Review

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The experience of caregivers of chronically ill patients during the COVID-19: A Systematic Review

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Abstract

Objectives: This study aimed to identify the difficulties that caregivers of chronically ill patients experienced during the COVID-19 pandemic and to provide directions for future studies.

Methods: Five electronic databases, including PubMed, Web of Science, CINAHL Plus Full Text, EMBASE, and Scopus, were systematically searched from January 2019 to February 2021. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses were employed for the literature screening, inclusion, and exclusion. The Mixed Methods Appraisal Tool was adopted for qualifying appraisal.

Results: Six studies met the study criteria, including three quantitative studies, two qualitative studies, and one mixed-method study. Mental health, personal experience, financial problems, physical health, and improvement approaches were the major five themes that participants reported regarding the impact of COVID-19 they encountered during the pandemic.

Discussion: The results could heighten healthcare providers, stakeholders, and policy leaders' awareness of providing appropriate support for caregivers. Future research incorporating programs that support caregivers' needs is recommended.

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Introduction

Providing care to family members suffering from chronic illness challenges caregivers' well-being.[1] The treatment of chronic disease and health outcomes burden both patients and their caregivers' lives as they encounter uncertainty about the disease's nature, limited ability to control their lives, dependence on others, or disruption of their caregivers' lives.[2] Moreover, after discharge from inpatient rehabilitation, they need continuing support from a caregiver.[3] Therefore, caregivers are one of the essential factors that affect these patients' quality of life.

Caregivers, typically friends or family members, contribute essential health services to patients and are recognized by many policy-makers as front-line healthcare workers.[4] For example, in the inpatient rehabilitation setting, caregivers assist the patients and prepare them for discharge to home.[5] Several studies illustrated that the caregiver's mental health and wellness are associated with the patient's functional and health outcomes[6–8] For example, Kuzuya et al. (2011)[6] reported that heavy caregiver burden is associated with mortality and hospitalization among older adults. Likewise, del Castillo et al. (2008)[9] found that caregivers reported multiple depression symptoms greater if they cared for terminally ill patients. This can conclude that the patient's illness directly burdens caregivers' well-being and influences the anxiety and depression symptoms of caregivers.

At the beginning of December 2019, the first novel pneumonia cases of unknown origin were recognized in Wuhan, Hubie province, China[10] and later identified as severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) or coronavirus disease 2019 (COVID-19).[11] Travel restriction measures have been established in several countries to reduce the spread of COVID-19.[12] The previous research stated that the number of journeys had decreased during the pandemic. Furthermore, the number of journeys is significantly associated with COVID-19 cases.[13] These restrictions affect particularly susceptible groups like chronically ill patients.[14] Moreover, a study from Sutter-Leve et al. (2021) revealed that the strict hospital visitor policy required to cope with COVID-19 aroused significant concerns among caregivers.[3] Although COVID-19 is still ongoing, it tremendously affected people's lives, including patients and their caregivers, when it first spread out as people did not prepare well enough for the sudden situation. Thus, this systematic review (SR) aimed to gather all empirical studies to explore the experience of caregivers of chronically ill patients during the COVID-19 pandemic. It is expected that this SR will provide a comprehensive overview of the caregivers' live experience during the pandemic, inform the researchers and policy-makers of the problems that caregivers are encountering, as well as their concerns and needs, so as to provide implications for future research and practice.

Methods

This systematic review includes original quantitative, qualitative, and mixed methods studies. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)[15] was applied to present the flow diagram of the identification, screening, exclusion, and inclusion of the literature. The review protocol was registered in the International Prospective Register of Systematic Reviews (PROSPERO) under registration number CRD42021241081.

The ethics approval number

Ethical approval was not required due to no human participants in this study.

Search strategy

Five electronic databases, including PubMed, Web of Science, CINAHL Plus Full Text, Excerpta Medica Database (EMBASE), and Scopus, were systematically searched from January 2019 to February 2021. We combined the search terms using Boolean phrases. Reference lists of the included studies were manually searched to obtain relevant studies. All references identified were stored in EndNote. The detailed search strategies are available in Supplementary Table 1.

Selection of studies

The details of the inclusion and exclusion criteria of this review are provided in Table 1. Titles and abstracts were screened by two authors (SR and WZ) independently. Afterward, the full text was also assessed by the two authors (SR and WZ) to judge the relevance strictly obeying the inclusion and exclusion criteria. A third author (LP) was required when discrepancies occurred to resolve disagreements.

Table 1. Inclusion and exclusion criteria.

Inclusion Criteria
• Human participants of all years of age • Original quantitative, qualitative, or mixed methods studies • The study investigated the impact of COVID-19 on the caregivers of patients with chronic diseases • Included caregivers of patients diagnosed with chronic diseases as participants • All types of settings are acceptable, including inpatient, outpatient, or home • Described in the English language
Exclusion Criteria
• The study did not include the population of interest or concerns animal subjects • Diagnostic accuracy and economic studies • Conference proceedings, abstracts, review articles, theoretical papers, pilot study, protocol, dissertation, letter to the editor, opinion (viewpoint), statement paper, government documents, or working papers • The study which reported the results of the impact of COVID-19 on caregivers is mixed with that of the chronic disease patients, not reporting the caregivers solely

Note: Caregivers are defined as persons who have not been professionally trained and provide care to those who need supervision or assistance in illness or disability. They may provide the care in the home, hospital, or healthcare facility. Chronic diseases in this review are defined as diseases that have one or more of the following characteristics: they are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation, or care.

Quality assessment

The methodological quality of each study was evaluated independently by two researchers using the Mixed Methods Appraisal Tool (MMAT) developed by Hong et al. (2018).[16] This tool is designed for the quality appraisal stage of systematic mixed studies reviews, which include quantitative, qualitative, and mixed methods studies. The evaluation criteria of the methodological quality of each category of studies were different, decided upon the report of the key methodology issues regarding the specific research types. For instance, for qualitative studies, the appraisal is based on whether 1) the approach is appropriate to answer the research question, 2) the data collection methods are adequate to address the research question, 3) findings adequately derived from the data, 4) interpretation of results is sufficiently substantiated by data, and 5) there is coherence between data sources, collection, analysis, and interpretation. If the answer to the appraisal question is "yes", then one score is added to this study. As for mixed methods studies, the appraisal includes the set of criteria for qualitative studies, that for quantitative ones and that for mixed methods ones. A quantitative appraisal score was calculated based on the scoring system proposed by Pluye et al.[17]: (the number of "yes" responses divided by the number of "appropriate criteria") × 100. Afterward, methodological quality results were synthesized in three categories[18]: low score: < 35%; medium score: 36 to 70%; high score: 71 to 100%.

Data extraction

A summary of included studies (Supplementary Table 2) developed for this review included the following data for each study: reference, year, country, study design, quality score, method of data collection, sample size (n), caregiver socio-demographics (age, sex, education, nationality-ethnicity, relationship to care recipient), care recipient characteristics (age, sex, pathology/diagnosis), and findings classified by main themes: for qualitative studies, reported impact of COVID-19 on caregivers of patients with chronic disease were extracted in the form of raw data (e.g. quotes) and reported themes and subthemes. For quantitative studies, all listing of the impact of COVID-19 on caregivers of patients with chronic disease were extracted along with results. Two authors (SR and WZ) completed data extraction and checked by the third author (LP).

Data synthesis

The convergent integrated analysis framework suggested by Joanna Briggs Institute (JBI) for systematic reviews was applied.[19] This framework is specialized for the simultaneous analysis of qualitative and quantitative data, which are transformed into the same format to facilitate data integration.[20] The quantitative data was converted into "qualitized" data. Since transforming qualitative data to quantitative data, namely "quantitizing", is more error-prone than "qualitizing", the latter is preferred when conducting the data synthesis.[19,21] Qualitizing the quantitative data also facilitates the presentation of the studies' risks and the way they were mitigated, such as sample sizes, attritions of participants, etc. Therefore, in this review, the "qualitizing" method was adopted. The "qualitizing" process included transforming the quantitative results into "qualitized" data, which were narrative interpretations or textual descriptions that answered the review question. Afterward, the "qualitized" data was assembled with the qualitative data. Assembled data were categorized and pooled together based on similarity in meaning to produce a set of integrated findings in the form of a line of action statements. In this review, this process means that themes were extracted from the main findings of the included studies, by examining the similarities and differences between the main findings, and sub-themes were then abstracted according to the more specific target of the corresponding findings (e.g. different targeting population: families, public), similar to the way that qualitative researchers produce themes.

Results

Search results

An initial search of the literature generated 1547 articles, of which two are additional records identified through other resources. Among these, 307 duplicates were identified and eliminated by using Endnote X7. After deduplication, the researchers prepared 1240 references for screening, of which 1229 articles were excluded through the title and abstracts screening phase following the inclusion and exclusion criteria (Table 1), leaving 11 articles eligible for the full-text screening. During this phase, five articles were excluded for the following reasons: irrelevant population (n = 2) and irrelevant study type (n = 3). A total of six articles were included in this systematic review for final screening and quality appraisal. The Preferred Reporting Items for Systematic

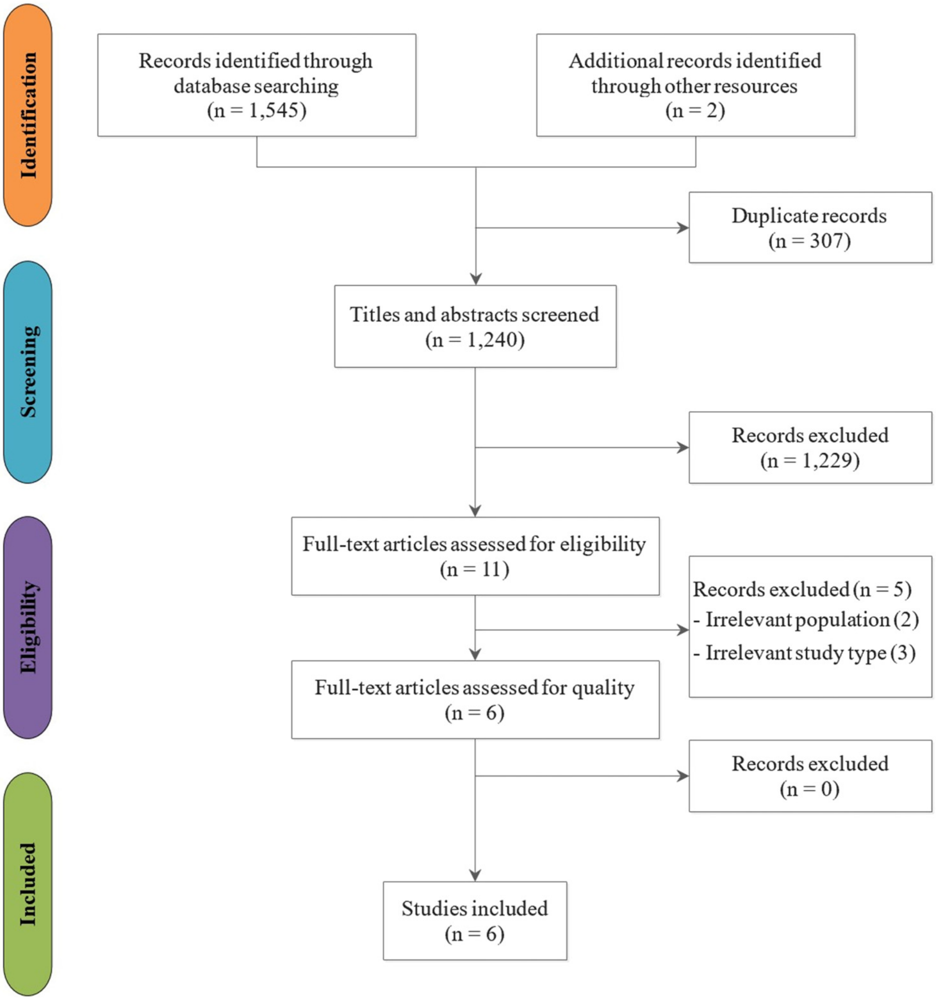

Figure 1. PRISMA flow chart.

Reviews and Meta-Analyses (PRISMA)[15] was utilized to outline the retrieval process (Figure 1).

Description of included studies

Table 2 shows that all included studies were published between 2020 (n = 3 studies, 50%) and 2021 (n = 3 studies, 50%). The included studies were conducted in the United States (n = 2 studies, 33.33%), Hong Kong (China) (n = 1 study, 16.67%), Republic of Macedonia (n = 1 study, 16.67%), India (n = 1 study, 16.67%), and Sri Lanka (n = 1 study, 16.67%). The study designs were quantitative studies (n = 3 studies, 50%), qualitative studies (n = 2 studies, 33.33%), and a mixed-methods study (n = 1 study, 16.67%). Three articles (42.86%) used questionnaires as data collection method. Likewise, semi-structured interview or an interview were utilized in three included studies (42.86%). Only one study applied a phenomenological approach (14.29%) to collect the data. The six included studies reported different

Table 2. The characteristics of the included studies.

Characteristic	Number (n)[*]	Percentage (%)
Publication year		
2021	3	50%
2020	3	50%
Country		
United States	2	33.33%
Hong Kong (China)	1	16.67%
Republic of Macedonia	1	16.67%
India	1	16.67%
Sir Lanka	1	16.67%
Study design		
Quantitative	3	50%
Qualitative	2	33.33%
Mixed methods	1	16.67%
Method of data collection		
Questionnaires	3	42.86%
Semi-structured interview/interview	3	42.86%
Phenomenological approach	1	14.29%
The duration of data collection		
5 weeks	1	16.67%
8 weeks	1	16.67%
12 weeks	1	16.67%
14 weeks	1	16.67%
N/A	2	33.33%
Sample size (n)		
1–50	3	50%
> 50–100	2	33.33%
> 100	1	16.67%
Caregiver socio-demographics		
Age (year)		
18–25	1	8.33%
26–44	4	33.33%
45–59	3	25%
60 or above	2	16.67%
N/A	2	16.67%
Sex		
Male	5	50%
Female	4	40%
N/A	1	10%
Education		
Primary - middle school	4	26.67%
High school	4	26.67%
Associate degree	1	6.67%
Bachelor degree	1	6.67%
Above bachelor degree	1	6.67%
N/A	4	26.67%
Nationality-ethnicity		
Latino/Hispanic	1	16.67%
White/ Caucasian	1	16.67%
Others[**]	1	16.67%
N/A	3	50%
Relationship to a care recipient		
Children	3	25%
Mother	2	16.67%
Father	2	16.67%
Spouse	2	16.67%
Sibling	2	16.67%
Others[***]	1	8.33%
Places caregiver providing care for the patients		
Home	5	83.33%
Inpatient	1	16.67%
Care recipient characteristics		
Age		
0–17	3	42.86%
45–59	1	14.29%
60 or above	1	14.29%
N/A	2	28.57%
Sex		
Male	2	25%
Female	3	37.5%
N/A	3	37.5%
Pathology/diagnosis		
Stroke[****]	2	20%
Epilepsy	1	10%
Developmental delay or intellectual disability	1	10%
Colon carcinoma	1	10%
Cystic fibrosis	1	10%
Asthma	1	10%
Tuberculosis	1	10%
Chronic rhinitis	1	10%
N/A	1	10%

(continued)

Table 2. Continued

[*] The number of included studies which one study may contribute to > 1 characteristic.
[**] Consist of Sinhala, Tamil, Muslim, and Bouguer.
[***] The researcher indicated "parents" as the caregivers .
[****] Consist of ischemic and haemorrhagic strokes.
N/A Not applicable.

durations of data collection; one each (16.67%) reported 5 weeks, 8 weeks, 12 weeks, 14 weeks, and two (33.33%) did not report the duration. The sample size is reported varied. Sample size ranged from 0 to 50 (n = 3 studies, 50%), 50 to 100 (n = 2 studies, 33.33%), and more than 100 (n = 1 study, 16.67%) consequently.

Caregiver characteristics

The target population in the included studies were individuals with age ranged from 18–25 years (n = 1 study, 8.33%), 26–44 years (n = 4 studies, 33.33%), 45–59 years (n = 3 studies, 25%), 60 years or above (n = 2 studies, 16.67%), and two studies (16.67%) did not specify the age of caregivers. 50% (n = 5 studies) of included study reported that caregivers were male and 40% (n = 4 studied) were female. Approximately 53% (n = 8 studies) of caregivers had education ranging from primary school to high school. Only one study included caregivers who obtained above bachelor's degree (6.67%). The nationality-ethnicity is reported that one research (16.67%) included Latino/Hispanic caregivers and another study (16.67%) included White/Caucasian caregivers. Interestingly, 50% (n = 3 studies) of included studies did not report nationality-ethnicity. Three studies (25%) reported that caregivers of chronic disease patients are their children. Mother (n = 2 studies, 16.67%), father (n = 2 studies, 16.67%), spouse (n = 2 studies, 16.67%), and sibling (n = 2 studies, 16.67%) were also reported as a caregiver of patients with chronic disease. Finally, five studies show that home is the place where most caregivers provide care for the patients (83.33%), and only one study shows that caregivers provided care for patients at the inpatient department (16.67%) (Table 2).

Care recipient characteristics

Care recipients in the included studies were individuals with age ranging from 0–17 years (n = 3 studies, 42.86%), 45–59 years (n = 1 study, 14.29%), and 60 year or above (n = 1 study, 14.29%). 25% (n = 2 studies) of the included study reported that the care recipients were male and 37.5% (n = 3 studies) were female. Finally, the pathology/diagnosis of care recipient in the included studies were individuals with stroke (ischemic and haemorrhagic) (n = 2 studies, 20%), epilepsy (n = 1 study, 10%), developmental delay (DD) or intellectual disability (ID) (n = 1 study, 10%), colon carcinoma (n = 1 study, 10%), cystic fibrosis (n = 1 study, 10%), asthma (n = 1 study, 10%), tuberculosis (n = 1 study, 10%), and chronic rhinitis (n = 1 study, 10%) (Table 2).

Assessment of methodological quality

As previously stated, the methodological appraisal was carried out through the MMAT.[16] According to the appraisal process described in the section quality assessment, the results related to the selected articles' methodological quality are summarized in Supplementary Table 3. Considering the scoring system, almost all selected articles had a high methodological quality,[3,22–25] except for one quantitative study with a medium score.[22] The unclear sampling strategy relevant to address the research question, the inadequate number of individuals included in the study, and the absence of statistical analysis appropriate to answer the research question are considered the study's weaknesses.

Description of the experience of COVID-19 on caregivers of chronically ill patients

A summary of the findings from the included studies is provided in Supplementary Table 2. Scrutiny of the table can be placed into five major themes: 1) Mental health, 2) Personal experience, 3) Financial problems, 4) Physical health, and 5) Improvement approaches. Some themes have been organized in sub-themes that are dealt with in-depth hereunder.

Mental health. Six studies reported that the COVID-19 pandemic affects caregivers' mental health[3,22–26] One quantitative descriptive study[22] stated that due to the COVID-19 pandemic, the caregiver of a patient with colon carcinoma demonstrated sadness, distress, fear, and being filled with hopelessness. Consequently, the caregiver recalled having insomnia, thinking about making himself get better without adversely affecting family members. This negative emotional experience made the caregiver reconsider visiting the hospital, where the risk of COVID-19 exposure was high. Nonetheless, this caregiver reported being confused and anxious in prioritizing what to do. Likewise, another study showed that concerning the health of family members, including chronically ill patients, would get COVID-19[3,23–26] and worry about the patients' functional prognosis[3,25] make caregivers experience negative emotions.

Interestingly, some literature reported that caregivers developed anxiety about the long-term impact of COVID-19 on their lives. For example, parents of DD or ID children expressed their anxiety about the long-term negative influences the pandemic would have on their employment and financial status, as well as their children's emotional health and development due to the possible long-term closing of school and services.[23]

Personal experience

Families. Four out of six studies reported impacts on the relationships between caregivers and their families during this period[22–25]. Three studies demonstrated increasing conflicts with stroke patients and other family members,[22,24,25] either in the form of arguments, anger, or frustration. One out of three studies[25] reported potential physical and verbal abuse on stroke survivors from intractable conflicts. One qualitative study[23] focusing on caregivers of young children with DD or ID showed caregivers' concern for the educational and developmental progress of their children.

Healthcare service. Four studies reported caregivers' difficulties in accessing healthcare services due to the COVID-19 pandemic[3,24–26] In the study of Neece et al.,[23] 92.5% of the participants reported that they experienced difficulties connecting with the medical staff, as well as shown in another study.[3,23] This situation was shown as multiple phone call exchanges before reaching the provider, and the phone calls were unscheduled, leading to the long waiting for the phone calls.[3] Moreover, unavailability or poor efficiency of the health care services was another difficulty that caregivers experienced[24–26] A study by Neece et al.[23] reported that 37.7% of participants in their study described that they had an absence of regular check-ups because of the unavailability of the health care institution affected by the pandemic.[23] Unannounced closure of the rehabilitation centre or refusal of the admission due to the pandemic leading to no preparations of the caregivers.[25,26] Additionally, the slow attitude of the health care providers, the shortage of medication in the hospitals, and transport service were reported as other difficulties.[26] In one quantitative descriptive study, participants were unable to reach the pharmacy and hospital due to halted and inconvenient transport services by 77.1% and 86.4%, respectively.[26]

Financial problem. Four studies reported that some of the caregivers of the patients with chronic diseases experienced financial problems during the pandemic[23–26] According to Neece et al.,[23] 47% of participants indicated that they had financial difficulties, while 28% had no such experience.[23] One of the main aspects of the financial difficulties was related to the purchase of hygiene products and medications.[25] Based on the results of the study of Gulia et al.,[22] losing caregivers' jobs due to the COVID-19 pandemic was one of the reasons causing the financial matters.[22]

Physical health. Two studies showed that caregivers of chronically ill patients' physical health were negatively impacted during the COVID-19 pandemic.[24,25] In a quantitative study, caregivers of children with chronic respiratory distress[24] demonstrated that over 53.5% of participants experienced more exhaustion during the pandemic. Similarly, another study that studied stroke caregivers' experience[25] reported worsened physical draining due to extended durations of care, increased caregiving tasks, and lack of care skills. For example, one participant stated that "I feel exhausted helping him with rehabilitation exercises all day because my limbs were already strained from pushing his wheelchair."

Improvement approaches. Although the COVID-19 pandemic situation is intense, some caregivers reported silver linings during the pandemic as the following;

Intrapersonal and interpersonal approaches. Three studies revealed that caregivers developed intrapersonal and interpersonal approaches during the pandemic.[3,23,24] A qualitative study[23] of caregivers' children with DD or ID indicated that caregivers developed coping skills to overcome this challenging time. 25.8% of participants implemented behavioural strategies and schedules for their children. Some coping skills that caregivers developed are strengthening interpersonal relationships, including engaging in enjoyable activities with family, connecting to each other by using technology, and providing space for family members to decompress in the family. Moreover, some coping skills allowed caregivers to take care of themselves, including practising meditation, exercising, and eating healthy. A quantitative study[24] demonstrated that over 73.5% of caregivers reported a very high level of self-contentment for completing all the required activities during the day. Another literature[3] revealed that caregivers obtained emotional support from family and friends.

Public approaches. The public approach was referred to as the assisted strategy from the public section, either government or non-governmental, to support people affected by the COVID-19 pandemic. Three included studies[3,22,24] have shown the benefit of public approaches from government and community. One study[23] reported that government approaches, including financial and food support and interdependence in a community, would assist caregivers not only with a livelihood but also with mental health. Furthermore, the same study[23] also demonstrated that some participants could maintain and even increase the amount and intensity of utilizing the child's service delivered online during the pandemic.

Another public approach shown in the review is the health education service. Two studies[3,25] reported that the health care team's general stroke care and rehabilitation were crucial to helping the caregiver take care of the patient and relieving stress. The participants also further asserted that improving the quality of providing health education needs to be addressed to aid the caregiver in taking care of patients during an unusual time.

Discussion

The studies incorporated in this review determined the experience of caregivers of chronically ill patients during the COVID-19 pandemic. As far as caregiving's impact is concerned, this review expands the knowledge about the impact of COVID-19 on caregivers' mental health, personal experience, financial problems, physical health, and improvement approaches. Moreover, the personal experience and improvement approach's theme has been organized in sub-themes which will be discussed further.

In our review, six studies illustrated that the caregivers experienced mental health issues[3,22–26] Sadness, fear, being filled with hopelessness, stress, or depression are the most prevalent mental health issues experienced by caregivers. Also, concerning the health of family members and long-term consequences of the COVID-19 pandemic, such as employment, the financial status of caregivers, and children's development, were demonstrated as leading causes of mental health issues[3,22–26] The previous study by Horiuchi et al.[27] reported that the number of caregivers with mental distress was more than twice during the COVID-19 pandemic, compared to the 2016 national survey.[27] Although the study did not consider risk factors of caregivers' mental distress, the findings highlight that the causes of caregivers' mental distress are the difficulty of supporting children and the lack of social support due to the emergency response policies.[27,28] Therefore, further research to identify caregivers' needs, vulnerable populations, and family members to develop feasible and sustainable social support initiatives particular to the current and future infectious pandemic should be reconsidered.

In addition, four out of six included studies reported that during the COVID-19 pandemic, the caregivers experienced difficult relations within their family members with chronically ill patients. There are mainly two possible reasons for the interpersonal conflicts between caregivers and their families, as revealed in research.[4] First, during the pandemic, caregivers spend significantly more time with their families, especially the patients, as compared to before the outbreak. Besides, for the caregivers, loss of employment rendered the hours spent at home longer.[29] As for the patients, on account of the restriction of travelling and the fewer hospital beds,[30,31] they had less access to professional health care leading to more time receiving medical care at home, which was mostly provided by informal caregivers.[30] Therefore, as the time they spent together became longer, they were more likely to have conflicts with each other. Negative feelings such as stress and frustration caused by the crisis may also contribute to this phenomenon. Firstly, Kuhlen et al.[32] suggested that the financial burden on the caregivers, which could be heavy since chronic illnesses usually entail long-term medical care, has strengthened due to the quarantine.[32] Secondly, owing to the restricted health service, caregivers had to shoulder the responsibility of attending to the patients all by themselves. As a result, caregivers are overwhelmed by the heavy burden and become irritable, resulting in a negative impact on the relationship between caregivers and their families.[31] The negative feelings may lead to physical and verbal abuse of the patients. With reference to the relationships between caregivers and their young children with chronic illnesses, the burden was possibly caused by a lack of childcare and insufficient professional medical support.[23] The schools, where their children stayed most of the time, were closed. And, the hospitals were unable to offer medical assistance as usual. Therefore, caregivers needed to satisfy both their children's daily life needs and their medical demands.

Participants in four studies had reported the problems they experienced in community or society, including the low efficiency of health care systems and transport systems[3,23–25]. The low efficiency of the health care system manifested as the slow attitude of medical staff, difficulties in connecting with the health care team, and absence of regular check-ups[3,23–25] It might be because of the shortage of healthcare team members caused by two possible reasons.[33] The first possible reason was that the pandemic led several hospitals to turmoil and reached maximal capacity.[32] This led to fewer health care team members working on the patients in regular routines. Additionally, routine services of provider's revenue are reduced to contain the pandemic increasing unemployment in the healthcare system.[32] Therefore, the shortage of healthcare team members and the mounting number of COVID-19 patients impaired the efficiency of health care services.

Also, participants in one study stated that they experienced difficulty in using transport services during the pandemic. The public had higher levels of concern about the hygiene of public transport during the pandemic leading to the reduction of ridership in public transport service.[34] Hence, to reduce the cost caused by the limited travel demand, some public transport services had been halted altogether, or only essential travel was permitted.[35] This might be one of the main reasons that caused the problem for the caregivers and patients in reaching the hospital.

The financial problem experienced by the caregivers has been stated in four included studies[23–26] As stated in these studies, consumption of healthcare products and medication brought about financial difficulties.[3,24] The utilization of hygiene products added to the household expenditure during the pandemic. The significantly growing need for medical products led to the producer-driven chain.[36,37] Therefore, the prices of medical supplies had risen after the pandemic.[37] Furthermore, one study revealed that unemployment or losing jobs is one of the main reasons causing the financial matters for the caregivers.[24] The COVID-19 pandemic created a global economic shock resulting in unprecedented unemployment at once.[33,38]

Caregivers generally experience fatigue and exhaustion despite normal situations resulting from several factors. One crucial factor is the duration of care. Previous literature reported that caregivers' physical exhaustion increased over the time of care, regardless of age, gender, education, and religion.[39] Likewise, Kang et al. (2020) stated that a prolonged illness period results in greater physical fatigue of caregivers.[40] Besides, caregiving tasks can also injure caregivers themselves, although they were well trained. A study showed that few caregivers had benefited from the training causing injury to themselves and did not seek medical care due to lack of time or substitute caregivers ending neglecting their own medical appointments.[41]

According to our review, two out of six studies mentioned physical issues among caregivers during the pandemic.[23,24] They reported fatigue and worsened physical exhaustion due to extended durations of care, increased caregiving workload, and the lack of care skills. The physical health of caregivers would affect the quality of care provided for patients. Then, good health would have a positive impact on patients' health outcomes. Further research may have a programme to promote caregivers' physical health for the optimal benefit of caregivers themselves and patients.

The pandemic does not always result in a negative impact on caregivers. Coping skills are ignited under serious situations and various individuals' roles. For example, Lutzky et al.[42] indicated that emergency healthcare providers, who work under time pressures, perform highly complex skills and assessments.[42] For caregivers, the crisis catalysts them to develop coping skills in taking care of patients during the pandemic, as seen in three studies.[3,23,24] On the other hand, exceeding pressure can also cause adverse outcomes. A study stated that emergency department nurses' workload and time assignment problems interrupt their problem-solving process, and some of them tend to select negative coping styles to solve problems.[43] Furthermore, the caregivers who develop an ineffective coping strategy could develop negative emotions in the future.[44] For that reason, developing coping strategies without crises by utilizing training programs fitting for specific situations would be essential for all caregivers. The current study results were consistent with a study by Almathami et al.,[45] who found the increased perceived self-efficacy in dealing with caregiving demand and self-control over their situation and decreased health risk of caregivers.[45] This study is also supported by Dang et al.,[46] who reported that the use and development of coping strategies might decrease caregivers' burden and psychological distress.[46] Therefore, opting strategies would allow caregivers to cope with situations appropriately, decreasing mental exhaustion. If coping skills can be developed by training programs and benefit caregivers, they should be provided to caregivers apart from providing care knowledge and techniques. Also, coping skills benefit caregivers, so it would affect providing care improving patients' health outcomes. During an uncertain situation, several policies responding to COVID-19 become promising prospects in some countries mentioned in previous study.[23] As the pandemic caused a financial burden on caregivers, government financial assistance can be partially substituted for the families of chronically ill patients' money loss. An example of a Medicaid programme in the US that used to pay for formal caregiving support was suspended during COVID-19 due to the physical distancing and other safety measures. To date, the Medicaid programme temporarily allows paying family caregivers, who are becoming formalized caregiver roles, to receive payment for a direct care service during the pandemic, and facilitate caregivers to file requirement forms via phone and other information technology (IT) platforms.[42,47] However, the lack of a population database and unpreparedness for emergency response at the local level has led to delays and uneven financial assistance provision in some countries.[48] Therefore, national-level preparedness in the population database and pandemic plan is needed to prepare for future circumstances. Technological advances also played a crucial role in healthcare services during the pandemic. The studies incorporated in this review showed the great advantage of telemedicine which helps patients and caregivers safe from exposure to COVID-19, maintain, and even increase care access for patients.[3,23,25] Telemedicine provides self and distance monitoring, treatment, follow-ups, and education, reducing morbidity and mortality during pandemics. The study from Chiang et al.[49] revealed that telehealth reduces caregiver burden, stresses, and waiting time for healthcare services and increases family relationships and social support[49]. Nonetheless, the impediment to implementing service remotely still exists. The technical and clinical quality, accreditation, payment systems, and insurance coverage needed to be prepared to respond to a pandemic.[50] Also, the internal level referring to the users' experience, technology device, and positive perception of technology is the key to benefiting from telemedicine.[45] All of these concerns cannot be created overnight. Although the pandemic provokes concern about delivering telemedicine and building technological capacity among caregivers and healthcare providers.

Additionally, the participants included in the review study emphasized the need for health education and communication during pandemics.[3,25] Thus, supporting staff and developing a systematic approach to assess patients and caregivers at the local level are recommended to improve the quality of care.[46] The future study is recommended to address the need and recommendations for internal, local levels, and national levels to support caregivers, who are the power for home-based healthcare in times of crisis.

Limitations

This systematic review has potential limitations that need to be acknowledged. First, since this systematic review is conducted in a retrospective manner, new data published after the period of data collection (e.g. the data on how long patients with chronic disease were providing care for) may be underreported, which can affect the results. Second, the limitations involved the inclusion criteria that only English studies were to be included. Excluding non-English studies may change the results. Third, since the very small number of studies and the heterogeneity of those studies (qualitative and quantitative) were included, it is difficult to draw a conclusion. Therefore, further research is needed. Lastly, identifying relevant studies among the many potential sources of information is usually a laborious process. However, the researchers have comprehensively searched relevant studies from the most common databases indexed.

Conclusion

This systematic review provided a better understanding of caregivers' experience of caring for chronically ill patients during the COVID-19 pandemic. The results could heighten healthcare providers' awareness of providing appropriate support for them. Therefore, future research incorporating programs that support caregivers' needs is recommended. Moreover, more studies that aim to determine the impact of COVID-19 on caregivers of chronically ill patients by disease type during COVID-19 need to be conducted, especially quantitative research with robust design and sampling and analytic strategies.

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Supplemental material

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