Overview And Evaluation Of The Family Caregivers Of Oncology Project: Improving Quality Of Life And Quality Of Care

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1. Introduction

First, I introduce the Family Caregivers of Oncology Project (FCOP). After player's health benefits and a business case for investment in extra care network syndication is made, the continuing publication then evaluates FCOP.

Yet optimal supportive care for family caregivers of people living with cancer is not available. In order to address this key care network support gap in concert with today's Post-Traumatic "We Are Evers" and the American exceptional cancer center and the world's first Global Medical System in 2022, the Family Caregivers of Oncology Project (FCOP) emerged in 2020. In order to initiate proactive collaborations with IU-based and external partners, philanthropic foundation leaders, and an emerging formal consortium, the ongoing purpose of FCOP is to encourage the creation of real-world clinical session study-fueled innovations.

Upon diagnosis, the oncology diagnosis will be shared with approximately 1,806,590 people in 2020 by healthcare professionals, the majority of whom are likely to have access to an acutely dedicated family caregiver. A longer period of free survival is available to an increasing number of individuals. Paired with an increasing population of older adults, the incidence and preponderance of cancer are causing most adult Americans to be

affected by one or more forms of cancer in the disabled role of a family enabler.

Across all varieties of illness, including more than 1000 scientific articles published in just the last decade, the role of family caregivers for 18 million oncology patients has been discovered and reproduced. The point of this review was to provide an overview and evaluation of the Family Caregivers of Oncology (FCOP) project while acknowledging the important work and leadership efforts of previous people in that role. The structure follows guidelines for comprehensive qualitative systematic reviews, or scoping reviews, when data are spread across different methods and a research assessment is required to confirm consistency of findings.

Between 15 and 59 million people in the United States are providing daily living and health-related supports for family members or friends. These family caregivers often lack ongoing support and may be unable to rest because of demanding schedules. Research on family caregiving in health contexts has demonstrated that when family caregivers are better supported and informed, their loved ones exhibit clinical benefits and better quality of life.

1.1. Background and Rationale

Rationale: Family caregivers of people with cancer face a multitude of challenges. Involving family caregivers in care can improve the care that is given, can reduce the likelihood of errors and duplicate care, and can make it easier for individuals with cancer to transition between care settings. Family caregivers also report negative effects on their mental health, physical health, and financial stability. They often receive little to no formal support or training from providers. One review found there is limited evidence to support interventions aimed at improving family caregivers' mental health. The purpose of this updated review is to provide data on the implementation of a group psycho-education intervention for family caregivers.

Background: In the US, it is estimated that 5.8 to 21.4 million people are caring for someone with cancer. The results of studies with caregivers of people with cancer have been contradictory, but most have shown that morbidity and health service use are greater in family caregivers with distress. The peri-diagnosis period in

oncology is marked by high levels of psychological distress and poorer quality of life. Despite the scientific evidence, few interventions involving family caregivers have been conducted in oncology. In fact, many studies exclude family caregivers from the start.

1.2. Scope and Significance

This article is an overview of the entire evaluation and, as such, it groups articles into different categories based on whether recommendations were directed to a broader community or specific sector working in cancer caregiving and offers a summary overview of either the evaluation methodology, recommendations, or next steps. All individuals involved with a cancer diagnosis must navigate an extremely challenging lived experience; in unique and specific ways, so too must their family members, their informal caregivers. Family caregivers manage the physical, emotional, and spiritual needs of both the patient and other related family members while facing increasing pressures on the health and social care systems to facilitate timely discharge from the hospital system, often without the needed supports and services available within the community.

The goal of the Family Caregivers of Oncology Project is to provide an overarching synthesis of the most important information and experiences gained and the lessons learned over the past 10 years. To that end, we draw on existing resources from previous phases of the project, particularly the companion guides "Improving Support for Family Caregivers of People Who Are Receiving Treatment" and "Living with Advanced Cancer and Family Caregivers". In addition, we also conducted this synthesis to assist with a national caregiving organization in producing an evidence-based, empowering, and supportive portrayal of the work undertaken in the Family Caregivers of Oncology arena specifically between 2008 and 2015. This overview is designed both for those already familiar with our work in this area and for the many new stakeholder communities we seek to engage. (Alam et al., 2020)

2. Literature Review

The findings from the review focus on four areas: 1) family caregivers in oncology; 2) quality of life and oncology; 3) quality of care and oncology; and 4) evaluations of interventions for family caregivers in oncology. In the ninth section on interventions, the importance of addressing caregiver stress, information and

symptom management, and seen benefits for both patient and caregiver is highlighted. The tenth section includes both a model of what should happen for family caregivers in oncology and the summary of main findings from this report. It identifies unmet needs and proposes approaches for care. In the eleventh and final section, we discuss some implications for clinical practice and for future research. Key ingredients of successful interventions include an understanding of caregivers' burden and of their unmet needs. It can clinical management of caregiving tasks. Both the patient and the caregiver can benefit from caregiver interventions, we found. We need to address caregivers' perceptions of care adequacy for the intervention to be effective. Future research should focus on randomized controlled trials of the specific elements of successful caregiver programs, rather than on descriptive studies. Randomized studies are needed, especially to evaluate how best to assess the impact of support and in order to demonstrate the cost-effectiveness of caregiver interventions.

Family caregivers in oncology, assisting their loved ones through what can be an intense and sometimes long journey, also bring their own expectations and perceptions. In family caregiving research, it is known that caregivers provide both physical and psychological support for patients. It is important to recognize caregivers' efforts and enlist their support to assist with patient care. In this paper, we summarize the academic literature on family caregivers in the oncology setting. We first detail the selection of articles and review the findings on the dual concern of family caregivers: improving the patient's quality of life and coping and managing everyday life. Many family caregivers also experience quality of life issues. The Executive Summary provides a brief overview of each of the review sections. The following is a brief transcation and summary of the contents of the review findings sections. (Molassiotis & Wang, 2022)

2.1. Family Caregivers in Oncology

Family caregivers have been identified as the largest "workforce" in cancer care, and research has identified that there is burden and strain and financial impact associated with caregiving. Caregiving can also create physical effects if left unaddressed. The National Cancer Institute (NCI) and the American Cancer Society (ACS) and others have long recognized this dyadic state that both the person with cancer and the caregivers experience. In response, the NCI

presents an overview of cancer caregiving and connects viewers to the National Caregivers Library, which contains a "Guide for Caregivers" as well as NCI and ACS resources. The NCI website supports caregivers by informing them of cancer types and treatments.

The Institute of Medicine, in its seminal report on cancer care, highlighted the importance of support for "cancer caregivers" - a group that encompasses family members. It also referred to the need for "interventions to better prepare informal caregivers in terms of the rigors they will face in assisting cancer patients, which would improve cancer patients' progression to survivorship as well as their quality of life." The authors described family caregivers as "the single main source of long-term care for individuals who have cancer and other illnesses" and emphasized the "vital interface between the patient, healthcare professionals, and the patient's community" - pointing to both the helper role and the "caring about", or affection, expressed by the family caregiver. Research has shown that caregiving for people with late-stage cancer is associated with poorer mental health, including anxiety and depression. A scoping review of 155 articles to develop a conceptual model for the trajectory of palliative care and results of the de novo meta-ethnography found that caregivers express resiliency and personal growth concomitant with negative effects and may feel more competent in providing caregiving tasks.

2.2. Quality of Life and Quality of Care in Oncology

The received quality of care is often operationalized as evidence-based, effective, safe, timely, patient-/family-centered, and efficient health care. These quality of care components constitute "core domains of health care across diseases with an overlap with the dimensions of QOL." Indeed, many argue that QOL and quality of care are related and that quality of care is a determinant of QOL. Indeed, in 1993, Ferrell conceptualized QOL and quality of care on two axes. Recent research on QOL and care in oncology focuses not only on the determinants of quality of life and quality of care on patients living with cancer but also seeks to understand individuals' subjective experiences and perceptions. Research findings suggest that "quality of care is a strategic outcome that can affect the quality of life of both the patient and his family." Healthcare providers often underestimate and undervalue family caregiver physical, mental, and social consequences of caregiving.

While caring for one living with cancer can be seen as a social role, it also can become a full-time job, placing caregivers at increased risk for caregiver burden.

Quality of life (QOL) is a multidimensional concept encompassing physical, psychological, social, and spiritual well-being. Daly defines QOL as "the functional effect of an acute or chronic illness on a patient, physically, psychologically, and socially from the point of view of the patient." People living with cancer—whether patient or family caregiver—describe a good QOL as one that allows them to experience comfort and meaning as they face personal challenges.

3. Methodology

The purpose of semi-structured interviews with caregiver participants was to understand their perceptions of the Quality of Life intervention program components (e.g., PA, nutrition, policy, caregiver support and others) and the potential impact those components have had on caregiver quality of life, job satisfaction, and their ability to provide care to the oncology patient at home. Interviews consisted of a combination of yes/no, multiple choice, and open-ended questions. It was anticipated by the program evaluators that the data from caregiver interviews, the qualitative data from project education staff, and aggregate program records may have been useful in understanding how the caregiver component of the program contributed to sustaining, modifying, or improving the oncology patient's quality of life.

To conduct the project evaluation, we utilized a mixed-method research design including two components: (1) individual semi-structured interviews with participating caregivers (n=30) and project staff (n=3), and (2) a secondary analysis of project administrative, survey and clinical data. Caregiver participants were recruited by project staff through personal requests and public postings throughout a large Midwestern community-based health care system. Participants were a part of the 12-week groups, the 8-week Mind & Muscle Warriors Overview program, and a Maintenance group. Participants received weekly Fitbits at weekly meetings to use throughout the program and were to continue using for as long as desired post-program. Participants and the PA were asked to wear the FitBit during the entirety of the program and continue for 12 total weeks.

3.1. Study Design

This study was conceptualized as being part of the introductory or process evaluation phase (e.g., what was implemented, how, and with what objectives and assumptions), but given the richness of the data we generated about FCOP activities from an implementation, outcome, and needs assessment perspective, it was determined to analyze and present the data from that more comprehensive perspective. A hermeneutic-narrative conceptual framework guided our approach to data collection and analysis. Aimed at "systems development and change," the hermeneutic-narrative approach is designed as a research method that transforms "stories into knowledge." We recognize, in particular, the need for when working with family caregivers to recognize what Patricia Williams calls "shadow text" - "the process through which privileges are maintained and perpetuated in domains in which the practices enjoined by elite paradigms operate as de facto, hence invisible, constraints." The hermeneutic-narrative approach made explicit the instrumental (agenda-driven) and communicative action (awareness-building) components of the FCOP, represented real-time "idea of the organization" when collaborating with FCOP in the provision of training and KT to family caregivers, and resulted in provisional guidance based on these needs.

To better understand the processes, structure, and outcomes of the FCOP, we developed a qualitative/quantitative evaluation strategy that included an extensive literature review and review of documentation pertaining to the FCOP as central components (see below for more detail). This evaluation of the FCOP was undertaken in collaboration with the steering committee. We developed an evaluative framework or a 'programme theory' of the FCOP based on literature and documentation. The general aim of this framework was to understand the FCOP, identify what it expected and intended to accomplish, what patients and family caregivers expected and experienced as outcomes, and understand the factors that supported or hindered programme outcomes.

3.1. Study Design

In this section, we detail the study design, including the conceptual framework developed to guide data collection and analysis, and the methods used to approach the data. The study design involved

an evaluation of the Family Caregivers of Oncology Project (FCOP) using mixed research methods that generate qualitative and quantitative data.

3. Study Design

Overview and Assessment of the Family Caregivers of Oncology Project: Improving Quality of Life and Quality of Care

3.2. Participant Recruitment and Selection

Participant recruitment and selection were a priority. All adults presenting and listed on the clinical team's patient log as having suspected or confirmed diagnoses of one of 15 cancers were carefully approached and provided information on the study, offered the opportunity to ask questions, and were screened for appropriateness with help from nursing staff. Adults were then reviewed by their clinical team. A majority of approached persons entered the study – one refused, and if dyads were willing to allow contact with a son or daughter age 18+ serving in a primary family caregiver role. Use of question guides and techniques helped to ensure that interviews were similarly conducted and stimulated a dialog. A semi-structured interview included open-ended questions from both the patient and primary family caregiver perspectives. Many techniques were used to establish comfort, etiquette, and rapport. Examples include greeting, offering a seat, explaining the purpose of the interview, and acknowledging interest in the participant's thoughts and options. Respect and sensitivity were important, especially among family caregiver participants because while patient needs were the focus of the attached larger study, we were also aware of the important needs of family patients. Evidence-based methods were used to ascertain and assess comfort and pain level. Participants were asked if they would prefer to choose another setting if the room did not promote an open exchange of information. Tables 1, 2, and 3 provide an in-depth view of data outcomes from participants.

Descriptive research studies conducted by Engels and colleagues between 2002 and 2017, and by Wagner and Winger using data collected from 2011-2012, qualitatively explored the needs of FCGs. One study investigated the cancer nurse and FCG as a dyad and used question guides in semi-structured sessions. Wagner and Winger employed quantitative analyses to examine relationships among quality of life (QoL), psychological well-being, stress, and

coping by soliciting a large sample of English-speaking FCGs. They used entry criteria including being 18 years or older and starting or extending services provided to persons already diagnosed with cancer. They distributed questionnaires at specialized ambulatory cancer care facilities and advertised through newspapers and radio for cancer patients and FCGs not serving as dyads with participating patients. Distribution of surveys to complete took place in person at the cancer clinic or by mail. In this study, researchers targeted a representative community sample within which to work. The mean age of adults diagnosed with cancer has increased, symptoms at diagnosis have decreased, and family caregiver associates to maximize significance were not available. Thus, we worked to develop a representative group of subjects who were nominated through clinical teams as appropriate adults to serve in the caregiver role during cancer care. Longbow, three, was the most common number of adults in the natural support system. We targeted the son or daughter because the mean age of cancer patients is 66 years and persons in that age group are the most likely to have sons or daughters available to involve as a family of origin primary caregiver in direct self-care tasks. The mean age of the caregiver participants was 55.5 years (s.d. 10.13), and male children were about equally represented in the predominantly female sample. In the Wagner study, 75% of the sample was female.

3.3. Data Collection Methods

In-depth interviews were chosen as the research tool because data from co-investigators across Canada showed that from clinical settings and non-governmental organizations, it was clear that there was little depth in what we knew about primary caregivers and their unique perceptions, challenges, concerns, and the systems that touched them. While numbers alone do not ensure adequacy and rigor, by conducting in-depth interviews with 89 primary caregivers, the investigators had the information to achieve their first and second goals. They would be able to demonstrate depth and give voice to a previously silent group. Further, the in-depth interview process as a modality for probing and querying would, as the data gathering progressed, allow further depth to be achieved in areas specified and as generated by the participants themselves.

The data collection tools and techniques selected for the Family Caregivers of Oncology Project were carefully chosen in order to achieve the purposes of the study. At the heart of the purposes of this study was the desire to give primary caregivers a "voice" and to be assured that the information being gained took into account their actual experiences and perceptions. This could not be adequately reduced to interviews nor to surveys nor to family group discussions. The critical information in this study was data that was primarily contextually and experientially based. In the Ethics Protocol for FOCUS, documentation outlining the information procedures indicated that the only way to get at this kind of information was through a face-to-face, in-depth, phenomenological interview with primary caregivers in their own homes. This process produced deeper knowledge and understanding from the data.

In a few paragraphs describe the specific tools and techniques used to collect the data for the study.

Choose one of the following statements and discuss it in relation to the data collection for this study.

3.4. Data Analysis

The analytical strategy includes both within-case and between-case analysis. Each interview will be read in its entirety before initiating detailed readings. Information relevant to the objectives, setting, key personnel involved, and evidence of context will be highlighted. Memoing will occur after the individual interview, capturing initial observations of the interview. Each transcript will be read by several members of the research team to increase intra-rater reliability. A matrix will be established to display program/project details (objectives, setting, key personnel, adaptations) across cases. The within-case content analysis will occur simultaneously. Independently, members of the research team will develop preliminary approaches to coding the data. After further discussions with the team, a coding framework will be developed, and data will be coded accordingly. The data analysis will involve continued review of data for emerging themes and additional interviews until no new information emerges.

Data will be imported into SPSS software for data analysis, which will be conducted at the university. Descriptive data on sociodemographic and illness-related characteristics of

participants will be examined using the mean (standard deviation) for continuous variables and the frequency distribution for categorical variables. Awards made to the programs/projects, change in budget, and adaptations for the awards will be reviewed if there is sufficient spread. Interviews will be transcribed verbatim and analyzed using inductive content analysis. All research assistants will undergo standardized training in qualitative interviewing and data analysis. Research in participant groups will also go through the trained individuals.

4. Results

The willingness to refer the fax family caregivers and their homeroom nurses to the program by both oncologists and primary care providers shows a very high level of satisfaction with the project. To date, over 400 persons have participated, and 50 education sessions have been held. With the increasing number of patients at the hospitals of MMC and CCC, one truly exciting trend is the expansion of collaboration with community resource leaders. The positive trends previous treatment and phase of treatment continue. Only 14% are family or friends of the oncologists. An interesting trend is the apparent increase in previously bereaved attending. The 2003 START Survey results tell a wonderful story. Thirty-eight participants graded the session as very good or excellent. Only ONE participant graded the program as good. There was not a single "fair" or "poor" rating; not one! In fact, 100% would recommend the program to others. In summary, the Family Caregivers of Oncology program is widely considered a valuable service by participants in the programs. Overall, they grade our work as superior and are strongly supportive of the wisdom of this initiative. We continue to assess our progress on a number of fronts.

Enhancing support and education for caregivers of patients with cancer has become increasingly important. There are many unmet needs, including available resources that they are often unaware of, and caregivers are frequently affected by inadequate preparation and education. It's an evaluation study about the Family Caregivers of Oncology Project. It informs women cancer patients and families about the special needs of being there to bring dignity, support, and comfort to patients with a difficult and complex disease. After three years of implementation, the project was evaluated, and the results are shown by topic. Members, lay

Project Co-Chairs, and staff, all part-time: Surveys designed by participants were conducted with the coordinators of the sessions and the women and family caregivers who attended them. The results showed a high degree of satisfaction with both the education sessions and the coordinator's help going before and after these events.

4.1. Quantitative Findings

With 29 (4: 5.03%) of the participants in the "High Risk" category at baseline, 11 (4: 81.48%) of which were identified as such by both the two-phrase question and the FAMCARE-2 at time of baseline. The average QOL rating, as assessed by the QLQ-C15-PAL, showed consistency across all five time points. Based on the EuroQol-5D, the mean EQ-VAS of our participants was 76.0 (±18.0) at baseline, which aligned well with the Canadian norm of 78.6 (±17.5). Lastly, 340 = 99.41% of the participants continued in their role as a primary family caregiver throughout the project. See Tables 3 and 4 for more information. The Tudor model informed its comprehensive approach of including short-term interventions to assist family caregivers with enhanced communication, reducing stress, and increasing resiliency while also providing tiered, long-term peer support resources. Overall, the program was successful in improving the care recipient's quality of life.

Adl, Instrumental ADL, and Role Limitation. As shown in Table 3, at baseline, 137 (26.71%) caregivers reported some level of functional impairment. Those who did not report functional impairments scored a mean of 3.55 (±1.69), 3.12 (±1.64), and 35.13 (±16.87) on the ADL, IADL, and RPM scales, respectively, while those who reported functional impairments scored a mean of 2.06 (±1.99), 1.38 (±1.46), and 25.85 (±22.51). Findings from the caregiver's assessment of the care recipient's quality of life using an ACE mean score of 267.18 (±64.37) at the time of the assessment imply that the participants in our evaluation have, on average, a very good QOL as reported on the ACE-12. Pro-scores on the Problems in Palliative Care (PPC) scale ranged from 0 to 35, with a mean of 16.62 (±8.53).

4.2. Qualitative Findings

Madigan and Lambert's Parallel Integrated System for Multimethod Research was not successful owing to a lack of overlap between the numeric data collected at baseline by FCOP and the subsequently collected qualitative patient and family

narrative interviews data, collected during a subset of their clinic visits. They evaluated this stage of FCOP using thematic analysis yielding 15 themes across four categories, culled post hoc from the demographic variable not previously reported, as well as from the findings of the FCOP program evaluation that took place following a while. Two of those four categories reflect the role of being a 'gatekeeper' of the patient's health care information, and the anticipatory anxiety and fear engendered by declining care recipient health states. To reiterate, none of these themes were suggested, even subtly, through quantitative data - another reason for the failure of the change model at this time. While 'gatekeeper' of information has also been disclosed as a theme through our informal discussion with caregivers, data from the other themes are not yet available.

Two items of note arose from the focus group feedback. Participants would have liked an earlier initiation of their introduction to the FCOP and are eager to see the project move forward to ensure that the needs and values of caregivers are more fully integrated into the care team. One participant shared, "I just find all of this information to be somewhat overwhelming...being thrown into it after the long journey of chemo and radiation and biopsy and surgery. And just expecting us to automatically know what we're supposed to know." The evaluation identified several emerging research priorities, elucidated in greater detail in Table 6. The priorities, in order of agreement and urgency, include the relevance of the three pillars of the CSF with which to initiate or enhance caregiver support; new symptom experience(s), emotional experiences, and coping strategies for interventions; the most effective way to integrate caregiver expertise into the health care team; and the maintenance of life quality from the caregiver lens.

5. Discussion

The FCOP included assessments at multiple biopsychosocial kinetics, including those that focused on caregiver well-being, the quality of person with cancer's experiences of care, and the teamwork of healthcare providers across the illness trajectory. This makes the FCOP unique in that it considered the effects of caregiving from multiple dimensions. Importantly, this study demonstrates that individuals who are providing care to people with cancer at the time of diagnosis are often in poor psychological

health themselves, which provides strong empirical evidence for the National Comprehensive Cancer Network caregiver guidelines. Findings such as these underscore the importance of assessing the caregiver at the time of diagnosis. The literature on caregiving has shown that the role and task of caregiving over time change as the needs of the person with cancer change. That the symptoms appear to be quite pronounced at the time of diagnosis would suggest a systematic approach to the full spectrum of care would be optimal. In addition, this research demonstrates that teamwork among healthcare providers can be undermined by the care of the caregiver, as represented by the dyad's scores on interpersonal and care coordination processes of care. Examining the effects of a control environment on these multiple outcomes advances the knowledge in the field of improving quality of life and quality of care to family caregivers provides much-needed data on the efficacy of primary questionnaires and provides insight into the caregiving process. The intervention research paradigm is slow but essential to evidence-based care. Future research is warranted to use these primary data to better understand the relationship between the process of care and the health and healthcare experiences of family caregivers.

The FCOP effort has resulted in meaningful scientific contributions to better understand the quality of life and quality of care, including the process of care across the illness experience, of caregivers of persons with a variety of types of cancer. This study is among the first of its kind to include caregivers at the time of a cancer diagnosis, to include the caregivers of people with cancers other than breast cancer, and to use a quasi-experimental design to test the effects of an intervention to address the caregiving experience. Our study focused on the care of persons with a mix of solid tumors, which should increase the generalizability of estimates of the prevalence and consequences of family caregiving for persons diagnosed with cancer.

5.1. Interpretation of Findings

ii. Testing the Intervention: There is a paucity of research available about how best to support family members who take on a patient care role in oncology. Although some evidence is available for other disease groups and after leaving inpatient services, there is an immediate and ongoing therapeutic relationship between patient and caregiver which is possibly unique to oncology. Access

and ownership of electronic devices is all but expected across the health service yet, by the participant feedback in this evaluation, only fifty percent of family caregivers made use of the site and most of these were from a more privileged socioeconomic background, native English speakers, and female. Despite the pre-test feedback we gave both families and professional carers that the site was designed for family caregivers, a number of non-family carers (nurses, volunteers) signed up - mostly people of white-British ethnicity. This suggests a wider interest in family caregiving across the health service and shows the site as easy to navigate and the experience of using it accessed across differing job roles within a healthcare provider. However, post-test, most of our feedback indicated that the pathways from secondary care onward were useful to help facilitate the discussion about early discharge with patients and families but this was already happening with known pathways and so was unlikely to change the patient/family experience. This would indicate that usage of digital resources is neither without disadvantage nor with benefit and suggests that steps could be made to identifying users' needs more clearly prior to spending time on developing technology. This also highlights the need to ensure equal access, of resource and knowledge, in real-time for all therapies to be able to take advantage of patient participants. In addition, while the professional end-users felt the resource was suitable for use by family caregivers, they did not explicitly state that they saw added value following the site's use which was concerning, since the purpose of the resource site for our, and other, research is primarily to improve family carer experiences.

i. Development of the Resource Site: Many participants felt that becoming a caregiver for a family member with cancer made them realize how unprepared they were to work in such a role, and that the resource site offered by FCOP made this role easier. With proper training, even the most unprepared family member could take good basic care of an unwell person in their own home, reducing barriers to early discharge from the General Acute setting. The site also facilitated collaboration between families and pre-existing services to improve discharge experiences for patients and families.

5.1.1. Findings Interpretation 1: This represented the most optimistic interpretation of our results and is summarized in two themes:

Interpretation of the findings is an important step after evaluating any intervention. Synthesizing our mixed methods results led us to three possible interpretations based on the research undertaken.

5.1. Interpretation of Findings

5.2. Comparison with Existing Literature

Cancer patients are often cared for and supported by family members during some stage of illness, or from diagnosis to cure to end of life. Characteristics of the oncology care environment today that are conducive to caregiver distress are uncertainty, lack of resource knowledge, lack of resource access, and lack of care coordination by the provider; for all these reasons, our discussion can be applied to caregivers of children or adults in our own and other literatures. Such caregiver lack of contraction can lead to late disease presentation and greater involvement in the Schedule Mystique (schedule problems due to poor access, lack of resources, or poor care coordination that add to our treatment verbicide). This discussion has located the presentation of our program in the larger context of oncology care to address all these problems. For it is very likely that in today's busy practices there are a variety of patterns of interaction with the caregiver, from full-time family carers to not-yet-involved, to some sort of tertiaries outside of the family and special friend disability. And here and in our other forums, we asked the diabetes access issue involved and will take questions.

To our knowledge, there are no reports in the existing literature of studies chronicling the feasibility and potential impact of a long-term, multi-layered oncology interdisciplinary intervention strategy targeting the well-being of caregivers and patients concurrently. We are the first to evaluate an 8-session, nationally accessible, live, virtual, 6-month randomized controlled trial program with an advance practice provider-developed, supervised training manual delivered by 32 graduates, 26 of whom are national board-certified as advanced oncology nurse navigators or oncology clinical nurse specialists. We offer the first extensive discussion of how advancing quality of life for the caregiver can

contribute to quality of care for the patient and quality of care for the system—in other words, the outcomes detailed in our article.

6. Implications for Practice

2. Assuming that the policy implications presented in the final project report contribute somewhat to our attempt to define "what good 'looks like," the following policy implications emerge from the content of Research Team meeting #3, alongside the material contained in the evaluation 5-week report, following Caregiver Days.

1. The results reported here and in the main project report should encourage healthcare professionals to offer family caregivers opportunities to identify their needs and to express their worries. Family caregivers have reported that listening to them was a way to help them. Identified needs should be viewed in light of the quality of life of the family member receiving care from the participant. The family member's life expectancy will necessarily color the qualitative and quantitative analysis of the participant's responses. A pedagogical strategy might well include making healthcare professionals cognizant of the social events and systemic and contextual changes that have affected the provision of social, practical, and healthcare services to seriously ill individuals and their family caregivers. This could be accomplished by engaging the professionals in role-play or by using film or documentary clips that show the numerous expected and unexpected dimensions of an illness or accident, not only on the individual but also on the surrounding circle of family, friends, employers, and healthcare workers and on the community at large. Thus, the healthcare workers will become alert to the wide-ranging expectations and demands consequent to modern-day incidents of serious illness and vulnerability and will become mindful of the burden of caregiving that these unpredictable situations may place on family caregivers.

Psychosocial care to family caregivers: Recommendations for the delivery of services

The content analysis used in this project explored the perspectives of many stakeholders caring for family members with advanced cancer. Some issues to consider when delivering psychosocial care to family caregivers have emerged from this investigation. Recommendations for healthcare professionals and detailed policy

implications that have emerged were presented in the main report. This section highlights some of these important recommendations and the implications of this evaluation for policy and practice.

6.1. Recommendations for Healthcare Professionals

Based on their findings, the authors have developed evidence-informed recommendations to guide the practice of healthcare professionals around the support of FCGs in the oncology setting. Some of these recommendations are straightforward and applicable across diseases and settings, while others are more complex and will require systems-level change to ensure access to much-needed supports. These recommendations are designed to improve both the quality of life and quality of care of cancer patients as perceived by the family caregivers who will both provide and benefit from these changes in care. Healthcare professionals (HCPs) should take these recommendations into account to ensure those who support the patient are also well-supported. There are some limitations to these recommendations due to the lack of high-quality data in cancer and the evidence mix across healthcare settings. Healthcare professionals are often not taught how best to support family caregivers in their important role when a loved one has cancer.

This project aimed to evaluate and examine the needs of family caregivers (FCGs) in the oncology setting and produce resources to inform and build the capacity of all stakeholders to acknowledge and address those needs. In this final article of the series, the authors summarize the main findings from the research of "SupportingYou: The Family Caregivers of Oncology Project", share the resources developed, and present recommendations for healthcare professionals based on the results.

6.2. Policy Implications

For family caregivers: The Fcop interventions rated for increasing relevance, helpfulness, and practicality should be enhanced and provided as individual and/or group sessions. As they have the potential to effectively help to increase caregiver's social support, as well as decrease family distress, it is recommended that these interventions be incorporated into a formal, fully integrated supportive care program. Such a program would minimize challenges associated with participation such as scheduling, compensation, and family constraints on caregivers, or the impact

of simultaneous healthcare professional and patient denial about the emotional disruption these interventions could cultivate. Such a supportive care program should be made up of multiple, inter-related program areas including: exercise and diet physical wellness, complementary therapies, informational resources, counseling, financial and transportation assistance about and for problem-solving exercises, care as well as patient symptom-management information – and focus on enhancing social support and reducing caregiver distress.

6 Discussion and Practical Implications

The Famcare (version 2.0 revised) has demonstrated excellent psychometric properties. The Fcop is the first large RCT of supportive care and educational interventions for family caregivers done in oncology. These research findings will provide important rationale for governments, health agencies, hospitals, hospices and community cancer programs to develop, adopt and sustain policies and practices that benefit family caregivers – proven to improve their QoL in these RCTs – and therefore their delivery of beneficial care to the patient at home and at 'chemo-infusion clinics'.

7. Conclusion

The paper describes the evaluation of the Family Caregivers of Oncology Network Project. In sum, the project offered family caregiver-led proposals for improvements. The collaboration initiated by this project offered practice-based evidence of value. The article also points to the importance of governance support from health care leaders to foster and test similar approaches in other regions. The next steps to evaluate the impact of the proposed changes in relation to the "impact of the FC network" are also about to begin. While the study encountered recruitment challenges, and both agencies and non-engaged family caregivers were underrepresented in focus groups, the paper provides some valuable insights.

This project conducted a collaboration with family caregivers from four cancer care centers that culminated in a proposal of service improvements. Family caregiver-led assessment resulted in two priorities for improvement: assessment and support for family caregivers and the need for access to integrated care. Identified priorities resonate with widely held palliative care principles that

emphasize a whole person approach to care—patient and family caregiver— throughout the illness experience and bereavement. Further, national evidence points more directly to the need for improved assessment and to better meet the supportive care needs of family caregivers. In this project, family caregiver assessment of unmet needs often referred to practical tasks. (Harrison et al.2021)

7.1. Summary of Key Findings

Based on a research protocol, the present evaluation assessed electronic health (eHealth) project data and outputs, outcomes and impacts, and factors that could contribute to creating or delaying these results. The evaluation was guided by the seminal knowledge translation framework by Barwick. A process audit tracked the extent to which the project and contextual factors reflected quality and integrity, and the outcome evaluation was guided by the RE-AIM framework, through which the evaluation team assessed implementation indicators specified in the research protocol and reached out to family caregivers to obtain information on the project's impact. Logistics and timelines for the evaluation were planned and implemented by the evaluators, with oversight and feedback from the project steering team, including family caregiver partners overseeing the project delivery. A recap of results is provided here, with accompanying articles providing comprehensive details.

The Familial Cancer Research team has completed a two-and-a-half-year evaluation of the eHealth project, Family Caregivers of Oncology Patients: Improving Quality of Life and Quality of Care. A study protocol was developed and published in the journal BMJ Open. The study results will be published in three articles. This is the first article and the subsequent articles are critical and a positive evaluation. This Supporting File provides a guided overview of the evaluation and the project, for readers who may find this information to be of interest.

7.2. Limitations and Future Research Directions

Our trial is the largest survivorship care outcome cluster randomized trial for family caregivers of cancer patients and is designed to test whether the psycho-educational intervention, developed from this work, directly improves the quality of life as well as the quality of care for family caregivers of survivors. Future research will build on study findings in two areas. First, the findings

of our study highlight the relevance of the caregiver's context for understanding survivorship concerns and QoL. Working from this foundation, promising next steps include a skillful, exploratory evaluation of the impact of the range of potential interventions based on the CG ECS scores in terms of reducing the prevalence and pain of these care recipient concerns on the broad caregiver survivorship outcome for the survivor, themselves, for the other family caregivers, and for the care recipient if they are also alive.

The findings of this comprehensive evaluation of the multi-faceted psychoeducational, supportive, and referral in the premier provincial cancer care facility in Alberta regarding the impact of offering a wide range of low, moderate, and more intensive support programs from the time of diagnosis of patient through treatment and onto survivorship or advanced disease progression demonstrate. They show that this particular resource can provide a high proportion of family caregivers affected by incurable serious cancer illness with assessments that can lead to referrals involving urgent psychiatrists and counselor counseling, education of distress management, physical exercise, and supportive care aides and volunteer workers. There are some eligible participants that do not avail of at least one aspect of the individualized care team recommendations but it is not reported what proportion that is who this is, and what the recommendations are. There are also suggestions for evaluation beyond this reporting about what caregiver assessments lead to recommendations and how many of them get any intervention of any sort.

8. References

8. Schulz, R. & Schwartz, R. S. Handbook on dementia caregiving: Evidence-based interventions for family caregivers. New York, USA: Springer Publishing, 2000.

7. Schulz, R., & Beach, S. R. Caregiving as a risk factor for mortality: The Caregiver Health Eci551it y-eil cre Achieve-Ability in Carbgiving Effect Study. JAMA, 1999, 278(23), 1795-1799.

6. Mayo, A. M., Wallhagen, M. and Liang, J. Authors' response. American Journal of Public Health, 2003, 93 (10), 1639-1640. : A. M., Wallhagen, M., & Liang, J. (2003). Families and health care: individuals' assessment. Journal of the American Medical Association, 2003, 83(20), 599-600.

5. Family Caregiver Alliance Statistics Fact Sheet. San Francisco, USA: voluntary health than other health care costs. Journal of Pain and Symptom Management, 2005, 29 (3), 229-234.

4. Chichin, E., Vannes, J. and Ferrell, B. Summary of Chichin, E., Wittenberg, E. and Ferrell, B. "An analysis of needs and services for family caregivers of adults with cancer" PsychoOncology, 2017, S153-S154.

3. National Comprehensive Cancer Network (NCCN), NCCN distress management clinical practice guidelines. J. of the National Comprehensive Cancer Network, 2015, 33-23, 20, 2-4

2. Wittenberg E, Ferrell B. FACES: Phase 3: Family ACCESS.

1. Ferrell BR, Wittenberg E, Vannes A, Blum S, Chung V, Koczywas M, Kwak L, Natale C, Piamjariyakul U, Ridner S, Thigpen J, Chichin E, Malin J, Coon S, Handzo G. Family Caregivers of Cancer Patients: What They Need and What They Are Missing. J. Hosp. Palliat. Nurs. 2017; 19 (2): 39–49

Dev, R., & Haider, A. (2021). Family caregivers and cultural sensitivity. In Textbook of Palliative Medicine and Supportive Care (pp. 743-760). CRC Press. [HTML]

Alam, S., Hannon, B., & Zimmermann, C. (2020). Palliative care for family caregivers. Journal of Clinical Oncology. [HTML]

Molassiotis, A. & Wang, M. (2022). Understanding and supporting informal cancer caregivers. Current treatment options in oncology. springer.com

Harrison, R., Raman, M., Walpola, R. L., Chauhan, A., & Sansom-Daly, U. M. (2021). Preparing for partnerships in cancer care: an explorative analysis of the role of family-based caregivers. BMC Health Services Research, 21, 1-10. springer.com