

IMPROVING CANCER CAREGIVER SUPPORT THROUGH A FOCUSED CAREGIVER
PREPAREDNESS PROGRAM

A Doctor of Nursing Practice Project Report

by

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This Doctor of Nursing Practice Project Report meets the standards for scope and quality of Texas A&M University-Corpus Christi College of Nursing and Health Sciences and is hereby approved.

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DEDICATION

This quality initiative project is dedicated to all cancer caregivers who works tirelessly for their loved ones without any expectation of reward in return. It is also dedicated to all frontline workers around the world, who in the wake of COVID- 19 pandemic work relentlessly to stop the spread of the virus and caring for their patients.

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ABSTRACT

Background: It is estimated that there are four million cancer caregivers (CG) in the United States. A majority (69.1%) of them experience various emotional burdens. Cancer CGs face various unmet emotional and psychological needs and are often expected to manage cancer patient symptoms for which they are largely unprepared. Since they are an integral part in cancer patients' treatment planning and care, it is important to reduce CG emotional burden and improve their self-efficacy. The purpose of this quality initiative is to determine if a structured treatment specific program can reduce emotional burden, improve self-efficacy for patient care demands, and improve CG support group enrollment among CGs of patients receiving brain radiation treatments at CNS-RO clinic at MDACC. Design and methods: CGs were screened and enrolled followed by administration of a pre-intervention assessment of the CG burden and self-efficacy using Zarit Burden Interview and CG Self-Efficacy Scale respectively. During the intervention phase, the project director provided interactive teaching sessions regarding patient symptom management, coping strategies, and CG support group enrollment. After the intervention, each CG received an assessment of CG burden, self-efficacy, and CG group enrollment. Findings: CGs had significant reduction of burden ($p = 0.0004$), improvement of self-efficacy ($p = 0.0152$) and improvement in CG support group enrollment. While the sample size is considered small, the clinical results support using a standardized treatment-specific CG preparedness program to ensure best possible care for both the patient and the cancer CG.

Keywords: Cancer, caregiver, burden, Preparedness, self-efficacy

Improving Cancer Caregiver Support through a Focused Caregiver Preparedness Program

There were more than 15.5 million Americans with a history of cancer in 2016 and about 1.7 million new cancer cases were expected in 2019 (American Cancer Society, 2019). Thirty two percent of cancer caregivers (CGs) provide more than 41 hours per week of care for their loved ones, which is equivalent to time spent on a full-time job (Hunt, Longacre, & Kent, 2016). Informal CGs, the focus of this project, are CGs within the family of a patient, who deliver complex physical, psychological, spiritual, and emotional care for patients (National Cancer Institute, 2017). Per the National Alliance for Caregiving (2015), approximately 43.5 million CGs have provided unpaid care to patients in the United States. The financial burden of the services provided by CGs has increased from \$450 billion in 2009 to \$470 billion in 2013 (National Alliance for Caregiving, 2015). A large majority (69.1%) of these cancer CGs suffer from emotional burden and are expected to perform complex care tasks for their loved ones without any preparation (Feinberg et al., 2011). A structured preparedness program for CGs that focuses on patient symptom management, stress reduction and coping strategies, and encourages support group involvement could increase self-efficacy and reduce CG burden, improving the health of CGs and their ability to provide quality care to the cancer patient.

Improving Cancer Caregiver Support Through a Focused Caregiver Preparedness Program

INTRODUCTION

Background

Cancer patient CGs can be an integral part of a cancer patient's treatment plan and care but are often unprepared for the significant responsibilities they face. Therefore, it is of the utmost importance to ensure they are properly prepared and possess adequate self-efficacy to care for the patient and stay healthy in the process. Cancer CG burden can be defined as the physical, emotional, psychological, social, and financial burden that taking care of terminally ill loved ones imposes on the lives of cancer CGs (Yoon et al., 2014). There are approximately 44 million CGs in the United States among which four million are CGs for cancer patients (Van et al., 2011). Family CGs can be considered the most vital patient care extension group, next in line to health care professionals (HCP). High levels of CG burden can lead to negative effects on CGs' overall health, which can in turn lead to the inability of CGs to deliver quality care for cancer patients (Irwin et al., 2018).

Review of the Literature

Cancer CGs face various unmet emotional and psychological needs and are often expected to manage cancer patient symptoms for which they are largely unprepared. A cross sectional survey conducted by Sklenarova et al. (2015) included 188 CG-patient dyads and found that CGs (mean distress score = 5.47, SD = 2.37) were more distressed than patients (mean distress score = 4.75, SD = 2.35) ($p < .01$), and that almost 43.6% of CGs expressed they had unmet emotional and psychological needs. Another cross-sectional correlational study conducted with 122 patient-CG dyads showed that cancer CGs experienced burden due to lack of social support, and challenges in meeting patients' physical and psychological needs (Chen et al., 2009). A longitudinal study

conducted among 85 CG-patient dyads at an outpatient medical oncology clinic found that CG burden was more among CGs of patients with a high number of symptoms (60%) when compared to those where patients had fewer symptoms (40%) (Palos et al., 2011). Evidence from these research studies shows that there is a gap in practice in meeting cancer CG needs and an urgent necessity to improve self-efficacy and decrease CG burden among cancer CGs. Structured treatment-specific CG preparedness programs addressing assessment and prevention of CG burden have been found to be successful in decreasing CG stress and improving self-efficacy. Sun et al. (2015) conducted a quasi-experimental study providing four educational sessions training 354 CGs conducted on symptom management, supportive care referrals, and personalized self-care plans resulting in a significant reduction of CG burden in the intervention group (mean = 4.20, SD = 2.36) versus the usual care group (mean = 4.61, SD = 2.88, $p=.008$) (Sun et al., 2015). A randomized controlled trial (RCT) evaluated the effects of an enhanced-CG training (CT) protocol in CG self-efficacy in symptom and CG stress management with 138 oncology patient-CG dyads. The study found that CGs randomized to the enhanced-CT protocol group had a significantly higher level of self-efficacy for managing patients' cancer symptoms (mean = 72.0, SD = 17.4) than the control group (mean = 69.0, SD = 18.3) (Hendrix et al., 2016). Another RCT conducted to assess the efficacy of CG educational programs, measured CG burden among 67 CG-patient dyads and found that educational programs for CGs encouraged the involvement of informal CGs in nursing care, symptom management, and meal support which led to a reduction in CG burden. The Zarit Burden Interview (ZBI) score of the experimental group (mean = 16, SD = 9.9) was significantly lower ($p < 0.001$) than that of the control group (mean: 31.4, SD: 14.9) (Belgacem et al., 2013). This evidence supports the implementation of a

structured treatment- specific CG preparedness program to reduce CG burden and improve self-efficacy.

Problem in the Clinical Setting

The setting for this project is the Central Nervous System Radiation Oncology (CNS-RO) outpatient clinic at MDACC. Due to various advancements in cancer treatment, most cancer care takes place in an outpatient setting. This has increased the burden on informal CGs. Cancer CGs are often unprepared to perform various intense and complex care tasks for the patients. As a result, CGs may be faced with various emotional burdens compounded by a lack of self-efficacy to render the best care for patients (Northhouse et al., 2012).

The needs of CGs may be different based on the type of cancer and the type of treatment the patient may be undergoing. Brain radiation involves various crucial clinical elements when it comes to patient symptom management and the timely communication of these symptoms to the medical team. The MD Anderson website offers educational materials for CGs to manage common patient symptoms; however, it lacks disease-specific and treatment-specific information. From discussions with CG support group coordinators, it was evident that the CG support programs were not specific for each department and that these support programs included CGs caring for patients with various cancers all in one group. CGs usually self-referred themselves to support groups if they felt the need for support. Cancer CGs were often unprepared to perform various intense and complex care task necessary for patients undergoing brain radiation treatments.

Purpose and Aims of the Project

The purpose of this QI project was to determine if a structured disease specific program can improve self-efficacy for patient care demands and reduce emotional burden among CGs of patients receiving brain radiation treatments at CNS-RO clinic at MDACC. The clinical practice question guiding this project was: Does a structured, care-specific CG-preparedness support program provided to CGs of cancer patients undergoing brain radiation treatments at MDACC, reduce CG burden, increase self- efficacy and increase the number of CGs enrolling in the support program, as compared to levels prior to intervention?

Specific project aims:

Aim #1: To reduce emotional burden among the cancer CGs and thereby improve their overall wellbeing and improve their ability to care for their loved ones. The emotional burden was evaluated, using the ZBI which has a maximum score of 22 points, indicating a high level of CG burden (Liew & Yap, 2019). The specific goal was to reduce post-intervention mean CG burden score by at least five points by the end of the three-month project.

Aim #2: To improve self-efficacy of CGs in managing patient symptoms and overall care of patient. The specific goal was to improve post- intervention mean self-efficacy score by at least five points from the pre-intervention self-efficacy over the period of three months as measured using the CG self-efficacy scale (CASES)

Aim #3: To improve CG enrollment in MDACC's CG support program. The specific goal was to achieve at least a 10% increase in CG support program enrollment from pre-intervention to post-intervention over a three-month period.

This project focused on DNP Essential I- Scientific Underpinnings of Practice and DNP Essential VIII- Advanced Nursing Practice. DNP essential I focuses on the importance of using nursing science- based concepts to assess and improve health care delivery and patient outcomes (American Association of Colleges of Nursing, 2006). This project exemplified DNP essential I by using an evidence based structured preparedness program to assess and improve CG burden and evaluate the health outcomes of the structured preparedness program for cancer CGs (American Association of Colleges of Nursing, 2006). DNP VIII focuses on advanced practice for improving the delivery of patient care. The project director, as an advanced practitioner used DNP essential VIII and applied the clinical expertise in the care of CGs of cancer patients. This project involved structured treatment-specific teaching sessions for CGs on patient brain radiation symptom management, which is ultimately aimed at improving patient outcomes.

Methods

Conceptual and Theoretical Frameworks

The theoretical framework used in this project was the Partners in Family Caregiving Framework (McCurry & Hunter, 2015). It was developed as a blueprint for HCPs to promote interprofessional collaborative effort in reducing CG burden. This theoretical framework focused on the role of nurses in ongoing education for CGs regarding acute episodic illness, safety concerns, and physical demands of providing care. This framework includes approaches that can improve a family's CG system using interprofessional relationships. The framework also discusses how inter professional communication and ongoing CG education can direct care, counseling, and coordination among healthcare teams. This framework guided the design of the support program which included education and counseling for the CGs, and care coordination between the radiation clinic nurses and the support group social workers (McCurry & Hunter,

2015). Due to changing demands and health statuses of these specialty patients, CGs require ongoing communication and reinforcement with health care professionals. Advanced practice registered nurses (APRNs), registered nurses (RNs) and social workers played a key role in improving health outcomes of these CGs. The role of nurses described in this framework was to ensure an uninterrupted interaction of CGs with HCPs. Achieving a balance in the system, led to optimal care for patients and CGs (McCurry & Hunter, 2015) in this project (See Appendix A).

The conceptual framework used to guide this project was Havelock's Change Theory, which formulated by Ronald G. Havelock as a blueprint to organize change agents and to execute these changes in a work setting (Havelock, 1973) (See Appendix B). The theory involves six steps:

- i. Care: attention to the need for change. The need for improving cancer CG self-efficacy and reducing their emotional burden was identified.
- ii. Relate: build a relationship. A trusting relationship was built with the CG support group leaders to ensure buy-in regarding the need for change and improvement.
- iii. Examine: diagnose the problem. An organizational assessment was conducted to diagnose the problem.
- iv. Acquire: the relevant sources. Various evidence-based studies were analyzed to create a best practice implementation plan.
- v. Try: choose the solution. A structured care-specific treatment- specific CG preparedness program was delivered to the caregivers to reduce CG burden, improve self-efficacy and CG support group enrollment.
- vi. Extend: disseminate, diffuse and gain acceptance. Results are disseminated and discussed with policymakers at MDACC.

- vii. Renew: stabilize and sustain. A YouTube based narrated PowerPoint presentation that the CGs can access any time was provided to increase sustainability of the change.

Ethics Considerations

This project was a QI initiative which used a structured treatment- specific CG preparedness program to reduce emotional burden and to increase self-efficacy among cancer CGs (CGs) of patients receiving radiation treatments at MDACC CNS-RO outpatient clinic. This project was reviewed by the MDACC Quality Improvement Assessment Board (QIAB) and Texas A&M University Corpus Christi's Institutional Review and received a determination of "Not Human Subjects Research" with permission to proceed as a quality improvement project (Please see Appendix D). Personal Health Information was not collected for project purposes. A letter of support was provided by the QIAB project administrator of MDACC and the facility fully supported the implementation of this project (See Appendix C). CG's contact information was collected after participants provided permission to contact for purposes of the project only (See consent from, Appendix E).

Project Design

The QI initiative used a series of educational sessions with CGs and a pre-test, post-test design to improve CG enrollment at MDACC CG support group, reduce emotional burden and to increase self-efficacy among cancer CGs (CGs) of patients receiving brain radiation treatments at MD Anderson Cancer Center (MDACC) CNS-RO outpatient clinic. Upon discussion with the CG support coordinator at MDACC, it was discovered that while rendering CG support programs, it was not customary for the CG support staff to inquire about the type of cancer the patient had or the specifics of the treatments that the CG's loved ones needed.

There were various barriers that could have affected the success of this quality improvement initiative. One of the major barriers faced was that it was not the current culture of the clinic to inquire about CG burden, which led to the lack of CG burden acknowledgement. The nursing staff were educated on the statistics and impacts of CG burden on direct patient care to help mitigate this barrier. They felt acknowledgment of the needs of CG burden was a time-consuming addition to their workload due to their hectic schedule. The staff were educated on how the efforts to reduce CG burden can improve the CG's ability to care for their loved ones. This was beneficial in changing the perspective of the nursing staff by acknowledging CG burden on a daily basis. Another potential barrier was that the same CGs might not accompany their loved ones for all the patient treatment sessions. CGs from out of state who had housing arrangements in town and accompanied their loved ones all the time during their treatments, were targeted for the project sample. The PD placed a phone call to the CG the day before each session and reminded them about the project and the educational session that was to be covered the next day. Time delays and slowing clinic workflow was another barrier in conducting this project. The PD chose participants from a clinic that had a lighter schedule to mitigate this barrier.

Intervention

The CNS- RO clinic staff and the social worker were introduced to the project and the importance of acknowledging CG burden. The social worker who was one of the project team members received scripted education on each of the three treatment- specific teaching sessions so that she could assist the PD during the intervention period. The clinic staff was instructed to provide CGs with the PD's contact information, if the project participants had any questions when the PD was away or not on the clinic premises. A convenience sample was recruited from

all interested CGs attending the clinic with their loved ones and meeting inclusion criteria. Participants were included if: (1) their loved one was undergoing long term fractionated brain radiation (six weeks); (2) they are informal CGs; (3) they are interested in participating; (4) they consent to provide their contact information and be contacted by the project team (5) they have local housing arrangement and they always accompany their loved one's during their radiation treatment sessions. The recruitment process was ongoing throughout the project, since each CG was enrolled in the project for six weeks as their loved ones were getting treatment. The recruitment carried on from weeks 1- 12 (Jan 16- April 15). The PD called eligible CGs, described the project aims and intervention to them and informed them their educational sessions would take place weekly, at the CNS-RO clinic while their loved one received brain radiation treatment. If the CGs were interested in participating, an informed consent to use their contact information for project purposes such as email address and phone numbers were collected. After recruitment, CGs were contacted via phone or email and reminded on a weekly basis, the day before the encounter with the PD, regarding the project and the session to be covered the next day. During the intervention phase, the PD met with CGs at the treatment center waiting area which was a private setting where the PD and the CG could have a one on one conversation and the delivery of treatment- specific teaching sessions. Since the recruitment phase was ongoing, each CG was in different phases of their teaching session. On week one of their loved one's treatment, during the first intervention phase, the PD provided a 10-minute interactive teaching session to the CG using a power point presentation on symptom management of patients receiving brain radiation regarding care for skin and radiation induced skin irritation, nutrition; oral care; watching out for neurological symptoms; care for hair loss and care for fatigue. The PD met with each CG during the second intervention phase (week 2 of loved one's treatment) to

discuss the challenges they faced during their loved one's treatments and provided them with an educational session using a power point presentation regarding coping strategies, relaxation and meditation, communicating with friends and family regarding their challenges and deep breathing exercises. On the third intervention phase (week 3 of their loved one's treatment), the CGs were provided with an educational session regarding the "Care 4 CG" support group and program enrollment. Flyers for the "Care 4 CG" support group program was also provided to the CGs. On week 5 of the loved one's treatment, the CGs were asked to fill out a post- intervention CASES (self-efficacy scale) and ZBI (CG burden scale). The PD had follow-up with the CGs via phone calls and emails inquiring if the CG's had any new concerns or issues and encouraged them to enroll in the CG program. After the intervention phase, the PD contacted the CG support group coordinator to evaluate post intervention improvement in CG support group enrollment during and after a month post intervention (See Appendix F for project timeline).

Project Team. The project team will be comprised of the PD who is a board certified family nurse practitioner (FNP) employed at CNS radiation oncology outpatient clinic at MDACC, will conduct the project, the CG support group coordinator who will provide information on various CG support group activities that the CGs can participate and giving data on pre and post-intervention CG support program enrollment. The project team also involves a social worker who assisting the PD in delivering the CG education sessions.

Data collection. The PD collected the demographic data such as age, gender and race from the CGs and asked the interested participants to complete the printed version of the CASES and ZBI questionnaires pre intervention assessment. On week one through 12 during the recruitment phase, the CG's contact information was obtained after the CG signed an informed consent providing consent to use their contact information for the project. CGs were asked to fill out a

post- test printed version of CASES and ZBI by the PD after the intervention phase. On week twelve, the PD met with the CG support group to evaluate post intervention improvement in CG support group enrollment during and after a month post intervention. Please refer to the timeline in Appendix I for a visual diagram of estimated time required for this project from collection of organization assessment to dissemination of results. Due to COVID-19 pandemic, MDACC had to place restrictions on CGs being able to accompany the patient to treatments, which had an impact on data collection. The post test CASES and ZBI scores were obtained via telephone for the last enrolled CG.

Measurement Tools

The ZBI is a widely used 22 item scale to assess CG burden that describes the CG's feelings towards the care of their loved ones (Zarit, Reever & Bach-Peterson, 1980). It was developed by Steven Zarit to evaluate the level of burden experienced by CGs. The questionnaire uses a CG self-report scale with a maximum score of 22. A high burden score indicates higher level of burden. This tool was used to determine if the structured treatment- specific CG preparedness program reduces the CG perceived level of burden. Hérbert, Bravo, and Prévile (2000) administered the ZBI to 312 CGs and the results showed that the measure had good internal consistency reliability, with a Cronbach's alpha coefficient of .92.

The CG Self-Efficacy Scale (CASES), is a four factor, 21 item questionnaire to evaluate self-efficacy among CGs of patients with advanced cancer (Ugalde, Krishnasamy, & Schofield, 2013). The four factors measured in this tool are resilience, self-maintenance, emotional connectivity, and instrumental caregiving. The test retest reliability and internal consistency ranges from 0.73-0.85 and 0.81-0.94 respectively which is considered an acceptable psychometric for a previously tested scale (.80) (Ugalde, Krishnasamy, & Schofield, 2013).

Analysis/Evaluation Plan

The demographic data of the sample was represented as a descriptive statistic in frequency and displayed in a demographic table. The outcomes measured in this project were: (a) CG burden (using the ZBI), (b) CG self-efficacy (using CASES), and (c) the number of CGs enrolled in CG support program post- intervention. The reduction of CG burden and improvement of self-efficacy of CG's ability to care for the patient were represented as pre and post-intervention paired t-tests and mean scores were depicted in a bar chart. Monthly CG enrollment for 6 months prior to the intervention and during the three months of the program were represented in a bar chart.

Results

Before the intervention of the project, the PD met with the RNs and nursing leadership team at CNS-RO clinic and discussed the clinic culture and the lack of acknowledgement of CG burden. It was found that in the current culture of the clinic it was not customary for staff to inquire about CG burden while they accompany their loved ones during the brain radiation treatments. During the meeting, the nursing leadership team brought up the concern regarding how the project implementation would impact the clinic workflow. Therefore, the project director decided to enroll the CGs of patients that were receiving brain radiation treatments from physicians who had lighter clinic schedules. By doing so, the clinic workflow was not impacted during the intervention. The PD also made sure to enroll CGs from out of town who had lodging arranged in Houston, so that the same CG would be able to attend the sessions throughout their loved one's treatment period. The CG's were introduced to the project and the consent were taken if they were interested in the project and the pre intervention scales were filled out by the CGs.

The PD found that often when CGs left the patient's treatment sessions, they often forgot about the project. The PD made phone calls and reminded the CGs on Mondays regarding the upcoming teaching session and the Care4 CG program that took place every Tuesday. The PD provided three different interactive treatment- specific teaching sessions to the CGs using a power point presentation on symptom management of patients receiving brain radiation, coping strategies, and CG support program. The PD also provided flyers of Care4 CG program to the population.

While introducing the project to the CGs, the PD found that CG were uneasy while filling out the ZBI in front of the patient as they did not want the patient to find out about burdens they face. Therefore, the PD decided to conduct the data collection and intervention for the CGs at the waiting area of the radiation treatment center, while their loved ones receives radiation treatments. There were 13 CGs who were enrolled in the project, however one of the patients receiving radiation treatment had deteriorated and had transitioned to hospice care and the CG of that patient was dropped from the project. In the wake of COVID-19 pandemic, MDACC had to place restrictions on CGs being able to accompany the patient to treatments, which had an impact on enrollment to the project. Therefore, the PD had to reduce the number of participants from 20 to 12. In the wake of the COVID-19 pandemic, the PD placed telephone calls with CG support program team to evaluate the progress of Care4 CG support group enrollment.

The PD had regular discussions with the CG support group coordinator in regard to following up with project participants to CG support program enrollment. It was brought to the attention of the PD that, in the wake of COVID-19, CG support programs were suspended in the month of March. By April, 13, 2020 the CG support program was restarted and was offered as a

daily Web Ex meeting for the CGs. The PD spoke to the project participants via phone calls regarding the Web EX support program and encouraged them to enroll in it. The PD called the participants to assess the number participants who enrolled in the Web ex support group meeting were obtained. (See Appendix G). The number of CGs from the CNS- RO clinic enrolled in Care 4 CG support group at MDACC, prior to the intervention was not available as, it was not customary for the support group coordinators to enquire about the specific treatment their loved ones received.

The mean age of the CGs enrolled in the program was 54.8 years (range = 38-68) among which 61.5% were female and 38.5% were male. Among the participants, the majority were Caucasians (69.2%).

Table 1 contains the demographic data of the participants.

Table 1

Demographic characteristics of study population

Demographics		
Age, Mean (SD) Range	54.08 (10.6)	38 - 68
Gender	Number	%
Female	8	61.5
Male	5	38.5
Race	Number	%
African American	1	7.7
Asian	1	7.7
Caucasian	9	69.2
Hispanic	2	15.4

Aim #1: The result depicts that after the structured teaching program there was a significant decrease in the CG burden. The mean pre- intervention ZBI scores was 9.42 (95% CI: 5.53 – 13.30) and post intervention ZBI was 3.58 (95: CI 1.93 – 5.24), which was a 5.84 point reduction in the CG burden score. There was a significant decrease in the pre- intervention vs post-

intervention ZBI scores ($p < .001$) (See Appendix H for the bar chart on the ZBI pre and post intervention scale. Table 2. indicates the paired t test for the ZBI pre and post intervention scales.

Table 2

Paired t test (. ttest ZBI Pre = ZBI Post)

Variable	Number of CGs	Mean	Std.Err	Std.Dev	95% Conf. Interval
ZBI Pre	12	9.416667	1.76371	6.11196	5.533312 13.30002
ZBI post	12	3.58333	.7533595	2.609714	1.9252 5.241466
Diff	12	5.8333	1.166667	4.041452	3.265517 8.401149

Mean (diff) = mean (ZBI Pre – ZBI Post) $t = 5.0000$

Aim#2: The result shows that after the interactive teaching program, there was a slight improvement in the CG self-efficacy. The mean PRE CASES scores was 19.92 (95% CI: 19.1 – 20.7) and POST CASES was 20.92 (95: CI 20.73 – 21.10). There was a slight, but statistically significant improvement in scores ($p = 0.0152$). (Please see Appendix G for the bar chart on the CASES pre and post). Table 3. represents paired t test for the CASES pre and post intervention scales.

Table 3

Paired t test (. t test CASES Pre = CASES Post)

Variables	Number of	Mean	Std. Err	Std. Dev	[95% Conf. Interval]	
CGs						
CASES pre	12	19.91667	.3579896	1.240112	19.12874	20.7046
CASES post	12	20.91667	.0833333	.2886751	20.73325	21.10008
Diff	12	-1	.3481553	1.206045	-1.766285	-.2337153

Mean (diff) = mean (CASES Pre – CASES Post) t = -2.8723

Aim #3: There were an average of 7 CGs who were enrolled in the CG support program at MDACC from October, 2019 to April, 2020 assuming that there were no CGs enrolled from the CNS- RO clinic. After the treatment- specific teaching sessions, there were 8 participants who were enrolled in the Care 4 CG support group. This shows that there was a significant improvement of CG enrollment in the support group after the interactive teaching sessions. (See Appendix H for a bar chart representation of the CG enrollment).

Discussion

In terms of clinical outcomes, the treatment specific structured teaching preparedness program had brought forth a statistically significant reduction in CG burden and improvement in CG self-efficacy in caring for their loved ones. The teaching session regarding CG support group

enrollment had resulted in a clinically significant improvement in CG support group enrollment from the CNS-RO clinic.

Relation to Other Evidence

The results of this QI project were consistent with several similar studies and projects. A RCT conducted to evaluate the effect of a supportive educational program on the caring burden and quality of life in the family caregivers of women with breast cancer showed that a supportive educational program can improve physical, mental, spiritual, environmental domains of the CGs there by reducing their caring burden. In the experimental group, the mean score of caring burden among the experimental group CG (mean: 29.5, SD: 8.40) was significantly decreased ($p = 0.859$) compared to the control group (mean: 31.37, SD: 11.18) (Bahrami & Farzi, 2014). A comprehensive systematic review of interventions for cancer caregivers conducted via an electronic literature search of publications between 1980 and January 13, 2011 showed that structured, goal-oriented, and time-limited interventions that are integrative appear to be the most feasible and offer the greatest benefits for CGs of cancer patients (Applebaum & Breitbart, 2013). A longitudinal study conducted on 81 cancer CGs to evaluate the ability of an integrative intervention program for caregivers of advanced cancer patients showed that Caregiver self-efficacy significantly increased and the subjective caregiving burden significantly decreased in the experimental group. The results showed significant decrease in caregiver burden scores ($B = -18.71, p < 0.001, \eta^2 = 0.49$) and improvement in self-efficiency scores ($B = 273.92, p < 0.001$).

Limitations

One of the major limitations in this project is the small sample size, largely due to the unprecedented pandemic which led to the reduction of the sample size and making changes to the support program enrollment. Another limitation was that the Care 4 CG Support Program was cancelled throughout the month of March due to the COVID-19 pandemic. As a result of the pandemic restrictions and the fact that CG support program was converted to a web-based program, there were some unforeseen results due to confounding variables. On the grounds that there were no CG support program specific for CNS- RO clinic, and that number of CG support program enrollment pre- intervention obtained was from throughout MDACC, the result might be skewed due to a confounding variables.

Interpretation

The intervention of this QI project was guided by The Partners in Family Caregiving theoretical framework. This framework enabled the PD to evaluate the improvement of a CG support at the facility using inter professional relationships. This project involved inter professional coordination between the PD and the support group coordinator. This project is also guided by the conceptual framework, Havelock's change theory. The implementation of the structured treatment-specific CG preparedness program can be correlated to choosing the solution step of this framework. During the recruitment and intervention phase, there were many unusual challenges faced due to the pandemic during the intervention phase, which resulted in reduction of the sample size. An implementation of a QI project that focuses on radiation treatment specific- CG support program can produce results in the next PDSA cycle to come closer to proposed goals.

For the outcomes of this project to be sustainable, this treatment specific CG preparedness training program would need to be standardized at this CNS radiation clinic. The results of this project will be shared with the nurses and the leadership staff and the next phase of the project will be planned and implemented with their input.,. A YouTube based narrated power point video regarding CG preparedness for CGs of patients receiving fractionated brain radiation is a long- term sustainability option. This video would be accessed by CGs at their own leisure. The results will also be shared with the CG support program coordinator, nurse manager and other leadership teams thereby these stakeholders will be able to recognize the potential improvement in CG support program in MDACC as well as the benefits of commencing treatment- specific CG support programs due to increase in CG support group enrollment.

Conclusion

The results of this project, confers legitimacy in regards to how HCPs in cancer care facilities enquiring CGs about their burdens can affect their ability in rendering best care practices for the patient. In the future, HCPs expanding their role in supporting cancer CGs by providing them appropriate support program resources can have great advantage in reducing cancer CG burdens. Educating CGs regarding various symptom management during cancer treatment is an important factor in rendering best care for the patient. It must be considered as important as educating patients regarding symptom management. Stakeholders promoting hospital policy changes to better meet the unmet needs of CGs work in favor for the care for CGs. CGs also can be provided with information on resources like CG support groups that can be used to improve their physical and psychosocial wellbeing. Future QI projects and research on CG support programs can be built on the basis of this QI project and improve the care for cancer CGs and their loved ones.

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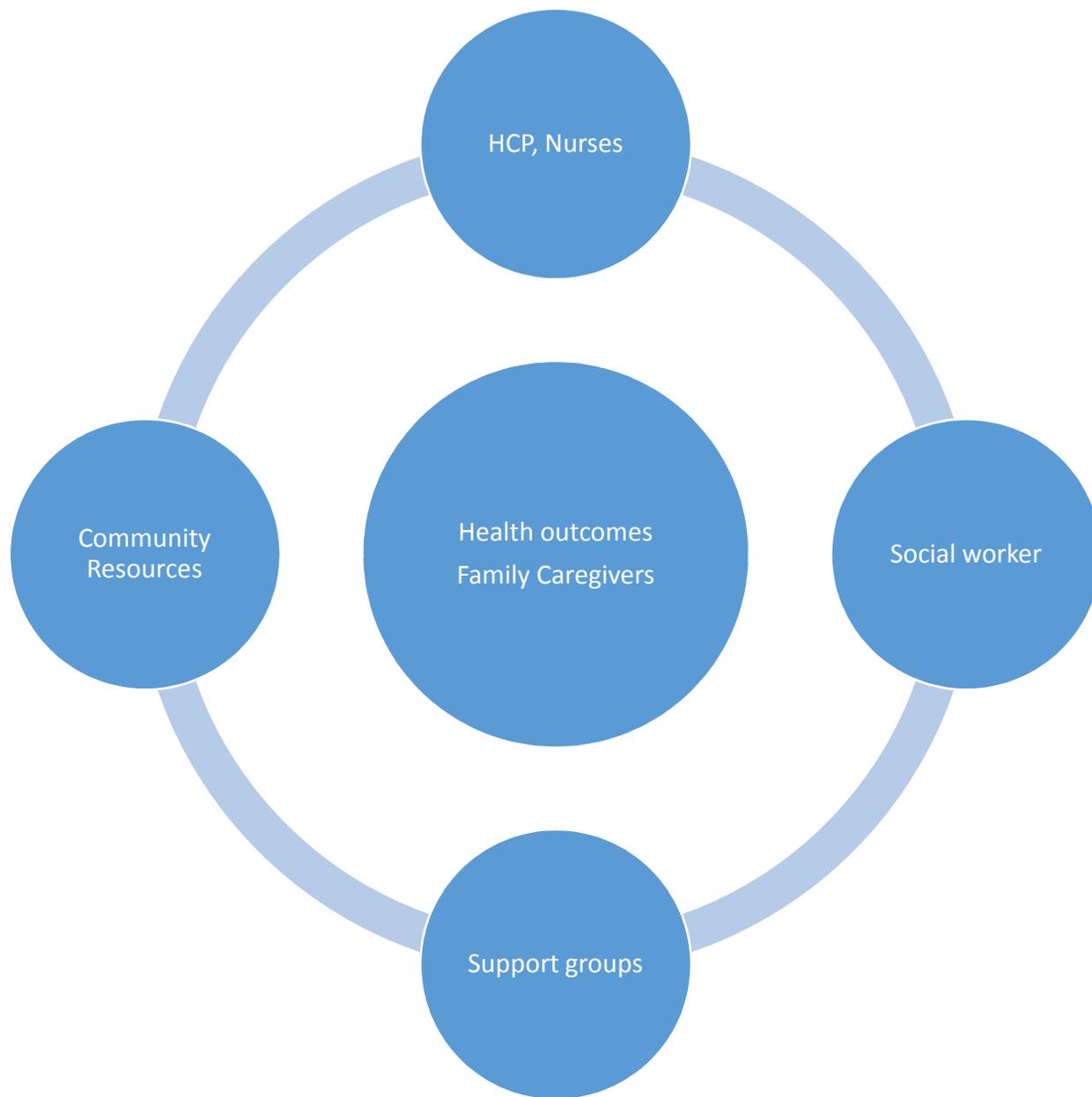
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APPENDIX A: Theoretical Framework- Partners in Family Caregiving Framework



APPENDIX B: Conceptual Framework- Havelock's Change Theory



APPENDIX C: MDACC Facility support letter



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11/6/19

Dr. Sara Baldwin

Associate Dean for Academic Programs

College of Nursing and Health Sciences

Texas A&M University – Corpus Christi

6300 Ocean Drive

Corpus Christi, TX 78412

Dear Dr. Baldwin,

The purpose of this letter is to provide Jincy George, a Doctor of Nursing Practice student at Texas A&M University College of Nursing and Health Sciences, support in conducting a quality improvement project at MD Anderson Cancer Center (MDACC). The project, reducing emotional burden and increasing self-efficacy for cancer CGs through implementation of a CG preparedness program, entails utilizing a structured CG preparedness program to reduce CG burden and improve their self-efficacy among CGs of patients receiving brain radiation treatments, and to improve CG support group enrollment.

The purpose of this project is to determine if a structured CG preparedness program can improve self-efficacy preparedness, reduce emotional burden, and improve enrollment in CG support group among the CGs of patients receiving brain radiation treatments at brain radiation outpatient clinic at MDACC. MDACC was selected for this

CARING INTEGRITY DISCOVERY

project because it is the #1 cancer center and it offers various cancer CG support programs, and she would be able to utilize ample amount of resources here for her project. Jincy George is employed at this institution, and has an interest in improving care at this facility.

I, Alissa Nguyen, Advanced Practice Provider Supervisory at MDACC, do hereby fully support Jincy George in the conduct of this quality improvement project, at reducing emotional burden and increasing self-efficacy for cancer CGs through implementation of a CG preparedness program at MDACC.

I also approve Jincy George to access contact information of Caregivers for purposes of conducting this quality improvement project.

Sincerely,

Handwritten signature of Alissa Nguyen in blue ink, with the text "AGNP-C" written below the signature.

Alissa Nguyen, MSN, APRN, AGNP-C

M.D. Anderson Cancer Center
Department of Radiation Oncology APP Supervisor
Clinic: 713-745-8000
Fax: 713-792-5245

APPENDIX D: TAMUCC IRB letter



OFFICE OF RESEARCH COMPLIANCE
Division of Research and Innovation
500 Ocean Drive, Unit 944
Corpus Christi, Texas 78401
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Human Subjects Protection Program Institutional Review Board

DATE: December 12, 2019
TO: Sara Baldwin, College of Nursing and Health Sciences
CC: Jincy George, Student
FROM: Office of Research Compliance
SUBJECT: Not Human Subjects Determination

Activities meeting the DHHS definition of research or the FDA definition of clinical investigation and involves human subjects are subject to IRB review and approval.

On December 12, 2019, the Texas A&M University-Corpus Christi Institutional Review Board reviewed the following submission:

Type of Review:	Not Human Subjects Determination
Title:	Improving Cancer Caregiver Support through a Focused Caregiver Preparedness Program
Project Lead:	Sara Baldwin
IRB ID:	NHS 62-19
Funding Source:	None
Documents Reviewed:	10.29.19 Jincy George Decision Letter 600.02 Template, Quality Improvement Project- final 12.3 Not Human Subjects Research Request- JG final

Texas A&M University-Corpus Christi Office of Research Compliance determined that the proposed activity does not meet the DHHS definition of research or the FDA definition of a clinical investigation.

Therefore, this project does not require IRB approval. You may proceed with this project.

This determination applies only to the activities described in the documents reviewed. Any planned changes require submission to the IRB to ensure that the research continues to meet criteria for a non-human subject research determination.

Please do not hesitate to contact me with any questions at irb@tamucc.edu or 361-825-2497.

Respectfully,

Matthew R. Digitally signed by Matthew R. Gaynor, III.
Date: 2019.12.12
15:42:06 -0500
Gaynor, J.D.

Office of Research Compliance

APPENDIX E: HIPPA Consent to Share Contact Information

HIPPA Consent to Share Contact Information with Project Team

I agree to permit the project team to obtain my contact information (name, telephone number, best time to call) so that a member of the project team can contact me. Information about me will be kept as confidential as possible, and it will be shared only once, with this project team. No additional information about me will be shared.

I therefore agree to allow you to share my information with the project team.

Name: _____

Signature: _____

Date/Time:

Phone: _____

Best time to call: _____

APPENDIX F: Project Timeline

Tasks on each week of loved one's treatment	
Jan 16- April 15	
Week 1	Recruitment: Informed consent, Pre intervention ZBI, cases
Week 2	Phase 1: treatment-specific symptom management.
Week 3	Phase 2: CG stress reduction and coping strategies.
Week 4	Phase 3: support group for the cancer CGs.
Week 5	Post self-efficacy and ZBI.
Week 6	Post intervention CG support group enrollment

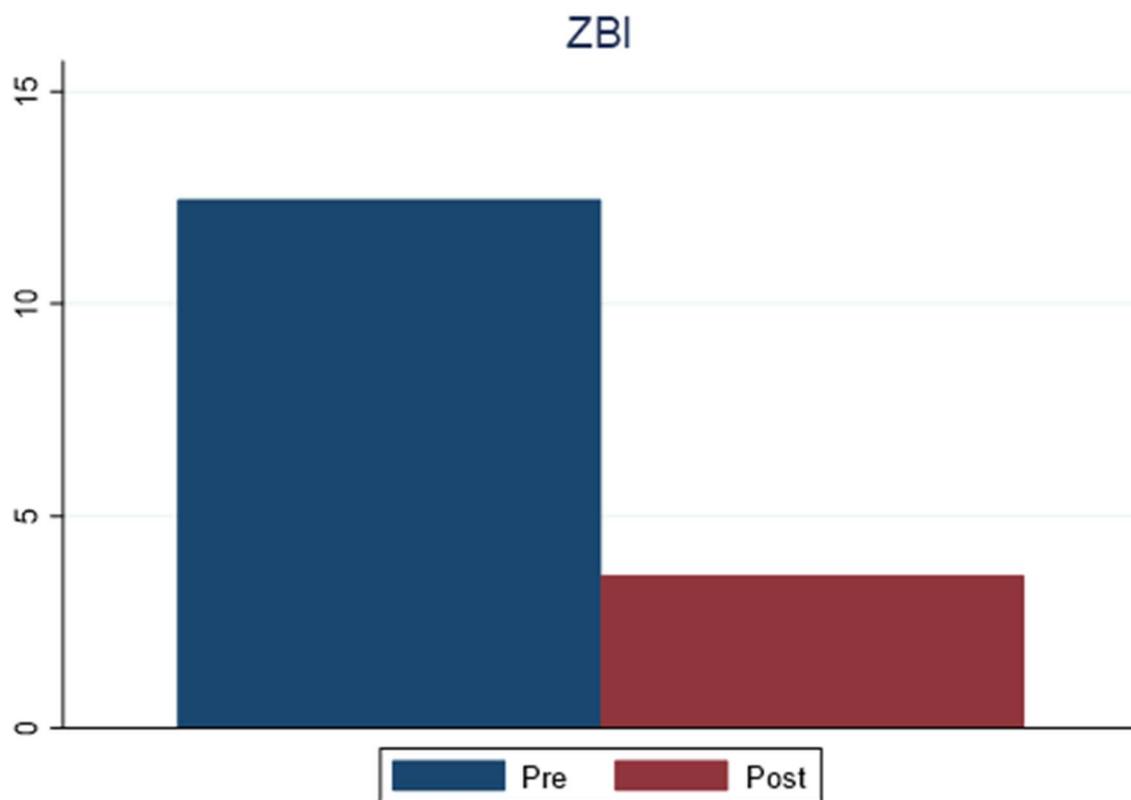
APPENDIX G: Implementation of Changes

Phase	Original Plan	Issue encountered	Revised Plan	Completion date
Data collection	No: of CG-20 t be enrolled in the project	Due to COVID-19 pandemic, there were restrictions placed on CGs not being able to accompany patients to the clinic	Reduced the sample size to 13	4/15/2020
	No: of CGs initially enrolled- 13	1 patient deteriorated, transferred to Hospice care	Total No: of participants at the end of the study= 12	4/15/2020
	Venue of data collection: at the clinic	CGs did not want their loves one to know about their distress and burden in caring	Data collection to be done at the waiting area of the radiation treatment	4/15/2020

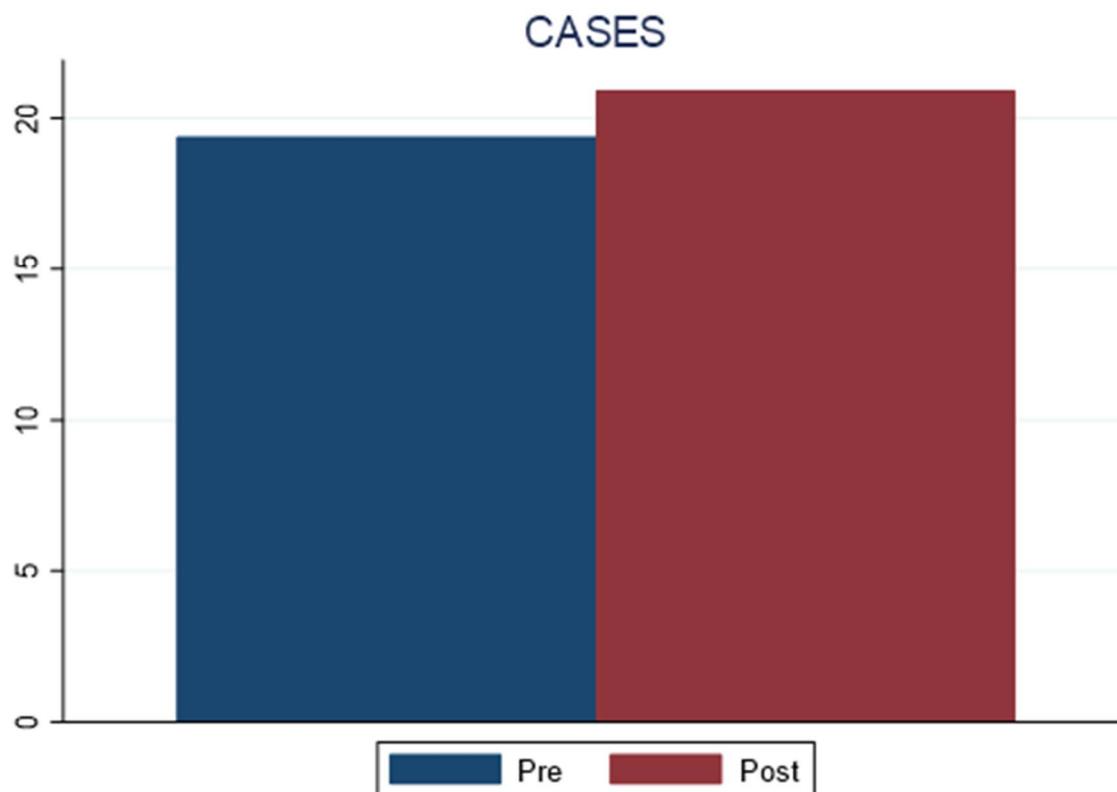
		for their loved ones.	center, while their loved ones receives treatment	
Intervention Phase 1	Face to face interactive teaching session on symptom management	With COVID 19 restrictions on CGs weren't allowed to accompany patients	With COVID 19 restrictions on CGs the teaching session for the last enrolled CGs was over telephone	4/20/2020
Intervention Phase 2	Face to face interactive teaching session on coping strategies	With COVID 19 restrictions on CGs weren't allowed to accompany patients	With COVID 19 restrictions on CGs, the teaching session for the last enrolled CGs	4/17/2020

			was over telephone	
Intervention phase 3	Tracking CG support group enrollment after the interactive teaching sessions.	Due to the pandemic, the CG support programs were suspended for the month of March and was restarted in April, as a daily Web Ex meeting for the CG.	PD called the CGs who were yet to enroll in the support program, encouraged to enroll in the Web based support program.	4/20/2020

APPENDIX H: Bar Chart Representation of the ZBI Pre and Post Intervention Scores



APPENDIX I: Bar Chart Representation of the CASES Pre and Post Intervention Scores



APPENDIX J: CG Support Program Enrollment

