff) (7). These units coexist with the traditional health centres, constituting groups of primary care centres, 15 of them in metropolitan Lisbon (8) (Figure 1). The multidisciplinary teams, considered the core teams, are supported by an extended team (e.g. social workers, psychologists) (8). Although this new model allows for the structural organisation of the teams, it still falls short of their functional organisation (i.e. team members having explicit functions to achieve a common goal (9)). In fact, the involvement of PNs in chronic disease management was proposed in 2014 and is still not fully implemented (10), being in place only for diabetes and hypertension. Other constraints on PNs' involvement in dementia care are related to insufficient dementia training, and their relative scarcity compared with other EU countries (11).

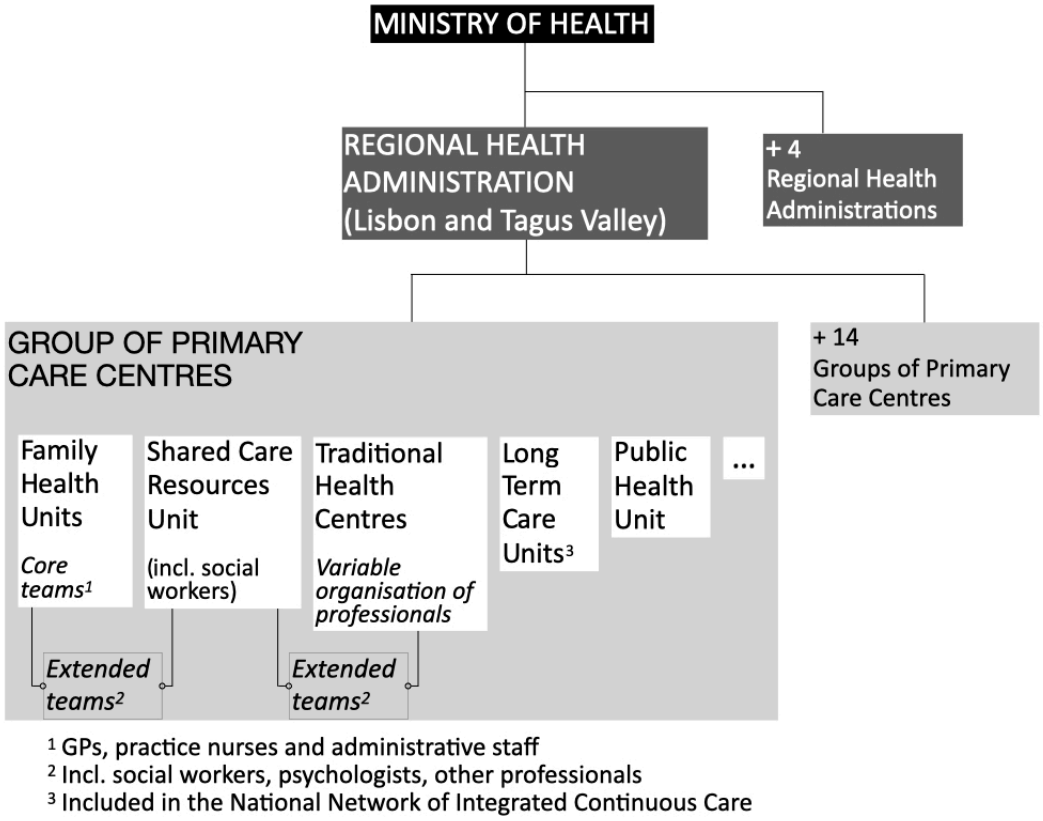

Figure 1. Overview of primary care organisation.

National dementia strategies in Europe emphasise the role of GPs in detecting new cases of dementia, and maintaining the general health of the people with dementia; however, their role in diagnosis, initiating anti-dementia drugs and providing social support is more controversial (4). The Portuguese Dementia Strategy, which was published only in 2018 (12) and has yet to be implemented, outlines the areas of intervention for primary care (e.g. fostering dementia management in coordination with secondary care, promote person-centred care in coordination with community services). However, dementia care pathways in primary care still have a long way to go. Social support for people with dementia is limited, being mostly provided at day care centres that are not specific for dementia, and at home by assistance with basic activities of daily living. Respite services are only available by referral (13).

In an earlier publications (14,15) we explored the role of GPs in dementia care in Portugal and found that GPs contributed little, working alone despite being members of multidisciplinary teams. The provision of dementia care by PNs has been explored in the literature; a recent systematic review identified its potential

benefits (e.g. increased patient accessibility to PNs, early recognition and management of cognitive changes, better care management) as well as limitations (e.g. lack of definition of PN roles, inadequate dementia training, time constraints, and poor communication with GPs) (16).

Despite team-based care being a feature of high-performing primary care (17), previous research on the barriers to dementia management in primary care has focused essentially on GPs' factors (5) and perspectives (4, 5). In our understanding, a comprehensive triangulated view of barriers to dementia management focusing on teamwork is missing. This could inform future strategies in countries with health systems similar to that of Portugal.

The aim of this study is to explore the obstacles and barriers to the implementation of the Portuguese Dementia Strategy by primary care teams, from the perspectives of service users and professionals.

Methods

Design

A qualitative approach was adopted to obtain an in-depth understanding of dementia care (18). Semi-structured face-to-face interviews were conducted. The interview guides drew on available literature (19-22), and were adapted for the different sets of participants (see Table 1).

Table 1. Interviews' topic guide

	GPs	PNs	Social Workers	Patients	Carers
Introductory questions	O	O	O	O	O
Biographical information	O	O	O	O	O
Access to professionals/community services	O	O	O	O	O
Role in dementia	O	O	O		
QoL determinants in dementia	O	O	O	O	O
Care coordination within healthcare teams	O	O	O		O
Care coordination health-social services	O	O	O		O

GPs - general practitioners; PNs - practice nurses; QoL - quality of life

Ten pilot interviews (two with each type of participants) were conducted, resulting in minor adaptations to the interview guide (rephrasing a few questions and adding prompts to clarify the answers). Interviews were informal in style, enabling specific issues to be explored as and when they arose (23).

Setting

As in our previous studies (14), four groups of primary care centres within the Lisbon metropolitan area were selected to reflect different socio-economic characteristics.

Sampling

A contact person (GP) in each family health unit recruited the GPs. Purposive sampling was used to recruit participants (24). The GPs' inclusion criterion was that they provided regular care to people with dementia. The GP sample comprised both genders and different durations of clinical experience. Practice nurses belonged to the same core team as the GPs. Social workers were recruited without any specific criteria given their reduced number in each group of primary care centres. People with dementia were recruited by their GPs, if they had a dementia diagnosis according to ICD-10 DCR (25) and could give informed consent. A purposive sample of people with dementia included both genders, individuals at different stages of dementia and with different types of kinship with their carers. All carers were family members. The sample size needed was estimated to be 10-12 participants per group, using Guest et al's methods (26).

Data collection

Data saturation criteria were based on an initial analysis of 8 interviews with each group and on a stopping criterion of two interviews where no new ideas would emerge (27). These criteria were met at the sixth interview with people with dementia and tenth interview with carers. In the case of GPs and PNs, only in the last interview did new ideas fail to emerge. The criteria were not met in the social workers' group.

A total of 40 participants were interviewed: 10 GPs, 8 PNs, 4 social workers, 8 people with dementia and 10 carers. Severity of dementia was assessed with the Clinical Dementia Rating (CDR) (28). Two of the ten people with dementia had advanced dementia and were not able to be interviewed. Three participants had difficulty recalling the care received, therefore we focused the interview on their subjective experiences (29). The interviews with people with dementia and their carers took place in their homes, and with professionals at their practices. Interviewing was completed before the onset of the Covid-19 pandemic, between March 2018 and May 2019.

Interviews lasted around 40 minutes and were digitally recorded. Transcriptions were done before the next interview, allowing for new ideas to be explored and

discussed by the interviewers (23). The accuracy of the transcripts was checked by the primary author.

Data analysis

The framework approach (30) and data triangulation were core components of the data analysis. All transcripts were coded by two researchers. Using NVivo 12®, the content of three transcripts was initially examined and the codes generated were grouped into categories. The initial analytical framework drew on these categories and was used to code fifteen interviews (three per group of participants) by two of the authors, independently. An analytical framework with six themes was then developed and applied to each transcript, and differences were resolved by discussion.

Ethics

Ethics approval was granted by the ARSLVT Research Ethics Committee n° 067/CES/INV/2017, and NOVA Medical School Ethics Committee n° 28/2017CEFCM, and written informed consent was obtained from each participant.

Findings

The characteristics of participants are summarised in Table 2

Table 2. Group characteristics (N = 41)

General practitioner (n=10)	
Age, years, median (min-max)	50 (31-64)
Sex, female, *n*	6
Specific postgraduate education in dementia /ageing, *n*	0 / 0
Years since medical school, median (min-max)	25 (7-41)
Number of people with dementia *per* GP, median (min-max)	12 (5-18)
List size *per* GP, mean (SD)	1850 (98)
Practice nurse (n=7)	
Age, years, median (min-max)	45 (34-58)
Sex, female, *n*	7
Specific postgraduate education in dementia /ageing, *n*	1 / 1
Years since nursing school, median (min-max)	24 (12-35)
Social worker (n=4)	
Age, years, median (min-max)	47 (38-58)
Sex, female, *n*	4
People with dementia (n=10)	
Age, years, median (min-max)	78 (71-84)
Sex, female, *n*	7
Education, years, median (min-max)	3,5 (0-11)
Living together with carer, *n*	7
Years with dementia since the diagnosis, median (min-max)	3 (1-9)
Dementia type, *n*	6
Alzheimer's disease	1
Vascular dementia	1
Mixed dementia	1
Fronto-temporal dementia	1
Lewy body dementia	7 / 1 / 2
CDR category 1/2/3, *n*	8
Having specialist consultations (neurology, psychiatry) for dementia, *n*	
Receiving support services on behalf of dementia, *n* (CDR category 1/2-3)	5 (3-2)
Time with current GP, years, median (min-max)	10 (1-20)
Carer (n=10)	
Age, years, median (min-max)	61 (44-87)
Sex, female, *n*	7
Education, years, median (min-max)	8 (2-17)
Type of relationship with people with dementia (spouse/child, *n*)	5 / 5
Dyad has the same GP, *n*	7
Time with current GP, years, median (min-max)	10 (1-20)

Four major themes and three sub-themes were identified and are summarised in Figure 2.

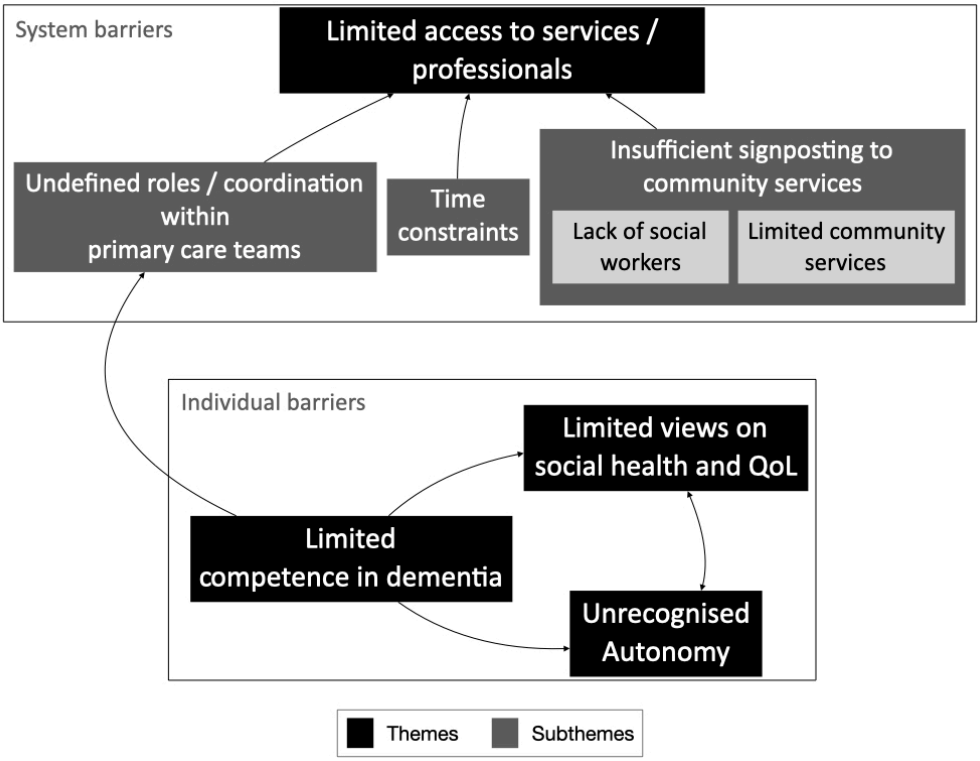

Figure 2. Thematic map.

Limited access to services/professionals

Most participants considered accessibility to be a fundamental feature in primary care; however, they identified several barriers for patients with dementia and their families to accessing primary care and community services (e.g. home care, day centres).

Undefined roles and coordination within primary care teams

All GPs and PNs reported that neither their roles nor coordination within the teams were well defined; which might lead to a dismissive attitude among professionals which could limit access to services, as this GP explained.

> *We are less involved [in dementia] than in other diseases in which we know our role. It's difficult to coordinate with the nurse, because it's not defined as it is for example for diabetes… and altogether this*

makes us dismissive. (…) Access would be better if there were consultations with nurses. GP5

In fact, most GPs and PNs explained that PNs would only know these patients if they had other chronic conditions.

I'm aware of some patients with dementia, but only those I follow for diabetes or hypertension. PN8

Otherwise, they would provide support for functional dependency only in the advanced stages of dementia.

When they become very dependent, that's when we visit them. PN7

Only one PN stated that planned coordination within core teams was necessary, similar to other chronic conditions.

We should have definite functions with these patients, as we have with the diabetics. Following them from the beginning of their illness. PN4

Other PNs took a different view; working together with GPs allowed informal coordination on an as-needed basis.

We don't have a defined role! I'll go to the GP and say 'Doctor, I think this lady is becoming forgetful ... there's something wrong with her!' There is this informality discussing these cases. PN1

None of the social workers questioned their role, but they reported limitations in coordinating with core teams because they were too few to be engaged with each team.

We don't belong to the core teams (…) it's difficult to be far from the family health units, but we are very few, so it wouldn't be possible anyway. SW4

Conversely, all social workers considered the coordination with community services to be good, reporting joint home visits and participation in work groups.

(…) we often do home visits together [with social workers from community services] to assess the situations. SW3

None of the people with dementia referred to professionals other than GPs; some mentioned PNs regarding flu vaccination.

Similarly, carers denied any patient interactions with primary care professionals regarding dementia, other than the GP, with the exception of two carers of patients with advanced dementia whom the nurses assisted regarding functional dependence.

the nurses came here a few times with the GP and told us how we should have our home adapted for this condition (…) C009

Time constraints

Some GPs reported having difficulty scheduling patients in general, and most of them reported that consultation time was insufficient. They explained that people with dementia needed assistance with other chronic conditions, their physical examination was more challenging, and that carers presented their own problems.

> *(…) time is short because these patients are not alone in the consultation and basically there are almost two consultations in one… although often the patient says little, they still have other conditions to be managed (…) GP10*

> *(…) usually adults are able to report their symptoms, but with these patients, we have to pay attention to the physical examination. GP6*

A few GPs believed that PNs played an important role in assessing and supporting the carers; however, most nurses denied having time for those tasks. Most often they only provide essential care to people with dementia and carers in intercurrent illnesses and advanced stages. Some PNs regretted this because they felt they should have a role in carers' psychoeducation.

> *If we had more time ... we're supposed to teach the families, but we're always in a rush, we don't have enough time….PN4*

None of the carers reported that the duration of consultations with GPs was insufficient; on the contrary, most of them perceived consultations to be longer than the standard 15-20 minutes.

> *The other day the GP was with us for almost an hour. C9*

Insufficient signposting to community services

Most professionals acknowledged the importance of advising carers about community services. However, two factors contributed to insufficient signposting: lack of social workers and inadequacy or limited availability of those services.

Most GPs felt that signposting to community services was not their function but a task for social workers. Some of them did not know which services were available and did not have enough time to get that information. They usually referred carers to social workers or to PNs when social workers were not available.

> *When social services are needed, it all becomes complicated. We only have one social worker and that's not enough. I don't have time to get to know all the services and… honestly, it's not my job! It turns out to be the nurse who signposts community services…GP5*

> *I often do the social worker's job! I briefly signpost the services, and carers do the rest… PN6*

We have a social worker one afternoon per week, for a population of 17,000, it's just not enough. GP7

Moreover, most professionals considered that community services were very few or of limited capacity. They focused on day care centres highlighting their inadequacy for many people with dementia, their strict opening hours, and the lack of a transport service.

There should be day centres adapted for dementia. But there are other problems too… In some places there's no transportation. If the carer is working till late, who will pick them up at 5 pm? SW2

Some professionals also reported respite care to be insufficient, which might lead to abuse or neglect.

In some cases, these services are urgently needed when there is a risk of neglecting the patient (…) carers are often at their limit, cannot endure it any longer. PN7

None of the carers recalled having met any social worker throughout the referral process. All reported having directly addressed the community services, but some felt lost in the process.

We should've been instructed at the family health unit, we had to find the services on our own (…) C8

Limited competence in dementia

Some professionals highlighted the need to gain competence in dementia care.

Some GPs attributed their own difficulties regarding dementia treatment to the overall limitations of Medicine in this field. Potential for clinical intervention in dementia was underestimated.

It's hard not to be able to do much for these patients… this is probably one of the great frustrations of medicine in general, right? GP3

For other GPs, having a colleague with a higher level of expertise in dementia could partly overcome the difficulties of speaking directly to specialists.

It would be very important to have someone in family health units who knew a lot about dementia… it's difficult to reach the hospital ... GP2

Some PNs disclosed the negative impact of their lack of competence in dementia on themselves (even their self-esteem) and on the quality of care delivered.

…families often want answers and we sometimes don't know what to say (…) and we think 'what could we have done? We didn't do anything!'… and we feel a little frustrated. PN4

A few people with dementia were unsure regarding their GP's ability to help them with cognitive decline.

> *[the GP] seems to help me, but maybe I needed another help for memory problems, another doctor… I don't know… P7*

In line with the professionals, one carer stated that primary care staff needed to be more competent in supporting them.

> *There should be someone more knowledgeable in how to help families, at the health centre (…) The things I know, came from internet searches…C2*

Unrecognised autonomy

Some GPs acknowledge the impact of the person with dementia's declining autonomy on care delivery. A few reported being sometimes difficult to have a person-centred attitude in consultations; their uncertainties about patients' cognitive abilities, associated with a carer's dominant attitude, might erode the autonomy of people with dementia.

> *When I see the patient, with the spouse or a child, and it's difficult to identify the stage of dementia, I end up addressing only the carer ... Or when I first address the patient and then the carer immediately contradicts them, I shift my focus to the carer... I feel that the patient is only a bystander and that bothers me ...GP10*

Conversely, one GP took the view that longstanding relationships with people with dementia and their families made it possible to respect wishes of people with dementia even in advanced stages of disease.

> *When we accompany these people to the end of their lives, we can work with the families in order to preserve the values and wishes of their relative. GP4*

A few professionals and half of the carers attributed some of the people with dementia's attitudes not to their expression of a will but to mere 'stubbornness'.

> *The son worries about her, but she doesn't want to go to the day centre… she doesn't want this, she doesn't want that, she doesn't want anything! She's very stubborn! SW1*
>
> *He's stubborn, he only does what he wants. If his wife doesn't stop him, it's complicated. GP1*
>
> *The problem is when they don't want to be helped: when they resist doing the things they should, they're like children ... C5*

Conversely, most people with dementia expressed great satisfaction with their ability to make their own decisions. One person explained the importance of having someone who admired their decisiveness.

> *I have a friend, at the day centre, who likes me a lot ... she is everything to me. She thinks I'm determined and that I know what I like and what I want… P5*

Limited views on social health and quality of life

The views of most professionals on people with dementia's QoL were limited to having a family that would keep them safe and support them in their daily activities. Only a few, like GP6, considered it important for people with dementia to have a meaningful occupation and maintain social relationships.

> *Food and hygiene care must be ensured. (…) Social inclusion is also crucial, as is keeping them occupied with things meaningful to them. GP6*

Most of the people with dementia highlighted the importance of social relations but few socialised regularly with friends or neighbours.

> *(…) and then I have breakfast with a group of friends ... knowing that I'm going to meet with them helps me to get out of bed. P7*

Discussion

Summary

This study describes the experiences of primary care teams and their users regarding barriers to dementia care, in a country without an operationalised Dementia Strategy but where teamwork in primary care should be normal practice. Our findings suggest that the teams lacked a defined role in dementia care, and the users had limited access to dementia services because of several system and individual barriers.

The roles of GPs and PNs were undefined, and their coordination of care for people with dementia was limited, relying on co-location. As a result, some GPs seemed to be unaware of the PNs' tasks and most participants suggested that GPs were alone in providing care to people with dementia. Surprisingly, most professionals did not seem to attach importance to formal coordination within teams. The lack of social workers and the inadequate community services for people with dementia explain the limited access to those services.

We have also identified individual barriers to dementia care. Some professionals claimed a lack of knowledge about dementia and few relevant skills. Most

professionals and carers have a limited view of the QoL and autonomy of people with dementia.

Strengths and limitations

To the best of our knowledge, this is the first study examining the barriers to dementia management in multidisciplinary primary care teams from the perspectives of team members and service users. The coding and analysis were performed by two authors with experience in consultations with dementia dyads, which could improve their reflexivity. The analytical framework allowed for a combination of inductive and deductive analysis.

There were some limitations. The sample of social workers was limited but we were able to recruit a social worker in each of the four groups of primary care centres. Our results are not necessarily transferable to other settings; however, primary care teams were drawn from different social settings and at least in Portugal, they could be considered as typical of urban communities and services. Purposive sampling may have introduced bias (e.g. people with dementia nominated by their GPs may have better doctor–patient relationships).

Comparison with existing literature

Our findings suggest that teamwork concerning the needs of people with dementia and their family carers was restricted, which is consistent with previous research (6, 31). The members of the core teams in our study did not have explicit functions regarding dementia care, a central feature of team-working (9). This was particularly evident in the case of PNs, who mostly delivered opportunistic care, despite previous research suggesting that PNs' systematic involvement in dementia care can improve assessment, screening, and counselling (32).

Our findings support others showing that GPs do not signpost to community services (31, 33, 34), and are not familiar with them (33). Despite our finding that PNs would take up the signposting role, they had not received this information from the primary care team. Although it is debatable whether this task belongs to GPs, previous research suggests that people with dementia and their family carers expect to get this information from their family doctor (34). Finally, the poor signposting of community services may be due to the limited supply of dementia-specific services. Best practice recommendations to improve access to and use of home care services or day care are far from being followed in Portugal, as elsewhere (35,36).

The Interdem consensus on social health and dementia advocates helping people with dementia to manage life despite the disease (2); however, our findings suggest that professionals and carers were challenged by the agency of people with dementia. Moreover, most professionals did not recognise the broader QoL and psychosocial needs of their patients, which is also consistent with previous research

(5). These negative attitudes may stem from deficits in knowledge, from biased observation of people living with dementia (37), and from the need to balance safety vs autonomy (36, 38). Importantly, these attitudes contrasted with people with dementia's appreciation of their agency and relationships, as other studies highlighted (3).

Implications for research, policy and practice

This research has identified obstacles to implementation of Portugal's Dementia Strategy in primary care, despite the Country having a well-developed, multi-disciplinary system of primary care. The lack of community support for people with dementia creates an obstacle to policy implementation. Enhanced knowledge of dementia, and nurse-led systematic care are necessary but without community support in the form of social work guidance, home care and re-location to more supportive environments, they may not improve the QoL of many people with dementia and their carers. To test our hypothesis an implementation study is needed, with investment in community resources as the primary intervention, and promotion of dementia pathways in primary care being a supplementary intervention.

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7

Conclusions

Pulling the pieces together

Our aim was to understand how dementia care is delivered in Primary Care. We defined a quality framework (see page 37) that guided our research, and presented our results in three separate studies. Now it is time to put the pieces together.

We found that the **access** to dementia care in primary care was generally undermined by the GPs' and nurses' undefined roles in dementia and the limited coordination within the teams.

In the interviews, was suggested that nurses provided their services to persons with dementia and their families opportunistically, focusing on dependence and only in the advanced stages of dementia. This was partially explained by time constraints and lack of training in dementia. Access to community services also seemed hampered by the inadequacy of those services for persons with dementia and the lack of social workers in primary care teams.

The analysis of consultations supported the interviews' findings: there were no references to nurses or social workers regarding dementia, with the notable exception of the two home visits to the patients with advanced dementia, in which nurses' contribution was nevertheless limited to issues related to general dependency.

Most of the patients in our study had longstanding **relationships** with their GPs, and when interviewed reported trusting and close relationships with those professionals. Importantly, most of the patients still felt entitled to make their own decisions. A few GPs took the view that these longstanding relationships enabled person-centred approaches; however, a few of them acknowledged that the dementia process could compromise those approaches (e.g. uncertainties about patients' cognitive abilities, the presence of carers during consultations).

The analysis of consultations favoured the latter, revealing a lack of person-centredness in GPs' enquiries. Moreover, the patients may have had difficulties to

express themselves on account of dementia-related disabilities but also of disabling dementia communication patterns within the triad.

The findings regarding the corollaries of dementia (**comprehensiveness**) concern mostly GPs' interventions, given the limited accessibility of the users to the other professionals.

The interviews revealed that GPs found the behavioural and psychological symptoms of dementia to be challenging and tended to rely on specialists for their management. Moreover, both GPs and carers also relied on specialists to manage anti-dementia drugs, partially due to the reimbursement issue, and lack of training in dementia of GPs. In fact, most carers took the view that dementia should be and was mostly managed by specialists, despite recognising the crucial role of GPs in managing their relatives' health problems in general terms. These limited expectations of what GPs can do about dementia may explain why carers did not usually ask GPs for information about dementia. In our study GPs did not tend to spontaneously provide this information.

The analysis of consultations supported some of the interviews' findings, but it also revealed that GPs addressed a variety of subjects (e.g. diabetes, hypertension) other than dementia, which might have limited dementia specific assessments. Most GPs assessed some of the impacts of dementia on daily life but their dementia-related interventions were, in general, uncommon. The reimbursement issue was also mentioned in the consultations and seemed to validate the specialists' responsibility for prescribing and managing these medications.

Additionally, the findings of GPs' interviews suggest that some comorbidities related to aging (16) and dementia were overlooked. This was supported by the analysis of consultations, in which only one GP assessed the risk of falling.

Surprisingly, the interviews and consultations data suggested that the patients with advanced dementia were no longer followed up by the specialists. In fact, the GPs and nurses were the only health professionals making home visits to these patients.

The importance of the psychosocial needs has been relatively undervalued in dementia (17). In the Portuguese sample of the Actifcare study (18) the unmet needs of the persons with dementia were mainly identified in the domains of daytime activities, and company. In the interviews, the persons with dementia attached importance to social relations; however, most carers and professionals had a limited view of the QoL and psychosocial needs of the persons with dementia. This may explain the limited interest in the consequences of dementia for social relationships and emotional wellbeing made by GPs in consultations.

Recent research on assessing the needs of carers of older people suggest that GPs conduct unstructured assessments with little focus on caregivers' physical and mental health (19). This is in line with our findings, but in our study most GPs argued

that they could only provide the support that carers needed if they were also registered in their files, as only this would allow them to schedule consultations for the carers themselves.

Most of the professionals of the different groups reported that **coordination** within primary care teams was limited. The coordination within the core teams (between GPs and nurses) was informal, relying mostly on co-location. The coordination between the core teams and the social workers (included in extended teams), was also limited mostly by the lack of these professionals. Conversely, all social workers considered the coordination with community services to be good.

The analysis of consultations supported the interviews' findings: none of the participants made any reference to other primary care professionals regarding dementia, with the exception of the home visits to the patients with advanced dementia.

The coordination with secondary care was also poor; in the interviews, most GPs identified carers as the key element ensuring their liaison with specialists. This was supported by the analysis of consultations, which revealed that carers were the facilitators of information exchange between the specialists and the GPs, in the absence of truly integrated care.

Summing up

The role and coordination of the health professionals regarding dementia were not defined in the primary care teams we studied. As a consequence, GPs seemed to be alone within these teams in providing dementia care. Additionally, liaison with dementia specialists (neurologists, psychiatrists) was poor. The GPs had to address a wide array of subjects in consultations, which may have conditioned their engagement in dementia care specifically. In fact, their contribution to dementia management was very limited, relying on specialists to manage clinical symptoms and specific medication. The GPs assessed the impact of dementia on daily life to some extent, but failed to notice the comorbidities related to dementia. The exception were patients with advanced stages of dementia, given that specialists no longer followed them up.

The patients seemed to also have a limited access to community dementia services on account of the lack of social workers and the inadequate community services for persons with dementia. Their psychosocial needs may have been overlooked, since most professionals and carers had a limited view of these needs. The patients may have had additional difficulties in expressing themselves, given the lack of person-centredness of GPs' enquiries and patterns of disabling dementia communication within the triad.

Finally, the carers tended to assume the role of informants in most consultations, and their needs were poorly assessed.

What are the implications for practice?

The dementia process has several social consequences for the patient. Traditionally, the task of helping people to manage the personal and social consequences of illness is the domain of the social care professions. Nevertheless, it is necessary to bring both the clinical and social perspectives together in consultations in the case of persons with dementia, in order to address many of their unmet needs.

Specialists have a salient role in dementia care in Portugal; however, the work with people with advanced dementia and their carers, who are often no longer seeing specialists, could be the first step in shifting dementia care into Primary Care.

Our findings could also have implications for practice training. In Portugal, the training of junior doctors' communication skills during their Family and General Medicine Internship is already complemented with the analysis of videotaped consultations (20). The analysis of triadic consultations might be useful in judging care quality in dementia, but also in improving communication skills in the context of triadic consultations; and be an outcome measure for educational interventions aimed at general practice. We have an ongoing project at Universidade Nova de Lisboa (The patient, the carer and the doctor in the medical encounter) that aims to explore triadic interactions in primary care consultations in the context of dementia(21), we hope that its findings may contribute to inform these interventions.

What are the implications for research and policy?

This research identified obstacles to the implementation of Portugal's Dementia Strategy in Primary Care: it is necessary to define and promote dementia pathways in Primary Care and, simultaneously, to straighten liaison between primary and secondary care, and to invest in community resources.

Enhancing competence in dementia for GPs and nurses seems necessary, despite the limited effects that isolated educational measures tend to have on care quality.

The complexity of dementia calls for a multidisciplinary approach in primary care services, such as having nurse-led systematic care of persons with dementia and their carers, but this requires further research. However, electronic clinical files must facilitate the specific assessments in dementia (e.g. by identifying the family carers, incorporating assessment scales in a user friendly basis) and allow sharing of information between GPs and nurses.

Family carers' assessments in Primary Care, and the need for strategies for their improvement have been a subject of debate (22, 23). Given that in Portugal many persons with dementia and their family carers would be registered with the same GP, it is possible that carers needs assessments occur in their own consultations, but again further research is needed.

More investigation focusing on care coordination should take into account the perspectives of other stakeholders involved in dementia care, namely neurologists and psychiatrists, and other primary care professionals (e.g. psychologists).

The Portuguese primary care services have a large number of performance indicators, but only a few are related to older age, and none assesses dementia or dementia related comorbidities. The extent to which performance indicators can improve the quality of care is not clear or consensual, but they can help to foster primary care teams' awareness of dementia, and possibly guide professionals in their roles.

Finally, these measures must be accompanied by community support in the form of social work guidance, home care and re-location to more supportive environments, in order to improve the QoL of many people with dementia and their carers. This may be an interesting topic for further research.

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