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Designing a multicomponent intervention to support caregivers of persons with dementia in primary care in Spain: a qualitative study of family and professional carers

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ABSTRACT

Objective The purpose of this study was to explore experiences of family and professional caregivers of persons with dementia in order to design a tailored community-based support programme.

Design A two-stage study was deployed. First, qualitative research draws on three focus groups. Two of these comprised family caregivers and the third was made up of care provision professionals. Thematic content analysis was conducted by interpretative description for applied practice. Second, an experience-based codesign methodology was applied to design a tailored support programme in accordance with carers' demands and contextual realities.

Setting and study period Rural region in Catalonia, at northeast of Spain. March–June 2019.

Participants We interviewed 12 family caregivers and 8 primary care providers.

Results 10 main themes were identified: caregivers' feelings, repercussions of caregiving in caregivers' lives, education about dementia and caring skills, education about time management and self-care, caregivers' needs to receive more information and training, improved patients' follow-up and social assistance and more psychologic support. Finally, three themes related to caregivers' demands: social services resources, multidisciplinary approach programmes and support from other caregivers. From these results, a multicomponent, professionally led community-based intervention was designed. The main components were the following: education and caring skills, professional psychological support, and social and community resources.

Conclusion This study allowed the design of a multicomponent support intervention for family caregivers of persons with dementia aimed at reducing their burden and improving their quality of life in ways consistent with their actual needs and the available local resources.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study generated two distinct datasets through focus groups discussions that provided the experiences and needs of family caregivers and primary care providers of persons with dementia.
- ⇒ The methodology allowed the design of a support programme to reduce the burnout of caregivers of people with dementia in a community health setting.
- ⇒ While the intervention design is valuably fitted to the study setting, it may need adaptation to other communities.

INTRODUCTION

Alzheimer disease and other dementias are diseases with enormous social and health repercussions on patients and patients' families. Currently, the family is mainly responsible for providing the support and care for affected people.[1] It is estimated that persons with Alzheimer disease require about 70 hours of care per week. In these circumstances, informal caregivers are crucially important and become the foundation upon which patients' assistance and care are built.[2] Nearly three-quarters (73.8%) of informal caregivers in Spain are women, with similar numbers in Europe.[3] These gender disparities are also apparent in the kind of care offered. Recent studies show that women spend more time on caregiving and obtain less assistance, and fewer than 5% attend support groups.[4 5] The quality of life of caregivers can vary depending on the psychological and behavioural symptoms associated with dementia, and on specific aspects related to caregivers' families and work responsibilities. Caregiving entails a complex set of tasks that affect various aspects of caregivers' lives: physical and emotional health, family, social life, leisure, work and finances.[2 6] In Spain, 40% of female caregivers reported impaired health (vs 24% of men) and 35% felt depressed (vs 20% of men). Female caregivers also experience greater mental illness and worse self-perceived health.[7] Pinquart and Sörensen found in their meta-analysis a positive relationship between the amount of provided care, depression and caregiver burden.[8] However, the literature is inconclusive on how men and women differ in terms of burden experienced. While some studies indicate that women are more severely burdened as a result of their greater caregiving role, others suggest that men may perceive a heavier burden because they have to fulfil a role for which they have not been socially prepared.[9] The gendered division of work, social class and migration must be accounted for when assessing the impact of caring on caregivers' lives.[10]

Proper assistance of people living with dementia and their caregivers requires the involvement and coordination of many local services to ensure that needs are fully met throughout the disease process: primary care, acute care in hospitals, social services and family associations.[11] However, there is still a lack of consensus about the most effective type of support.[12] Several non-pharmacological interventions seem to be effective in treating depression and anxiety, improving quality of life and reducing caregiver burden for informal caregivers of people with dementia.[13] Concretely, there is evidence demonstrating that interventions aimed at psychological well-being positively impact stress and social outcomes of informal caregivers. As well, interventions focused on knowledge and training on disease management are effective.[14] Furthermore, review of various studies indicates that the most effective interventions identified for decreasing caregiver burden were home care visits and psychoeducational strategies, whether conducted individually or in groups.[15] Also interestingly, when looking at interventions focused on financial assistance separately from those centred on training and other non-financial services, it appears that non-financial support measures have a greater protective effect on caregivers' health compared with financial support measures, irrespective of the caregiver's gender.[16]

Nonetheless, recent systemic reviews and meta-analyses have founded conflicting findings about dementia caregiver interventions mainly due to a high heterogeneity in the methodologies used.[17–19] The use of qualitative methodology is considered essential to enable specific types of burden to be identified and to tailor more effective interventions by considering the demands and needs of the particular target population with respect to the available resources and social context.

The present study aimed to establish the needs of caregivers of persons with dementia and the opinion of professionals across disciplines about educational aspects and caring skills training, in order to codesign with main stakeholders a flexible, dynamic and effective caregiver support programme based on community primary care assistance. This study stems from the first phase of the *School of Caring Project*, which aims to improve caregivers' quality of life, levels of overload, self-care and social support. The project involves a mixed-methods study of three phases: phase I: modelling and operationalisation of the intervention (qualitative); phase II: quasiexperimental effectiveness study with repeated preintervention and postintervention measures (quantitative); phase III: evaluation of the intervention programme (qualitative).[20]

METHODS

Study design

This study employed a qualitative methodology for applied practice[21] based on focus groups (FGs) and a codesign process consisting of a tailored community programme designed to support family caregivers.[22] The theoretical framework encompassed the methodological basis of phenomenology and descriptive/interpretative thematic content analysis.[23] The main findings served to define the components of the codesigned intervention.[24] The Consolidated Criteria for Reporting Qualitative Research, a 32-item checklist, was used to accurately describe the design, conduct, analysis and findings of the study[25] (online supplemental Annex 1).

Setting and participants

Participants were professionals representing different care provision disciplines and family caregivers of persons with dementia with recognised social dependence grade 1 or 2,[26] from Montsià, a rural region of Catalonia in the northeast of Spain.

Participants were selected by purposive sampling.[27] A list of caregivers, of whom at least 60% were women,[28] was obtained from the electronic health record of the Catalan Institute of Health primary care census of persons with dementia with a registered main caregiver. They were contacted by phone following the census list according to sex, age and caregiving duration, in order to obtain a heterogeneous and diverse sample. We contacted 20 caregivers until we obtained the agreement of 12 of them to participate. Professionals were selected according to their professional role and years employed in dementia assistance (primary care, local social services or local Association of Relatives of Alzheimer's Patients), and approached face-to-face by the research team. Eight professionals accepted the invitation to participate in the FG. All participants orally agreed to participate in the study and gave their signed, informed consent. Characteristics of family caregivers and care provision professionals are presented in tables 1 and 2, respectively.

Data collection

Data were generated from three FGs, two with family caregivers and one involving care provision professionals. The FGs were held in a room of a primary care centre and led by a member of the research team who had broad expertise in qualitative research (GML). A second member of the team with considerable expertise in dementia care acted as an observer and took field notes during the FGs (NBR). Neither team member had had any previous

Table 1 Demographics of family caregivers

Code	Sex	Age (years)	Educational level	Occupation	Relationship to patient	Caregiving duration (years)
C1	Female	60–70	Primary education	Homemaker	Daughter	1–5
C2	Female	60–70	Secondary education	Active	Daughter	<1
C3	Male	70–80	Primary education	Retired	Husband	1–5
C4	Male	50–60	Primary education	Active	Nephew	1–5
C5	Male	70–80	Illiterate	Retired	Husband	6–10
C6	Female	50–60	Primary education	Active	Daughter	6–10
C7	Female	70–80	Primary education	Retired	Sister	1–5
C8	Female	60–70	Higher education	Retired	Daughter	1–5
C9	Female	60–70	Primary education	Homemaker	Daughter	6–10
C10	Female	80–90	Secondary education	Homemaker	Wife	1–5
C11	Male	60–70	Primary education	Retired	Husband	1–5
C12	Female	50–60	Primary education	Active	Daughter	6–10

relationship or contact with the participants. FGs were held in March 2019.

The FGs explored the experiences and narratives of caregivers and professionals relating to their role as carers of persons with dementia and how their visions could contribute to designing a programme that matched their realities. To this end, we created two topic-scheduled interview guides, one for family caregivers and the other for care provision professionals. Both guides covered the following main topics for discussion: (1) impact of being a caregiver, (2) education received about the role of being a caregiver, (3) caregivers' needs and (4) demands for programmes to support caregivers (Online supplemental Table S1). FG sessions lasted 60–70min, were video-recorded and audio-recorded and were transcribed verbatim anonymously by an independent expert in qualitative healthcare research. Transcripts were not returned to participants for comment or correction.

Data analysis

FG transcripts were initially coded and analysed following an interpretivist paradigm by the independent professional who transcribed verbatim. A first triangulation with the principal investigator of the study (CCR) was conducted to reconcile differences of interpretation. A second triangulation was carried out by another member of the research team (MPA) in which the interpretative analysis of the three researchers was considered. Subsequently, coding sorting and organisation were undertaken to construct rational relationships between the codes and patterns, thereby to define the meaningful themes. An inductive/deductive approach was used to identify themes. No specific software was used to manage the data. Differences in data structuring and theme construction were discussed, deliberated and resolved to reach agreement about the main emerging themes,[29] which were then arranged to tackle each topic of interest. At this point, it was considered that informational redundancy was achieved. Finally, interpretations were summarised and supporting quotations provided in order to present the most relevant findings.[30]

Intervention codesign approach

A coproduction group of nine experts was set up, consisting of four members of the research team, two primary healthcare professionals (a nurse and a general practitioner), a local social worker and two members of the Association of Relatives of Alzheimer Patients

Table 2 Profile of care provision professionals

Code	Sex	Age (years)	Profession	Years employed
P1	Female	50–60	Nurse	24
P2	Female	30–40	Physiotherapist	10
P3	Female	30–40	Nurse	8
P4	Female	50–60	Nurse	33
P5	Female	40–50	General practitioner	23
P6	Female	40–50	General practitioner	19
P7	Female	30–40	Social worker	6
P8	Female	40–50	Social worker	17

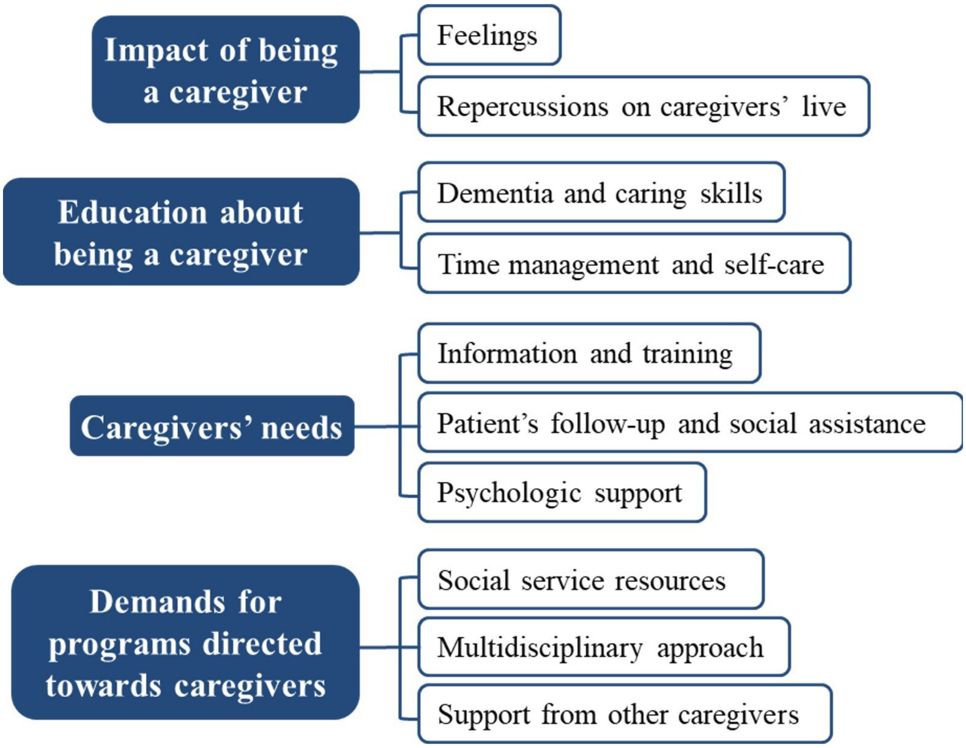

Figure 1 Findings of thematic analysis. Main themes emerging from thematic content analysis (white boxes) were organised to address each topic of study (dark blue boxes).

(a psychologist and an experienced family caregiver). Overall, we engaged experts in research methodology, intervention implementation, management of behavioural and psychological symptoms of dementia, and management of caregivers of people living with dementia. The coproduction group met four times during June 2019 to define the main components required for the tailored intervention: first session: expose and discuss the main findings of the thematic analysis; second session: expose and compile evidence from existing interventions; third session: integrate the results obtained in the present study with previous evidence. fourth session: define the setting, timings, session content and duration, materials, instructors and dissemination plan of the *School of Caring* intervention.

Patient and public involvement

Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

RESULTS

Findings of the thematic analysis

We identified 10 themes from the thematic content analysis. As described in the methods, each theme was allocated to address the main topics under study (figure 1). Caregivers described their wide range of feelings about the diverse repercussions of caring on their lives, and their perceptions of the education received about dementia and self-care. The caregiver and professional groups both identified receiving information, patient follow-up and social assistance, and psychological support as being prior needs of caregivers.

Impact of being a family caregiver

Feelings

Participating caregivers tended to take on the task of caring as a personal obligation. Depending on the case, this task resulted in different degrees of overload, determined by various factors such as the behaviour of the patient, the progression of the disease and family circumstances.

> It is something that I must do, I have no choice, but I do it and provide everything so that she will be fine. (C3)

The professional participants also identified feelings of commitment in some caregivers and reported that most of them assumed the role of caregiver as a personal, self-imposed responsibility and in order not to disappoint the cared-for family member.

> I have to do it, they say. A caregiver told me: I promised my mum that I would take care of her. (P3)

Some caregivers felt frustrated because they were unsure if they were taking proper care of their family member.

> I don't know if I am doing it right, if I am acting right or not, if I take good care of her, it is a constant concern all day long. (C5)

Professionals also perceived that, especially when the dementia was first diagnosed, caregivers were not aware about what caring for a person with this type of disease involved.

> They [caregivers] ask for help because since they spend much time at work, they cannot assume 100% of caring and are afraid of giving up. (P8)

Caregivers felt pain and sadness to see how their loved one was deteriorating, and felt lonely because they had had to stop doing many of the things that they used to do together. Further, they sometimes felt mistreated by the patient, which affected them deeply.

> She was a very nice person but now their words are always to offend you, I know she is insane, but it hurts anyway… (C1)

In general, caregivers considered that the caring overload always fell on the same person, the main caregiver. Thus, they were disappointed that other family members remain uncommitted. This situation caused them to feel a lack of recognition and support from the rest of the family and friends, and a profound sense of being misunderstood.

> Family and friends have many opinions… not everyone understands it, which makes me very angry. (C10)

Repercussions on caregivers' lives

Caregivers identified some aspects of their life that were directly affected by their role as a caregiver. They perceived detrimental effects, above all on their physical and psychological health, also on their free time and social relationships, and finally on their financial circumstances. With regard to physical effects, caregivers reported tiredness, anaemia and sleep disorders. They noted the psychological effects of a distressing feeling of uncertainty when the initial diagnosis was made that hindered their acceptance of the situation, and of suffering the tremendous pressure of the continuous and permanent responsibility of their caring tasks.

> …very tired. I work seven hours a day and then I get home. I had to ask for a houseworker. I can't, I can't… (C8)
>
> For us it is an everyday job, day after day. (C11)

Referring to their social relationships and free time, caregivers mentioned that since their involvement in caring was almost full-time, they did not have time to do anything or go anywhere, which made them feel isolated, displeased and unmotivated.

> I haven't gone there [leisure activity] for two years… the truth is that I'm not excited about going out or anything… you're withdrawing yourself. (C6)

Professionals also identified the frustration of the caregivers, even those who did not show it explicitly.

> 'If I can't go out, it's OK,' they say, but you notice from their voice that it is not OK at all… (P1)

In terms of the financial consequences, caregivers were most insistent that it was very difficult to access resources and social grants and that they sometimes had to bear the costs themselves, which had an impact on family finances, especially in families with fewer resources.

> When I needed help, I had to pay for it. (C1).

Education about the caregiver role

Education about dementia and caring skills

All caregivers agreed that the information they initially received was very limited. Interestingly, they pointed out that the information received from primary care and social service professionals was better than that provided by medical specialists. Specifically, caregivers believed that specialists did not provide them with either a definitive diagnosis when the dementia symptoms first appeared, or a prognosis of how the disease would evolve. Consequently, they felt at a loss when it came to dealing with aspects of the management and care of the patient. Primary care professionals stated that they were aware that family caregivers had little information about dementia-related diseases.

> I think the information is given years late, instead it should be provided from the very beginning… you must follow your intuition, since they [health professionals] don't teach you how to treat them [patients]. (C5)

Time management and self-care

A major complaint of caregivers was that they did not receive information from health professionals about how to take care of themselves, or how to develop activities that help them avoid the problems they faced and to interact with others and do other activities.

> They [professionals] don't explain much about how to take care of ourselves, well sometimes my nurse insists that I must leave free time for myself. (C10)

Accordingly, professionals recognised that when a burden was identified they should be able to respond to it and provide counselling or advice.

> We, as professionals, […] should try to boost their [the caregivers] self-esteem and encourage them to have time for themselves. (P6)

Caregiver needs

Information and training

Almost all caregivers stated that they had a great need for information about the new situation they were facing when their family member received their dementia diagnosis. They believed that it would be very useful for them to be provided with guidelines as early as possible, in particular regarding how to act, how to treat the patient, what to expect about the development of the disease and how to react to potential behaviours of the patient.

> No one explained to me… this or that can happen to you, you have to do this when it happens or try that… (C5)

Patient follow-up and social assistance

It was abundantly clear that the lack of follow-up globally outraged many caregivers, who described how, after the first visit, professionals usually did nothing more than prescribe a treatment and make a follow-up appointment for 1 year later, and that during the intervening period they did not receive any additional information or have any further contact.

> They [the professionals] give you the results of the diagnostic tests and do not schedule you a follow-up for up to 12 months. (C2)

In a similar vein, caregivers complained about the long wait they experienced before receiving the social grants.

> We had to wait two and a half years to get the dependence grant. (C4).

Psychological support

Caregivers globally claimed that the support they received must aim to facilitate their caring task and to minimise the toll this task took on their physical, emotional and psychological health, and on other aspects of their daily life. Specifically, they were convinced of the importance of being able to have recourse to psychological support, especially in the case of caregivers who found it difficult to accept their relative's disease.

> I felt really bad because it was very hard to understand the situation. (C9)

Professionals also considered emotional support to be an essential approach in attending to caregivers' health. Specifically, they considered it of the greatest importance to reinforce caregivers' self-esteem and psychological well-being, and to promote their self-care, while offering them information and training resources to support their task as a caregiver, helping them to face their situation positively and to avoid it becoming a burden.

> There are caregivers who don't accept it, they take it very badly and for these people it is necessary to access a little psychological support. (P7)

Demands for programmes directed towards caregivers

Social service resources

Caregivers said that the first support they would like to receive was from their family. However, on many occasions, this support was absent. As a second line of support, some caregivers referred to daycare centres for the patient as an important resource that liberated them from caregiving for a few hours.

> She goes to the day center very happy, she does many things there… and I have a little time for myself. (C5)

In relation to grant access and acquisition, caregivers were clear about the urgent need to speed up the entire grant provision procedure.

> I no longer say anything, but he is already 80 years old and when the grant arrives he will be…to me it is not fair. (C12)

Social workers shared the same opinion as caregivers about social services' delay with the process of grant provision:

> In fact, this is a major problem, when we detect that there is an overload, the response of the social services is very slow, very slow. (P7)

Multidisciplinary approach

All professionals agreed that promoting coordination and communication between professionals and multidisciplinary work would be essential. Specifically, they pointed to regular multidisciplinary meetings to plan approaches for patients and caregivers by which caregivers' burdens could be detected early on, and rapid referral made to social services.

> multidisciplinary work should be the basis of the entire approach since it is a complex disease for the person in charge of taking care of it. (P7)

Support from other caregivers

Many caregivers suggested that it would be helpful to be able to share doubts, fears and feelings with other caregivers to relieve the pressure, feel understood and receive inputs and mutual support.

> It would be good for us to share experiences, you can always get some benefit and have a good time. (C11)

Findings of the thematic analysis: relation to caregiving duration

This study allowed the identification of various themes regarding the impact of being a caregiver of patients with dementia on caregivers' lives, their actual knowledge about dementia disease and caring skills, and their main needs and demands. To further explore the relation of these meaningful aspects of caregivers' lives and tasks with the years committed to caregiving their relatives, a post hoc analysis was performed according to the caregiving duration categories registered (<1 year, 1–5 years, 6–10 years). In the first term, there were no significant differences regarding the main feelings described and the knowledge and training received about dementia disease and caring skills among all participant caregivers. However, it was noteworthy that caregivers which had already dedicated more years of their life to caregiving (6–10 years) saliently mentioned isolation as a hard repercussion of caregiving on their lives. Furthermore,

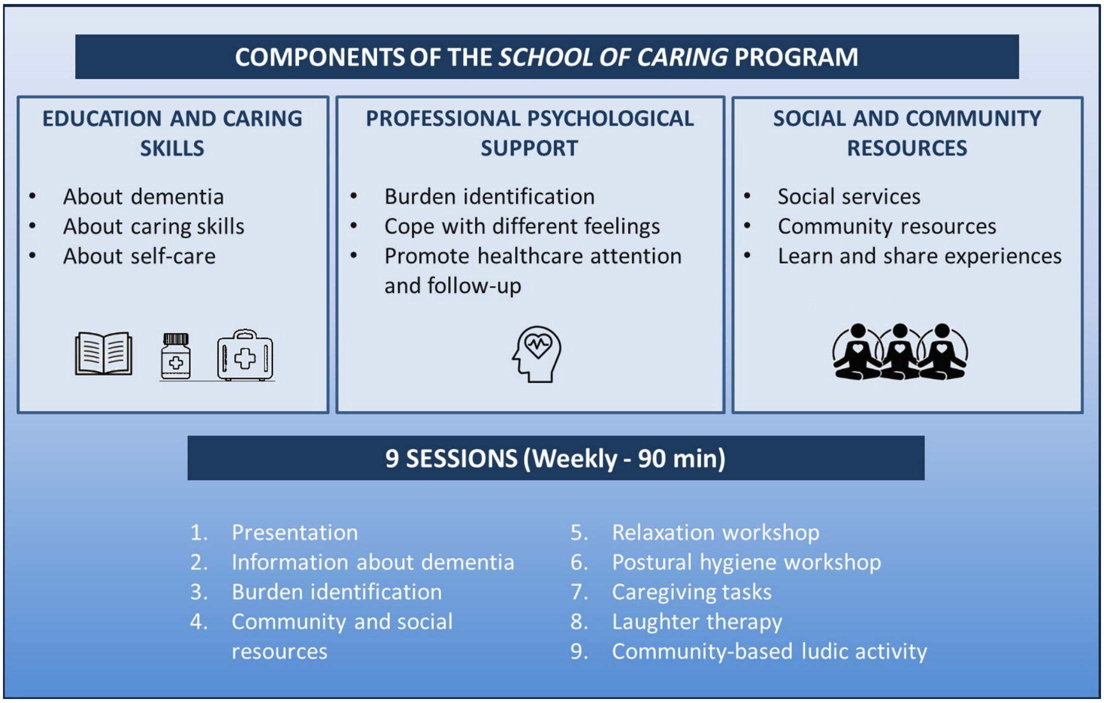

Figure 2 Tailored intervention design. Above: three main components of the support programme directed at caregivers of persons with dementia based on the thematic analysis of caregivers' and professionals' focus groups. Below: support programme sessions.

this group of caregivers stood out for requesting more psychological support and social grants when asked for their demands in comparison to the rest of caregivers. Contrary, mutual and group support was more valued and demanded by the intermediate-experienced group of caregivers (1–5 years).

Tailored intervention design: School of Caring programme

Based on the findings of the thematic analysis, we were able to identify the elements that need to be incorporated in a multicomponent intervention. Basically, three main components were formulated: (1) education and training, (2) professional psychological support and (3) social and community resources. The first block will address caregivers' theoretical and practical knowledge of dementias and their role as caregivers to this type of patient. The second block will deal with identifying caregivers' burdens and helping them cope with the spectrum of feelings arising at different stages of their relative's disease. The third block will facilitate caregivers' access to social grants and community resources, and promote sharing of experiences and interaction among caregivers (figure 2, above).

These components will be integrated in a programme with a group-based setting that is directed towards family caregivers. To this end, we propose a professionally led, multidisciplinary-based (neurologist, general practitioner, nurse, social worker, psychologist and physiotherapist) programme comprising nine sessions of 90 min each. Sessions will be held weekly for 9 consecutive weeks in a community space, and not in any health or therapy-related venue (figure 2, below). The effectiveness of the intervention will be evaluated in the second phase of the *School of Caring Project*.[20]

DISCUSSION

In this study, we provide valuable information about key components that a support programme for dementia carers needs to incorporate, based on the experiences of caregivers and professional care providers. By conducting FGs, we aimed to find out the impact of being a caregiver for the family members with dementia and the main needs of this population. Adopting an experience-based, codesign approach, we were then able to model an intervention directed towards caregivers that is driven by primary care and supported by social and community agents. The effectiveness of the intervention will be tested through a stepped wedged clustered single-arm with preintervention and postintervention repeated measures clinical trial.

In the first place, caregivers' description of the impact of their role as carers of relatives with dementia was of major importance. Although the carers mentioned some physical repercussions, like tiredness and sleep disorders, and complained mildly about the negative financial impact, caregivers were most intensely concerned about the psychological and emotional consequences. Essentially, they drew attention to the aspects of responsibility, uncertainty, sadness, anger and loneliness. There was also a strong and commonly held feeling about the stress and anxiety arising from their full-time commitment to a dependent person on a daily basis. These feelings are consistent with previously reported psychological effects associated with caregivers' burdens.[31 32] Our analysis allowed us to attribute many of these feelings to a lack of information and training about the behaviour and evolution of dementias, and about caring skills and self-care abilities. These shortcomings usually arose from the very limited and insufficient follow-up. Fortunately, this deficit of information and training as part of caregiver support may be easily and affordably made good. Providing information to the caregiver, ensuring that they understand the patient's diagnosis and instigating psychoeducational interventions have been proved to be highly effective in reducing caregiver burden.[33 34] The assessment of caregivers' needs revealed findings similar to those of previous studies with regard to self-efficacy training, psychological support and the sharing of experiences.[35–37] Another study illustrated the importance of considering the different needs of caregivers and the contextual conditions in relation to their life satisfaction when designing strategies for individuals with dementia and their carers.[38]

The use of qualitative research methodology has been fundamental to codesigning a multicomponent intervention from a patient-centred perspective that can guarantee better adherence and impact. In addition, the participation of care provision professionals and community stakeholders is of great importance for ensuring the acceptance of programmes and making it feasible to implement them. Multicomponent interventions are relatively inexpensive to deliver, acceptable and widely applicable.[39] Further, cost analysis suggests that effective support initiatives to ease the burden of informal caregivers may be cost-effective.[40] In the context of our study, caregivers' needs were not addressed even though the main local stakeholders could easily have afforded to meet their demands. As shown by cross-sectional data from the 2015 National Study of Caregiving, social services and support resources for caregivers are not adopted equitably.[41]

Study limitations

Limitations of this study include generalisability of findings. The study was solely conducted at one community and primary care service; thus, it cannot be concluded that the range of experiences is exhaustive when considering other community and primary care settings. Additionally, the distinctions and motives between caregivers who reject to engage in research and those who decide to participate in the study should be taken into consideration. In this line, the gender disparity among the professional participants which shows a notable predominance of women is remarkable. While there is a considerable higher presence of professional women in primary care services, efforts should be made to obtain the male perspective in qualitative studies.

CONCLUSION

This study allowed the design of a multicomponent support intervention for family caregivers of persons with dementia that aimed to reduce the carers' burden and improve their quality of life in accordance with their actual needs and available local resources. We urge that patient and public engagement should be incorporated as elements in future studies of the management of dementia.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants. The School of Caring project was approved by the clinical research committee of the Institut d'Investigació en Atenció Primària Jordi Gol (code P18/072). All participants received an information sheet of the study where the aim, procedures, data management, safety, privacy, autonomy and confidentiality were stated. Also, all participants signed consent forms before engaging the study. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. The data sets used and analysed during the current study are available from the corresponding author on reasonable request.

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