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Research Article

Urban Share of the "Burden": Impact of a Support Organisation on Caregiver Burden of People Affected by Dementia

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Purpose. This study investigated the experiences and expectations of unpaid caregivers who were members of a nonprofit social support organisation. *Design and Methods*. Colaizzi's phenomenological exploration was followed. Data were saturated after 15 in-depth individual interviews at a centre for people affected with dementia. *Findings*. The themes reported with the COREQ checklist were contributory to caregiver burden, the escalation of dementia symptoms, changes in family roles, psychological distress, social challenges, membership in a social network, and developing effective coping skills. *Practice Implications*. Access, availability, and continuity of psychosocial support programs are vital for the wellbeing of people affected with dementia.

1. Introduction

Over 55 million people live with dementia, with numbers projected to increase, and two-thirds of those live in low- and middle-income countries [1, 2]. Dementia is the sixth highest cause of mortality [3, 4], and the care of people with dementia is demanding for caregivers and health systems. The gradual neurodegeneration in dementia is a significant factor when considering the burden on national health systems. Caregiver burden can be defined as the strain that is experienced by a person who cares for a chronically ill, disabled, or older family member [5]. Unpaid dementia caregivers face this as the recipients become increasingly dependent. The burden is worsened by the erosion of social support and additional economic demands placed upon the caregiver, such as loss of consequences of leaving workforce for the caregiver or out of pocket home care or social care service expenses [1, 6, 7]. The challenges are further compounded with dementia symptoms, such as anger, confusion, memory loss, and sleep deprivation. Caregivers' quality of life diminishes with associated sleep disturbance, grief, and low mood [8, 9]. Caregivers commonly experience anxiety and depression, and some previous studies have shown that this can lead to earlier institutionalisation for the person with dementia [1, 10–13]. Therefore, early identification of deprived mental health and implementing of attenuating strategies are essential for caregivers. The contemporary literature identified psychosocial interventions, education, and peer support as crucial in promoting caregivers' wellbeing [14, 15].

According to the Turkish Health Ministry's current dementia care plan report, 50% of caregivers in Turkey are over the age of 50, 86% are women, 64% are university graduates, 62% are unemployed, and 66% are diagnosed with depression. In addition, 70% of the caregivers stated that regardless of the dependency level of the recipient, caregivers do not want to locate their relative to a care centre [16].

Gender inequalities and additional responsibilities in a family structure should also be considered when the caregiver burden is examined in the context of dementia care in the community [17, 18]. Most of the unpaid caregivers of people with dementia are women over 60 years old in Turkey, which is similar to global statistics [1, 2, 19, 20]. This demographic also has complexity in their own life, for example, end of career or retirement and changes to their health. Emerging chronic diseases, frailty related to aging or menopause, or postmenopause issues are prevalent in this population [14, 17, 21]. Added responsibilities emerge as a result of adjustments to the caring responsibilities or role changes in the family, such as managing finances, insurance, and property maintenance, which can be a cumulative burden [4, 20]. New skills and time are required to adapt and manage these changes. For example, with the recent pandemic, many services have pivoted to telehealth and video consultation, which may be unfamiliar technological landscapes to navigate for some people despite the convenience of it [22].

Nurses are central to this significant public health issue, responsible for research and planning suitable support for caregivers. It has been identified that in some acute care settings where comorbidity exists, nurses fail to provide a family-centred approach to caregivers of people with dementia, instead prioritising physical health tasks and omitting the psychosocial support needs of people with dementia. In doing so, nurses miss a vital opportunity to provide family-centred care for the people affected [8, 9]. It has become essential for nurses to identify the barriers and enablers to change health systems in support of people affected with dementia and devise recommendations that will strengthen the wellbeing and capability of caregivers overall. Caregiver burden has been a prominent issue for aging populations and the implications of the burden on public and health systems have been studied considerably [5, 23]. However, few studies examine caregivers' expectations and the effectiveness of existing implementations. This study was designed to identify caregivers' psychosocial issues and understand their expectations from health care professionals and support organisations. A secondary aim was to evaluate the impact of social support provided by the *Center* for people affected with dementia and provide an example for adopting similar support programs in other local districts. To our knowledge, no prior studies have investigated this type of intervention in the national context.

2. Methods

2.1. Research Questions. Are there differences in caregivers' experiences in the support centre compared to those described in the literature?

What were the most and the least effective implementations for their psychosocial wellbeing in the existing support systems?

2.2. Study Design. This study was designed by following Colaizzi's phenomenological exploratory method to allow caregivers of people with dementia to express their struggles, expectations, and any benefits they have gained from the existing support programs [24, 25]. There are seven steps of analysis following the data collection that was indicated as in the approach; the steps are as follows: researchers' familiarization of the data, identifying significant statements, formulating meanings, clustering themes, developing an exhaustive description, producing the fundamental structure, and seeking verification of the fundamental structure [24]. This approach was selected to form a comprehensive investigation of the dimensions of the phenomenon [25–28].

2.3. Settings. The research was conducted in a local district, in Istanbul, Turkey. The local council established a non-government social support organisation for people affected by dementia. The center employs four health professionals, has several volunteers who provide activities and support, and provides psychosocial services for over 500 local members. The center provides mental health activities exercise activities, arts/crafts, and other therapeutical activities, as well as information sessions in a two-story building dedicated to this service.

2.4. Participants. The study population was limited to caregivers of people with dementia, and a purposeful sampling method was applied. The caregivers had access to the support services provided by the center by membership; the researchers approached the members of the center and invited them to the study. The caregivers who volunteered to participate were recruited until data saturation was reached when the sample reached fifteen participants. The researchers explored the suitability and effectiveness of this support and caregivers' expectations.

Inclusion criteria were primary unpaid caregiver of a person with dementia, ability to communicate (no cognitive impairment, no speech disorder, and speaks Turkish), membership of the centre, and voluntary participation, and exclusion criterion was any communication barrier.

2.5. Ethical Approach. Initially, the research protocol was presented at the mentioned centre, and their institutional permission with a condition of ethical approval was obtained. Afterwards, ethical approval was obtained with the affiliated institution (Yeditepe University Clinical Research Ethical Committee 14.02.2018/809), in line with the human research ethics protocols. Before each interview, the research was explained in plain language to the participant, an opportunity for questions to be addressed was provided, and if agreed, participants proceeded with signing the informed consent. Participant confidentiality was ensured by both parties signing the consent form, including that only the researchers could access the records, identifiable information would not be available and that anonymity was assured.

2.6. Data Collection. A semistructured 14-item questionnaire was developed according to the related literature Table 1 and was used to moderate the individual in-depth interviews [10, 29–31].

Table 1: Semistructured interview form.

(1) Caregiver demographics: age, gender, relationship with the care recipient, and care period
(2) Health status of caregiver: was there any acute or chronic disease?
(3) How did the caregiver's role affect your financial situation?
(4) Can you get professional support? What support do you receive and what support do you need?
(5) What are the physical/psychological changes you noticed in yourself with the care process?
(6) What changes have you made in your personal life when you started caregiving?
(7) What things do you find easy or difficult about caregiving?
(8) How is your relationship with the person you care for? Have there been any changes in this relationship compared to the previous one?
(9) During this period of care, did you receive financial or morale support from your social environment? How sufficient was this support?

The third author II and another mental health nurse, VA (VA had a master's degree and II had a PhD degree in mental health nursing) conducted the interviews in a private setting at the centre at designated appointments. During the interviews, care recipients were engaged in occupational therapy activities. The two researchers interviewed different participants one-on-one to avoid any personal researcher bias, and the interviews were audio-recorded. The interviews averaged 40 (range 35–55) minutes, which were conducted in November-December 2017; afterwards, they were manually transcribed [32].

2.7. Conventional and Summative Content Analysis. The data arose from the answers to open-ended questions such as "how would you describe…?" or "what has changed…?." The researchers individually familiarised themselves with the data by listening to all recordings several times and rereading all the data word-by-word (in Turkish) to derive codes. The codes were derived by underlining the exact words from the transcribed text to capture key concepts with cultural nuisances retained independently [25, 32, 33]. After this initial analysis, derived codes were compared for summative and conventional content analysis [34]. We attempted to avoid any preconceived themes or classification by in-depth discussions, questioning, and visual (on paper) mapping of each researchers' thought process to derive codes. The diversity in the researchers' professional backgrounds was also valuable to avoid bias. We created the subthemes in consensus, such as "dementia symptoms, psychological challenges, and role changes".

2.8. Quality of Data and Analysis. The researchers individually analysed the data, then compared the codes, and excluded the codes/themes on which a consensus had not been reached. We used triangulation for data accuracy and reliability. We followed Ho et al.'s report on sensitive data translation [32]. We analysed the data in Turkish, developed codes, subcategories, and categories in Turkish, translated the coded data from Turkish to English, developed subcategories and categories in English, coded the translated data in English, compared the two versions of codes, subcategories, and categories, and developed meaning-based translated findings. The data report was translated into English. Final themes were translated back to the original language to check the integrity and retention of the meaning of the data [32]. We ensured research quality by reporting on all items of Tong et al.'s 32-item checklist such as researcher characteristics, study design, and analysis and reporting [35]. The diversity in the researchers' professional backgrounds (mental health, perioperative, women health, and leadership in nursing) was valuable for the analysis. The field notes and reflection on the narrative coherence between these notes also informed the themes that emerged. The themes were confirmed with the participants, which were found relevant and matched their expressions [36]. Similar subthemes were merged into the main categories. Following the retest, the final themes and subthemes were agreed by consensus across the research team. COREQ 32-item checklist was used for reporting [35].

3. Results

Table 2 demonstrates the characteristics of the participants. Two main themes arose from the data analysis as follows: Theme 1: Factors *increasing* caregiver burden, and Theme 2: Factors *decreasing* the caregiver burden.

3.1. Main Theme 1: Factors Increasing the Caregiver Burden. Participants stated that the burden for the caregiver of a person with dementia is more significant than in other disease categories. The increase of caregiver burden was described by participants in four subthemes as follows: (1) the impact of dementia symptoms; (2) changes in family roles and relationships; (3) psychological distress; (4) social challenges.

3.2. The Impact of the Dementia Symptoms. The caregivers stated that dementia symptoms had a detrimental effect on their psychology and relationships with care recipients. These symptoms include but are not limited to forgetfulness, nervousness, scepticism, delusions, stubbornness, negative emotional state, limited communication, excessive attachment behaviour to the caregiver and consequently acting distant to others, apathy, cruelty towards the caregiver, amnesia, and fatigue. These symptoms caused the caregivers to feel sad and anguished, and they limited their daily activities and had deteriorated their relationship with the person with dementia. The following are some of the participants' expressions about this subject:

> *"She has become very hurtful… after she got sick. Sometimes she says things like: "This one stays here a lot; she should go home…" Then all of a sudden she starts pulling my clothes out of the draw, tells me to put my shoes on and leave… Would not it hurt?" (daughter, 56 year old).*

> *"My husband calls me "mum"…" (wife, 67 year old).*

Table 2: Participant characteristics.

No.	Caregiver's relationship with the care recipient	Age	Gender	Duration of care*
1	Daughter	57	Female	2 years
2	Spouse	74	Female	4 years
3	Daughter	59	Female	2.5 years
4	Daughter	54	Female	9 years
5	Daughter	63	Female	13 years
6	Daughter	68	Female	14 years
7	Spouse	68	Female	11 years
8	Daughter	65	Female	6 years
9	Spouse	72	Female	8 years
10	Daughter	56	Female	2.5 years
11	Spouse	79	Female	3 years
12	Spouse	67	Female	8 years
13	Spouse	74	Female	4 years
14	Daughter	62	Female	3 years
15	Spouse	75	Female	5 years

*Since dementia was identified.

3.3. Changes in Family Roles and Relationships. The participants stated that their relationship with the relatives they care for and their role in the family had changed and that these changes resulted in a deterioration of the quality of time spent together. The following are some of the participants' expressions about this subject:

> *"Sometimes his demands bother me a lot. . . what can I do? . . .I take him as my grandchildren because he is like a child now, he whines about like a child,. but of course, you cannot tell him off as you do with a child.." (wife, 74 year old).*

3.4. Psychological Distress. The participants described the elevated distress and issues associated with their caregiving responsibilities. They experienced a perpetual state of sadness that pervaded all areas of their daily life. They tended towards self-neglect and had a diminished quality in their social communications. The stress was magnified through their struggle to accept the illness, grief, loss, and desperation as dementia manifested. Overall, they felt conflicted between the emotional endurance, the need for practical endurance, and the loss of personal freedoms related to the need to provide around-the-clock care. The following are some of the participants' expressions:

> *"I realise I'm wrecked. . . I love him. . . it should not have happened. . ." (daughter, 54 year old).*
>
> *"when he calls me "mum" I get upset. . ." (wife, 74 year old).*
>
> *"I have become less tolerant to people. . . this is not me. just do not know how to deal with this." (daughter, 57 year old).*

3.5. Social Challenges. The caregivers indicated that caring for a person with dementia had a severe impact on their social lives. They felt compelled to leave the paid workforce and felt there were limited social activities suitable for people with dementia. An indefinite duration of caregiving period left them feeling constrained. Shame and self-stigma also restricted the social interactions. Participants reported family and friends' visits decreased after the manifestation of dementia, further isolating them. The following are some of the participants' expressions about this subject:

> *"You are tied to the house. I am an engineer, I have worked in international companies, and in good positions. I felt like I fell into a void." (daughter, caregiver of both parents, 57 year old).*
>
> *"You are pulled away from your social life, your friends. . . I cannot bare to leave them. So, I left my own life. . .." (wife, 74 year old).*
>
> *"The last two years, I have not been able to leave my mother alone. . . I cannot go to events in the evenings. . . it stops me from living my life. . ." (daughter, 63 year old).*

3.6. Main Theme 2: Factors Decreasing the Caregiver Burden. Participants indicated that since the centre accepted members and provided the services, their caregiver burden was reduced significantly. This was described by participants in two subthemes that were overlapping and one enabling the other as follows: (1) effective coping skills; (2) membership of a support organisation for people with dementia and their caregivers.

3.7. Effective Coping Skills. The participants noted the significance of effective coping skills in reducing the burden. The stated methods were music, reading, empathy, a positive attitude, endurance, and acceptance of dementia overall. The improvements in caregivers' skills of effective coping were enabled through the point of contact with other caregivers and the activities provided by the centre. These included exchanging experience/emotions, creative expressions such as painting, crafts, exercise such as plates/yoga, and dementia seminars.

> *"I'm trying to read as much as I can. It takes my mind off everything. . . try to listen to music that I like "(daughter, caregiver of both parents, 57 year-old)". . .as I said, since that time, I've committed to courses. . . English course, dance course whatever. . . They keep me going, keep me alive." (wife, 68 year old).*
>
> *"It is so good for him and me. I come here I see others and how they are doing." (daughter, 68 year old).*

3.8. Social Support Organisations for People Affected by Dementia. The caregivers stated that membership of the center allowed them to interact with peers. Their quality of life was increased, and their perception of the disease and caregiving was improved. The activities at the centre enhanced their social needs and developed their effective coping skills. The emotional support was received through the comradery of shared experiences and empathy, which bolstered their agency. The informative meetings and the education programs reduced their anguish regarding dementia management.

> *"This place is so good for me. My partner comes here and spends time with other people with dementia. I know that he is safe, so I go upstairs and do Pilates with other caregivers…" (wife, 72 year old).*
>
> *"I am trying to join as many events of the center as possible. Every day I learn something new about the disease. I attend caregiver support programs… trying to learn more. There are huge contributions. I have gained awareness…" (daughter, 63 year old).*

4. Discussion

The study assessed the burden, quality of life, and emotional and social wellbeing of caregivers of people with dementia in a community in Turkey that has access to a social support service. Two main themes arose from the data analysis as follows: Theme 1: Factors *increasing* caregiver burden and Theme 2: Factors *decreasing* the caregiver burden. The factors that increase caregiver burden included four subthemes as follows: the impact of clinical manifestations of dementia; changes in family roles/relationships; psychological distress; and social challenges.

Dementia is known for its slow progression; neuropathological symptoms gradually appear over a relatively long period. Symptoms such as verbal aggression and behavioural disorders, apathy, sleep disturbance, or risk of injury may seriously affect caregivers' physical and mental health [37]. Behavioural issues can be more detrimental for caregivers compared to physiological care. The caregivers of people with cognitive impairments were reported to have higher depression, anxiety, and burnout scores than other caregivers [38, 39]. Factors directly affecting the caregiver's burden were reported in Viñas→Diez et al.'s [30] study, namely, family relationships, living arrangements, behavioural disorders, and severity of dementia [30]. The caregivers in this study indicated that amnesia, temporary loss of identification, anxiety, delusions, scepticism, or excessive attachment caused caregivers to feel helpless, exhausted, and restricted. It is emphasised that caregiver burden is more significant parallel to the severity of cognitive symptoms and in response to physical, psychological, emotional, and financial stress [12, 31].

The participants reported a dramatic change in their social roles. They have become the primary caregiver-"like a parent"-of their parents or partners. Several qualitative research studies draw attention to the social role changes as the most challenging aspect of caregiving [7]. The literature highlights the ever-increasing responsibilities and additional roles that a caregiver to a family member assumes [12]. In the Amici et al.'s [40] study, caregivers stated being the primary long-term caregiver, care manager, companion, agent, and decision-maker for the person with dementia [40].

Correlation between caregiving burden, depression, and other psychological consequences has been extensively reported in the literature. The caregivers in this study expressed self-neglect, reduced quality in relationships, stress, and anguish. Some of the participants have been diagnosed with depression since becoming a caregiver. One in two caregivers had experienced clinical symptoms of depression or anxiety, and an association between further cognitive decline of the person with dementia and mental decline of the caregiver was reported in the literature [41–43]. Randomised controlled trials provide further evidence that increased psychiatric distress of caregivers which further deteriorates and leads to earlier institutionalisation of the person with dementia, which becomes a strain on health care systems ([23, 30, 44]). The results in our study, in line with the literature, indicated the significance of adequate psychological and social support for caregivers.

The participants stated that caring for a person with dementia disrupted their social life, careers, isolated them, reduced self-care, and diminished their quality of life. Both the caregiver and the person with dementia are isolated due to the reduction in social interactions, which is particularly significant in Turkish culture. Kalinkara and Kalayci [20] reported highly comparable experiences of caregivers, such as lack of freedom, limited, or no social activities, being increasingly withdrawn from society, and being isolated affected nearly half of the families in their study [20]. Amili and colleagues (2017) emphasised that one out of every four caregivers was forced to leave work [40]. Bailes et al. [41] indicated that caregivers do not have enough time to fulfil their own health needs [41]. It is repeatedly reported that caregivers experience burnout increasingly [31, 45–47]. The behavioural disturbance of the people with dementia further alienates both parties from the extended family social circle [11, 31].

The two most commonly used psychometric measures of self-reported caregiver burden in the literature were the Zarit Burden Interview (ZBI) and Caregiver Burden Inventory to our knowledge [48, 49]. Our results of social isolation, low mood, and psychological challenges expressed by participants were parallel to the findings regarding the effect on the psychosocial and personal life of caregivers. Correlation between the burden and the care quality, recipients' health, and early institutionalisation were demonstrated and both measures were descriptive for our themes in regards to time-dependence, developmental, physical, emotional, and social burden of caregivers [50, 51].

Two subthemes that reduce the burden were identified as positive coping mechanisms and membership in a psychosocial support organisation.

The participants expressed that music, reading, empathy, positivity, patience, and acceptance of the illness helped them emotionally. Psychosocial interventions were demonstrated as essential to alleviate the caregiver burden [52]. A good understanding of dementia and the associated burden can help develop strategies and improve the coping among caregivers [12]. Physical activity, meditation, cognitive behavioural therapy, and relaxation exercises were also reported as beneficial and feasible in community settings, with additional benefit to reduce depression, anxiety, and medication of caregivers [31, 53–55].

The participants expressed that the membership of the center has significantly increased their life quality and improved their perspective regarding dementia as they had the opportunity to interact with peers. Moreover, the occupational therapy activities organised at the centre allowed them to socialize, and the dementia seminars reduced their anguish. These outcomes were similar to previous studies. These support resources and institutions play an essential role in caregivers' health and resilience [20, 56] that limited health and social services fiscal resources are deployed to support the quality of life of caregivers and people with dementia in the most impactful way.

4.1. Limitations. This study was qualitative; therefore, large samples are not feasible for the analysis. The study was conducted with caregivers who are a member of a local non-government organisation for people with dementia and their caregivers in Istanbul, Turkey which contributed to their health status; therefore, it may not represent the national results.

4.2. Conclusion. Psychosocial challenges experienced by caregivers of people with dementia are a significant public health issue. These can be alleviated with practical, low-cost psychosocial support interventions that are relatively feasible. It is clear from the findings that social support, whether provided by governments or other organisations, is vital, as it empowers caregivers. Empowered, informed, and supported caregivers are less likely to experience depression or anxiety. The caregivers' resilience thereby can avoid premature institutionalisation of people with dementia. Further research measuring the improvements in caregiver wellbeing and the reduction of experiences of burden and establishing the economic benefits for health systems is required.

4.3. Recommendations for Practice. In clinical or nonclinical settings, several recommendations can be derived from the study and concur with other literature. These strategies included psychosocial interventions to decrease the caregiver burden in the dementia context:

(i) Promote the early identification and mitigation of psychological stress experienced by caregivers
(ii) Support caregivers in the development of coping skills
(iii) Develop individually tailored programs aligned with the needs of the caregiver and person with dementia
(iv) Provide referral to support organisations to enable early navigation to appropriate supports
(v) Activate ease of accessibility to the psychosocial support services
(vi) Create opportunities and linkages for social support for caregivers

4.4. Educational Recommendations for Caregivers

(i) Deliver relevant information and education regarding dementia care and effective coping strategies aligned with the insidious phases of cognitive and functional deterioration

4.5. Professional Development Recommendations for Health Professionals

(i) Mapping the available care and social support services (facilities) and familiarising with location and referral procedures
(ii) Developing skills in the early recognition of caregiver burden and psychological stress experienced by caregivers
(iii) Maintaining life-long learning knowledge of the latest evidence regarding holistic and person-centred care for people with dementia and their caregivers

4.6. Research Implications. Various scales were used to measure the caregiver burden and life quality of caregivers of people with dementia or dementia in the literature. However, these scales were not comprehensive to evaluate the complex phenomenon of caregiver burden in multiple aspects. A specific and broad scale for caregiver burden is needed considering organisational, cultural, and socio-economical characteristics relevant to caregiving activities.

Data Availability

The data used to support the findings of this study are available from the corresponding author upon request.

Ethical Approval

The methods section stated that the relevant Ethics Committee or Institutional Review Board provided approval (Yeditepe University Clinical Research Ethical Committee 14.02.2018/809). The manuscript conforms to the COREQ reporting guidelines. The confidentiality and anonymity of findings were preserved under World Medical Association Declaration of Helsinki.

Consent

Verbal and written informed consent was obtained from each participant. Consent to access interview data was obtained for the research team and regulatory authorities only.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Authors' Contributions

OG contributed in design, data collection, transcription, analysis, reporting, translation, and correspondence; SS contributed in transcription, data analysis, and manuscript development; II contributed in data collection, transcription, analysis, and reporting; VA contributed in data collection; HAO contributed in design and overall supervision; RW contributed in design, data analysis, manuscript development, and overall supervision.

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