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# Daughters and daughters-in-law providing elderly care: a qualitative study from Karachi, Pakistan

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## Abstract

**Background and context** Providing care to the elderly is an emerging area of interest due to the increase in elderly population not only in the developed world but also in low and middle income countries. In Pakistan a country with an overall population of over 200 million, the elderly population amounts to 11.3 million. Caregiving of the elderly tends to occur within the kinship motivated by sociocultural norms as well as absence of government support facilities. While quantitative literature exists in Pakistan describing the “caregiver’s burden,” an in-depth analysis into the experiences of familial caregivers is missing.

**Methods** The research used qualitative methods with the aim to explore the lived experiences of 7 daughters and 3 daughters-in-law, living in Karachi, Pakistan providing care to the elderly requiring assistance in at least two tasks of daily living.

**Results** Five themes were developed inductively through the phenomenological method. All participants were Muslim and belonged to the upper economic strata of the society. Findings reveal that obligations to care are dominant in kinship circles particularly among women. Participants highlighted the importance of elderly in the Pakistani society, especially due to the religious lens that considers them as blessings. Daughter caregivers spoke about caregiving of their parents as a form of role reversal, emphasizing also upon the life-long emotional bond that served as a strong motivator. On the other hand, for daughter-in-law caregivers, motivations to care also stemmed from social expectations and kinship obligations. All participants reported multiple difficulties during the caregiving experience, despite existence of paid formal help, with respect to balancing multiple role demands and the nature of caregiving that requires constant effort. Results also illustrate that despite the desire to care for the elderly within a collectivist and patrilocal society, participants experienced multiple physical and emotional effects. However, a few also reported an increase in self-mastery and self-worth.

**Conclusion** This study reveals that despite increasing urbanization and more women working outside the home, providing care to the elderly appears to be centered within the kinship circle. The research makes important contributions to the ageing literature in Pakistan with relevance to other South Asian contexts.

**Keywords** Caregiving, Collectivist, Elderly, Pakistan, South Asia

## Introduction

According to World Health Organization (2018) the proportion of population over 60 years will double from 12% to 22% between 2015 and 2050, and by 2050, 80% of the ageing population will be from low and middle income countries (LMICs). Within this context, providing

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support to the elderly has gained importance in contemporary social and health debates, extending to developing countries, which are now experiencing a rapid increase in ageing population, often within a single generation [1].

Pakistan, a South Asian country has trends similar to other parts of the developing world. It has an elderly population of 11.3 million (out of a total population of more than 200 million) projected to increase to 43.3 million by 2050 [2]. Elderly caregiving responsibilities in the country tend to be centered within the household relying on kinship networks. Thereby, majority caregiving tends to be informal defined as “the unpaid care provided to older and dependent persons by a person with whom they have a social relationship, such as a spouse, parent, child, other relative, neighbor, friend or another non-kin” [3].

This informal caregiving in Pakistan occurs due to sociocultural norms, which dictate that support for the elderly ought to come from within the familial domain. Strong religious values also in the country place moral responsibility upon children to take care of their aged parents. Literature from other countries with a “collectivist” orientation that teaches cooperation, duty, interdependence and obedience across generations supports this notion [4]. Collectivist cultures governed by high values of familism also view elders through the lens of respect, where filial children are expected to serve their parents without any conditions, and sacrifice for their well-being [5]. In Japanese society, for example, the experience of ageing is “anchored in the household,” and that the elderly are not perceived as someone being “on the dole, but rather as receiving their due” [6].

Another important factor that plays a role in the dominance of familial caregiving is the absence of social support services in many LMICs, which stands in contrast to developed countries, particularly European nations with a strong welfare system. In Pakistan, professional caregiving particularly nursing homes may also not be a culturally accepted solution because of the aforementioned sociocultural reasons [7].

One of the most consistent findings from the caregiving literature is that majority of such responsibilities are shouldered by women in the family across the family life cycle [8]. Despite women working outside the home, they still occupy roles as “primary nurturers” and “kin keepers” making caregiving a gendered duty [8]. Evidence of this is reported from the Pakistan context in both peer-reviewed literature and the lay press. An article in a national newspaper of Pakistan, Dawn highlighted that women and girls provide the bulk of unpaid care work including child rearing and caring for elderly, sick or disabled family members [9]. This is magnified through the existence of joint family structures that

create a system of mutual interdependence—as parents grow older, they expect the younger generation to take care of them with their sons providing financial support and their sons’ wives caring for the sick, the elderly and the children in the family [10]. However, women caregivers are known as to experience stress due to this as documented widely [11–13].

Evidence from other South Asian societies suggests that elderly care is provided within the familial domain out of a sense of moral obligation along with satisfaction that caregivers derived from the experience, and that women largely adopt this role [14]. In India, the cultural norm of *dharma*, with its roots in the teachings of the dominant religion, Hinduism also motivates the younger generation to provide care to ageing parents [15]. Another qualitative study from India demonstrated that a combination of cultural and religious factors influence individuals’ decisions to provide care including the hope that providing this care would offer them a better birth or life in the next life [16].

However, limited literature is available from Pakistan documenting the experience of caregivers. Available studies use quantitative methods based on scales imported from the Western world which are based on terminologies such as ‘caregiver’s burden.’ This term has been criticized for it fails to consider societies that place family at the center of existence and for its disregard towards the multi-faceted nature of this experience [17].

A quantitative study conducted in an urban center in Pakistan with 60 caregivers reported high caregiving stress, leading to low quality of life [18]. A household study reported stress among caregivers but for some family members (other than daughters-in-law), satisfaction with caregiving duties was also reported as part of the experience highlighting that caregiving may not necessarily be viewed solely through the lens of stress [19]. Another study in the cosmopolitan city of Karachi with cancer patients’ caregivers reported high feelings of stress, predominantly among female caregivers [20].

However, quantitative literature does not describe the holistic experience associated with the caregiving phenomenon, often medicalizing this phenomenon by correlating stress with depression and anxiety. The driving force for the current study therefore was the paucity of literature available about experience and process of elderly caregiving in the country, as well as the voices of Pakistani caregivers generally underrepresented in international literature. Recognizing that caregiving is a gendered duty and expectation, the study focuses on exploring the experience of caregiving in its totality by daughters and daughters-in-law providing care.

## Theoretical framework

The study was guided through the “ethics of care” perspective, which recognizes that at the core of human existence lies interdependency, and mutuality. Initially developed by Gilligan and Noddings, the care of ethics approach considers “caregiving” as a complex human interaction influenced through responsibilities and duties existing within relationships. Other care ethics theorists including Eva Feder Kittay (1997) views intergenerational care as a form of “transitive responsiveness”—one cares for the older generation assuming that the next generation will care for oneself [21].

This model also acknowledges that these duties are strongly gendered within most cultural contexts thus making this an apt framework to explore the lives of female caregivers in the current study. This model also reaffirms that care is often romanticized as a “feeling” without realizing that it requires work. Tronto built on her theory of care by explaining that the process requires four distinct yet interconnected phases including i) *car-ing about*, perceiving the need for care, ii) *taking care of*, requiring concrete steps to undertake the activity, iii) *car-egiving*, the hands-on labor required to provide care and iv) *care-receiving*, perceiving the specific needs of the caregiver. All four phases require attentiveness as a crucial ethical element [22].

Fisher and Tronto also advocate that the context of caregiving should not only focus on motivations to care but on the actual activities that the process involves. The current study therefore seeks to capture the lived experiences of individuals and considers the “holistic” experience of caregivers [23].

## Methodology

### Study design

The epistemological positioning of the paper is interpretive social science using the phenomenological mode of inquiry which seeks to study meanings of people’s experiences [24]. As van Manen (2014) has described, the phenomenological method “begins with wonder at what gives itself and how something gives itself. It can only be pursued while surrounding to a state of wonder (p.27).” The paper does not attempt to develop a theory rather it provides a glimpse into the lifeworld of caregivers. This mode of inquiry has been used in nursing literature previously [25, 26].

### Participants

Participants included 7 daughters and 3 daughters-in-law providing care to the elderly. These two sets were chosen since literature from around the world report that women including daughters, daughters in law and wives assume

responsibility of the caregiving [27–29]. However, I did not include wives in my sample.<sup>1</sup>

Convenience sampling was used to recruit participants for this study, with the researcher mainly relying on personal contacts through friends and family to get access to potential participants (unknown to the researcher). Twelve individuals were approached, and only one refusal citing lack of time. One wife caregiver was excluded from the final sample for reasons mentioned above.

This study, conducted to fulfill the requirements of a Master’s in Bioethics thesis from Centre of Biomedical Ethics and Culture, was approved by the Ethical Review Committee at Sindh Institute of Urology and Transplantation, Karachi, Pakistan. Since the study explored personal details of participants’ lives, verbal informed consent was taken from them after reassuring them of the privacy and confidentiality of the data obtained.

Eligibility criteria for participation included: a) daughters and daughters-in-law providing care, b) 18 years or older c) caring for an elderly aged 60 and above requiring assistance in at least two Activities of Daily Living (ADLs) including: fundamental skills needed to manage basic physical needs: 1) grooming 2) dressing 3) toileting/continence 4) transferring/ambulating 5) eating 6) walking and 7) bathing), d) providing care for at least six months or more.

### Interview procedures

Ten face-to-face, in-depth interviews were conducted with 7 daughters and 3 daughters-in-law. These were

<sup>1</sup> I had interviewed a wife caregiver initially, but found that the responses were adding too much variation to my data. Therefore, I restricted my sample to daughters and daughters-in-law. The motivation to care for wives can be potentially different because marital bonds differ from parent-child relationship, or relationship with in-laws. A study states, “While the relationship between parents and grown-up children is often perceived as indissoluble, lifelong connection, marriage or partnership is interpreted as a relationship that is based on certain conditions and expectations, and that can, under some circumstances, be terminated.” (Jungbauer J, Wittmund B, Dietrich S, Angermeyer MC. The disregarded caregivers: subjective burden in spouses of schizophrenia patients. *Schizophrenia bulletin*. 2004 Jan 1;30(3):665-75.)

In another research (unpublished, presented at a conference in Pakistan, see: [shorturl.at/ntvV8](http://shorturl.at/ntvV8)) that I was involved in, exploring the effects of mental illnesses on marriages, it was observed that majority of the healthy spouses were women, as opposed to men. This study employing qualitative methods found that caregivers of those who are mentally ill again tend to be wives. The data also seems to indicate that marriages broke down if the female spouse had a mental illness, whereas marriages tend to remain intact, if the male spouse was suffering from a mental illness. Wives’ motivations to take care of someone afflicted with mental illness potentially have their roots in sociocultural values such as stigma of divorce, economic dependence on part of females, and presence of children. While it cannot be conclusively established, wives’ motivations to take care of their sick ageing husbands may be influenced by some of these factors, and the experiences would indefinitely vary from that of the daughters and daughters-in-law experiences.

**Table 1** Data analysis method

Significant Statements	Formulated Meanings	Theme Clusters	Emergent Themes
It is privilege and you know his [father's] blessings (F5)	Elderly provide blessings hence caregiving is considered a privilege	(1) Religious perceptions towards elderly and caregiving	Motivations for caring: daughters and daughters-in-law
You have to take care of your parents. It's mentioned in the Quran you have to take care of parents (F7)	Religion has explicit instructions about taking care of parents		
Whatever we have in the house, it's because of her (F8)	Parents are seen as bringing blessings in the house	(2) There is a role reversal when parents become old	
There must have been a time when my parents had to match my pace, they must have held my finger to walk with me at my pace (F1)	Awareness that there is a role reversal as parents traditionally taken care of children		
Because you know my father is like baby now (F5)	The realization that there has been a switch in roles		
I would put him in his shorts [when changing his diaper]. And I would say good boy, and he would laugh, and say that look she is calling me a good boy, she is like my <i>Amma</i> (F7)	Care recipients start seeing the caregivers in the opposite role also		

mostly conducted in a mix of English and Urdu (the national language of Pakistan) since participants from the background included in this study spoke in such a manner. Ten interviews was deemed as an adequate sample size as recommended in the literature. Boyd (2001) regards 2 to 10 participants sufficient to reach saturation and Creswell & Poth (2016) recommend “long interviews with up to 10 people” for a phenomenological method of qualitative research [30, 31].

The interviews, which lasted for around 45 minutes to 90 minutes each, were conducted using a semi-structured interview guideline specifically drawn for this study containing open-ended question that explored the difficulties associated with the caregiving, the circumstances that led to women adopting this role, thus trying to assess their holistic experience. All interviews were audio-recorded after asking permission from the participants.

Interviews mostly took place at the participants' homes although three took place in restaurants. At the latter, steps were taken to ensure that a quiet spot was chosen to ensure ease of audio-recording and to safeguard participants' privacy. The location was decided according to participants' convenience. In one of the interviews that took place at home with a daughter-in-law caregiver, the husband was present throughout the interview. Informed consent was however provided by the participant herself and questions were directed to her with the husband occasionally adding onto her responses. The researcher acknowledges the possibility of certain information being withheld due to the husband's presence. However, his presence was also useful since he added details about his mother's illness which the daughter-in-law missed. Since the participant was approached through a mutual friend,

it would have been socially inappropriate to ask the husband for privacy to conduct the interview. In other interviews however, the women (including the two other daughters-in-law) were unaccompanied by other family members and appeared to speak freely.

#### Data analyses

Interviews were transcribed verbatim. The author translated the Urdu phrases and sentences into English. Colaizzi's inductive method of phenomenological analysis was used to analyze data [21]. The author read the transcripts multiple times in order to extract “significant statements” following the process of horizontalization. Meanings were then attributed to significant statements, in a step known as formulation of meanings. Formulated meanings were then grouped to form theme clusters, with the inter-related clusters further grouped to develop “themes.” A snapshot of this process, which led to the emerging of five themes, is shown in Table 1 [see pg.9].

Thematic analysis revealed a variety of interconnected themes that characterize the holistic experience of caregiving of the elderly by two subgroups of women. The conversations uncovered the range of challenges women experienced as they engaged in this “labor of love” and brought forward their unique emotional responses.

#### Results

##### Characteristics of study participants

Seven daughters and three daughters-in-law participated in this study. The age varied from 29 years to 70 years. Seven participants were married, 2 single and 1 widowed. Six women (four daughters, 2 daughters-in-law) were employed in full-time work. All participants possessed

at least secondary level education, were Muslims and belonged to upper and upper-middle income group. Four lived in a nuclear family setting, five lived in a joint family (three or more generations living under the roof), and one resided in an extended family network (several generations of people including biological children, their offspring, aunts, uncles, and cousins). Three participants were taking care of male care recipients, 6 were taking care of females, whereas one daughter caregiver was taking care of both parents. The care recipients required assistance in ADLs due to stroke, cancer, dementia, Alzheimer's disease with psychosis and general frailty associated with longevity. All participants were living with the care recipients and had formal help hired to assist in the day-to-day management.

#### **Motivations for caring: daughters and daughters-in-law**

The study revealed different motivations for women assuming caregiving responsibilities. For daughters, it appeared that their role as a caregiver was similar to what their own parents had done for them in their childhood. A married participant who had moved to Karachi from a high-income country in order to take care of her ailing parents, narrated a powerful incident in which she had taken her father to the bank. There, she held his hand in order to guide him, and it dawned upon her that *"there must have been a time when my parents had to match my pace, they must have held my finger to walk with me at my pace."* (F1, daughter caregiver, married) It became clear to her that it was her turn now, and that it was important to *"...switch gears, switch roles."* (F1)

This adaptation to a new role, of taking care of someone who had previously taken care of you, was brought forward by all daughters in this study, *"I have seen them in the driving seat, and now we are in the driving seat, and they're not."* (F1) Participants regarded this as a role reversal: their parents were now like their own children, *"He is almost like my 5th child,"* (F5, daughter caregiver, married) according to one female participant with four children. As her father's dementia rapidly progressed, she realized that he was *"almost like a baby now."* (F5) When another participant's mother returned from psychiatric rehabilitation, she saw a drastic change in her mother, *"she transformed from an adult into a baby. I overnight transformed into a mother from a daughter"* (F9, daughter caregiver, single), thus conveying how the participants underwent internal changes. This role reversal also influenced how other members of the family started viewing caregivers. As one daughter caregiver explained, *"I am more like a motherly figure of the house. I am also a saas [mother-in-law] to my [elder] brother's wife"* (F9).

This role reversal was considered natural since caregivers became heavily involved in taking care of integral and

intimate tasks, such as changing clothes, and bathing that even the recipient started viewing them in the opposite role. One female participant laughingly spoke about how when she would bathe her father, *"putting on his shorts first... you know to not affect his ego..."* (F7, daughter caregiver, widowed) she would say, *"Come on, good boy"* and he would laugh with her and tell his other children, *"look, she now calls me a good boy... she has become my amma [mother]."* (F7)

Caregiving, in this context, was therefore seen as *"not having a choice because they [parents] were there before and now it's your [children's] turn"* (F7) and something almost *"natural,"* (F3), *"something you're supposed to do for your parents,"* (F5) and *"a responsibility because he [my father] brought me up and has been with me through thick and thin."* (F5) One daughter caregiver, who had moved back with her parents along with her three children after her husband passed away mentioned how her parents had *"taken her in, and raised her children as if they were their own"* (F7) and that it was now her turn to take care of her father.

Religious perspectives about elderly and caregiving were considered powerful motivations. In the backdrop of a society which regards the elderly as *"rehmat [a blessing];"* (F5) and an *"integral part of us,"* (F1) taking care of them in their times of need was considered a *"privilege"* (F5) and a *"matter of good fortune."* (F5) This view that the elderly were a blessing for the household was further accentuated by one participant attributing the financial prosperity of her household since *"...mother has moved in with us."* (F10, daughter caregiver, married) Others believed that Quranic (Muslim scripture) injunctions were quite clear on taking care of parents, especially in their old age, and that a child could not say *"uff [express impatience]"* (F10) to their parents, and that parents have an *"esteemed place"* (F5) and as such, should be accorded a high level of respect. Doing *"khidmat [taking care of parents]"* (F10) was also perceived as the pathway to heaven.

The study found that daughters and daughters-in-law alike considered caregiving of the elderly to be their responsibility. According to one daughter-in-law, she viewed caregiving of her mother-in-law as a *"responsibility just like as it is for my mother"* (F2, daughter-in-law caregiver) which has to be done with the *"best of intentions."* Another daughter-in-law caregiver considered her mother-in-law almost *"like a mother"* (F3, daughter-in-law caregiver) who had also *"helped me when my first child was born"* (F3) and thus taking care of her was, in a way, form of repayment.

Both groups appeared to share the viewpoint that caregiving lies in the domain of women. One daughter caregiver expressed how her brother did not provide care to

their mother because she felt that *“boys do not have it in them [to take care properly]. It doesn't come naturally to them”* (F9) and that it occurred because he is *“mostly outside and he is working. He doesn't give her time as much as I do.”* (F9) A daughter-in-law also provided the perspective that caregiving was largely confined to women due to the societal belief that women possess the *“maternal instincts necessary to provide care.”* (F3)

However, there were subtle differences in the way daughters-in-law spoke about their experiences as compared to the daughters. According to two daughters-in-law, the responsibility to take care of the ageing parents-in-law was automatically transferred to them because *“being the family member living with them, there was this expectation that I will take care of everything.”* (F3) This occurred, as she went on to explain, because *“there was this implicit understanding [at the time of our marriage], that I will keep on working, and we will live with his [husband's] parents.”* (F3) Hence, she had to assume the responsibilities of caregiving because *“I cannot question [now] as to why we live with his parents, and he cannot question why I work.”* (F3) In fact, the expectation to care was such that it negatively affected her relationship with her husband because he was *“expecting me to be the person his mother was.”* (F3) In this situation, where she was not only responsible for taking care of her sick mother-in-law but also expected to run the household as her mother-in-law used to, the tasks of caregiving, at times, almost became like a *“majburi [compulsion]”* (F3) for her. On the other hand, she believed that this was not the case for her husband who took care of his parents (although sporadically) *“dil say [wholeheartedly].”* (F3)

Conversely, for another daughter-in-law, once her mother-in-law fell ill, the couple decided that the elderly mother-in-law would move into their household so that she could be taken better care of, a step which she *“took in her stride”* (F2) because *“it had to be done.”* (F2) She also believed that her prior experience of dealing with her ageing parents and grandparents had prepared her for the inevitability of taking care of her ailing mother-in-law.

Within the daughters-in-law cohort, caregiving was considered something that was part of life. Participants were of the view that old age and its associated difficulties *“can happen to me anytime.”* (F2) In a way, daughters-in-law viewed caregiving within the context of circle of life, something that they may also require (from their children, and children-in-law) once they age. One daughter-in-law caregiver, when questioned as to the reasons for taking care of her mother-in-law, elaborated that she is *“answerable to God.”* (F2) Another one felt that she was *“chosen for this purpose”* (F4) by God, and therefore, it was her responsibility to fulfill this role.

While the study showed that daughters and daughters-in-law differed in some of motivations to provide care, both groups by and large expressed disapproval of old age homes. It was unthinkable to consider the possibility of old age homes because *“Why do we need old age homes? We are there to take care of our parents because they were there when we were young...”* (F7) particularly because *“they are an integral part of us”* (F7) and henceforth, *“should be with us.”* (F7) A daughter-in-law also shared distaste for children belonging to affluent families by speaking pejoratively of those, who *“abandoned”* (F2) their parents in such places, a concept she simply *“could not understand.”* (F2)

### The difficulties of caregiving

Caregiving is a time-consuming endeavor requiring constant effort thus making the experience *“taxing”* (F1) and *“demanding.”* (F1) The caregiving duties combined with multiple other responsibilities in the lives of these women, including household, child-care and full-time employment compounded the associated difficulties.

Despite the presence of formal help, participants considered caregiving as something that necessitated presence *“at all times”* (F1), was like *“clockwork”* (F1) leaving little *“free time”* (F5) for leisure. Physical health of a few participants suffered, as a result of their caregiving duties because of *“lack of sleep. I only sleep 3 hours a day.”* (F4)

Responsibilities overall included supervision and constant monitoring such as keeping tabs on the formal help, ensuring that medications were sorted, and communicating with the physicians, *“If, for example, she [the mother-in-law] has diarrhea, then I am [in contact] with the doctor, adjusting the medications.”* (F3) In the absence of formal help at times, some caregivers also performed hands-on work including uncomfortable tasks, such as *“[washing] soiled clothes”* (F3) and *“changing diapers.”* (F8) Both daughters and daughters-in-law expressed their surprise at performing a duty which they had *“thought they will never do [for anyone].”* (F9)

Participants highlighted the unpredictability of the process adding to the difficulties since *“every day is a new day with a new routine.”* (F9) The responsibility and the *“hassle”* (F3) increased exponentially if the care recipient had to be taken to the hospital due to an emergency. According to one daughter-in-law, *“Every three to four months, she ends up getting hospitalized. Those days are very difficult”* (F3) especially *“because I am a physician, and there is this expectation that I will not only visit her everyday but also be there during doctor rounds.”* (F3)

For women who worked outside the home, professional life was considerably affected, with one participant moving back to the city to provide care to her ailing parents. Another daughter found it difficult to provide adequate

time to her elderly mother, suffering from psychosis, and therefore was forced to “quit her job three times.” (F9) A daughter-in-law shared how she was expected to leave her career once her mother-in-law fell ill, since her father-in-law thought “The nurse would take care of her during the day, I’ll take care of her during the night.” (F3) When this happened, the participant stood up to her husband stating that she will not quit her career.

Caregiving duties strained relationships with other people, particularly spouses. One daughter caregiver’s husband had been reluctant to move into her father’s house so that she could take better care of him, “it took almost a year of convincing him,” (F5) and when it happened, “there were some eyebrows raised from everyone.” (F5) A daughter-in-law stated that, as a couple, she and her husband were unable to socialize, “People often forget that she [the caregiver] may have her own family, her work, and her kids.” (F3) One daughter-in-law added that her exhausting routine of caregiving, with minimal support from other family members, negatively affected her sexual life (F4).

Participants reported that their children complained about the lack of time devoted to them. One daughter-in-law spoke about her 10-year old daughter’s anger for not being able to go out together as a family because one parent had to stay at home (F3). According to a daughter, “... there were tears, there were bad times, because they [the children] couldn’t deal with so much of it, because they were not allowed to be home alone with the formal help” explaining that the children could not understand why she did what she did because “...you know he is my dad, he is not their dad.” (F5) For another older daughter-in-law, managing their own children did not pose a problem because “we are fortunate that our kids are older, and we can devote more time to her.” (F2)

Social life was significantly affected for both married and single caregivers. The extent of socialization with friends gradually decreased over time. According to a single daughter caregiver, “It’s not easy...you feel bad because you missed your friend’s birthday party because the maid wasn’t there to stay with mom.” (F9) Couples, who had been married recently, also felt that they were unable to socialize with their friends together. A couple married for a while had restructured their social life in order to fit the needs of the mother-in-law because “she is our priority.” (F2)

### **Role of other family members in caregiving**

Despite majority of the participants living in joint family setups (existence of three or more generations under one roof), caregivers expressed that the ultimate responsibility to provide care rested with them firmly establishing their role as the ‘primary’ caregiver. The single

daughter caregiver, living with her brothers and sisters-in-law mentioned how whenever medications ran out, her father “would ask me to get it, even if it is at 10 pm at night” (F8) whereupon she would get often get irritated and say, “Why don’t you ask your sons to sometimes do it?” (F8) A daughter-in-law caregiver commented how even after three years of her mother-in-law falling ill, “if her medications are about to finish, my husband still expects me to ensure that they are there.” (F3)

At times, quick medical decisions on the spot had to be undertaken by the primary caregivers. For one daughter caregiver, while her four sisters (living in separate houses) “pitched in with advice”, “[they say to me] you should have taken him to the doctor,” asking questions like “how come Papa has fever, this and that?” It was clear to her that she was “responsible” and that “I do not appreciate it because you know, I am doing my best here.” This perception of feeling solely responsible for the ill parent also led to feelings of alienation, “The other sisters don’t like it [when I tell them not to interfere]. After all, he is their dad too, but I am very possessive, because after five years,, I feel he is just my dad.” (F5) In contrast, daughters-in-law did not believe that they were the ultimate decision-makers since such decisions appeared to be taken by male members of the family.

Two daughters-in-law also highlighted the lack of familial support. One shared how her husband did not look after his own mother despite her feeling that it was his responsibility (F3). Instead of confronting her husband as she used to initially, she resorted to using different tools of negotiation, “I ask him [now], for example, to look after his mother by telling him that I am looking after [our] daughter.” (F3) The same respondent expressed how her sisters-in-law (wives of her husband’s siblings) did not help leading to feelings of resentment towards “those people who should be pitching in more.” Another daughter-in-law mentioned that when she had to step out with her husband, she asked her sisters-in-law for help, which always had to be requested, and never offered itself (F4). In contrast, another one gained support from her older son living in the house (F2).

Lack of daily support did not mean that other family members were completely absent from the overall dynamics. Male members provided financial support particularly when the care recipient had multiple children. One daughter caregiver noted that her family had struggled finding a suitable rehabilitation centre for her mother during her psychotic breakdown because they could not afford the more expensive ones, since her brother was the sole breadwinner of the house (F9). It became much easier for caregivers when they had financially well-settled older children. Two daughter caregivers (F6, F10) had children who were physicians which

helped tremendously in medical management and in recruiting suitable formal help.

The study revealed that the extended family network played a limited role in providing support, *“there is no additional support that comes from them [the extended family]. Even when it [the illness] was really aggressive, we [brother and sister] were largely on our own.”* (F9) While members of the extended family expressed to caregivers that they were fulfilling a role that was almost *“holy”* (F9), the absence of moral support meant that caregivers felt that *“Humein kon poochta hai? [Nobody recognizes our troubles.]”* (F3)

### Emotional and psychological effects of caregiving

Daughters found it difficult to come to terms with the reality that someone they loved dearly was no longer what they used to be, *“It was quite difficult when you see someone so close who is in so much pain.”* (F5) A daughter caregiver spoke about how her composed father gradually started losing control of his urinary functions, and would have accidents at the dinner table, in front of his grandchildren, *“it was very discomforting for me, to see my dad in such a weird and ashamed state.”* (F5) Daughters reported moments of *“breakdown especially when he [father] is sick, or when I am not doing too well emotionally myself.”* (F5) One daughter-in-law caregiver expressed that it was *“traumatic”* (F2) for her to see her mother-in-law who used to be *“fiercely independent, with a mind of her own”* disintegrate to a state *“where she cannot even go to the washroom by herself.”* (F2)

Participants reported *“[feeling drained] because of the physical stress of taking care of him”* (F5) and *“feeling irritable”,* (F4) *“feeling burdened all the time”* because of *“too much responsibility.”* (F4) These feelings were compounded for many since they felt, *“It’s just me on my own sometimes”* (F5) conveying a sense of loneliness. Daughters reported feelings of guilt for *“not doing enough, or not being around all the time.”* (F5)

Daughters shared preoccupation with the thought of a loved one’s death, *“the first thing that comes to my mind [whenever he falls even more ill], what if he leaves me?”* (F5) Single daughter caregivers expressed their worry with respect to, *“If I get married, who will take care of her?”* (F9)

A daughter caregiver, in her late twenties, shared the story of physical and emotional abuse she endured at the hands of her elderly mother diagnosed with paranoid schizophrenia. She spoke, with her tears in her eyes, about the time when her mother had yet been undiagnosed, so *“no one really knew what was wrong with her. This was a really rough patch because before we put her [in a rehab], there was a lot of physical abuse, [constant screaming and shouting, and throwing things at me]”* until

*“it became normalized for me. I became like a robot.”* (F9) It was not until her brother pointed out her gradual emotional decline that she regained a sense of herself.

The caregiving experience was however not always negative, for both groups of participants also explained how they were *“better off.... Because before I was unable to do so much in life.”* (F5) Participants therefore alluded to the idea of self-mastery since caregiving gives one *“skills to deal with other things, because when you’re dealing with such a [huge] problem, you know you can deal with anything.”* (F9) For younger children with elderly parents, caregiving transitioned them into adulthood quicker than their peers, *“We [siblings] have become tough. Small things don’t affect us anymore.”* (F9)

Participants believed that in order to cope better with the difficulties of caregiving, it was essential to *“take breaks”* (F5) and failure to do so would lead to negative consequences, as stated by a daughter caregiver, *“I would really crumble with the whole stress of it.”* (F5) Going on a vacation, and *“sometimes just getting out of the house”* (F5) were helpful ways to cope. Others felt that doing something for oneself regularly helped, *“Running and jogging relaxes me. I find it very therapeutic. I get things out of my system.”* (F1) One participant spoke about how going on a trip with her friends had helped (F9), whereas another went on a *“solo trip.... And found herself again.”* (F5) Participants believed this was important because it allowed them to *“to be a good daughter, to be a good caregiver, and to be a good person.”* (F1)

The multifaceted nature of caregiving was also apparent because interviewees, particularly daughters, while finding it stressful also considered it *“rewarding.”* (F9) They spoke about internal transformations. For some, it was this gradual realization that death is inevitable after seeing someone so close standing in the face of death, creating a *“spiritual change”* (F8) which led them to *“become closer to Allah [God].”* (F8) Others seemed to become better versions of themselves, *“It requires so much dedication. I couldn’t ever imagine cleaning someone’s poop. I didn’t think I would be able to do it for anyone, but now it’s normal.”* (F9)

### Role of formal paid help

All participants had some form of formal help, who were hired to look after the specific physical needs of the care recipients. The realization that formal help was needed to cater to the demands of care recipients was often a gradual process, with other family members often pointing out that extra support would help, *“My sister [living abroad] pointed out that it’s about time [to get formal help] because I couldn’t see the big picture. For me, he was always my papa [and I had to take care of him]”* (F5) This was particularly important in the context of management



of activities such as changing diapers, and clothes, or giving a bath to the recipient, something which was not possible for female caregivers to do so, “because of course I cannot lift him [father] up.” (F1)

Other caregivers also felt that “there was no need for one of us [siblings] to be doing these things. Little jobs that others can do” (F1) even though “we are all caring, and loving, and we are there.” (F1) According to the daughter-in-law caregiver, the family hired formal help when “my kid’s education was getting neglected” and “I had started feeling extremely exhausted.” (F4)

The urgency of formal help was felt for better medical management of the care recipient, because “You see, I couldn’t change the catheter. I couldn’t change the NG tube. I, of course, couldn’t manage bedsores.” (F7) Nevertheless, the family caregivers still closely monitored the formal help, “I remember I initially used to get up at 2 am in the morning to check up on the nurses, and then check up at 5 am, and then 8 am.” (F2) This continued until “I was sure of the formal staff. I would randomly spot check also...” (F2) Caregivers acknowledged that without the formal help, “I would have to remain with her [mother] constantly” (F9) but due to their presence, “I just have to see whether the clothes have been changed, or the diaper has been changed. I see whether there are any bruises etc. I don’t have to do anything by hand.” (F6) It was also obvious that trust in formal help did not come easily and, according to a daughter-in-law caregiver, “I give food myself, I give her [mother-in-law] a shower myself. I don’t trust anybody.” (F4)

Formal help however did pose significant challenges for many caregivers, from “finding the right help” especially trained ones, for “bedridden patients.” (F3) Hiring formal help was also expensive “Just the formal help costs us 2 lakhs per month [USD 1500]” (F3) but there were times when the help proved to be unreliable in terms of leaving the job without prior notice, “finding the right help was the single most difficult thing I have done [during my caregiving].” (F9)

## Discussion

While numerous studies using qualitative methods have been conducted to explore the experience of caregiving of the elderly in different parts of the world, including India, China and Japan, as well as the viewpoints of minority groups in the United States, holistic studies within the context of Pakistan have been missing [32–34]. This study was an attempt to map the ‘essence’ of the caregiving experience. The limited literature in Pakistan looks at issues of caregiving through a quantitative approach. As argued above, this is a limited lens to employ since it circumscribes the rich experiences associated with this phenomenon. As Gubrium states, caregiving is “a mosaic

.... of distinct and complex interpersonal experiences of the real world of the persons involved [35]. Keeping this in perspective, the study employed the ‘ethics of care’ framework since it offers an explanation to the experiences of caring for older adults in Pakistan. Grounded in the phenomenological mode of inquiry, this study offers a valuable contribution to the international literature providing a LMIC perspective of a collectivistic society.

The study focused on informal caregiving since literature from different parts of the world supports the notion that caring for an elderly family member is an increasingly normative experience grounded in high values of familism [36]. These values may derive themselves from cultural and religious representations. For instance, in Islam, the dominant religion in Pakistan, obligations to kin are thought to be moral injunctions, and such explanations are based in the Quran, and traditions of the Prophet [37]. One of the much quoted *Hadith* of the Prophet states that the best beloved of God is one who loves his family the most. The study findings support the notion regarding the importance of kinship networks with participants expressing their desire of taking care of the elderly in the family, often basing their motivations on Islamic injunctions and beliefs.

Another important aspect to comment upon is that within filial networks of care, women tend to shoulder majority of the caregiving responsibilities [38]. The study illustrated that despite the existence of adult male children in the family, and even living in a joint family system, the primary responsibility of care fell upon the women in the family. Some women, especially those in the younger age group, perceived that the caregiving role was somewhat an extension of their roles as mothers. In the Pakistani society, the role of a nurturer is traditionally seen as the domain of the woman, a notion shared by study participants. A proposed explanation is that caring in different South Asian societies is “embedded in women’s moral and ethical selves” which can potentially explain the intrinsic drive to care among caregivers, particularly daughters [39]. However, sociological explanations also assert that such views may be ingrained in females through social and cultural expectations, a value that is inculcated in their upbringing [40]. The ethics of care framework also supports this notion that women demonstrate their moral selves through caring responsibilities [41]. This has however also been criticized since many women may internalize the caregiving role due to gender expectations in society.

This study did not look at the viewpoints of male members of the family, a comparison of the level of family obligation between male and female members cannot be made. However, the study appears to indicate that although daughters provide routine care and take on the

reigns as primary caregivers, sons tend to perform activities that are sporadic (e.g. providing help during periods of hospitalization, as shown here) [51]. In addition, sons are likely to assist in financial management, as highlighted in the current work. Studies in the United States have previously shown that men and women respond differently to filial obligations, and thus their involvement in caregiving duties varies [42]. Montgomery and Kamo (1990) compared sons and daughters' levels of obligations and found that while sons feel as obligated as daughters do, the extent of their involvement tends to differ [43].

The study involved two distinct groups of women, daughters and daughters-in-law. Interviewing these two groups allowed for a useful comparison in the Pakistani context. One can reasonably assume that there are differences in the relationships that daughters have with their parents, as opposed to daughters-in-law with their in-laws. The caregiving role of daughters-in-law is provided in the context of affinal kin, kin related by marriage whereas daughters have a shared history with their parents from the time of birth. Previous research has demonstrated that affinal kin generally evoke lower obligations than consanguineal kin [44]. Kivett (1989) highlighted based on her research in the US that while daughters-in-law provided care to their in-laws, obligations appeared to be more important than attachment [45]. Obligation to care, on part of this group, seems to stem from obligations to their husbands rather than a more direct obligation. This is based on a feeling that one must do what has to be done especially in a situation where no other alternative exists. For daughters-in-law in particular, norms of patrilocal residence in which the woman moves in to live with her husband and his family, and the existence joint family system, have an important influence in them assuming the duties of caregiving. For at least two of the daughters-in-law in this study, this assertion holds true. The case of the daughter-in-law who had an implicit understanding with her husband at the time of their marriage to live with his parents (and consequently take care of them) also supports this proposition. In addition, without undermining the affection that daughters-in-law in this study voiced for their in-laws, one can also reasonably state that daughters-in-law sense of obligation also stemmed from their duty as wives, and internalization of norms regarding gender-role behavior, something which Brody (2003) has previously suggested [46].

In contrast, caregiving seemed to be embedded in the life experience of daughters in the study as they appeared to accept the role readily without any questions because they did not consider themselves as having any other choice, as far as parents were considered. Due to Muslim religious perspectives concerning the elderly, daughters in my study, all Muslims, also considered it a right unto

their parents for them to be taken care of in their old age and recognized that it was now time for them to give back to them. This was also based on the premise of reciprocity, of giving back to one's parent, depicted by ethics of care as well. This has also been found in Confucian societies, like Hong Kong [22].

Despite the fact that a few female participants, both daughters and daughters-in-law, in this study held full-time jobs, they were also responsible for caregiving. The example of a daughter caregiver in the study, who had to temporarily quit her jobs on multiple occasions, in order to take care of her mother supports the assertion that the household and care duties tend to be assigned to women. This also came at a significant cost to her career aspirations. Previous research has highlighted that women frequently withdraw from work, or reduce the number of working hours due to their roles as caregivers in the family [47]. An interesting contrast can also be made from the case of the daughter-in-law who was expected to leave her career by her father-in-law and to some extent, her husband, an expectation that she resisted. This conveys a difference in the degree of emotional involvement between daughters and daughters-in-law. Moreover, the expectation for women to leave their profession, as well as a daughter actually quitting her jobs can also be traced back to the belief in traditional gender norms that view the household as the domain of the woman, and breadwinning the job of the man. It appears therefore that traditional gender roles continue to be pervasive in Pakistani society, something which is supported by other studies from the country [48, 49].

Traditional norms in patrilineal societies like Pakistan emphasize that once a daughter is married, her duties are now transferred to her parents-in-law as seen in the current work [35]. Married daughters however may assume responsibility when a son is not available due to immigration or otherwise, shown from an Indian study [50]. Against this cultural backdrop, women face considerable dilemmas, as mentioned by one daughter caregiver who had to negotiate with her husband before moving into her childhood home to take care of her father who had no male offspring. Breaking away from the norms of patrilocal residence also leads to social disapproval. Amidst these cultural norms governing the lives of women in Pakistan, what emerged was that whilst daughters had an intrinsic motivation to take care of their elderly parents particularly due to the sense of invoked reciprocity, this may not be true for daughters-in-law who were perhaps fulfilling the societal roles expected of them.

The existence of joint family systems in the study requires elaboration and sheds light onto the various family caregiving models that may exist even when one primary caregiver is identified [51]. Majority of the

participants resided in households with more than two generations living under one roof. In the case of at least two caregivers (one daughter and one daughter-in-law) in the current study, it appeared as if other people were also providing help. The case of the husband and wife exhibiting a more partnership model in providing care, or that of a daughter caregiver who lived in an extended family network shows that joint family systems can be supportive in terms of providing care. However, in other cases, the involvement or detachment of others in the family also appeared to be disadvantageous. For one daughter caregiver, her siblings providing advice to her on how to handle their father led to feelings of frustrations whereas for one daughter-in-law caregiver, other sons and their wives not taking on the caregiving tasks created resentments. While explored previously,[52] such phenomena require further investigation from the Pakistani perspective through understanding the family dynamics by involving other family members in research.

The study cohort mainly consisted of women from a specific segment within the Pakistani society, those who were more affluent and therefore had access to more resources. Therefore, they could hire paid 'formal' help to handle the bulk of the ambulatory tasks. This allowed some of them in this study to pursue employment, and have their own lives separate from caregiving duties thereby minimizing the difficulties associated with the caregiving role. However, Keith (1995) makes a distinction between allocation of responsibilities for tasks and delegation of authority. In many cases, despite the existence of formal help, the final authority appeared to rest with the primary caregivers—they were the ones ultimately responsible. In the care ethics model that identifies four phases, women in this study appeared to imbibe the ethical value behind caring—attentiveness even if the hands-on labor was not always performed by them. Nevertheless, more research is required to explore the experiences of those who did not have access to these resources which may make the experience of caregiving quite different from those exhibited by women in this cohort.

The acceptance of hiring formal help placed within the household reflects an important trend in Pakistani society. There was widespread disapproval of nursing homes and old age homes which places the elderly away from the center of the kinship circle was evident. Research has demonstrated that individuals believe that better caregiving can be provided at home, with more benefits accrued to the elderly such as happiness and satisfaction with old age [53, 54]. A qualitative study conducted in elderly sheltered homes located in Karachi illustrates that while institutionalization is slowly gaining prominence, it remains widely frowned upon [55]. In addition, systematic structures will pose problems in expansion

of this trend. The number of old age homes are low, and when such facilities exist, their standards are low [56]. These findings also hold international relevance—those planning for increasing support services for caregivers in multi-ethnic backgrounds need to be cognizant of these realities for South Asian population in general and those of Pakistani origins in particular.

The current study also adds knowledge in the area of geriatric care that despite the existence of formal help, women continue to face difficulties in juggling the demands of their professional lives and their caregiving duties [26]. The role conflict theory which states that societal structures are made of roles, with designated responsibilities/demands is applicable in caregiving context. Multiple roles evoke different obligations thus leading to conflicts [57]. The narratives of caregivers in this research corroborate this, since many of them described feelings of stress and frustrations due to their multiple roles as mothers, wives, professional workers and caregivers. This is particularly true for the 'sandwich generation,' a term coined by Dorothy Miller (1981) [58]. She wrote about the struggle of individuals, aged between 45 and 65 years of age, who with their spousal and parental responsibilities also provided care of their ageing parents. The current work highlighted that this generation in Pakistan appears to be those aged between 30 and 40 years. More support needs to be directed towards women within this demographic.

Due to difficulties and conflicts associated with caregiving role, the study also supports findings from elsewhere that this role can lead to multiple stressors causing physical and mental health issues [59, 60]. Despite the struggles and frustrations that appeared to be a part and parcel of this experience, none of the women used the word 'burden' to describe their experience. The terminology of 'caregiver burden' has been utilized extensively in literature worldwide including Pakistan. Possible explanations for non-usage of the term in this study may include that the Urdu translation for the word burden is "*bojh*" which has disrespectful and pejorative undertones. Therefore, for daughters and to some extent the daughters-in-law, parents and in-laws respectively are unlikely to be regarded as "*bojh*" considering the level of respect accorded to the elderly. For daughters, the affective dimension and emotional attachment also has a role to play. Conversely, daughters-in-law may not voice such sentiments due to the social norms governing elderly respect. However, this has pertinent implications for daughters-in-law, in particular, who may continue to provide care despite the deep personal costs attached without actually finding the experience rewarding, as in the case of daughters. This may actually lead to increased psychological distress among this sub-group. The

non-usage of the term ‘burden’ has been evident from elsewhere as well [61]. A cross-sectional study in the US highlighted that minority groups while finding the experience burdensome expressed it in “different” ways (including feelings of frustrations and somatic complaints) [62]. The likely explanation is that within the Pakistani cultural landscape, quite similar to other collectivist groups/societies, women may not directly term their experience as a “burden” while still finding the experience burdensome. Support groups and healthcare services need to consider the physical health implications on caregivers.

An important element that emerged from this study was that for majority of the participants in this group, their personal needs appeared to remain prominent despite their caregiving role [63]. This therefore adds to the ethics of care that caregivers should not ignore their own personal needs but should consciously fulfill them. Examples from this study include one daughter-in-law caregiver continuing to work and a daughter caregiver making solo trips. However, this finding should be considered keeping in mind the affluent nature of the study participants, since for the majority of the Pakistani population, this may not reflect the reality.

There are a few limitations to the study findings. It was conducted in an urban cosmopolitan city with participants belonging to affluent section of the society, therefore the findings may not be applicable to other parts of the country, including rural areas or other segments of the population. As identified above, experiences of caregivers who cannot afford to hire formal help at home may be different, since they may face greater challenges while providing care. The study also had two selected groups of female participants, the daughters and daughters-in-law and the motivations to care for a spouse by a wife, for example, may be different since the bonds of marriage are dissimilar. Additionally, it may be worthwhile to investigate the experiences of formal paid help who perform this labor in exchange for fee, rather than due to the bonds of love or relational affinity.

Despite these limitations, the present study adds a qualitative dimension to the caregiving literature in Pakistan, where none exists. It also provides future directions of research particularly to explore the impacts of the caregiving experience on families of modest means. In addition, this study focused primarily on women but it would be useful to explore the perspectives of men towards caregiving since their experiences may be different due to their sociocultural and economic positions.

#### Authors' contributions

SS conceived the idea, collected the data, wrote the manuscript. The research was carried out for her Master's thesis.

#### Funding

The study was conducted for Master's in Bioethics (MBE) thesis. There was no funding for this study.

#### Availability of data and materials

The transcripts of the audio recorded interviews may be furnished upon request by the corresponding author.

#### Declarations

##### Ethics approval and consent to participate

The Ethical Review Committee of Sindh Institute of Urology and Transplantation (SIUT) provided ethical approval for the study. All participants provided verbal informed consent for participation in research.

##### Consent for publication

The verbal informed consent provided information that the findings of the study may be published.

##### Competing interests

The authors declare no competing interests.

Received: 12 September 2023 Accepted: 9 August 2024

Published online: 25 September 2024

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