# Systematic Review On Educational Interventions To Improve Coping Strategies And Quality Of Life Among Primary Caregivers Of Cancer Patients

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#### Abstract

**Background:** In past studies, numerous challenges faced by primary caregivers of cancer patients have been classified as mental and physical health burdens, financial strain, and social isolation. Educational interventions can help improve primary caregivers' coping mechanisms and quality of life.

**Objective**: To examine the challenges that primary caregivers of cancer patients face, the impact that these challenges have on their coping skills and quality of life, and to present a framework that can be used for improving the quality of life and coping skills of primary caregivers of breast cancer patients.

**Methods**: The researcher conducted a database search on six databases, including Medline, Embase, CINAHL, PubMed, SCOPUS, and Web of Science. Studies included in this review lay between 2013 to 2023. The focus was on the extraction of primary caregivers' experiences and enhanced QoL

**Results**: The search yielded 31 studies that had met the inclusion-exclusion criteria. The themes from the 31 studies included the challenges faced by primary caregivers, the educational interventions, and their positive effects on quality of life and coping skills. The foremost effective interventions recognized in the results included psychoeducation, cognitive behavioural therapy, and resilience-building activities.

**Conclusion**: The findings of the review indicate the need to develop policies and intervention programs that provide educational, emotional, social, and financial support to the primary caregivers of cancer patients.

**Keywords**: Primary Caregivers, Educational Interventions, Cancer Patients, Coping Strategies, Quality of Life, Breast Cancer. Authors:

#### Introduction

Cancer is a major global health problem with impacts beyond the patient affecting the families and caregivers significantly (Lau et al., 2020). The primary caregivers (PCs) of cancer patients are an essential factor for the patient's overall care as they are responsible for providing them with physical, emotional, and practical support (Streck et al., 2020; Üzar-Özçetin & Dursun, 2020).

Being a primary caregiver to a cancer patient is challenging and can impact a person's quality of life (QoL) (Chua et al., 2020; Lau et al., 2020; Peh, Liu, & Mahendran, 2020). There is a significant amount of literature in the past that documents the mental health burdens faced by PCs of cancer patients with outcomes like stress, fatigue, depression, anxiety, and others that lead to reducing the QoL (Ferrell, Kravitz, Borneman, & Friedmann, 2018; Rhondali, Chirac, Laurent, Terra, & Filbet, 2015). PCs often face financial strain, employment difficulties, and social isolation, which leads to increased economic, psychological, and social burdens (Mishra et al., 2018; Muriuki, Oluchina, & Mbithi, 2023; Owoo, Ninnoni, Ampofo, & Seidu, 2022). Studies also show the importance of PCs' mental and physical health for cancer patients' QoL, treatment response, and medical interventions(Arias-Rojas, Leon, & Moreno, 2021; Kassir, Li, Harrison, Johnson, & Nilsen, 2021; Rocio, Rojas, & González, 2017). Therefore, it is essential to understand the challenges that might be faced by the PCs and provide them with the required support to enhance their QoL.

Literature analysis shows that there are different kinds of interceptive measures in place to face problems faced by PCs in terms of improving the ability to cope with the mental burdens that

caring for a cancer patient brings with it (Adejoh et al., 2021; Litzelman, 2019; Sun, Raz, & Kim, 2019). Educational intervention is one of the most significant interceptive techniques that has been reported in the past literature to improve the QoL of PCs and reduce their anxiety levels, help them in overcoming their stress, and provide them with tools to improve their coping methods(Gabriel & Mayers, 2019; Kizza & Muliira, 2019; Kusi et al., 2020). However, the effectiveness of these techniques can depend upon the type of cancer and the individualized needs of the primary caregivers(Ahn, Romo, & Campbell, 2020; Demiris, Washington, Ulrich, Popescu, & Oliver, 2019; Litzelman, 2019).

Breast cancer is globally the most prevalent cancer in women, and breast cancer patients' PCs can face several unique challenges (Kusi et al., 2020; Li, Wang, Yin, Li, & Li, 2018). Therefore, it is crucial to understand how these challenges can be overcome using effective educational interventions to improve coping mechanisms and quality of life. However, literature is scarce explicitly discussing QoL or coping mechanisms for breast cancer patients. Therefore, in this systematic review, the researcher aims to explore the challenges that PCs of cancer patients can face and the impact educational interventions can have on coping mechanisms and QoL. Based on these findings, the researcher will present a framework for improving coping mechanisms used by PCs of breast cancer patients to enhance the QoL. To summarize, the objectives of the current study are as follows.

- 1. To examine the challenges faced by PCs of cancer patients.
- 2. To examine the impact of educational interventions on QoL and Coping mechanisms of PCs of cancer patients
- To present a framework for improving the PCs' QoL and Coping mechanisms using educational interventions for PCs of breast cancer patients.

The following section outlines the materials and methods used in this review, followed by results, the main body of the thematic findings in the study, discussion and recommendations for breast cancer PCs' QoL improvement, implications, limitations, and future research directions, and conclusions.

#### **Materials and Methods**

#### 2.1 Study selection

For this review, the researcher conducted a systematic search using six databases. Medline, Embase, CINAHL, and PubMed were used as primary sources as the topic is of medical origins. Moreover, the researcher also included searches run on SCOPUS and Web of

Science to ensure coverage of papers published in other types of journals. The search syntax is presented in the table below. In addition to the listed keywords, combinations of these keywords were also used while searching with "AND" and "OR" operators. Databases were searched for relevant documents from this paper's inception till 30<sup>th</sup> April 2023. The researcher included quantitative and qualitative style studies in this review. Therefore, no study design filters were used.

Moreover, the researcher reviewed the included studies' reference lists to increase the search width and add additional studies not identified in the initial investigation and screening. Duplicate papers were removed in the first stage, after which the researcher screened the filtered studies by over-viewing titles and abstracts to exclude any studies that did not fulfil the criteria. Full texts of potentially eligible studies were overviewed at the last filtration stage.

**Table 1: Search Syntax** 

#	Main Keyword	Possible Alternatives
1	Cancer	-
2	Quality of Life	QoL OR life quality OR Depression OR Psychological distress OR unmet
		needs OR Burden
3	Coping Mechanisms	Resilience OR Coping Strategies OR Coping techniques OR cope
4	Personal Caregiver	Family caregiver OR PCs OR Caregiver OR Carer OR family OR relative
		OR Family relations
5	Educational Intervention	Psychosocial intervention OR education intervention OR resilience
		building OR Emotional response training OR training of PCs OR
		educating PCs OR Intervention

#### 2.2 Terminology and Definitions

There are several basic terms included in this study. The quality-of-life variable can be defined as an individual's subjective perception regarding their physical and psychological health, emotional well-being, and social well-being(Hwang et al., 2018; Kassir et al., 2021; Owoo et al., 2022; Sharma, Saneha, & Phligbua, 2021). Caregiver burden can be defined as the subjective (financial, social, psychological) and objective (physical and health) burdens that are faced by a caregiver of a patient as a result of the expectations of care provision(Li et al., 2018; Üzar-Özçetin & Dursun, 2020). Coping mechanisms are the strategies adopted by individuals to overcome issues faced during some ordeal, as for the current study, the provision of care to cancer patients(Greer, Applebaum, Jacobsen, Temel, & Jackson, 2020; Hwang et al., 2018; Kassir et al., 2021; Sharma et al., 2021). Educational intervention, in the context of the current study, is steps taken to give educational support to the

caregivers to help them in providing the best care and support to cancer patients (Buonaccorso et al., 2023; Leow, Chan, & Fai Chan, 2015; Mahendran et al., 2017; Titler et al., 2017). Caregivers are also of two types, formal and informal. Formal caregivers are relatives, friends, or acquaintances that are not traditionally trained in the medical field but are responsible for taking care of the patients as they spend the most time in proximity with them. Informal caregivers are trained professionals that are responsible for providing healthcare to the patients.

#### 2.3 Eligibility criteria

The inclusion criteria for the study were as follows.

- All methodologies were acceptable, as no filter was applied in terms of method.
- Studies were included if they reported data regarding the burdens and challenges faced by PCs of cancer patients and discussed their QoL, coping mechanisms, or educational interventions.
- Studies published between 2013 to 2023.
- Studies published in English journals.
   The exclusion criteria of this study were as follows.
- Studies published outside the time frame, i.e., before 2013 or after 2023.
- Studies fail to report on caregiver experience directly but focus on results generated by obtaining data from a second person, i.e., healthcare providers, patients, etc. Studies needed to have to report directly from caregivers.
- Conference papers, case reports, editorials, books, and sections were discarded.

#### 2.4 Quality appraisal

To perform the quality appraisal of selected studies, two researchers examined the research articles independently and later compared the results. A third researcher resolved any disagreements. Qualitative studies were ranked using the CASP (Critical Appraisal Skill Program) Qualitative Checklist, comprised of 11 questions (Long, French, & Brooks, 2020). A qualitative study can achieve a maximum score of 22. Therefore, the studies obtaining points between 17 to 22 were considered good, between 11-16 were fair, and below that were poor, as per the strategy used by (Chong, Crowe, Mentor, Pandanaboyana, & Sharp, 2023). The quantitative studies were ranked using the MINORS (Methodological Index of Non-randomized Studies) tool, which has 8 or 12 items depending on the type of study, i.e., comparative studies had 12 and non-comparative had the highest value of 8 (Hwang et al., 2018; Won et

al., 2014). Thus, as per the method used by Chong et al., 2023, comparative studies could achieve a maximum of 24 scores, and non-comparative studies could obtain a total of 16. A score of 16-24 was considered a good score, and 8-16 was considered fair and below that poor, irrespective of comparative or non-comparative study.

#### 2.5 Data extraction and Synthesis

The two main authors extracted data, and the rest resolved the disagreements. The data was extracted from the selected papers in Excel worksheets. The extracted information included author names, year of publishing, aim, design, country, data collection method, analysis techniques, challenges of PCs listed, Coping strategy discussed, QoL determinants, and interventions for PCs to improve QoL and Coping Mechanisms. The researcher adopted a deductive thematic analysis approach to analyse the content of included papers in light of the study objectives. The characteristics of the included research were analyzed using descriptive techniques, and the themes were analyzed using the narrative, thematic style. This allowed the researcher to summarise recent research on caregivers' QoL, coping mechanisms, and educational intervention techniques.

#### Result

#### 3.1 Search Result

The screening process used in this study is based on the PRISMA technique, summarized in Figure 1. The systematic search of the databases returned 263 citations. Initial pre-processing steps like removal of duplicates, books, book chapters, conference papers, and other types of literature that have been excluded led to leaving behind 106 papers. Reviewing titles and abstracts further reduced the bundle of citations to 72. Upon analysis of full text and quality evaluation, 31 papers were finalized. Moreover, the analysis of reference lists of these papers also did not contribute any new studies that fit the criteria. Thus, 31 papers were included, of which 13 were qualitative, 16 were quantitative, and 2 were mixed method based.

#### 3.2 Description of the Studies

As summarized in the above sections, there are 31 papers included in this review. These papers have been selected from database searches by restricting the result to the past decade, i.e., 2013-2023. The number of papers included from each of the years is mapped in

Figure 2 below. The maximum number of papers are from 2018 and onwards, with 8 papers from 2018, 4 each from 2015, 2020, and 2021, 3 from 2017, 2 each from 2016, 2022, and 2023, and 1 each from 2013 and 2019.

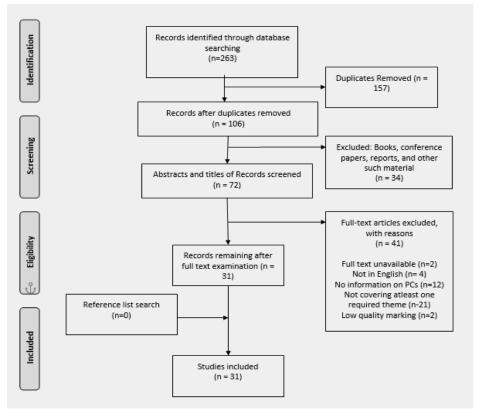
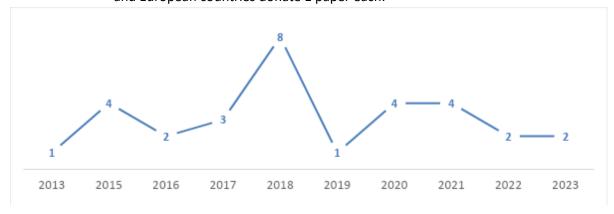


Figure 1: PRISMA Flowchart

As for the papers' geographical origins, figure 3 shows that most papers were studies conducted in the USA, followed by China, Colombia, Singapore, and Turkey. The rest various African, Asian, and European countries donate 1 paper each.



**Figure 2: Yearly Distribution** 

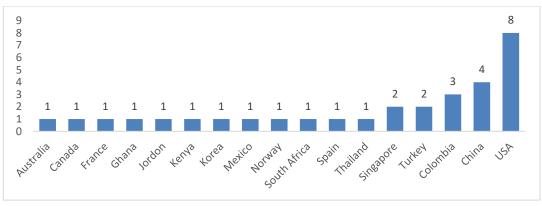


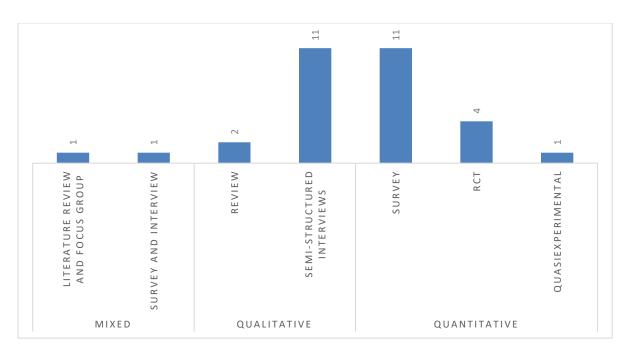
Figure 3: Country-wise Distribution

The papers selected in this review all belonged to English journals and were well-ranked journals. These journals are mostly on Nursing, Cancer, Clinical Oncology, Health education, etc., as the review topic requires. Table 2 shows the list of included journals, along with each Journal's contribution by number of papers.

**Table 2: Journal-wise Distribution** 

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Journal Name	# of papers
American Journal of Hospice and Palliative Medicine	1
Asia-Pacific Journal of Oncology Nursing	1
BMC cancer	1
BMC Palliative Care	1
Breast Cancer: Targets and Therapy	1
Cancer Nursing	1
Clinical Journal of oncology nursing	1
Health and Quality of Life Outcomes	1
Health Education & Behavior	1
International Journal of Environmental Research and Public Health	1
International Journal of nursing studies	1
International Journal of Palliative Nursing	1
Journal of Evidence-Informed Social Work	1
Journal of Hospice & Palliative Nursing	1
Journal of palliative medicine	1
Journal of Pediatric Oncology Nursing	1
Journal of Psychosocial Oncology	1
OMEGA-Journal of Death and Dying	1
Palliative & supportive care	1
Psycho-Oncology	1
Quality of Life Research	1
Palliative Medicine	2
European Journal of Oncology Nursing	3
Supportive Care in Cancer	5

As for methodological distribution, it is shown in Figure 4. There are two mixed method-based studies. Rosenberg et al. (2013) conducted their mixed method study using a qualitative design comprised of a literature review and focus group analysis. Mahendran et al. (2017), on the other hand, used a mixed design comprised of a quantitative survey and semi-structured interviews. As for the qualitative studies, two of the papers (Guerra-Martin, Casado-Espinosa, Gavira-López, Holgado-Castro, & López-Latorre, 2023; Üzar-Özçetin & Dursun, 2020) were narrative reviews, whereas the rest 11 papers (Ferrell et al., 2018; Francis, Kypriotakis, O'Toole, Bowman, & Rose, 2015; Francis, Kypriotakis, O'Toole, & Rose, 2016; Lee et al., 2015; McDonald et al., 2018; Mishra et al., 2018; Owoo et al., 2022; Rhondali et al., 2015; Rocio et al., 2017; Røen et al., 2018; Weaver et al., 2022), were semi-structured interviews. Of the 16 quantitative papers, the study was based on a quasi-experimental design; four papers(Lau et al., 2020, 2018; Xiu et al., 2020; Younis, Norsa'adah, & Othman, 2021) were random control trials based studies, and the rest of the papers, were surveyed.



**Figure 4: Methodological Distribution** 

Three underlying themes can be identified QoL, Intervention, and Resilience strategies (or coping mechanisms). The basic characteristics of the studies, themes, and their main findings are summarized in Table 3 below.

Table 3: Summary of Major Characteristics and Findings of **Included Literature** 

A	Country	Tuna Of Mathad	Danulat	Th	amaaa Cawanad	Danis findings
Authors and Years	Country	Type Of Method	Populat ion	ın	emes Covered	Main findings
(Rosenberg et al., 2013)	USA	Mixed-Literature Review and Focus Group	18 PCs	•	Coping strategies	Educational and psychosoci interventions can increase resilience of PCs.
(Francis et al., 2015)	USA	Qualitative-Semi- Structured Interviews	199 PCs	•	Challenges	Grief is the main predictor depression and anxiety in P Due to grief, PCs face many social, physical, and psychological health issues.
(Lee et al., 2015)	Singapore	Qualitative-Semi- Structured Interviews	26 PCs	•	Challenges Quality of Life	Literature is more focused in past on physical, social, and mental health. There needs be increased focus on spirit emotional, and financial he in the future.
(Rhondali et al., 2015)	France	Qualitative-Semi- Structured Interviews	15 PCs	•	Challenges	There is a need for education training programs targeted towards PCs of cancer patients to help them learn coping strategies, reduce adverse effects on their well-being, better manage the patient.
(Tokem, Ozcelik, & Cicik, 2015)	Turkey	Quantitative-Survey	110 PCs	•	Coping strategies	Nurses should indulge in intervention programs to provide the required supports and improve the use of problem-oriented coping strategies.
(Francis et al., 2016)	USA	Qualitative-Semi- Structured Interviews	199 PCs	•	Challenges	Caring for middle-aged paticarries more emotional and psychological strain as com to older/younger patients, the life burden of middle-aged patients is much more
(Hendrix et al., 2016)	USA	Quantitative-Survey	138 PCs	•	Intervention	Educational interventions of help improve disease management, caregiving, a other factors related to supporting the patient but

						not significantly impacting
						PC's psychological status.
(Rocio et al.,	Colombia	Qualitative-Semi-	12	•	Challenges	The social, educational, and
2017)		Structured	dyads	•	Quality of Life	financial support system is
		interviews				required to help provide th
						best care to the patients ar
						maintain QoL for PCs
(Mahendran	Singapore	Mixed-Survey and	97 PCs		<ul> <li>Intervention</li> </ul>	COPE strategy is viable for
et al., 2017)		Interview				improvement in Family
						caregivers' resilience and co
						mechanisms leading to
						potentially improved QoL
(Titler et al.,	USA	Quantitative-Survey	36		<ul> <li>Intervention</li> </ul>	Outcomes of FOCUS
2017)			dyads			intervention were positive
						QoL, burden, and other fac
(Ferrell et	USA	Qualitative-Semi-	20 PCs	•	Challenges	PCs need care and support
al., 2018)		Structured		•	Quality of Life	interventions in all aspects
		Interviews				domains of QoL
(Li et al.,	China	Quantitative study-	108	•	Challenges	The caregiver burden can
2018)		Survey	dyads			negatively affect the patien
						Therefore interventions are
						needed to educate PCs and
						them improve coping strate
(McDonald	Canada	Qualitative-Semi-	23 PCs	•	Challenges	Instruments for monitoring
et al., 2018)		Structured		•	Quality of Life	in PCs are required to ensu
		Interviews				they are not faced with an
						unmanageable psychologic
						and physical burden to red
						the harmful effects of canc
(Mishra et	Mexico	Qualitative-Semi-	8 dyads	•	Challenges	Educational and social
al., 2018)		Structured		•	Quality of Life	interventions are needed to
		Interviews				support young patients and
						PCs.
(Litzelman et	USA	Quantitative-Survey	1482		• Coping	Health behaviour and copir
al., 2018)		·	PCs		strategies	mechanisms of PCs are
						interlinked to health outcome
						for patients.
(Røen et al.,	Norway	Qualitative-Semi-	14 PCs		• Coping	Simple Educational interve
2018)	-	Structured			strategies	that can address the carers
		Interviews			<ul> <li>Intervention</li> </ul>	support needs can lead to
						increased resilience toward
						cancer-related difficulties a
						improved QoL for the PCs
						-

(Hwang et al., 2018)	Korea	Quantitative-Survey	273 PCs		•	Coping strategies Intervention	There is a need to provide support and intervention educational programs to PC support increased resilience when faced with difficulties caring for cancer patients
(Lau et al., 2018)	China	quantitative-RCT	Undefin ed		•	CBT and integrative body-mind-spirit intervention	Improved QoL of patients a PCs is expected as a respor this CBT intervention proto
(Gabriel & Mayers, 2018)	South Africa	Quantitative-Quasi- Experimental	108 PCs		•	Intervention	Interventive programs were successful in reducing the sand psychological burden caregiving.
(Arias-Rojas et al., 2020)	Colombia	Quantitative-Survey	80 PCs		•	Intervention	Intervention programs like "palliative Caregivers" can improve PCs' socioeconom psychological, and health-related burdens.
(Üzar- Özçetin & Dursun, 2020)	Thailand	qualitative-review	27 studies		•	Intervention	A mix of various types of interventions is suggested formulate an integrated intervention technique.
(Xiu et al., 2020)	China	quantitative-RCT	157 PCs		•	CBT and integrative body-mind-spirit intervention	I-BMS and CBT were found equally effective in improv psychological distress and enhancing the generic QoL PCs
(Lau et al., 2020)	China	quantitative-RCT	157 dyads		•	CBT and integrative body-mind-spirit intervention	CBT is effective in the improvement of emotional being. On the other hand, I overall enhances QoL more significantly.
(Kassir et al., 2021)	USA	Quantitative-Survey	47 PCs		•	QoL of PCs	Interventions are required identify and support at-risk
(López León et al., 2020)	Colombia	Quantitative-Survey	97 PCs	•	Ch	allenges	Socio-demographic factors the PC can impact their competence, QoL, and Pati QoL and treatment quality.
(Younis et al., 2021)	Jordon	quantitative-RCT	200 PCs	•	Co	ping strategies	An education intervention programme (PEIP) reduces cancer's psychological and strain on patients and PCs.
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(Sharma et	Turkey	Quantitative-Survey	210 PCs	•	Intervention	Interventions can help in
al., 2021)						improving resilience buildir
						PCs
(Owoo et al.,	Ghana	Qualitative-Semi-	12 PCs	•	Challenges	Educational and practical
2022)		Structured				interventions are needed to
		Interviews				PCs learn techniques for
						managing patients and redu
						the impact on personal Qol
(Weaver et	Australia	Qualitative-Semi-	20 PCs	•	QoL of PCs	PCs need to be supported
al., 2022)		Structured				through educational
		interviews				interventions and must be
						encouraged to value their h
						as well.
(Muriuki et	Kenya	Quantitative study-	255 PCs	•	Challenges	Need for educational,
al., 2023)		Survey				psychological, financial, and
						social interventions
(Guerra-	Spain	qualitative-	36	•	QoL of PCs	Most of the PCs are womer
Martin et al.,		Descriptive Review	studies			need supportive intervention
2023)						maintain their own QoL alo
						with the provision of qualit
						care to cancer patients.

## PC Challenges, QoL, Coping Mechanisms, and Educational Intervention

#### 4.1 Primary Caregivers' Challenges

Examining literature regarding the challenges caregivers of cancer patients face, four main challenges were recognised: physical, mental, psychological, social, and spiritual well-being. As reported in the reviewed literature, the physical challenges indicate that a conflict often arises between the cancer patient's well-being and their informal caregivers' physical health(Lee et al., 2015; McDonald et al., 2018). This is due to the fact that informal caregivers find it challenging to balance their health and needs and the needs of the cancer patient. The caregiving activities for cancer patients may include physically intensive activities like lifting the patients and massaging. Which may be physically tiring for the PCs (Lee et al., 2015).

Moreover, as studies reported, PCs can be overburdened with caregiving work, leading to a lack of rest and can cause the deterioration of their physical health status (Lee et al., 2015; Li et al., 2018). The PCs have reduced sleep time and may experience insomnia, body pains, cough, stress, and headaches, among many other health issues, including low or high blood pressure and blood

sugar(Lee et al., 2015; Li et al., 2018; McDonald et al., 2018; Mishra et al., 2018). Any informal caregiver who already has some chronic disease, like hypo or hypertension, hypo or hyperglycemia, asthma, etc., can have aggravated symptoms leading to disease exacerbation(McDonald et al., 2018).

The PCs or the informal caregivers are also faced with social challenges, such as financial burdens, role adjustment, etc., since from the time the patient is diagnosed with cancer, they have no choice but to assume the role of care provider at home(Ferrell et al., 2018; Lee et al., 2015). The first job of a PC, as a close family member, is to ensure that the cancer patient's mindset remains positive so that psychological changes and challenges can be avoided for as long as possible(Ferrell et al., 2018; Mishra et al., 2018; Muriuki et al., 2023; Owoo et al., 2022). However, the patient's psychological burden of disease and treatment is inevitable. It eventually alters their personality, making it hard for both the patient and the PC (Ferrell et al., 2018; McDonald et al., 2018). Additionally, the PCs are also burdened with financial challenges as most of the cancer patients are unable to work due to disease. The PCs need to earn money for daily life needs, in addition to treatment and medication costs(Lee et al., 2015; Li et al., 2018; Mishra et al., 2018).

In addition to the psychological effects on the patients, PCs are also faced with various stages of psychological health. The patient's diagnosis may come as a shock for both equally, and the PC also travels through shock to acceptance, just as the patient does. The PCs may face anger and refusal feelings making it harder to accept the health status of a close person (Ferrell et al., 2018; Lee et al., 2015; Owoo et al., 2022). Studies show that people who cared for close ones who faced cancer feared the unpredictability of their future, the uncertainty of cancer development, and the complications of the disease (McDonald et al., 2018; Mishra et al., 2018; Muriuki et al., 2023). PCs may feel a sense of guilt, uselessness, and stress because they could not do anything for their loved ones or were unable to care for them in the best way (Francis et al., 2016; Mishra et al., 2018; Rhondali et al., 2015). Some informal caregivers were also anxious about the issues caused by the patient's death, such as the upbringing of the patient's children, etc.

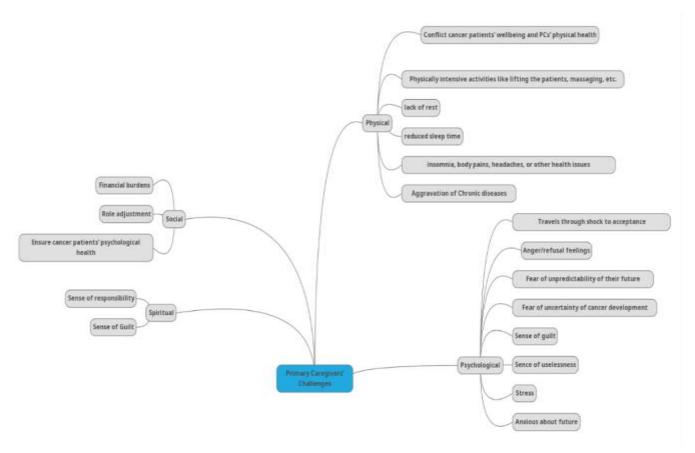


Figure 5: Mind Map for PCs' Challenges

The PCs can also be faced with spiritual burdens. Studies report that more often than, the PCs feel that it is their responsibility to care for cancer patients above and beyond their health. This leads the PCs to hide their own physical, psychological, or social struggle from the patients and try and provide all the support that might be needed. The PCs also reported that except for some rest or spare time, any other form of personal or social entertainment was not acceptable when their loved ones were suffering, leading to increased anxiety and depression in the PCs.

#### 4.2 Primary Caregivers' Quality of Life

Quality of life is a multidimensional concept that includes physical, social, psychological, and environmental health factors. It can be defined as an individual's perception of their health status in the context of the value system in which they live and personal standards, expectations, goals, and concerns(Ferrell et al., 2018; Guerra-Martin et al., 2023; Lee et al., 2015). In simpler words, the QoL of a PC can be defined as their personal beliefs regarding their psychological and physical health, their social interactions, financial burdens, and their relationship to their environment(Guerra-Martin et al., 2023).

Studies show that a decline in QoL can negatively affect the status and quality of care provided to cancer patients (Arias-Rojas et al., 2020; Li et al., 2018; Muriuki et al., 2023). The trends and expectations of caregiving can vary with cultural differences as some studies point to increased PCs' burden and strenuous responsibility perceptions with increased cultural embed deadness, leading to greater negative impacts on their QoL (Kassir et al., 2021; Weaver et al., 2022). Several other researchers point out an inverse correlation between the factors of QoL and PCs' burden (López León et al., 2020; Rocio et al., 2017).

Socio-demographic factors like PCs' marital status, age, educational background, gender, family size and structure, income, religion, and relation to the patient can influence the PC's QoL Clinical characteristics of the PC themselves, such as the presence of chronic disease, can also affect the QoL predictor(Arias-Rojas et al., 2020; McDonald et al., 2018).

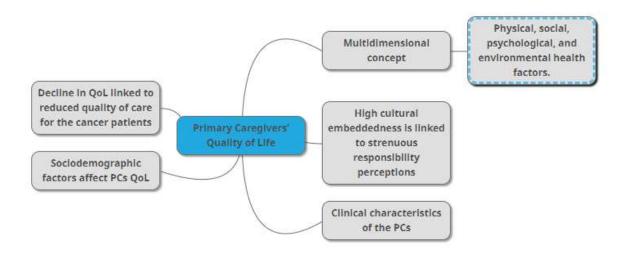


Figure 6: Mind Map for PCs' Qo

#### 4.3 Primary Caregivers' Coping Mechanisms

Coping strategies have been defined in terms of cognitive and behavioural trials that may be performed by primary caregivers in order to deal with the stressful situations that they are faced with while caring for cancer patients (Younis et al., 2021). These strategies include any social or educational steps that may be taken to reduce the intensity of stress and burdens of caring for cancer patients (Arias-Rojas et al., 2020; Younis et al., 2021). An increase in stress is an outcome of the deterioration of the resources of PCs and needs to be managed using coping strategies (Gabriel & Mayers, 2018).

Researchers discuss two types of coping strategies: problem-focused and emotion-focused(Younis et al., 2021). In problem-focused coping mechanisms, the focus is on resolving problems using caregivers find themselves in stressful caregiving situations and need to try to adjust their attitude and behaviour to cope in a better way by looking for environmental or individual resources like more information on the problem or the situation(Litzelman et al., 2018; Younis et al., 2021). Problem-focused coping methods can be active coping, restrain coping, planning, or seeking social support(Tokem et al., 2015).

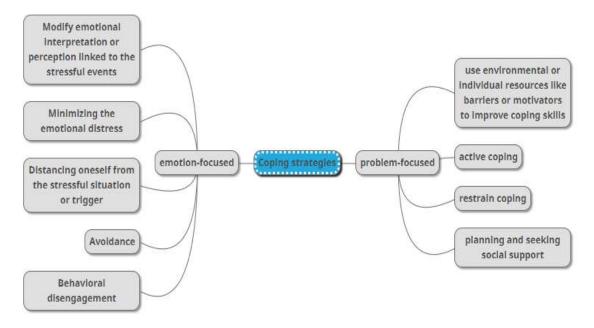


Figure 7: Mind Map for PCs' Coping Mechanisms

Individuals seek to modify the interpretation or perception of the stressful events that are causing the stress in order to reduce negative or stressful emotions in case of emotion-focused coping(Francis et al., 2015; McDonald et al., 2018; Owoo et al., 2022; Tokem et al., 2015; Younis et al., 2021). Strategies like minimizing emotional distress, distancing oneself from the stressful situation or trigger, and avoidance, etc., can be used for improved emotion-focused coping. Behavioural disengagement, seeking social support, positive reinforcement, etc., are some adaptive measures that may be taken. However, if a PC exhibits avoidance, it can lead to creating a negative impact on the patient or their own health (Mishra et al., 2018; Younis et al., 2021).

# **4.4 Educational Interventions to Improve Coping and QoL** As already highlighted by the reviewed literature, a cancer diagnosis can lead to causing a wide range of emotional, social, and

psychological burdens on the PCs that can affect their QoL significantly. Educational interventions are one approach that can help PCs and patients to improve their coping mechanisms and QoL. The findings of this review can classify the educational interventions into three groups: education, cognitive-behavioural therapy (CBT), and resilience-based interventions.

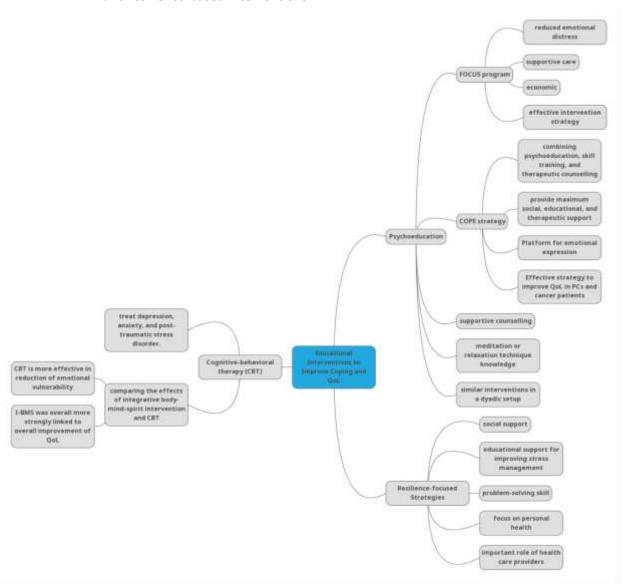


Figure 8: Mind Map for Educational Interventions for Coping and QoL

Many factors related to cancer diagnosis and treatment lead to psychological burdens for the patient and their family caretakers. Educational interventions can provide information regarding the disease, treatment options, and management of symptoms of psychological burden in the patients as well as their caregivers. Such education has recently been termed education in intervention literature(Gabriel & Mayers, 2018; Sharma et al., 2021). Education program aims to enhance coping skills, knowledge base, and quality

of life. The caregivers can be guided under this concept to learn about the disease and its related factors and make better and more informed decisions regarding symptom management and treatment opportunities (Hendrix et al., 2016; Rocio et al., 2017; Tokem et al., 2015).

Several studies have indicated that education can enhance the quality of life and coping skills of the family caregivers or the PCs of the patients. Titler et al., (2017) examined the impact of the FOCUS program, an evidence-based educational intervention program that promises improved QoL, reduced emotional distress, and provided supportive care to both the patients and their family caregivers.

The findings of this study showed that FOCUS intervention program was an economical and effective intervention strategy for improving QoL for PC dyads that enhances symptom recognition and management and improves communication between stakeholders (patients, PCs, and medical staff). Similarly, Mahendran et al., (2017) examined the eligibility of COPE ("Caregivers of cancer Outpatients' Education support group therapy") as a possible intervention strategy for providing PCs with support by combining education, skill training, and therapeutic counselling to provide them with maximum social, educational, and therapeutic support. The findings of this study established that COPE is a possibly effective strategy to improve QoL in PCs and cancer patients as it can equip them with necessary coping skills and provide them with a platform where they could be emotionally expressive.

In another study by Gabriel & Mayers (2019), the researchers evaluated a psychosocial intervention, which included supportive counselling, education, and meditation or relaxation technique knowledge, that was aimed to improve the QoL in PCs of breast cancer patients. The findings of this study showed significant improvement in the caregivers' QoL as the interventions reduced stress and feelings of burden. Sharma et al., (2021) also examined the impact of similar interventions but in a dyadic setup. The findings showed similar results, i.e., educational interventions were positively associated with improvement in the QoL of caregivers and patients.

Cognitive-behavioural therapy (CBT) is also used as an intervention technique to improve coping capabilities and QoL in PCs. CBT is a type of cycle therapy that aims to change negative emotions, thoughts, and behaviours and treats depression, anxiety, and post-traumatic stress disorder. A number of studies have adopted CBT as a possible support mechanism for enhancing coping capabilities in caregivers and reducing their emotional and psychological distress (Lau et al., 2020, 2018; Xiu et al., 2020).

In their earlier study, Lau et al., (2018). compared the effects of integrative body-mind-spirit intervention and CBT in PCs and cancer patients. It was discussed that since both strategies had the same underlying aim, improving coping skills and QoL in PCs and patients(Lau et al., 2018), they would have similar outcomes. In their later report, it was confirmed that both intervention techniques significantly positively impacted the quality of life and coping skills(Lau et al., 2020). It was highlighted that CBT is more effective in reducing emotional vulnerability, and I-BMS is all more strongly linked to an overall improvement of QoL and reduction in depressive symptoms. Xiu et al., (2020) also compared the outcomes of CBT and I-BMS in a dyadic intervention design. The findings were similar to those reported by Lau et al. (2020).

A number of studies also highlighted the importance of strategies that focused on increasing the resilience of the PCs in terms of the physical, emotional, and social burden of caregiving. Røen et al., (2018) examined a resilience-based intervention program to improve QoL in PCs of advanced cancer patients. They included supportive services like social and educational support for improving stress management, problem-solving skills, etc. The findings showed decreased psychological distress, increased coping skills, and improvement in QoL. Another study showed a similar resilience-building intervention program that aimed to support PCs of patients with terminal cancers (Hwang et al., 2018). The family members must maintain their health status, social support, and mental health. In such cases, otherwise, the burden of caregiving can take a heavy toll. Üzar-Özçetin & Dursun, (2020) highlighted the importance of healthcare providers for improving the support provided to PCs for their psychological well-being and the psychological and physical of their patients. In an older study, Rosenberg et al., (2013) also discussed that the patient's and the patient's psychosocial factors and baseline characteristics can change over time. Therefore, coping strategies, social support, provider interactions, etc., can improve with increased resiliencebuilding interventions.

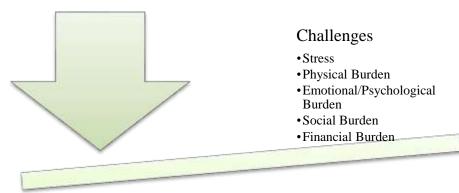
#### Discussion and Recommendations for PCs of Breast Cancer Patients

Breast cancer is one of the most common cancers affecting women worldwide and requires long-term care and treatment. Family members or friends of the patient are often burdened with the patient's caretaking task. Such primary caregivers often face unique challenges impacting their quality of life and coping mechanisms. In the current review, these challenges have been uncovered as unmet needs, physical health, social and financial burdens, emotional

burdens, spiritual and psychological health. Furthermore, the current systematic review identified that educational interventions could enhance the coping strategies and quality of life of the primary caregivers of various cancer patients. While the review was generic regarding types of cancer, the findings can also be generalized toward breast cancer.

An important finding from the review suggests that healthcare professionals should be involved in providing comprehensive training and education to primary caregivers through intervention programs, cognitive behaviour therapy, or resilience-building practices. These strategies can increase the knowledge, skill set, and symptom recognition regarding cancer or its comorbidities risks (Bilgin & Ozdemir, 2022; Çalık, Küçük, & Halimoğlu, 2022; Cheng, Xu, Ng, Duan, & So, 2022). Furthermore, the educational interventions should also be focused on enhancing the understanding of the importance of daily life activities, personal health, physical and mental clarity and health, PCs' self-care strategies, and communication between the patient and caregivers (Jadalla et al., 2020; Kusi et al., 2020; Toledano-Toledano & Luna, 2021). Furthermore, effective educational interventions can also improve the emotions that allow the primary caregivers to strengthen their ability to make better decisions. Services like support groups, counselling services, social support programs, and other such safe spaces as platforms can allow primary caregivers to share their experiences and concerns(Çalık et al., 2022; Jadalla et al., 2020; Üzar-Özçetin & Dursun, 2020; Xiu et al., 2020). Financial burdens also need to be recognized in educational intervention programs, and primary caregivers must be provided with knowledge regarding available financial assistance programs, resources, or practical strategies that they can use to manage the financial impact of caring for a patient that may be developing breast cancer.

Overall, the findings of this review indicate the need for an integrative intervention strategy that involves various types of strategies that have been discussed in the reviewed literature. The PCs of breast cancer patients can take advice based on the framework developed in Figure 9. The framework shows that an increase in intervention strategies can reduce the negative impacts of the challenges faced by PCs.



### Interventions to improve QoL and Coping Skills

- •Disease releated knowledge and skill set development
- •Cognitive Behavior Therapy
- •Resilience Building Practices
- Communication
- Self-care Strategies
- Counseling and Social Support Programs
- •Safe Spaces for Emotional Expression
- Financial Assistance Programs and Resources

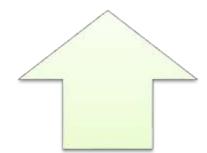


Figure 9: Framework for Increasing QoL and Coping Skills in PCs

#### Conclusion

The researcher used the PRISMA strategy to conduct this review. 31 papers were included after the filtration process. The review's findings highlighted the significance of intervention strategies to increase knowledge and skill in primary caregivers of cancer patients. The study has revealed that most studies have shown similar challenges for PCs and family members of critical cancer patients. Most of these are physical, psychological, social, and financial health and challenges.

Moreover, many studies promoted educational, psychological, and social intervention techniques. Most educational interventions that were promoted and tested indicated the need to promote personal physical and mental health for PCs, prioritise selfcare, and seek assistance if facing social or financial burdens. Overall, the results of this study were summarized to formulate a framework that can be used to enhance QoL and Coping skills in PCs of cancer patients through educational interventions. It is vital to provide PCs with the necessary support and resources to care for their loved ones and maintain their health.

There are several theoretical and policy-related benefits of this study. First, the most significant theoretical perspective is that the study has highlighted the importance of formatting positive adjustment for challenges faced by primary caregivers by using resilience-based coping strategies, educational strategies, and cognitive behavioural therapy-based strategies. The study has

presented theoretical evidence for the importance of educational intervention and its role in improving quality of life.

From a policy perspective, this study has implications for policies that are aimed toward providing social, educational, psychological, and financial support to primary caregivers of cancer patients. Educational interventions can be incorporated within the regular cancer care programs to educate the primary caregivers regarding the skills they might need during caregiving duties and responsibilities. Policies that can alleviate the burden of caregiving in terms of financial, social, and psychological burdens can lead to better care for cancer patients. Furthermore, these policies can also improve the primary caregivers' quality of life.

As with any other study, this study also has some limitations. First, the sample size of this study is limited as it included a small number of studies, 31, that were highly concentrated in the past five years. Secondly, most of the studies included in this review had self-reported measures. Third, all included studies were of different types of methodological origins and designs. Moreover, studies also varied in terms of the type and duration of intervention strategies used. Therefore, in the future, the researchers should increase the sample of literature reviewed, include secondary data-based studies, limit the methodological type that is being reviewed, and focus on a single type of intervention strategy.

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