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Unsung Heroes of Cancer Care: Loneliness, Social Support, and Quality of Life in Informal Cancer Caregivers During COVID-19 Pandemic

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COVID-19 has caused an anomalous disruption globally; impacting vulnerable pre-existing health condition groups, particularly cancer patients and their caregivers. This research investigated informal cancer caregivers' loneliness, social support, and quality of life during the COVID-19 pandemic. A mixed method design was used. In the quantitative phase, a sample of 35 informal cancer caregivers (21 men and 14 women) was recruited via snowball sampling from Pakistan. Participants were requested to fill a basic demographic questionnaire, UCLA Loneliness Scale Version 3 (Russell, 1996), The Multidimensional Scale of Perceived Social Support (Zimet et al., 1988), and The CareGiver Oncology Quality of Life Questionnaire (Minaya et al., 2012) via Google Forms. Quantitative results revealed a significant negative correlation between loneliness and social support as well as loneliness and quality of life. Social support was found to have a significant positive relationship with quality of life. Nonsignificant gender differences were found in the variables. In the qualitative phase, 4 consenting participants (2 men and 2 women) were interviewed telephonically via a semi-structured interview to explore the impact of the COVID-19 pandemic on informal caregivers' caregiving experiences. Thematic analysis highlighted five themes including rewards, patient facilitation, detriments of caregiving as well as COVID-19 specific caregiving stressors, and obstacles of caregiving. Implications of the results pertaining to informal caregivers, patients, and healthcare in COVID-19 pandemic are discussed.

Keywords: COVID-19, informal cancer caregivers, loneliness, social support, quality of life

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In December 2019, the dawn of the novel Coronavirus (COVID-19) turned into a paralyzing contretemps for the world. To flatten the curve of infections, social distancing, movement curtailment, and quarantine sanctions were imposed; impacting access to healthcare and support for vulnerable populations such as cancer patients and their informal caregivers (Gallagher & Wetherell., 2020). In the light of the threat COVID-19 posed, caregiving for cancer patients required special attention amidst this pandemic; increasing the caregiving burden exponentially (Mishra et al., 2020).

Globally as the second leading cause of death, cancer claims approximately 9.6 million lives a year (World Health Organization., 2019). Pakistan has the highest incidence of breast cancer in Asia with one in every ten women being impacted by this belligerent disease (Agha Khan University Hospital, 2020). The WHO-China Joint Mission on COVID-19 reported an increased two-fold risk of COVID-19 infections in cancer patients compared to the general population (Raymond et al., 2020). The tumultuous change in the delivery of treatment from the conventional hospital centered care to a home-family centered model for patients coupled with pandemic sanctions burdened informal caregivers to help beyond their customary caring duties, impacting their lives significantly (Mishra et al., 2020). Informal cancer caregivers who provided 70% to 89% care to patients prior to COVID-19, became more encumbered with caregiving during this pandemic than ever before (Romito et al., 2013).

An informal caregiver is an individual “who provides some type of unpaid, ongoing assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to a person with a chronic illness or disability” (Roth et al., 2015, p. 03). These individuals may be children, spouses, partners, parents, friends, or extended family who delivers vital support to patients throughout the course of the illness without monetary compensation for their services (Romito et al., 2013).

Variance in the involvement and impact of the informal caregiving duties are capricious and are seen as differing across cultures and genders. In Asian cultures particularly, it was evidently observed that caregiving was seen with emphasis on filial piety, propelling informal caregivers to be the first line of support expected to take on the caregiver role (Chua et al., 2016). Particularly in an indigenous context, Pakistani informal caregivers are often inclined to morally uphold the caregiving obligations grounded in the generational contracts of caring for family (Arora et al., 2020). Regardless of the type of family system (nuclear or joint), reduced social support leads to loneliness and stress in Pakistani informal caregivers (Ansari & Qureshi, 2013).

Informal caregiving is also perceived to be a specific gender-oriented activity, with women shouldering greater family care than men (Arora et al., 2020). Female caregivers reported facing more psychological distress, lower levels of social support, and poorer quality of life than men (Ekwall et al., 2005; Gaugler et al., 2009; Kim & Spillers, 2010; Maguire et al., 2017).

Informal caregiving is an arduous task. Cancer has an unpredictable disease trajectory creating its own share of challenges for the caregiving role for these patients (Mishra et al., 2020). With the advent of the COVID-19 pandemic, informal cancer caregivers are induced in triple crises: of confronting the COVID-19 pandemic, handling the evident care needs of the cancer patients, and coping with their own physical and psychological needs (Su et al., 2021).

During caregiving, informal cancer caregivers neglect and lose social contacts, withdraw from previous social habits, and face reduced social support. Such a lifestyle embeds loneliness in them (Gray et al., 2019). Loneliness is described as the personalized feeling of perceived discrepancy between the quantity and quality of social relations (Cacioppo et al., 2014). The caregiving duties, coupled with meagre social interactions, dwindled personal space, deprivation in relationships along with a sagacity of being solely responsible for patient’s welfare have been identified as markers causing loneliness in these caregivers (Segrin et al., 2018). With these burdensome responsibilities and reduced time for self, caregivers divulge into an isolated state of loneliness that inadvertently even reduces their quality of life (Caputo et al., 2016; Ekwall et al., 2005; Gallegos & Segrin, 2019; Gaugler et al., 2009; Maguire et al., 2017; Segrin et al., 2018).

The emergence of the COVID-19 pandemic led the already vulnerable population of informal cancer caregivers to being exposed to more social distancing norms along with quarantines, exacerbating their loneliness. Informal cancer caregivers reported feeling 41.4% lonelier than before in the current pandemic (Schellekens & van der Lee., 2020). Furthermore, with external contact being limited due to the risk of contracting COVID-19, the imposed restrictions reduced social support, an indispensable need for informal cancer caregivers (Shah et al., 2020).

Social support is defined as the perceived level of the support received by an individual from their family, friends, and significant other (Zimet et al., 1988). The impact of availability of social support is directly related in relieving emotional and psychological stress, aiding psychological and physical well-being, emotional regulation, and in providing higher quality medical care in informal cancer caregivers (Kuscu et al., 2009). Furthermore, social support is also observed to improve the quality of life and reduce loneliness in these caregivers (Oven-Ustaallioglu et al., 2017). As informal cancer caregivers shoulder the burden of majority of responsibilities in regards to the patient, social support also benefits them in relieving some of their physical burdens by receiving assistance in transportation, managing daily activities, and sharing emotional burdens (Mishra et al., 2020).

With the advent of the COVID-19 pandemic, informal cancer caregivers experienced an amplified burden of caregiving and increased responsibilities leading to the absence of social support. The abolishment of the social support cycle in the pandemic and the extended impacts of social isolation led to increased feelings of loneliness and disconnectedness for the caregivers. Literature purports that social support has an inverse relationship with loneliness even prior to the COVID-19 pandemic (Cacioppo et al., 2009; Demir et al., 2007; Rokach et al., 2014; Sahin & Tan, 2012).

Furthermore, extended periods of loneliness with increased burden and reduced social support also risked detrimental ramifications for the quality of life for these caregivers (Mishra et al., 2020). Pre-pandemic research findings also validate that decreased social support plays an integral role in reducing the quality of life in informal cancer caregivers (Burnette et al., 2016; Ketcher & Remblin, 2019; Nabors et al., 2002; Nightingale et al., 2016; Northouse et al., 2012; Pearlin et al., 1990; Rokach et al., 2014).

Quality of life is circumscribed as the overall well-being of caregivers outlining negative and positive features of life in terms of psychological well-being, social support, burden, coping, leisure, relationship with health care, physical well-being, self-esteem, administration and finances, and private life domains (Minaya et al., 2012). Caregiving to cancer patients is a significant experience. However, it is also analogous with declining quality of life, a variety of psychiatric issues and a rising peril of mortality in informal caregivers (Lim et al., 2017). The tasks of caregiving, coupled with the constant fear of loss, financial well-being as well as restrictions regarding social life act as significant markers in effecting informal caregivers' quality of life (Hacialioglu et al., 2010).

With the addition of COVID-19 pandemic sanctions and the shift of the entire hospital healthcare system to a homecare system, informal cancer caregivers are more overwhelmed than ever. Increased caregiving tasks along with reduction in social support forces these caregivers to feel lonelier and unsupported than ever before. With the ever-lasting fear of contracting the infection and passing it down to their patients, informal cancer caregivers are stressed; essentially causing a slump in their quality of life in the COVID-19 pandemic (Zhang & Ma, 2020).

The COVID-19 pandemic endangered individuals across the globe. However, immuno-comprised individuals when faced with the additional risk of contracting this virus place them at a higher risk than ever. This increases the caregiving burden of their caregivers exponentially. With this novel situation, the healthcare system cannot afford the collapse of these informal cancer caregivers, as they are the quintessential population aiding the absentee oncology community, while simultaneously catering to patient's needs. With this pandemic halting cancer care and treatment, informal cancer caregivers are carrying greater than 70% of the patient's caregiving duties (Su et al., 2021).

Hence, the context of the COVID-19 pandemic transforms the way in which these informal caregivers not only manage their increased caregiving duties, but also how they experience loneliness and disruptions in their quality of life in lieu of the reduced and absent social support due to imposed pandemic sanctions. However, there is scarcity of data that recognizes how social support affects the quality of life of these caregivers in the context of this pandemic. Moreover, examination of the loneliness experienced by informal caregivers in the absence of social support cycle owing to the imposed curtailment of movement is also limited. The unparalleled experiences of caregiving in the pandemic also require scrutiny. Given these unique circumstances, the loneliness, social support, and quality of life of cancer caregivers and their novel experiences during the COVID-19 pandemic shall hence be examined in this study. It is essential to evaluate their current situation to aid them in doing an effective job to support the overburdened healthcare system effectively (Shah et al., 2020).

Method

The aim of this research was to investigate informal cancer caregivers' loneliness, social support, and quality of life in the COVID-19 pandemic. Moreover, it also aimed to examine the impact of the COVID-19 pandemic on the caregiving experiences of these caregivers. This research was based on a mixed method design that was conducted in two phases: quantitative and qualitative.

Phase I: Quantitative Research

Quantitative data was collected using standardized questionnaires to examine the relationships between loneliness, social support, and quality of life in informal cancer caregivers.

Hypotheses

1. There is a negative relationship between informal cancer caregivers' loneliness and social support during the COVID-19 pandemic era.
2. There is a positive relationship between informal cancer caregivers' social support and quality of life during the COVID-19 pandemic era.
3. There is a negative relationship between informal cancer caregivers' loneliness and quality of life during the COVID-19 pandemic era.
4. Female informal cancer caregivers experience greater loneliness than male informal cancer caregivers in the COVID-19 pandemic era.
5. Male informal cancer caregivers experience greater social support than female informal cancer caregivers in the COVID-19 pandemic era.
6. Female informal cancer caregivers experience lower quality of life than male informal cancer caregivers in the COVID-19 pandemic era.

Participants

A sample of adult informal cancer caregivers ($N = 35$) 18 years and older ($M = 39.39$, $SD = 14.24$) including both men ($n = 21$) and women ($n = 14$) was recruited across Pakistan using snowball sampling. Out of the total number, most of the participants belonged to a large family setup than belonging to a small family setup. The caregivers spent a mean of 13.9 hours ($SD = 5.93$) performing their duties. Among them, most caregivers were involved in caring for patients with Stage 3 or 4 of cancer as compared to caregiving to Stage 1 or 2 cancer patients.

The inclusion criteria stated that all participants must have no history of a psychiatric illness or terminal health-condition themselves. They must be active primary informal caregivers to a breast cancer patient diagnosed since March 2020 with the advent of the COVID-19 pandemic. Moreover, the breast cancer patient of the family caregiver must be currently actively seeking or has sought chemotherapy as a mode of treatment since March 2020. Participants must be utilizing at least one form of electronic medium of communication and were willing to be part of the research under their own free will. The demographic characteristics of participants are discussed in Table 1.

Table 1

Demographic Characteristics of Participants (N = 35)

Variables	*f*	%	*M*	*SD*
Age of Informal Caregiver	-	-	39.39	14.24
Young Adults (18-39 years)	22	62.9	-	-
Middle Aged Adults (40-59 years)	11	31.4	-	-
Older Adults (60 and above years)	2	5.7	-	-
Gender of Informal Caregiver			-	-
Men	21	60	-	-
Women	14	40	-	-
Work Status			-	-
Working	21	60	-	-
Nonworking	14	40	-	-
Marital Status			-	-
Single	12	34.3	-	-
Married	22	62.9	-	-
Widowed	1	2.9	-	-
Family Structure			-	-
Large Family (Extended/Joint/Step Family)	24	68.6	-	-
Small Family (Nuclear/Single-Parent/Empty nest)	11	31.4	-	-
Hours Spent Caregiving per day	-	-	13.9	5.93
0 to 6 hours	2	5.7	-	-
7 to 12 hours	16	45.7	-	-
13 to 18 hours	6	17.1	-	-
19 to 24 hours	11	31.4	-	-
Patients' Relation with Caregiver				
Mother	22	62.9	-	-
Wife	6	17.1	-	-
Sister	4	11.4	-	-
Mother-in-law	1	2.9	-	-
Aunt	1	2.9	-	-
Father-in-law	1	2.9	-	-
Stage of Cancer				
Stage 1 or 2	14	40	-	-
Stage 3 or 4	21	60	-	-

Measures

Demographic Questionnaire. A basic demographic questionnaire was utilized by the researchers to obtain specific information regarding the socio-demographic details of the participants. This included questions on initials of name, age, gender, contact number, email address, employment, marital status, family structure, hours spent caregiving per day, relationship of patient with caregiver, date of cancer diagnosis, the stage of cancer along with the treatment the patient was undergoing.

UCLA Loneliness Scale (Version 3). Russell (1996) developed the UCLA Loneliness Scale (Version 3) to assess loneliness. It consisted of 20 items in the form of statements such as Item 1 “How often do you feel that you are "in tune" with the people around you?” It had a 4-point Likert-type scale response format ranging from 1 = *never* to 4 = *often*. The scores ranged from 20 to 80. Higher scores showed a higher subjective experience of loneliness (Russell, 1996). This tool has established psychometric properties. Using a sample of 487 students, 305 nurses, 311 teachers, and 284 elderly, results indicated that the UCLA Loneliness Scale (version 3) had significantly high reliability. This included test-retest reliability over a year (r = .73) and a significant internal consistency (α = .89 to .94). The Scale also has significant convergent validity with constructs of loneliness as well as construct validity with other measures of well-being and social support (Russell et al., 1980). The scale has also been translated in Urdu by Anjum and Batool (2016) and was used across a variety of studies in Pakistan, concluding its item suitability for this sample.

The Multidimensional Scale of Perceived Social Support (MSPSS). Zimet et al. (1988) developed this tool to assess the level of perceived support an individual receives from their significant other, family and friends. It consisted of 12 items in the form of statements such as Item 3 “My family really tries to help me.” Responses are chosen from a 7-point Likert-type scale ranging from 1 (*very strongly disagree*) to 7 (*very strongly agree*). The scores ranged from 12 to 84 whereby higher scores signified higher social support. The scale has well-established psychometric properties. A sample of 275 undergraduates was recruited from Duke University of which 69 were recruited for retesting revealing a significant internal consistency (α = .72 to .85) with a good test-retest reliability of (r = .88). Furthermore, the scale also has a moderate construct validity. The Scale was translated in Urdu by Tonsing et al. (2012) and was used in a wide range of studies in Pakistan highlighting its item applicability of usage to this sample (Tonsing et al., 2012).

The CareGiver Oncology Quality of Life Questionnaire (CarGOQoL). This tool was specifically designed to measure the quality of life of cancer caregivers by Minaya et al. (2012). It consisted of 29 items listed in context to what the caregiver had been feeling in the previous month in regard to the patient they have been caring for. Responses ranged from a 5-point Likert-type scale with 1 = *never/not at all* to 5 = *always/enormously*. The range of scores was from 29 to 100. Except for items 22 to 27 and item 29, all items were reverse coded whereby the responses were coded as 1 = *always/ enormously*, 2 = *often/a lot*, 3 = *sometimes/moderately*, 4 = *rarely/a little*, and 5 *never/not at all*. The scale has established psychometric properties with a good internal consistency (α = .72 to .89) and a satisfactory test-retest reliability. Moreover, the construct validity was also reported to be satisfactory. This scale is relatively new and has not been translated to Urdu or widely used in Pakistan. However, careful examination of items rendered it an effective tool to assess this special population of cancer caregivers.

Procedure

Formalized permission for the usage of the tools was obtained from the respective authors of the scales. After receiving the respective authorizations, a pilot study was conducted on a segment of the target population. For the main research, snowball sampling initiating from two patients at a private clinic in Lahore, Pakistan was used on the target population to collect data. Participants were asked if they would willingly be a part of the research on Google Forms. Consenting participants were provided the Google Forms hyperlink to the questionnaire. The research questionnaire clearly requested an informed consent with the assurance of the maintenance of confidentiality, debriefing about purpose of study with clear instructions. The participants filled out the demographic and assessment questionnaires on Google Forms. All participants completed the questionnaire in a single viewing online. At the end of the questionnaire, each participant was asked if they would like to consent to an interview for phase II of the research and were requested to share contact details for further communication. Data was collected and analyzed later.

Phase II: Qualitative Research

Qualitative exploration of the impact of the COVID-19 pandemic on the experiences of informal cancer caregivers was examined through in-depth semi-structured interviews.

Research Question

1. What impact has the COVID-19 pandemic on informal cancer caregivers?

Sample

Four informal cancer caregivers including men (*n* = 2) and women (*n* = 2) who were approached via snowball sampling in Phase I consented to be part of the interview process in Phase II. The age range of the participants was from 18 years to 45 years. All participants were assigned pseudonyms to maintain confidentiality and privacy.

Table 2
Demographic Characteristics of Participants (N = 4)

Participant	Age	Gender	Relation with Caregiver
Ayesha	30	Female	Father-in-law
Bilal	18	Male	Mother
Chanda	29	Female	Sister
Daniyal	45	Male	Wife

Note. Participants were assigned the pseudonyms to maintain confidentiality and privacy.

Measures

An open-ended semi-structured interview schedule was used. The interview schedule included questions relevant to the exploration of the impact of COVID-19 on informal cancer caregiver’s caregiving experiences. A total of 7 open-ended questions were asked with room for feedback from the participants. Items were devised by the researchers after key examination of literature in the field regarding the COVID-19 pandemic. Questions in the interview specifically probed the individualistic experiences of caregiving that impacted the informal caregivers during the COVID-19 pandemic.

Procedure

Each of the consenting participants from phase I were contacted individually using the contact details they provided on the Google Forms questionnaire. Once contacted, they were requested to schedule a time for a one-on-one interview. After agreeing upon a date, the interview audio call was conducted. Before the interview commenced, participants were asked to verbally consent for being part of the interview. Their basic ethical rights, confidentiality, and their willingness to participate were communicated to them. Once the consent was obtained and their rights were communicated, interviews were conducted on audio call. Open ended semi-structured questions were asked, and responses were probed for enriching details. Typically, interviews spanned from 30 to 45 minutes. Verbatim of responses was recorded and were analyzed later to derive themes using Thematic Analysis.

Results

The current research was aimed to quantitatively explore informal cancer caregiver's loneliness, social support and quality of life during the COVID-19 pandemic era in Phase I. The data was collected from a sample of 35 informal cancer caregivers in Pakistan. Data was entered with caution and analyzed using IBM Statistical Package for Social Sciences (SPSS) Version 22. Thematic Analysis for qualitative data in Phase II was used to explore the impact of COVID-19 pandemic on the caregiving experiences of informal cancer caregivers.

Phase I: Quantitative Analysis

Pearson Product Moment correlation was used to test the hypotheses describing the relationship between the variables. Results are summarized in Table 3.

Table 3

Pearson's Correlation Matrix Between Loneliness, Social Support, and Quality of Life Index (N = 35)

Variables	1	2	3
1. Loneliness	-	$-.54^{**}$	$-.79^{**}$
2. Social Support	-	-	$.49^{**}$
3. Quality of Life	-	-	-

$^{**}p < .001$.

It was hypothesized in H1 that there is a significant negative relationship between informal cancer caregivers' loneliness and social support which is observed in Table 3. It was also postulated that there is a significant positive relationship between informal cancer caregivers' social support and quality of life during the COVID-19 pandemic. H2 is confirmed by the findings of the said correlation between social support and quality of life. H3 suggested a negative relationship between informal cancer caregivers' loneliness and quality of life during the COVID-19 pandemic. Results confirmed a significant negative relationship between the two variables exists.

An independent sample *t*-test was carried out to investigate the gender differences in the responses of the informal cancer caregivers in terms of their loneliness, social support, and quality of life during the COVID-19 pandemic era. The results of the gender differences in each category are summarized in Table 4.

Table 4

Mean, Standard Deviation, and t-values on Loneliness, Social Support, and Quality of Life Across Genders (N = 35)

	Men (*n* = 21)		Women (*n* = 14)				95% CI	
Variable	*M*	*SD*	*M*	*SD*	*t*(33)	*p*	LL	UL
Loneliness	41.95	12.37	47.36	14.30	-1.19	.24	-14.64	3.84
Social Support	64.71	10.64	58.21	19.24	1.15	.26	-3.78	16.78
Quality of Life	61.29	16.62	55.49	15.99	1.03	.31	-5.69	17.29

Note. CI = Confidence Interval; LL = Lower Limit; UL = Upper Limit.

It was hypothesized that there would be significant gender differences in informal caregiver's loneliness whereby female caregivers would experience greater loneliness than male caregivers (H4). H5 purported that male caregivers would experience greater social support than female caregivers. It was also hypothesized that female caregivers would experience lower quality of life than males (H6). However, results of Table 4 show that there are nonsignificant gender differences in loneliness, social support, and quality of life in the caregivers.

An additional independent sample *t*-test was conducted to assess the differences in loneliness, social support, quality of life and the hours spent caregiving based on the family structure of large and small families of the participants. Results are summarized in Table 5.

Results of the independent sample *t*-test reveal that there is a significant difference between the quality of life of caregivers with larger families than smaller families. However, nonsignificant differences in loneliness, social support, and hours spent caregiving are found. Implications are analyzed in the discussion.

Table 5

Mean, Standard Deviation, and t-values on Loneliness, Social Support, Quality of Life, and Hours Spent in Caregiving across Family Structure (N = 35)

	Large Families (*n* = 24)		Small Families (*n* = 11)				95% CI		*Cohen's*
Variable	*M*	*SD*	*M*	*SD*	*t*(33)	*p*	LL	UL	*d*
Loneliness	41.58	11.44	49.64	15.70	-1.72	.10	-17.59	1.49	-
Social Support	5.44	1.06	4.60	1.42	1.96	.06	-.03	1.72	-
Quality of Life	64.08	13.68	47.82	16.83	3.04	.01	5.37	27.15	1.06
Hours Spent Caregiving	2.7	.95	2.8	1.08	-.30	.76	-.85	.63	-

Note. Large Families covered joint family, extended family, stepfamily; Small Families covered nuclear family, single-parent family, empty nest household); CI = Confidence Interval; LL = Lower Limit; UL = Upper Limit.

Another independent sample *t*-test was conducted to assess the differences in loneliness, social support, quality of life, and the hours spent caregiving based on the stage of cancer of the patients that the informal caregivers were looking after. Results are summarized in Table 6.

Table 6

Mean, Standard Deviation, and t-values on Loneliness, Social Support, Quality of Life and Hours Spent Caregiving across Stage of Cancer (N = 35)

	Stage 1 or 2 (*n* = 14)		Stage 3 or 4 (*n* = 21)				95% CI		
Variables	*M*	*SD*	*M*	*SD*	*t*(33)	*p*	LL	UL	*Cohen's d*
Loneliness	40.29	11.29	46.67	14.08	-1.42	.17	-15.54	2.78	-
Social Support	68.93	9.95	57.57	15.90	2.37	.02	1.62	21.09	.86
Quality of Life	62.17	14.12	56.84	17.74	.94	.35	-6.18	16.86	-

Note. CI = Confidence Interval; LL = Lower Limit; UL = Upper Limit.

Results of the independent sample *t*-test reveal that there is a significant difference between the social support of caregivers with Stage 1 or 2 cancer patients and Stage 3 or 4 cancer patients. However, nonsignificant differences in loneliness, quality of life, and hours spent caregiving were found. Implications are analyzed later.

Phase II - Qualitative Analysis

In this phase of the study, 4 participants (n = 4; 2 men and 2 women) consented to give interviews. Telephonic interviews were conducted with these participants using a semi-structured interview schedule. The data was transcribed, and themes were generated using Thematic Analysis.

Thematic Overview

Table 7 displays a thematic map of the most prevalent themes and subthemes generated from the transcriptions. A total of 5 themes were generated from the data which further had a total of 21 subthemes. The basic themes of the entire analysis were the contributing factors leading to both positive and negative impact of the COVID-19 pandemic on caregiving.

Table 7

Thematic Map of the Most Common Themes, Subthemes, and Transcription Codes from the Interview Transcriptions (N = 4)

Basic Themes	Subthemes	Transcription Codes
Rewards for Caregiving	Prayers	Prayers/*Duas*
		Blessings
	Bonding	Bond well/Closer to each other
		Improved relationship
	Feeling Privileged	Privileged
		Honor to do so
	Religiosity Increment	Increased faith
		Increased praying
		More *duas*
	Source of Help	Make a difference
	Gratitude	Thankful
Patient Facilitation	Availability	Care for the patient a lot more
		Spend a lot of time
		More time
	Increased Task Assistance	Assist
		Help them
	Understanding of Needs	Understand needs better
		Know their (patients) problems much better

Continued…

Basic Themes	Subthemes	Transcription Codes
COVID-19 Specific Caregiving Stressors	Fear of Infection	Scared of catching COVID
		Paranoid about contracting COVID
		Biggest fear is to catch the virus
	Guilt	Live with guilt
		Gives a lot of guilt
	Social Distancing	Socially restricted our movement from others.
		Socially distance
	Helplessness	What should I do?
		No one available to help
	Stress	Tough
		Stressful
		Difficult
Obstacle to Caregiving in Pandemic	Inaccessibility to Healthcare Workers	Hard to get a hold of doctors.
		No timely meetings
		Huge availability gap
		Difficult to get ahold of doctors
	Financial Problems	Financial burden
		Job insecurity
		Pay cuts
	Lack of Support	Wish there was more help.
		No help
		No understanding
	Irresponsible Visitors	No social distancing
		No SOP’s followed
		Don’t behave responsibly
Detriments of Caregiving in Pandemic	Exhaustion	Going to combust
		Tiring
		Physically and emotionally draining
	Isolation	Isolated at home
		Not possible to leave
		Restricted movement
	Neglected Health	Negative impact on mental as well as physical health.
		Mentally crashed.
		Depressed
	Trapped	Wasn’t ready for this.
		Don’t have choice

Description of Themes

Theme 01: Rewards for caregiving. Rewards for caregiving was a theme that emerged when examining the positive aspects of caregiving for the informal cancer caregivers in the COVID-19 pandemic. Examination revealed the manifestation of subthemes like prayers, bonding, feeling privileged, religiosity increment, source of help, and gratitude.

Prayers enabled caregivers to feel that their efforts were being recognized and acted as a reinforcer for their caregiving. They felt like it was a great perk of caregiving providing blessings and good deeds to them. Ayesha stated, “I received a lot of prayers, love and appreciation from my patient.” Bonding with the patient during the COVID-19 pandemic due to the continued presence of the caregiver strengthened the relationship and all dyads felt closer. Chanda said, “I just feel, rather I am sure that that my relationship with the patient has improved. We are very close to each other now.” Caregiving without compensation was also considered a privilege. Caregivers felt privileged to be bestowed with such responsibility and felt chosen for said responsibility. Ayesha believed, “I feel so privileged to have taken care of such a nice person and see their pain up-close.”

Moreover, an increment in religiosity was also seen as it became a source of comfort and hope for them. Chanda reported:

> The fear of losing a loved one has just propelled me more towards Allah SWT. So going those extra miles for prayers and fearing and praying that nothing bad happens to the patient you are looking after. That has made my connection to Allah SWT stronger.

All respondents were of the belief that they were a great source of help to their patients. By holding on to said perception, it propelled them to continue to engage in the task of informal caregiving. Daniyal stated, “…I can do things that help them more.” Gratitude enabled participants to feel thankful for all the positive aspects in their lives. Chanda said, “I am very thankful to spend more time with the patient…..I am grateful just being there for someone.”

Theme 02: Patient facilitation. Several positive aspects for the patients that the informal cancer caregivers catered to emerged as various patient facilitation opportunities were available during the COVID-19 pandemic. It enabled caregivers to cater to the needs of their patients better in these trying times. A plethora of subthemes like increased availability, increased task assistance, and understanding needs of the patient were identified.

All caregivers reported that they were much more available to provide constant care to their patients than they would not be able to do so if the COVID-19 pandemic was not around. With the change of the climate of the workplace to more home-based work practices and remote education offering online classes; caregivers were more readily available to aid their patients. Daniyal reported, “My company allowed me to work from home. That meant I could stay at home with the patient at all times…Being available at home has been a huge huge plus.” With caregivers being more readily available and spending far more time with the patients in person, they were all able to provide increased task assistance. Bilal stated, “I took the patient out for walks and socialize with friends and family….it made the patient feel a lot better mentally.”

The respondents also reported they were able to better identify and understand the needs and demands of the patients and how to cater to them better. Daniyal claimed:

> You get to understand the patient’s perspective much better. You get to know their problems better. You get to attend to them better. You get to understand them better, get to know what troubles them better, how to do things that help them more… You can understand better what you can do for them and make their life easier.

Theme 03: COVID-19 specific caregiving stressors. The COVID-19 pandemic with its advent brought about a variety of novel situations that produced unprecedented problems. Informal caregivers of cancer patients have been battling pandemic specific stressors that are immensely impacting their caregiving such as fear of infection, guilt, social distancing, helplessness, and stress.

COVID-19 with its constantly evolving variants has a significantly fast rate of transmission to human beings. In the case of individuals with already immuno-compromised systems like cancer patients, the fear of contracting the virus by the patient themselves or all caregivers passing it on the patient is ever looming. Chanda reported:

> The biggest fear during COVID is to keep myself safe and not to contract the virus because I am dealing with someone who is very immuno-compromised, may not be able to survive this if they contract it. You know there is an overpowering fear of staying protected.

The burden of caregiving coupled with fear of transmitting the virus to their vulnerable patients by simple actions such as stepping out of the house produces guilt in caregivers. Bilal stated:

> My main concern is not that I will get COVID but my concern had been and still is that if I get COVID the patient will get it from me. And you know living with that fear is quite difficult because if something happens then you will have to live with

> the guilt. Guilt is a very big part of it. That fear was and still is always constant.

One of the major precursors to curb the spread of the COVID-19 virus was the implementation of measures such as social distancing. However, implementation has been reported as a major stressor by all respondents. Daniyal reported, “You have to be careful about people in general. The guests, the house help, everyone. You don’t want the patient exposed to anything…With the fear of contracting COVID, we have isolated and restricted movement.” Caregivers also felt very helpless in not knowing how to help the patients effectively. Ayesha stated:

> I had never taken care of a sick elder, much less someone with cancer…Because you have to realize that when the patient was feeling down or they would say that I am feeling nauseous or I am in pain, or it feels like my whole body is on fire, I didn’t know if this was normal or not. Should I rush them to the ER? What should I do?

All caregivers also felt extreme stress due to the pandemic and illness. Chanda stated, “Caregiving for a cancer patient itself is very stressful and COVID-19 has added this extra burden of stress to the whole situation”.

Theme 04: Obstacles to caregiving in pandemic. The COVID-19 pandemic brought with it a plethora of novel problems. Informal cancer caregivers experienced a variety of obstacles in terms of caregiving during this COVID-19 pandemic. Identified subthemes include inaccessibility to healthcare workers, financial problems, lack of support, and irresponsible visitors.

Healthcare workers are the most important component of cancer treatment. Inaccessibility to these healthcare workers is burdening all caregivers immensely. Chanda stated “I think the healthcare system needs to be more present. They need to be more accessible to people like us. You need some kind of help every now and then for such patients to help them.” Cancer treatment is an expensive endeavor. However, with the implication of COVID-19, economies across the globe were detrimentally impacted, raising the costs of treatments higher but causing caregivers to suffer from financial strain. Daniyal purported:

> Finances have also been a problem. Because companies started firing people and I also got pay cuts as part of it. And there is an added stress of job insecurity that comes with it…Stable finances would act as a helping factor.

Informal caregivers while caring for their patients are typically doing so single-handedly and reported a lack of support from family and friends. Ayesha said "I wish I had more help. I wish I had more physical help. It was hard. Very hard." Visitors are a significant component of having a patient at home. However, in the times of this COVID-19 pandemic, exposure to such large number of people is excessively dangerous for cancer patients. All informal caregivers reported facing extreme obstacles in dealing with visitors who behaved irresponsibly by not following social distancing and standard operating procedures. Bilal reported:

> Everyone who visits doesn't follow SOP's. It's very difficult to manage that as people come in normally and they don't understand that they can't do that, not in this house…People aren't aware of how much of a serious thing this is. And it creates problems in caregiving."

Theme 05: Detriments of caregiving in pandemic. The COVID-19 pandemic is indeed a challenging era for all those alive. Informal cancer caregivers have been the backbone of providing healthcare to their patients during the pandemic. This consuming act comes with its perils identified as subthemes of being exhausted, isolated, neglected health, and trapped.

Informal caregiving to cancer patients is a laborious endeavor. Most respondents are of the opinion that the act of caregiving greatly exhausted them during the pandemic. Ayesha stated, "I felt like I was going to combust." Isolation is a common practice in today's COVID-19 pandemic world. Caregivers reported excessive feelings of isolation as well as being socially isolated from those around them. Daniyal said, "With the fear of contracting COVID, we have isolated and restricted movements…Cutting off people has also been hard. Especially the isolation part." Providing care to cancer patients is a labor-intensive task. Adding a pandemic into the mix impacted caregiver's health greatly. Chanda stated, "Caregiving is physically and emotionally very draining." Moreover, the sudden imposition of the caregiving role on caregivers evokes feelings of being trapped in a role they were not ready for. Ayesha stated, "the thing is I wasn't ready for this. Nobody is right?... But I didn't have a choice."

Discussion

This research examined the loneliness, social support, and quality of life of informal cancer caregivers during the COVID-19 pandemic era. Further exploration was also done to examine the impact of the COVID-19 pandemic on informal cancer caregiver's experiences.

In Phase I of the study, H1 purporting a negative relationship between loneliness and social support in informal cancer caregivers was confirmed. Informal cancer caregivers typically have higher reports of self-alienation from social interactions with the increased burden of tasks and greater focus on caregiving for their patients (Lohne et al., 2012; Ross et al., 2020; Sahin & Tan, 2012). It is however imperative to note that in the pandemic era of COVID-19, loneliness was most greatly experienced owing to the enforced isolation to curb infections. Individuals became more isolated encumbered by reduced social support (Gallagher et al., 2020). Moreover, COVID-19 greatly threatens the life of individuals who are immuno-compromised such as those patients with diseases like cancer, making caregivers overly self-protective with greater social fears, further increasing the risk of loneliness (Shi et al., 2021).

A positive relationship between social support and quality of life (H2) was also confirmed. Caregiving is a distress evoking task that is both physically and mentally exhausting for the individuals involved in it. Social support affects not only the mental health of caregivers but also their physical health. Moreover, social support from family aids caregivers to have a better well-being consequently supporting them to have a better quality of life (García-Carmona et al., 2021). With the arrival of the pandemic, the absence of said social support systems caused informal caregivers to spend extended periods of time fulfilling caregiving tasks; leading to exhaustion and deteriorating quality of life (García-Carmona et al., 2021). Research hence supports that the existence of resources, such as family and friends support positively impacts quality of life (Burnette et al., 2016; García-Carmona et al., 2021; Hsu et al., 2019; Lee et al., 2018).

An inverse relationship between loneliness and quality of life in informal cancer caregivers was also reported (H3) and confirmed (Golant & Haskins, 2008; Segrin et al., 2018). The loss of control throughout the illness trajectory of the patients coupled with perceiving oneself different from others around them, creates gaps in intimacy for these caregivers. The resulting loneliness caused by such gaps significantly impact the caregiver’s quality of life (Golant & Haskins, 2008). Regarding the COVID-19 pandemic era, with the disruption of face-to-face medical treatment modes, the burden of care fell solely on the shoulders of the informal cancer caregivers afflicting them more than ever before. This coupled with social distancing norms and reduced interactions owing to the fear of contracting the virus limited social interaction. It created a vortex of loneliness for informal cancer caregivers, consequently impacting their quality of life (Shi et al., 2021).

Hypotheses on gender differences proposed increased loneliness in female caregivers (H4), greater social support in male caregivers (H5) and lower quality of life in female caregivers (H6). Results revealed nonsignificant gender differences. In today's world, the COVID-19 pandemic is uniformly impacting all individuals irrespective of gender. Global implementation of restrictive measures including social distancing and isolation are adopted to curtail the spread of the COVID-19 virus. This, coupled with the overload of responsibilities during this pandemic has caused caregivers to experience isolation and absent social support impacting their quality of life. Male and female caregivers both have been subjected to these restrictions and impositions, experiencing identical life situations equitably. This supports this study's findings of nonsignificant gender differences in loneliness, social support, and quality of life (Bertuzzi et al., 2021; Giusti et al., 2020).

Additional findings highlighted that family structure also predicted quality of life. Moreover, independent sample *t*-test's findings also reported that informal caregivers with larger families had a greater quality of life than those with smaller families. Ansari and Qureshi (2013) reported that informal caregivers in nuclear families received lesser social support and felt more loneliness compared to those in joint family systems. With a greater number of individuals present at home, joint family systems provide an intrinsic support system to caregivers that is absent in reducing the burden for nuclear family caregivers. Moreover, the concept of filial piety that is, family first also enables members in the joint family system to extend support to a cancer patient when they are ill; aiding the caregivers in the process (Chua et al., 2016).

Informal caregivers received less social support as the stage of cancer increased. These findings are in line with previous research findings whereby informal cancer caregivers of patients with Stage I and II cancer received greater social support than caregivers of patients with Stage III and IV cancer. Caregivers looking after patients with advanced stage cancer have greater unmet needs, increased stress, and more caregiver burden in terms of providing increased assistance to patients with activities of daily functioning; hence, requiring greater support that may be provided initially but is not consistent as the burden increases (Burnette et al., 2016; Daly et al., 2009).

In Phase II of the study, qualitative analysis of the experiences of informal caregiver's caregiving during the COVID-19 pandemic was explored. A total of five themes with varying subthemes emerged in the Thematic Analysis of the semi-structured interviews conducted.

One of the most predominant themes was reward for caregiving. This elicited a variety of subthemes that included prayers, bonding, feeling privileged, source of help, and gratitude. These are in line with prior research literature findings. Research purports that while cancer caregiving is a grueling task, informal cancer caregivers experience positive changes caused by the illness experiences of their patients (Cassidy, 2013; Zwahlen et al., 2010). Informal cancer caregivers develop a closer relationship with their patients with better bonding experiences, gratitude, and appreciation of life. An increment in faith as well as prayers received for caregiving are also reported (Mosher et al., 2016).

Patient facilitation also emerged as a theme. The emergence of subthemes like availability, increased task assistance, and understanding of needs were evident. With the transition from conventional hospital centered care to a home-family centered model owing to the COVID-19 pandemic, informal caregivers have more load on their hands than ever. The implementation of work from home policies during lockdowns enabled caregivers to be more available for their patients. Moreover, with the burden of responsibility on the caregivers owing to limited healthcare access, extended periods of time spent with patients required and enabled caregivers to understand and fulfill their needs (Mishra et al., 2020).

The theme of COVID-19 specific caregiver stressors is in line with current research findings. These stressors included fear of infection, guilt, social distancing, helplessness, and stress. Cancer patients are an immuno-compromised population. With such a tumultuous condition, fear of contracting COVID-19 or infecting the patient was one of the most predominant themes evident in the pandemic era. Research showed that informal cancer caregivers existed in a constant state of stress of the fear and guilt of contracting and passing on the virus to their patients (Mishra et al., 2020). Caregivers engaged in the task of socially isolating and distancing themselves to protect their patients against the COVID-19 virus infection. It has been reported that caregivers typically quarantined at home for 20–24 hours a day with 75.2% of them manifesting worry about this virus. It was also revealed that caregivers reported helplessness and increased fear of virus contraction in spite of taking several measures to secure themselves (Shi et al., 2021).

Obstacles to caregiving, another identified theme, highlighted inaccessibility to healthcare workers, financial problems, lack of support, and irresponsible visitors. As mentioned before, the COVID-19 pandemic has transformed the system of health-care provision from hospital care to home-based care, creating a depletion in the healthcare of cancer patients and increased burden for caregivers (Amiel & Ulitzur, 2020; Mishra et al., 2020). Moreover, the inflation in medication and treatment prices during the pandemic cause finances to be a strain on these caregivers hindering their ability to care for the patient (Shi et al., 2021).

COVID-19 as evident is a contagious and fatalistic virus; especially for individuals with low immunity like cancer patients. Hence, the act of irresponsible visitations which typically acts a source of healing became a trial and stressor for caregivers (Yusuf, 2020). Culturally speaking, individuals in Asian cultures have a belief system of *ayaadat* [visiting the sick; a cultural obligation] (Rashidi & Rajaram., 2001). With visitors not following preventative protocols and the cultural constraints of not being able to forbid them in fear of discord, caregivers are caught between moral obligations to the patient and the visitors (Arora et al., 2020). Simultaneously, with the imposed mobility constraints to the curb the virus, the pandemic inadvertently robbed the informal cancer caregivers from an indispensable source of support where they had no one to aid them with daily activities, transportation or psychological support impacting caregiving significantly (Mishra et al., 2020).

The theme of caregiving detriments such as exhaustion, isolation, neglected health, and feeling trapped were also elicited. Findings are in line with past research. As mentioned, owing to the pressure of managing all caregiving tasks with the home-based care along with socially distanced lifestyles, caregivers reported feeling drained, lonely, and neglected their physical and mental health to aid their patient (Fisher et al., 2020; Shi et al., 2021). Being thrust into the novel pandemic world with additional responsibilities, caregivers did not feel prepared to deal with the role. Feelings of being trapped emerged as a consequence of the pandemic around them such as cancer related fears and COVID-19 related fears of infection and death (Hashemi-Ghasemabadi et al., 2015; Shi et al., 2021; Stamataki et al., 2013).

Implications

The findings of the current research hold significant implications for informal cancer caregivers during the COVID-19 pandemic era. It highlights the experiences and unmet needs of informal cancer caregivers while caring for their patients in uncertain times. The study provides a deeper understanding of the impact the COVID-19 pandemic had on caregiving using cultural narratives from participants. It also provides valuable insights for mental healthcare professionals and support staff to aid informal caregivers in their endeavor to help patients with cancer. The current research contributes to the literature, particularly in an indigenous context on informal cancer caregivers and their experiences of caregiving in the COVID-19 pandemic in Pakistan.

Limitations and Suggestions

Due to COVID-19 restrictions and limited time constraints, data was collected only from participants who could speak English and fill out a Google Form, limiting the sample size. The present study only studied a few of the factors for informal cancer caregivers that were found in consistency in Western Literature. The current study focused primarily on the experiences of breast cancer informal caregivers of a certain class and locality; hence, the results should be generalized with caution. A larger sample size with participants from diverse areas of Pakistan will help findings to be more generalized. Inclusion of patients as part of caregiver-patient dyads research to compare the experiences of both individuals in the same situation would enrich future findings. Follow-up investigation from participants post-cancer treatment completion should be done to assess any post-traumatic growth and resilience that may have evolved in them. Moreover, since the focus of the research was to examine the experiences of these caregivers only in the COVID-19 pandemic era, it may be beneficial to further explore the experiences of caregivers once the pandemic ends.

Conclusion

The present study aimed to explore the loneliness, social support, and quality of life in the neglected population of informal cancer caregivers during the COVID-19 pandemic era. The impact the pandemic had on the caregiving experiences of these caregivers was also examined. Successful support was found in lieu of the proposed hypotheses; revealing that study variables of loneliness, social support, and quality of life were significantly correlated. Moreover, a larger family size and a lower diagnosis stage of cancer of the patient produced a higher level of social support received by informal cancer caregivers in the pandemic.

The impact of the COVID-19 pandemic on caregiving was explored via interviews; yielding responses that highlighted positive factors including rewards for caregiving and better patient facilitation during the pandemic. Moreover, COVID-19 specific caregiving stressors and obstacles as well as detriments of caregiving in this novel pandemic also emerged. Findings were supported by evidence found in prior literature. The study is able to shed light on the experiences of informal cancer caregivers during the testing times of the COVID-19 pandemic, paving way for considerations for better caregiving experiences in this population.

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