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Managing care in gynaecological cancers:
Role of health communication in enabling women's health choices in India

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Declaration

To the best of my knowledge and belief this thesis does not contain any material previously published by any other person, except where due acknowledgement has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any other university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007)- updated March 2014. The research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262): Approval Number HRE2017-0739.

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Abstract

The cancer care continuum has several challenges and dilemmas for patients, providers and personal caregivers. Globally, increasing attention has been given to access and equity in care for individuals dealing with cancers. Low- and middle-income countries face the extra burden of inadequate resources in all spheres that enable cancer care. The psychosocial perspective is a rarity in such contexts in which the focus is towards clinical dimensions of caregiving and receiving. This research considers one such context—India—and investigates the constraints in the management of gynaecological cancers.

Interventions, programs and research that address resource constraints will remain incomplete unless there are holistic efforts between stakeholders that seek care and those who provide that care. This research strives to show directions on how that can be achieved with the aid of perspectives from three primary categories of people in gynaecological cancer care—the women who are diagnosed with a gynaecological malignancy, their personal caregivers, and their healthcare providers.

Sixty semi-structured in-depth interviews were conducted with these participant groups (women: n = 15, personal caregivers: n = 10 and healthcare providers: n = 35). Women and their personal caregivers were recruited from a tertiary hospital in southern India that offered advanced oncology services. Healthcare providers were recruited from the same hospital, two other tertiary hospitals providing advanced oncology services, one support service organisation and one community health organisation. The health belief model and the theory of communicative rationality have been used as the theoretical underpinnings of the study.

The research revealed five important findings that give specific directions in the gynaecological cancer care continuum in India.

1) Collusion along with co-operation among family and women plays a critical role in negotiations that occur in the cancer care trajectory.
2) There are multi-layered dimensions to financial transactions in treatment trajectories that suggest economics cannot be merely understood as affordability or costs in cancer care.

3) Ethics in gynaecological cancer research in a constrained setting is not only about the conduct of the research, but about its implications in all aspects of a study from conceptualisation to completion.
4) There is an urgent need for support services of personal caregivers who are grappling with multiple responsibilities both during and after treatment for cancers.
5) The burnout and burdens of healthcare providers require immediate attention since their psychological and emotional interests are severely neglected.

Based on the findings from this study and with the aid of the study frameworks, this research proposes the collaborative efficacy of care model. The model recommends a holistic framework of care that does not separate patients as entities in their treatment journeys. The role of the care providers (both clinical and personal) are included in this care model with as many joint aspects in care as those that occur at an individual level. This model promotes and proposes the view that the collaborative initiative of care is most sustainable for long-term conditions like gynaecological cancers, which require the cooperation of other individuals towards the patient at every step of care seeking and receiving. The thesis concludes that, given the life threatening nature of the disease, collaboration is key in the care continuum and will notably improve the efficacy of individuals, institutions and systemic partnerships in the health context.

Co-author Contributions:

Chapter 3: *Ethical issues in research with women cancer patients in India*

	Conceptualisation & Design	Acquisition of Data & Method	Data Conditioning & Manipulation	Analysis & Statistical Method	Interpretation & Discussion	Final Approval
Kalyani Subbiah PhD Student Researcher	+++	++++	++++	++++	++++	
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I acknowledge that these represent my contribution to the above research output Signed: Jaya Dantas						
Professor Arima Mishra	+			+	++	++
I acknowledge that these represent my contribution to the above research output Signed: Arima Mishra						

Chapter 4: Gynaecological cancers in India: The less heard perspectives of healthcare providers

	Conceptualisation & Design	Acquisition of Data & Method	Data Conditioning & Manipulation	Analysis & Statistical Method	Interpretation & Discussion	Final Approval
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Chapter 5: *Unravelling partial silences: The limits of language and communication among women with gynaecological cancers in India*.

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Chapter 6: *Beyond money matters: The hidden costs of gynaecological cancer care in India.* *&*

Chapter *7: Undiagnosed burdens in care: Gynaecological cancers and the lonely challenges of personal caregivers in India*

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Professor Arima Mishra	+			+	++	++
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Chapter 1

Introduction and Overview of the Thesis

1.0 Introduction to the Chapter

This thesis presents a qualitative study with women patients diagnosed with gynaecological cancers (cervical, ovarian uterine, vaginal, vulvar and fallopian tube cancers) (CDC 2021), their personal caregivers and healthcare providers in an urban setting in southern India. The focus of this chapter is the study background, aims and objectives, conceptualisation and the relevant experiences of the present researcher. It also sets the stage with a brief overview of each chapter in this thesis and then moves on to discuss both the significance and the limitations of this study.

India is an extremely vast country with diverse dimensions of culture, context, belief systems and practices. The findings of this study cannot claim to be representative of specific groups of people in India. Culture in the context refers to practices and social norms that are prevalent and impact behaviour, choice and decision within a specific geographical context, in this case India. The study makes a genuine attempt to break the barriers of silence in health communication that have existed among different categories of people in a care continuum. Health communication can be defined as the process by which a health behaviour or condition is examined and enabled towards well-being with the aid of different methods and forms of communication. The women patients, their families and healthcare providers in this study have shared aspects of their stories that hold significance and relevance. Through identifying and pointing out such relevance this study hopes to highlight bigger gaps that lay hidden between the lines of their narratives. In our view, the research has legitimate scope of applicability in contexts beyond its own—especially those where women, families and providers are collective stakeholders in the cancer continuum. Rather than generalisability, this research has the scope to open questions, reveal barriers and show gaps in more contexts through the glimpses of one.

1.1 Background, Conceptualisation and Research Context

This research area is understudied and gynaecological cancers are fraught with multiple complexities due to few avenues being easily available for study. The specific resource constraints of contexts further aggravate these gaps. India suffers from many of these challenges and there is a pressing need for research that dwells on the missing links. Gynaecological cancers, particularly gynaecological cancers feature low in the research prioritisation determined in India. The research that does exist tends to focus on the clinical dimensions of disease management whereas the psychological and social angles are mostly neglected. There is an urgent requirement in the country for a focus on these angles in order to design interventions that are more inclusive, useful and integrated to provide care that both enables and heals.

The present researcher has worked in the realm of women's health with training, experience and educational background in health communication and a focus on women's health in India. Since 2004 she has been associated with several studies that have focused on women's health research and health promotion in the same setting in India as where this research has been conducted. The researcher's interest in women's health promotion combined with risk-mitigation first translated into a research interest area in 2015 with both women and gynaecological cancers. At that stage it was developed as a research idea and proposal with the support of the Associate Supervisor of this study (Professor Arima Mishra). Subsequently in 2017, this research idea was further developed under the guidance of the Primary Supervisor, Professor Jaya Dantas, as a PhD study in International Health. The researcher received a Research Training Program scholarship of the Australian Government and Curtin University. The opportunity paved the way for the research idea to be fully developed, reviewed, implemented, conducted, analysed and written.

1.2 Study Sites and Participants

Hospitals offering advanced oncology care for gynaecological cancers for women in a specific urban setting in southern India were the study sites. The rationale for this is because such tertiary care facilities cater to large populations in India, including those from different regions in the country. Though the study was designed to collect data from both public and private tertiary hospitals, only private tertiary care providers gave permission to collect data from their settings and services.

The role of women in the marital and social context have considerable importance in India and decisions they make in healthcare have complex linkages with those roles as a result. The study of such personal issues is sensitive, as is the study of two other major stakeholder categories who both influence and participate in those choices - healthcare providers and personal caregivers of women. Choice and decision in healthcare cannot be understood in isolation, since psychological, social, financial and cultural factors impact them consistently. The personal caregivers (typically the families of women) at the familial level and the healthcare providers at the social level, are both crucial networks in a woman's journey in and across the cancer care spectrum. The rationale for conceptualising this research to study the three participant groups (women diagnosed with gynaecological malignancies, their personal caregivers and their healthcare providers) was based on the reasoning that challenges of women can be understood fully only along with their vital relationships during care seeking. In addition, the health research context in India has nuances that require a deep cultural understanding to make holistic interpretations.

Participants were women diagnosed with gynaecological cancers and taking treatment in a tertiary hospital providing care, their personal caregivers were individuals accompanying them at the hospital, and healthcare providers were individuals in varying roles with responsibilities for advanced cancer care provision. Sixty semi-structured interviews were conducted to gauge the barriers and gaps in the cancer care trajectory that involve the participants. The efficacy of existing practices, treatments and support services were also explored to measure how gaps can be addressed in the future. The research was conducted with healthcare providers from three tertiary institutions offering advanced oncology care, one support service organisation and one community based organisation. Women who were diagnosed with a gynaecological malignancy and their personal caregivers were recruited from one of the three tertiary care institutions.

1.3 Research Aim and Objectives

The overarching aim of this research was to improve health outcomes for affected women in the continuum of gynaecological cancer care in India by identifying gaps in communication that occur. The research aim was guided by four objectives.

1) First, to have a holistic understanding of the interpersonal communication that currently occurs in the cancer care continuum in the identified research sites, through in-depth interviews conducted with patients, their personal caregivers and their healthcare providers.

2) Second, to examine the barriers and challenges to health-seeking behaviour encountered by (a) women diagnosed with a gynaecological malignancy, (b) their personal caregivers and (c) the challenges faced in healthcare provision by their providers in the cancer care spectrum. Specifically, to better understand participants' challenges to care-seeking and provision and movement in the cancer care continuum with behavior and decision-making.

3) Third, to understand decision-making processes among patients and their personal caregivers and the related communication process that occurs in and with the health system (institution and healthcare providers). This objective has covered areas related to preventive behaviour, choosing health institutions, stigma, treatment options, costs, institutional issues, treatment procedures, duration and long-term care. Collaborative decision-making vis-à-vis relationship interplays will be studied towards this understanding.

4) Fourth, to propose an adapted model of communication based on an integration of the communicative rationality framework and the health belief model from the evidence and directions gathered from the study. This model will present the rationale and need for more holistic and integrated models of care.

1.4 Global Burden of Gynaecological Cancers

Our times have seen the heavy burden of deaths from non-communicable diseases globally and a heavier burden in low- and middle-income countries (Benziger, Roth, & Moran, 2016). Of the major killers in non-communicable diseases, cancer is responsible for close to eight million deaths (Roura & Arulkumaran, 2015). Global surveillance of cancer survival showed that survival rates in gynaecological cancers leave much to be desired with the five-year survival rate for ovarian cancer being less than 50 percent in most countries (Allemani et al., 2018). The incidence of cancer has seen a steady increase over the last few decades and in 2012 there were more than 14 million new cases of which close to half were women (del Carmen, Rice, & Schmeler, 2015). The burden of disease and mortality is largely on the middle and low-income countries (IARC, 2012) that already are challenged by access and affordability. The arrest of the incidence of cancers is still a long-term goal for most contexts.

When gynaecological cancers are specifically considered, one of the tragic realities is that despite the advancements in medical science the mortality rates are still extremely high. There were 230,000 in 2012 due to cervical cancer in low- and middle-income countries (del Carmen et al., 2015) despite it being a cancer with a high cure rate with timely diagnosis. Predictions estimate a fast growth in cancer rates with gynaecological cancers contributing to one fourth of the incidence and each of them having distinct risk factors (Sekhon & Bhatla, 2016). Effective care management in gynaecological cancer is about protocols, systems and resource allocations combined with monitoring mechanisms, which are typically available in more resource-equipped countries that also have less than ideal outcomes in cancer pathways (Askew & Gangji, 2016).

Pain and Support-seeking in Gynaecological Cancers

A much neglected area in cancers is pain and seeking support through pain management. Even in resource rich contexts, the complex nature of pain management in gynaecological cancer care requires ongoing evaluations, along with support through interdisciplinary intervention (Allano et al., 2019). Learning how to cope with pain is one of the most frequently cited need that women have when dealing with gynaecological cancers (Akkuzu et al., 2018). Low- and middle-income countries suffer from several problems in pain management in care due to inadequacy of protocols in clinical care, existing practices in healthcare provision, accessibility and affordability of options, socio-cultural issues, awareness as well as training needs of healthcare providers (Zhang et al., 2018).

Palliative care, already overburdened as a support service, plays an important role in the cancer trajectory in pain management because clinical care cannot afford to invest time on patients after clinical interventions (Atreya, 2017). The direct and indirect costs of cancer pain are tremendous, although medical costs and loss of productivity costs are difficult to measure and gauge in the context of a developing country. Gynaecological cancers suffer from the additional challenge of stigma, embarrassment and trepidation that women face, which hampers their willingness to be open about pain and discomfort during treatment or recovery. Seeking post-treatment help can become extremely challenging for women if healthcare providers perceive the women are fortunate to have had their disease detected and treated (Thisted, Zoffmann, & Olesen, 2020). The role that support plays in a woman's life in acceptance of gynaecological cancer is both understudied and underestimated, an acceptance of which is a fundamental step towards her emotional post treatment wellbeing by seeking support when required and social reintegration (Manne et al., 2018).

Gynaecological Cancers and Women's Roles

We cannot look at gynaecological cancers separately from women's roles as wives, sexual partners and mothers. Literature shows that apprehensions and trauma related to adverse impact on fertility and sexual functioning create ongoing psychological anxiety, reduction in the quality of life and dissatisfaction with self and the need for clinical interventions to have integrated approaches that do not separate treatment options from women's personal and social roles as women, mothers and sexual partners (Rosa Valentina Lucia et al., 2020). Evidence shows that gynaecological cancer treatment does not stop with treatment of the malignancy. Rather, women face psychological ramifications that are both isolating and severe, and connected to their long-term health; proactive measures to address them require planning from the commencement of treatment (Sandsund et al., 2020). The healthcare providers play a crucial role in this pathway and can be the essential bridge between women and their reintegration into their personal spaces.

Depressive symptoms among women diagnosed with gynaecological cancers is common and have a sharp impact on a patient's health value (Yu, Yeo, & Kang, 2020). Evidence shows strong correlations between diagnosis, disease management, pain, psychological symptoms, and quality of life in gynaecological cancers. The need for health systems to recognise that none of these are independent of each other in a woman's life and roles with others is of paramount importance. It is of even greater relevance in cultural contexts where heightened importance is given to women's marital relationships and there are silences around gynaecological cancers since they directly impact women's role and performance in those relationships (Yeh, Lu, Chen, Kuo, & Huang, 2020). Discussions related to symptoms, pain and treatment options become that much more challenging for women due to the silences and shame that accompany their condition. While the global literature has given attention to the importance of spouse and marriage in cancer survival (Syse & Lyngstad, 2017) there is less focus on the roles, social expectations and personal norms people have in such partnerships and the resulting impact on health decisions in management.

Culture and Gynaecological Cancers

The criticality of the setting and context in which a woman seeks care for gynaecological cancers cannot be ignored at any stage in the cancer continuum. Women seeking care for gynaecological cancers have to deal with ongoing stigma, shame and apprehensions that are linked to ideals of womanhood, as dictated by their social norms, face disadvantageous hierarchies within the health system, adverse attitudes towards them while seeking care, conflicting beliefs and acceptance of intrusive screening tests or diagnostic procedures, and the cultural linkages between disease and death, which could hamper the very process of seeking care (Kani & Bekar, 2020). Culture and the social setting play pivotal roles in how women come to terms with their condition, and how they respond and seek care for side effects such as sexual functioning and fertility impairments, which are linked strongly to their marital lives and identities as women (Chow, Winnie Kwok Wei, Kai Chow, & Han Chan, 2018; Sobota & Ozakinci, 2018).

These challenges can result in long-term ramifications in emotional and psychological wellbeing of women in addition to the physiological problem they need help with. The health system's connectedness with women's experiences in addition to cultural and contextual awareness of health interventions are the foundation for efficacious programs for such problems. However, such interventions rarely have the luxury of resource support to ensure this. Evidence shows that support and care needs for women diagnosed with a gynaecological malignancy is not necessarily restricted to resource constrained settings (Sandsund et al., 2020; Williams et al., 2018). Even women in settings that are more economically advanced have challenges related to holistic care, psychological trauma, sexual dysfunction, apprehensions about fertility and timely sensitive information to deal with such problems. Both resource rich and resource poor health settings are equally challenged in multiple ways when responding to gynaecological cancers. One of the primary needs in any health setting is culturally sensitive administration of measures to assess trauma, distress and pain due to gynaecological cancers (V. L. Beesley et al., 2020; Olesen et al., 2018).

Survivorship, Mortality and Gynaecological Cancers

The study of gynaecological cancers is also the study of mortality and fear of death, which is clinically manifested as the fear of recurrence of disease and is very common among women diagnosed with a gynaecological malignancy (Manne et al., 2017). Though the literature focuses on the psychological impacts of such fear there is little evidence that looks at the fear of cancer in relation to the fears of life and mortality which cancer is often associated with, albeit silently. Even in countries where the best medical care is available to women, insights into their post- treatment survivorship, fears and struggles during recovery and reconciliations that occur in a woman that period are limited (Phillips, Montague, & Archer, 2017).

Interventions that seek to improve outcomes tend to focus on death rates due to disease whereas there are important insights related to mortality in the quality of life and survivorship of women (Askew & Gangji, 2016). While this is true of contexts that have better resources and offer advanced care to women, there is even less evidence in resource constrained contexts that tend to focus on the clinical dimensions of gynaecological cancers and less on the impact of disease post recovery and during survivorship (Sukyati, Afiyanti, Rahmah, & Milanti, 2019). This situation is difficult to shift in countries that deal with the exigencies of late diagnosis, limited means, and women seeking care only at advanced stages, because the health setting priority becomes the saving of lives of women during and through treatment rather than their lives or survival after (Bibi, Ashfaque, & Laghari, 2016). A vital awareness needed in each contextual setting and by a well-knit, trained team of healthcare providers is sensitivity that survival is not just about staying alive but about a woman reclaiming her life (whatever her disease prognosis is) with integrated aid from rehabilitation, counselling and palliative care services (Kolben et al., 2018).

Economic Burden and Gynaecological Cancers

Women diagnosed with gynaecological cancers confront a dimension that can be as daunting as the disease: the economic burden and responsibility it brings with it. The uncertainties that the disease brings is also about the uncertainties of economic viability, which includes the woman's capacity to work as well as employability (Mamguem Kamga et al., 2020). The economic challenges of managing the disease are often considered as relating to the costs of hospitalisation and treatment. However, economic pressures and burdens extend way beyond the clinical management of the disease that affect a woman's quality of life in the long term when dealing with gynaecological cancers (Wu et al., 2020). Unless a comprehensive review is made of both direct and indirect costs in the cancer care spectrum it is difficult to make an accurate estimate of the kind of costs women and their families bear in an ongoing basis.

Global literature shows that even in women-headed households the likelihood of spending on their own health is low among women (Ezzatabadi, Khosravi, Bahrami, & Rafiei, 2018). Even in more advanced economies in the West, the literature looking at longitudinal effects of gynaecological cancer treatment costs, secondary costs of cancer, affordability both before and after treatment and their impacts on the quality of life is extremely limited (Pynnä et al., 2019). Similarly, there is little literature on the exact economic burden on health systems and countries that provide care for gynaecological cancers, despite several years of attention given to the growing responsibility and resource constraints health systems deal with world over (Stephens, Chatterjee, Coles, & Crawford, 2020).

An important dimension rarely discussed is the costs and investments in research and clinical trials focused on the treatment efficacy of gynaecological cancers and the neglect of such research in many contexts due to their steep costs, although there is increasing recognition of the need for such efforts (Bagnoli et al., 2019). Such research is the very foundation from which we evaluate the services, care and interventions that occur across the cancer care continuum.

Stigma and Gynaecological Cancers

Stigma is a recurring reality for many women who face and deal with gynaecological cancers. It is linked to many aspects of their experience in the cancer care continuum including their engagement with information related to cancer care, which by itself can aggravate social stigma associated with the disease (Westbrook & Fourie, 2015). Stigma associated with gynaecological cancers could be due to a range of issues such as a woman's sex life, her roles within family, fertility decisions and side effects of treatment. These reactions are heightened by embarrassment a woman may feel when experiencing symptoms, which in turn hampers her decisions to seek screening or preventive measures for her health (Teng et al., 2014). In cultural contexts where gender interplays and imbalances co-exist with health choices, stigma could be driven by a variety of factors including a personal sense of responsibility for being affected by a gynaecological malignancy (Nyblade, Stockton, Travasso, & Krishnan, 2017).

A veil of stigma around discussions and experiences women have is thrown up in societies that react in such ways as avoiding women who are affected, fatalistic beliefs that the disease is a punishment for wrong-doing, and debilitating associations with mortality. The literature on cancer-related stigma clearly shows the burden of shame, fear and responsibility impacting the cancer care spectrum, more so in cancers where patients see that their lifestyle practices and behaviours has resulted in disease risk and contribution (Lebel & Devins, 2008). The literature also shows the challenges of measuring stigma, but the implications suggest that stigma may be greater than what is measured or expressed. Gender and stigma interplays can have a major impact on disclosure and end of life palliative care (Harding, Nair, & Ekstrand, 2019) which in turn sharply impede a woman’s chances for peaceful end-of-life options and care. Belief systems that have linkages of shame to sex and sexual health can also stigmatise crucial conversations between women and their healthcare providers, which can delay or prevent care seeking in gynaecological cancers (Ak, OGünüşen, Türkcü, & Özkan, 2020).

Communication and Gynaecological Cancers

Even in countries with more developed healthcare systems the criticality of relevant health communication for a patient has been addressed and studied only in recent times in research related to patient satisfaction (Loehberg et al., 2020). A woman diagnosed with a gynaecological malignancy is often at a disadvantage in the health institution where the hierarchy is in favour of the healthcare providers and the institution. Guidelines and enabling communication protocols that inform and include such women are still rare. Women’s self-efficacy in communication when dealing with gynaecological cancers is understudied resulting in limited knowledge about predictors that enable them to openly dialogue and deal with the disease (Manne et al., 2020). There are longitudinal studies that look at multiple variables that enhance or mitigate women’s communication efficacy in areas related to gynaecological cancer coping, interpersonal relationships, support services, management of disease and emotional health.

One severe challenge in gynaecological cancer communication for both women and their healthcare providers is sexual dysfunction due to treatment side effects (Roberts et al., 2020). Barriers such as culture, shame, stigma, lack of training among healthcare providers, grief and loss experiences by women in treatment trajectories impact these conversations and the possibility for efficacious responses. It is imperative that gynaecological cancer units and healthcare providers are effective communicators and work with each other in ever-changing global circumstances, especially in resource constrained settings since the disease is not only life threatening but can impact fundamental coping mechanisms of women both during and after treatment (Okunade, Okunowo, Ohazurike, & Anorlu Rose, 2020).

Such communication can save valuable time and result in both saving and enhancing the quality of life for women post treatment. Literature also shows the importance of not categorising all women as one in health interventions for gynaecological cancers since the physiological, social, psychological needs of older women are distinctly different compared to the needs of younger women (Anna-Lena et al., 2019). Listening to what women have to say about these needs is the first step and often the step that is sidelined in the exigencies of treatment response. Evidence shows that however well-intentioned cancer care information may be, the effect could be negative unless there is a clear understanding of how the information itself can impact women (de Rooij, Ezendam, et al., 2018). In summary, the literature clearly shows that communication at multiple levels, be it individual, institutional or public, occurs without necessarily including women's direct perspectives on what their needs are in gynaecological cancer care and how they need to be met.

1.5 Brief Overview of Methods

This present research is an exploratory qualitative study underpinned with the frameworks Health Belief Model and Theory of Communicative Rationality. Semi-structured interviews were conducted with women patients diagnosed with a gynaecological malignancy (*n* = 15), their personal caregivers (*n* = 10) and healthcare providers who serve in the area of gynaecological cancers (*n* = 35). The patient and personal caregivers were from one private tertiary referral hospital in an urban setting in Southern India offering subsidised care in the city and the healthcare providers were from three different tertiary hospitals (including the institution where patients and personal caregivers were interviewed). Healthcare providers from cancer support services and a community based organisation were also interviewed.

The detailed methodology of the study, including the research process is explained in chapter 3. The methodology is important since it served as a sound channel of ethical enquiry for the researcher at different stages of the research process. The enquiry did not simply mean that there were ethical dilemmas that required resolutions. Rather, the process revealed that ethics in cancer research were not separate from any aspect of the study. Right from conceptualisation to the development of study questionnaires (included in the appendices) to the implementation and analysis of the study, ethical enquiry accompanied the researcher at all stages of conducting this research.

1.6 Results of the Study

There were five key findings of this study. 1) Collusion between family members and women results in several challenges for both patients and healthcare providers. 2) Financial costs in gynaecological cancer care cannot be merely boxed into affordability and costs of care. There are many nuanced layers to what implications financial considerations and transactions have in care. 3) There is a severe dearth of support services such as counselling, women's peer support groups and short-stay homes, services that can better serve the overburdened providers and alleviate burdens of personal caregivers. 4) Provider burnout is common and is a severely neglected area in the cancer care spectrum. 5) Ethical engagement and enquiry in cancer research is not restricted to certain aspects, times or protocols—research cannot be separated from ethics at any stage.

Several signposts in this study pinpointed ways in which services in oncology care for women can be improved. Not all require high investments of resources and some can be woven into caregiving with conscious networks within the existing tertiary care. The intent to look at care provision as a network of united resources that aims to provide the best effort for a woman's recovery, rather than as specialised mutually exclusive treatment plans, is one of the most important findings that has emerged. Such willingness can open multiple doors to address limitations and inadequacy that affect care provision and how women receive care. Women's gynaecological cancer care in India requires equal and undivided attention to three inseparable aspects whether in interpretation of literature, study findings or researcher experiences in the study sites—women, India and gynaecological cancers. Knowing when to look at them independently and when interlinked was the first step of critical learning in the research journey that this thesis documents.

1.7 Significance of the Study

The study significance lies in several aspects, beginning with two main gaps in the current research in India.

First, there is limited focus on non-communicable diseases such as cancers because of higher prioritisation given to communicable diseases in health agendas in the country. Second, there is very little resource investment both in terms of healthcare and research in the area of gynaecological cancers, since the focus of women’s health is typically towards reproductive and maternal health care and research. This research is significant as a result since it addresses both these existing gaps.

The three stakeholder participant categories in the study (women, personal caregivers and healthcare providers) are rarely considered as joint stakeholders in gynaecological cancers management. They are looked at as separate groups with separate challenges in the few studies that have included them as participant groups. Together, these three participant groups hold critical insights into both the gaps in psychosocial research in gynaecological cancers and how best they can be addressed. Most importantly, through their perspectives in this study they have given insight into the reasons these gaps exist and ways in which they need to be circumvented. These groups of people have been identified and recruited from hospitals offering advanced oncology care. The women (patients) and their families (caregivers) are from constrained socio-income settings in India. Their access to care is largely impacted by availability of their own resources combined with aid and support they can get through schemes. The location or study site is in an urban setting in India where there is access to most advanced oncology care and different institutions. The reason this setting was chosen is that a diverse group of healthcare providers have given consent to participate from different types of institutions. Also, due to the existence of advanced oncology services people from different parts of the state and country seek care in this city.

The clinical aspects of gynaecological cancers are what get attention in cancer research. The psychosocial aspects of research, however, are important for a disease that is not only life threatening but which directly threatens women’s roles in a cultural context where marriage and motherhood are vital. Gynaecological cancer management typically does not account for this dimension, which is why the results of this present study are key for programs, interventions and cancer care to be more holistic in nature. There is a tremendous amount of cultural sensitivity surrounding the topics of gynaecological cancers. On the one hand there is discomfort with the subject since it is associated with reproductive parts and health that are typically not discussed openly in the context. On the other hand, there is stigma associated with gynaecological cancers due to their adverse impacts on the body and the roles women perform in the familial setting. There are silences surrounding aspects that involve support networks and how they can overcome obstacles to provide holistic care. This study highlights the views of stakeholders on these issues.

It is not feasible to understand cancers without understanding their complex connections to mortality and death. Palliative care is at a very constrained state in India and plays an invaluable role in end-of-life care, and in the lives of those diagnosed at an advanced stage. Many women in this context seek tertiary care only at a late stage of the disease. This study has sought to gain insights into interplays between gynaecological cancers, palliative care and stigma that are fundamental to efficacy of interventions with women and their families. The cultural importance of family and their role in decision-making in the cancer care spectrum need to be highlighted through recording perspectives from both concurrently and this research has attempted the dyadic data collection for that purpose.

1.8 Summary of Chapters

This is a hybrid thesis with multiple chapters (3, 4, 5, 6 and 7) written in preparation for submission to different journals for consideration.

This **Chapter 1** explains the background of the research and researcher and sets the stage for the research idea in the global context. It gives a brief outline of the aims of the study, an introduction to the literature, the methods adopted, the theoretical frameworks and the study significance.

Chapter 2 presents the detailed literature pertinent to the study in India, the setting of the study and highlights the necessity for such research as well as the clear gaps in the subject area.

Chapter 3 presents the methods and the research process for this study from the ethical dimensions and reflections of the researcher. The sensitive nature of the topic has required an ethical lens to be reflected on throughout the research. The paper in this chapter is titled *Ethical issues in research with women cancer patients in India*.
, will be submitted for consideration to the ***Journal of Ethics and Social Welfare***.

Chapter 4 focuses on one of the participant categories—the healthcare providers and their challenges in providing care in the cancer continuum. The chapter is written as a publication for submission to the ***BMC Journal of Public Health*** and is titled *Gynaecological cancers in India: The less heard perspectives of healthcare providers.*

Chapter 5 is a research article looking at the barriers and silences in cancer care that women patients encounter and is titled: *Unravelling partial silences: The limits of language and communication among women with gynaecological cancers in India* and will be submitted to the journal: ***Healthcare for Women International***.

Chapter 6 describes the manifestations of financial pressures confronted by patients and their families in gynaecological cancer care. The paper in this chapter is titled, *Beyond money matters: The hidden costs of gynaecological cancer care in India* and will be submitted to the ***Indian Journal of Medical Ethics.***

Chapter 7 is a portrayal of the unexpressed burdens and difficulties of the personal caregivers in gynaecological cancer care, is titled: *Undiagnosed burdens in care: Gynaecological cancers and the lonely challenges of personal caregivers in India* and will be submitted to ***PLoS One*** for publication.

Chapter 8 concludes the thesis with a detailed discussion of the study findings, a response to the research objectives, the implications for future research, and the programs or interventions and recommendations inferred as a result of the findings of this research. This chapter proposes an adapted model of communication based on the theoretical frameworks and the findings from this study.

Chapter 2

India and Gynaecological Cancers

2.0 Chapter Overview

This literature review is of articles that have highlighted the limitations of current research on gynaecological cancers in India. It presents the intermittent areas of focus, the gaps in the evidence, and the rationale for neglected dimensions to be addressed through research. It also addresses the specificity of cultural context in the management of care through literature related to cancer care in India. It shows cancer trends in low- and middle-income countries and goes on to delineate the challenges India faces because of a dearth of data and evidence in several aspects related to cancer care. The interplay of culture, context and psychosocial dimensions are highlighted in order to set the stage for the relevance of the research and the current study.

2.1 Cancer Trends in India

Low- and middle-income countries bear the brunt of the global increase in cancers due to the increase in both cancer incidence and mortality over the past few decades (Sivaram et al., 2018). The involvement of the state in facilitating organised and carefully coordinated efforts for better screening by the national health system is seen as critical to reduce the alarming predictions of future mortality due to the disease. India is one of the countries dealing with an increase in the burden of non-communicable diseases in terms of disease and death rates (Arokiasamy, 2018).

The cancer burden in India has increased slowly but steadily over the last three decades and though there has been a reduction of a few cancers that affect both genders the pressure of a large population, lifestyle related changes and pressures of urban living together impact the overall incidence and prevalence (Mathew, George, K M, Vasudevan, & James, 2019). While the incidence of cancer in India is lower compared to many Western countries the death rate remains high as does the lack of awareness on basic measures to curtail and respond to the disease (Pharmabiz, 2019). Cancer rates and trends are not homogenous in India and there are differences between states across the country that require focused forms of intervention in response and treatment (Initiative-Cancer-Collaborators, 2018).

2.2 Gynaecological Cancers in India

Among all cancers, gynaecological cancers require a very specific understanding because of the complexity surrounding them at many levels. Despite a growing acknowledgement that basic reproductive health services are not accessible to many of the women in India, the implementation of women’s health initiatives remain at formative stages because of the lack of state level coordination and investments (Mishra & Lohiya, 2016). At one level the challenge is intertwined with the geographical location of women in rural areas, because the lack of knowledge about preventive practices combined with shame and stigma associated with gynaecological cancers in rural area raise barriers to change (Mahajan et al., 2019), making cancer screening efforts both challenging and time intensive. There are predictions of a reduction in cancer incidence due to the increased efforts at awareness and preventive mechanisms (Srivastava, Misra, Srivastava, Das, & Gupta, 2018).

However, a clear and holistic understanding of gynaecological cancers is missing in the country giving rise to speculation on the future trajectory of both incidence and management of those cancers. The reason for fear may vary according to the cultural heritage and experience of a woman since the psychological pressures vary according to the context (Sukyati et al., 2019). Overall, the literature pinpoints the gaps for women feeling an enabling environment in the trajectory of cancer care regardless of the cultural context they are seeking care in. Literature clearly suggests that a multi-disciplinary effort is needed to address needs on a case by case evaluation. While holistic integrated protocols and guidelines are required, the nature of their execution should be rooted in the local, culturally aware and specific aspects of caregiving.

2.3 Gynaecological Cancer Trends and Status

In recent times the number of cases and deaths due to cervical cancer have risen in India, and screening rates and preventive measures remain low (Van Dyne et al., 2019). While some reports show an increase in ovarian cancer and a decrease in cervical cancers (Maheshwari, Kumar, & Mahantshetty, 2016), given the late stage of disease presentation and diagnosis the mortality from all gynaecological cancers remain high. The decline in the disease rate is offset by the lack of awareness which translates into several thousands of women presenting their symptoms and conditions late in a large population (Sreedevi, Javed, & Dinesh, 2015). The screening programs require rigorous planning and understanding since prevalence has predictors such as age, education, marital status and the role of men as enablers.

Context plays an important role in facilitating preventive measures for women and one of the challenges in India is that the importance given to women's health is largely in the context of childbearing and communicable diseases (Van Dyne et al., 2019). Preventive measures in general, including genetic testing for predisposition of gynaecological cancers, tend to be resisted in India due to economic constraints, social stigma and a lack of knowledge about the efficacy of testing (N. Singh, Shukla, Agrawal, Singh, & Kumar, 2019). One other challenge in India is that there is very limited evidence of the causal or risk factors of gynaecological cancers, and such research is vital for the planning of preventive measures and screening efforts in the country (P. Sharma & Pattanshetty, 2018).

2. 4 Health System and Gynaecological Cancers

Healthcare in India can be understood only partially unless traditional health practices and belief systems are understood. Streams of traditional Indian medicine such as ayurveda, yoga and naturopathy, unani, siddha, and homeopathy (AYUSH) has different forms of practice in many households in India, in addition to gaining momentum in recent times where allopathic healthcare traditionally has had more takers (Rudra, Kalra, Kumar, & Joe, 2017). Evidence shows self-medication and treatment are common in AYUSH. There is very little evidence on AYUSH care-seeking behaviour among women in gynaecological cancer care. Since there are significant variances in the way Indian women seek care for themselves, whether in the private sector or public sector, it is important to understand every link and option they have and might access in the care seeking spectrum (Bhasin, Shukla, & Desai, 2020).

A thorough understanding of the Indian tertiary care in the health system is imperative since most women at an advanced stage of the disease still seek care for gynaecological cancers through the health system which is largely allopathic medicine. Evidence shows that while delayed care seeking and late diagnosis leads to an advanced stage of disease when treatment commences, the Indian health system does have strengths (Pati et al., 2017). For instance, a traditional respect for healthcare providers and a willingness to consider care-seeking when recommended by them, can work well in treatment adherence in gynaecological cancer care. This is especially true when there are delays of disease presentation and time is of essence. Since late diagnosis is a challenge in cancer care, improving knowledge and awareness with the aid of the health system is the ideal step forward to enable preventive practices and better screening, which lead to earlier diagnosis (Narayana et al., 2017). The effectiveness of population-based screening continues to be one of the hardest challenges in India.

Research in this area keeps returning to the conclusion that such initiatives need a holistic knowledge of existing constraints and be implemented at the closest point to the women, rather than with top-down approaches or with requirements for the women to take the first step towards available tertiary care (Gupta, Gupta, Mehrotra, & Sodhani, 2017). This knowledge is additionally relevant where the cancer burden is because of the increase in risky behaviours and neglect that can be corrected or prevented (Gandhi, Kumar, Bhandari, Devnani, & Rath, 2017). Collaborative ventures between allied areas such as public health surveillance systems and registries, awareness through public communication and the health institutions themselves will contain and prevent the rising incidence of gynaecological cancers (Barman et al., 2017).

2. 5Contextual Challenges in Gynaecological Cancers

The psychological and social interplays with such risk factors will reveal directions for the next clinical and social improvements in an overworked health system that often responds to an emergency rather than preventing it before it occurs. The risk factors for cervical cancer continue to be high in India and women’s awareness of such risk requires multi-pronged initiatives with the health system at the forefront (Krishnaveni et al., 2018). Where the healthcare providers are the most important points of contact for women seeking care for cancer, the lack of investment in capacity building, knowledge and training of second-in-line providers acts as a deterrent for women’s optimal use of the health system (Moses, Karthika, & Patel, 2018). This is one of the main reasons why well organised, trained and proactive opportunistic screening efforts are critical windows of possibility for the health care providers managing gynaecological cancers in such a context (Rupani et al., 2017).

Though Western countries have access to the human papillomavirus (HPV) vaccine for preventive initiatives for cervical cancer, this has not wide usage in India because of political, social and ethical concerns (M. Das, 2018). Gynaecological oncology and health care in India need to be understood in the light of all health decisions at an individual, institutional and political level in order to avoid the mistake of assessing complexities in a limited manner. The context is influenced by culture, religion, the location of stigma in society, linguistic variance and ethical specificity—none of which can be underestimated in the study of cancers in India (Broom, Kenny, Bowden, Muppavaram, & Chittem, 2018). Only with such inclusive focus can social norms and gender codes in gynaecological cancer care be interpreted accurately.

2.6 Current Realities and Gynaecological Cancer Care

In 2020 the COVID 19 pandemic had impacted the frequency of treatments and procedures being scheduled in tertiary facilities for different health conditions in India. This in turn severely hampered women’s access to basic care for gynaecological cancers in a timely manner (Subbian, Kaur, Patel, & Rajanbabu, 2020). Restrictions in the form of travel, availability of healthcare providers and limited treatment procedures made an already fraught health system more difficult for women. Such situations increase the risk of challenges for women both in terms of access to standard care and the scope for circumventing blockages to access healthcare when they need it the most.

In a country with diverse backgrounds, belief systems, practices and educational levels, the knowledge and awareness women have may vary considerably among subgroups. Myths and misconceptions about a preventive measure combined with lack of awareness creates hurdles to acceptance of new methods of prevention in cancer and willingness to try them (Joshi, Chaudhari, & Chaudhari, 2020). Sensitivity, knowledge of the context and understanding are key in presenting options to women and these options need to be customised according to the specific needs of subgroups being screened or seeking care in the cancer continuum (Kung et al., 2019).

The degree of diversity in the country requires interventions to look at cost-effectiveness vis-à-vis the most resource strapped families that require support and multi-layered innovative approaches in prevention or diagnosis (Akashdeep Singh et al., 2020). It might mean the same method is available generically at reduced costs for some women and at a higher cost for others who can afford the treatment. Such options need to be made available at the grassroots level for different age groups of women when the first stage of screening for cancer commences, since the maximum resistance exists at the community level at that time, where risk is perceived as low. Such sensitivity is required at multiple stages of treatment in cancer since even after the commencement of treatment during surgery or radiotherapy, costs of care might trigger a decision to discontinue with treatment (Munshi, Tharmarnadar, & Mohanti, 2019).

2.7 Culture, Holistic Care and Gynaecological Cancers

Social norms, patriarchy and hierarchy in the health system in India can occasionally cause other unanticipated challenges, such as unindicated hysterectomies to mitigate the risk of a gynaecological cancer (Davis, 2019). Fears and apprehensions in normal health-seeking behaviour can increase since women can fear that a hysterectomy would be recommended when there is no need for one. Such situations are common among women who seek care with few financial resources and support networks, because their informed choices are completely dependent on the healthcare providers who might not always make the best decisions for them in the care trajectory of cancer (Kamath & Kamath, 2020). The situation is similar in options that may be in conflict with cultural practices as seen with mishaps such as top-down approaches in the promotion of HPV vaccination among adolescent girls (Sankaranarayanan et al., 2019).

Stigma is a strong reality among cancers, particularly breast and cervical cancers that women face but literature shows that there is inadequate attention to it especially in the context of bias related to transmission, disclosure, personal responsibility for having caused cancers and fears related to cancer (Nyblade, Stockton, Travasso, & Krishnan, 2017).Despite cervical cancer being a leading cause for death among women in India there is a severe need and dearth of integrated initiatives in communication, education and awareness that can aid in addressing prejudice and information deficits in the country (Taneja et al., 2021). Though the cervical cancer screening programme is a few years old India there are multiple issues the context faces that impedes its progress. Some are systemic issues such as staffing, infrastructural, evidence gathering blocks in the health system while others are awareness and access constraints (Dhillon et al., 2020).There is limited research available in the country that records patients preferences in caregiving and support. The existing evidence shows that there is clarity among patients about what they need from each person in their lives be it the healthcare providers, family members who are personal caregivers, other patients or relatives and friends (Chawak, Chittem, Butow, & Huilgol, 2019). There is an urgent requirement for more such literature that captures the preference and needs of patients. One such is the communication that exists in the cancer care continuum between patients, personal caregivers and healthcare providers all of which are critical but tend of neglected (Datta et al., 2017). Communication skills between these stakeholder groups hold invaluable insight that not only determines types of care in the clinical and personal realms but also ways in which such communication can be enabled and enhanced. Another aspect that is sidelined in India are the concerns on sex, sexuality and body imaging that accompany treatments related to gynaecological cancers. A study shows that these are areas that have considerable silence surrounding both by healthcare providers and women do not voluntarily ask for information due to the cultural norms that surround such sensitive subjects (Kaur 2013).

Cancer care research in India cannot be separated from overall research agendas of health inequity research. Research priorities and agendas are currently determined by several factors such as the pathways of inequities, study of the environment, the role of the health system and the efficacy of interventions (Ravindran & Seshadri, 2018). While such priorities may indirectly focus on aspects related to cancer care they tend to neglect or ignore issues such as the role of allied health services, the personal circumstances of the individual and family unit and the specific forms of burden that tertiary care experiences in cancer management. Unless studies focus on such dimensions, cancer research will not throw light on the interplays between the individual and the inclusive collective which determine the most vital decisions in the gynaecological cancer care.

One way to address such inequities and apprehensions is to increase accuracy of testing methods. A second way this can be achieved is with capacity building of frontline workers and healthcare workers who are often the first point of contact for women in disadvantaged circumstances (D. Sharma et al., 2018). Such efforts can provide an egalitarian platform for all women to seek care with knowledge and support provided on their own terms. Technology similarly can aid in access, reach and informative exchanges during crucial stages such as screening so that valuable time is saved for women who need to immediately access cancer care (Bhatt et al., 2018).

The role of culture in health decisions and behaviour cannot be underestimated in India. The lens of cultural hegemony in health information typically tends to present culture as a dominating force in the lives of individuals who may face subtle or direct coercion to follow the norms it sets. Yet, such study gives too much focus on the external information that is being imparted, and how it gets hampered by cultural practice, rather than the manner and intent of information exchange, the withholding of or disclosure of information, which may actually have greater significance in terms of cultural implications (Van Hollen, 2018).

The national health protection mission has attempted a large scale linkage between cancer registries in different parts of the country and systems of treatment (Kalita & Krishnatreya, 2019). One of the largest public health initiatives, the National Cancer Registry Programme makes an assessment of cancer registries data in India shows the correlations and variance of cancer trends by several demographic variables across the country including by sex and geographical spread (Mathur et al., 2020). Among women's cancers importance has been given in India to the study of breast and cervical cancers and there is emerging data on the trends and patters in the two cancers. (Sathishkumar et al., 2021). There is very little data available on the communication that occurs between women and their households in India though this is an area of importance in global literature (Surbone, 2013). This study seeks to highlight this need in the context specifically in the context of non-communication and silence surrounding the disease.

Public health initiatives in India for gynaecological cancers deal with several challenges in their attempt to mobilise, create awareness and facilitate movement of women towards screening and treatment options. Evidence shows that several cervical cancer prevention efforts have been ongoing for several decades their impact is far less than intended (Bhatla et al., 2021). Vaccination efforts for young girls, screening among women and treatment for women diagnosed with cancer have been priority areas in such initiatives. The deterrents for such efforts continue to be cultural barriers, socio-economic factors, awareness and resource constraints. For instance the HPV vaccine has faced several challenges related to norms surrounding sexuality and vaccinating young unmarried girls. Though the National Cancer Control Program began in 1986 and has been implemented in multiple ways since then, these blocks have adversely impacted a greater success in cancer control. The National Cancer Registries Programme has grown from strength to strength since its inception in 1982 with a comprehensive record and collaborative network between institutions offering care for cancer. Such large public health initiatives require the cooperation and support of professional associations, non-profit organisations and community based organisations that play a pivotal role on mobilisation, awareness and implementation of larger scale programmes in their communities. The public health initiatives for cervical cancers have definitely benefitted tremendously from their support. Regardless of multiple and sustained efforts such as these the awareness, willingness to seek treatment and treatment adherence continue to remain low.One of the other factors is that focus has been given to cervical cancer and breast cancer in awareness programmes with no literature on other gynaecological cancers women are affected by.

The role and integration of gender in medical education and practice is another important project that has looked to build equity in women's health issues in the country. Clinicians in the Department of Obstetrics and Gynaecology in the Aurangabad Government Medical College Hospital administered these changes through training and teaching, towards extremely efficient functioning in "gender informed health services" (Stories of Change, 2019-2020). Rural Women's Social Education Center is a non-profit organisation in India that has initiated several training, education, service provision and capacity building modules on gender, reproductive and sexual health. Topics and awareness introduced by such initiatives are very relevant as precursors for further specific modules on gynaecological cancers, especially in rural India where facilities are few and far between (RUWSEC, 2022). In India, families and health providers choosing to collude to "protect" the interests of patients comes from a cultural paradigm that is less understood in the Western paradigm where knowledge and information may take precedence over ensuring someone else's wellbeing without their direct consent. However, in India a woman can perceive strong support and love in such collusion where, rather than exclusion, perceptions are of protection and enablement. The role of culture and social norms remain vital from the stage of screening to diagnosis and interpreting them accurately is crucial. For those reasons, screening initiatives need to work with existing health systems in culturally appropriate ways, instead of top-down or paternalistic approaches in information dissemination and promotion of screening (Anderson de Cuevas et al., 2018).

The manner in which women seek and work with health information has a foundation in their culture and working with that cultural heritage is the first step for efficacious health information in gynaecological cancers (Marfani, Rimal, & Juon, 2013). Evidence suggests that culture is not separate from identity or individuality and women carry their acculturation wherever they go and reside (Howard, Bottorff, Balneaves, & Grewal, 2007). Several factors have impacted cancer management in India such as varying national and state government priorities, health systems, international agendas, historical priorities, development politics and advocacy groups shaping the course of cancer care and cure through the decades (Sivaramakrishnan, 2019). India not only has a context of strong dimensions of cultural influence but also a context in which Western medicine flourishes as a mainstream line of treatment for many Indian women. Effective juxtaposition of the two realities that are both a part of life is essential for any long-term treatment and cancer care most clearly falls under this category.

Stigma and fatalism surrounding cancer is strong and their interplays with cultural patterns further aggravate women's situations when they seek treatment especially when dislocated by geography. Several women leave their primary residential areas in order to seek treatment in cities where tertiary facilities function. Unless there is a deep understanding of the cultural heritage a woman carries as she attempts to access healthcare, the services rendered to her will at best be partial and misunderstood. A holistic understanding cannot fully separate women, cancers and culture from the tertiary services, and barriers related to gynaecological cancer care. The literature shows the challenges of tertiary services need to be weighed with as much care and attention as their accountability for cancer service and management (Mahantshetty et al., 2012). This present study has been designed on this premise: a woman’s health is vital but is not separate from the burdens of her family or the constraints of her healthcare providers or the cultural paradigms she functions with in her determinations and choices of care. Accountability and responsibility in access is seen as shared by her as is the experience. It is with this lens that this present research has viewed and decoded what participants have shared in their interviews.

2.8 Summary of the Chapter

This chapter focused on context-specific patterns in gynaecological cancers in India. The literature presented is pertinent to the specific challenges of the disease burden in India. The review of this literature has guided the rationale for the aim and objectives of this study. The next chapter considers the ethical enquiry that a study of this nature encounters in its methodology from commencement to completion of the research.

Chapter 3

The Research Methods and Ethical Issues

The conceptualisation of the chapter had two thematic focus areas.

1. To present the audit trail of the research conducted with different aspects of study design, ethical oversight, vigilance and intent.
2. To record the experiences of the researcher during the implementation of the study with regard to ethical enquiry, dilemmas and responses.

Undertaken in consultation with and the supervisory guidance, the central theme of this paper is the continuum that research ethics needs to be nested holistically within a study rather than in predefined frameworks and protocols that form the ethical guidelines of a research study. This chapter delineates these aspects along with the methodology of the study which, by itself, is crucial and foundational for setting the tone of the ethical responsibility of such research. The article highlights the risks of separating the research from operational ethics since all aspects of the journey require the accompaniment of ethical vigilance.

The chapter has been written in the format of a journal article. This chapter will be submitted for publication to the ***Journal of Ethics and Social Welfare*** with the title:

Ethical issues in research with women cancer patients in India.

Abstract

There are several complex dimensions to conducting public health research in a resource constrained setting. While evidence discusses them in the research contexts they are set in, few perspectives focus on the research process, which can pose ethical risks, uncertainties and enquiries. This article explores the ethical aspects in research through a study focused on gynaecological cancers in India and the role of health promotion in risk-mitigation. The institutional follow-ups for ethics clearance for the study began in 2017, and the data was collected between 2018 and 2019. The study has shown that the ethical aspects in such research cannot be restricted to traditional research categorisation or stages such as conceptualisation, methodology, implementation and analysis. Rather, the researchers should give priority to ethical inquiry in all aspects through the research engagement. It is imperative to have an anticipatory and preparatory checklist of such issues. However, it is more important not to separate ethical considerations from any aspect of the research or researcher's role and responsibility from start to finish. Such inherent inclusion will provide the foundations of an enabled research environment where ethics in research methods will be natural, proactive and holistic.

Keywords: Ethics, ethical enquiry, ethical dilemma, research integrity, ethics and methods

3.0 Introduction and Background

Clinical care is inextricably linked with research since advancements in medical science, knowledge and best practices are nested in research (N. Das & Sil, 2017). The ethics of clinical care as a result tend to be dynamic and interconnected with the norms and changes in societies, economic contexts and cultural realities where they are situated. Research conducted in such settings needs to be doubly conscious of this relationship since study designs and protocols for their administration can vary not only according to context, but by the times in which they are conducted.

A pivotal issue that confronts research on cancer is the standard of care that is available to its potential participants who are patients and the ethical ramifications when such care is not made available. Clinical trials that test and study efficacy of treatments and interventions tread a grey area in terms of the ethical accountability towards the control groups vis-à-vis the study design, fair accessibility to available clinical resources and care (Srinivasan, 2013). Such scope can be misused in the provision of standard services. For example, voluntariness of research participation can be compromised by the need to access services referrals and care provided in research studies, especially in settings where there are resource constraints, scarcity of data and less rigorous protocols for research.

The role of institutional ethics committees is invaluable. Since many of the committees in health institutions are comprised of health professionals, exposure and familiarity to research ethics and pertinent training of such individuals is critical (Ong et al., 2020). Training needs, nature of competencies and priorities for such committees may have evolved over the years but the importance of their role in clinical care, best practices and the scope for research remain unchanged. While most countries have recognised the criticality of such committees, it is extremely challenging for standardisation of research protocols that are often divided by design and priorities of individual countries, regions, institutions and individual healthcare professionals and researchers (Walanj, 2014). The Indian Council of Medical Research plays a critical role in both development of protocols for research as well as regulatory guidelines for individual ethics committees across the country. Under these guidelines there is requirement by organisations conducting biomedical research to adhere to common protocols set by the ICMR especially in relation to confidentiality, informed consent and working with vulnerable populations along with accountability in research (Bagla 2000).

The Indian Council of Medical Research has articulated some very essential ethical guidelines for research in India. These range over a wide range of issues some of which are *the essential nature of engaging human participants, the voluntary nature of research participation, the fair balance of benefits and risks in engagement, social responsibility in not creating or reiterating existing divides and ensuring privacy, confidentiality and accountability* (ICMR 2017). These guidelines speak at length about responsibility in research and ways to ensure them in situations of inequity and divide along with the role of the research scientist as one of significant responsibility. The protection of human subjects is discussed in a nuanced and lucid manner and reiterated as critical in the research journey from commencement to completion. The ICMR also attempts to differentiate between areas where research needs to take mandatory steps and those where the spirit of the guideline needs to be administered in subject specific ways. The complexity of collaborative research is also discussed in the even distribution of burdens and benefits and in the determining of acceptable standards of care. The role of the Ethics Committee, its responsibilities, convening of ECs, regulations, capacity building, independent functioning and monitoring are all included in the guidelines as are the distinctions between clinical trials and public health research. In public health as well as social and behavioural research the ICMR has discussed the range of subjects, types of research as well as the role of ECs in regulatory oversight in the research implementation. While all these guidelines are theoretically available, the individual institutions are not in a position to adhere to all of them due to a variety of constraints such as time, staff, regulatory bodies, capacity and knowledge systems. Several research studies get conducted with the collaboration of research organisations, non profit organisations and hospitals in India. It would not be incorrect to say that their research activities are not fully informed of these guidelines nor nested in the fundamental constructs they promote. There is much inequity in India both in terms of regions and individual institutions. This research speaks from the perspective of experience of the researcher in her engagement in this specific research journey. Though the ICMR ethical guidelines for research are comprehensive and pertinent what needs to be considered here is the application of them by individual institutions.

The diversity of composition, imbalances in resources, access and customised protocols specific to an institution can make these guidelines secondary even when applied. Regulatory systems are not standardised and this makes it harder especially for hospitals in the private sector to adhere to them. Ethics committees are difficult to convene in institutions where there is a severe staff and other constraints. Where they exist, other research challenges such as pressure to review multiple studies (including external research studies) and to supervise protocol adherence become difficult in the face of limited capacity and training needs of researchers. In short, while ICMR has a proactive set of guidelines for different kinds of research, the consistent translation of these guidelines to research practice is not widespread among health institutions.

Registration of ethics committees is a requirement for the research review process and when there are resource and time limitations, few hospitals have the scope or willingness to cater to external research studies. In India, there are situations where there is paucity of time for healthcare researchers to undertake their own internal research studies in a health institution, let alone review research from outside (Walanj, 2014). Valuable research insights on psychosocial aspects of cancer care are extremely limited due to this limitation because independent public health researchers from outside may have no option but to present their studies for ethics review to clinical committees. The delays by the committees are understandable since they deal with multiple commitments and dearth of staff time. Neglect from these committees is also because research participant protection is not considered holistically when ethics committee procedures are not standardised, there is a lack of regulatory mechanisms and oversight, accreditation is inconsistent, and training of the members vary according to the institution (Thatte & Marathe, 2017).

Some of the major issues that impact the effective functioning of such committees in India are limited resources and formal and structured capacity building initiatives, as well as the fact that most members are volunteers with other full-time responsibilities (Patel, Sridharan, & Patel, 2016). Regulatory mechanisms and governance for ethics committees are either inconsistent or loosely defined and as a result time management and allocation to specific research evaluation is contingent on members' availability. It would be very helpful to have legal expertise guide the evaluation of protocols since there is a close affinity between law and ethics in certain types of research. For example not all issues that are legal need necessarily be ethical towards a participant. The need to understand how to bridge what is right by law with what is best by ethical guidelines is essential with research with vulnerable populations. The areas this would help are related to age or educational qualifications or social hierarchies of participants which impact decisions and participations. A married minor though an emancipated minor by law could be under pressure from guardians who in turn make decisions that are not suitable for her. Such gaps are more due to the systemic challenges organisations and individuals deal with rather than by intent. These issues are further aggravated by differing institutional policies and lack of centralised regulatory mechanisms for the committees. Ethical conflicts may also arise in collaborative sponsored research, adaptation of protocols designed for a resource endowed setting and the cultural appropriateness of review and response to ethical aspects that impact human subjects (Patel et al., 2016). While there are several challenges ethics committees in India confront, there is also a deep commitment to the enablement of biomedical research that has occurred over the last two decades. The site where this study was conducted is one of the major urban centers in India where regional cancer service exists. More than four decades old, it is located in a metropolitan city in southern India.The hospital is one of the larger private hospitals offering oncology care at lower rates to populations all over the state as well as from other states. It has more than 1600 beds and well-trained specialists with significant experience in their fields of work. It has advanced oncology care with specialists and is a multi-specialty hospital with a range of services as we as a focus on education and a teaching hospital. Young professions trained in the educational arm of the hospital also do internships in the hospital gaining tremendous experience. The perceived credibility of the hospital has a key role in participants' considering speaking to a researcher. Participants were women diagnosed with a gynaecological malignancy and admitted for long-term care in the gynaecological department ward of the hospital. All women in the study were more than 18 years of age.

The ethical issues in cancer research cannot be understood without a thorough understanding of the systemic issues in healthcare in India and its problems in services and care provision (Kapoor, 2011). The first dimension in this discernment is the sociodemographic variance caused by whether a patient is from rural or urban India since the experience of access and experience of care are determined by this residential reality. Cultural appropriateness of health education, information access provided to participants, innovative methodology in health awareness campaigns, localised message mechanisms and role of non-profit organisations and key informants in the communities all have equal relevance in research linked to cancer education. Cultural appropriateness of health education is whether a message or campaign is suitably created or tailored to reach a participant efficaciously in a language, format and medium that is acceptable to them. Information access of participants change drastically based on several factors such as their gender, age, education, mobility, exposure, urban versus rural residence and nature of the information—its subject, content and social acceptability.

Innovative methodology is closely linked to cultural appropriateness since the two co-exist. Methods of reaching women in cancer research will need a presentation format that is distinct and unique but simultaneously appropriate and in keeping with the social norms the participants adhere to. Localised message mechanisms are ways in which the message is taken to the women directly rather than expecting them to make an effort to receive the message. The role of a non-profit or community based organisation becomes important here, since they can aid the process of information dissemination without adversely impacting the comfort of the participants in the community.

Research on the psychosocial aspects of gynaecological cancers has multi-layered complexities in resource poor developing countries (Dreyer, Mnisi, & Maphalala, 2013). These include staff time management with clinical responsibilities and the conduct of research; space constraints to ensure confidentiality, capacity and availability of staff to coordinate research, infrastructural resources within the health institution where research is conducted, internal referral systems and inter-departmental communication systems as well as ethical and unobtrusive separation of research participants from other patients.

It is necessary for considerable planning from the research end to ensure that these constraints do not hamper the interests of the patients, clinical responsibilities of the institution and the research itself. Determining the research relationship between the institution and the research team is critical in this so that adequate emphasis is placed on the rapport built with the institution, participants and the individuals who play a role in the research continuum in a clinical setting that is hard pressed for time (Arvidson, 2013). The robust nature of such a relationship is contingent on ongoing rigorous self-evaluation measures in the research process that are inclusive, egalitarian and corrective in nature. Of these a crucial acknowledgement is that clinicians and cancer care provision in a developing country are confronted with several ethical dilemmas on a day-to-day basis resulting from agenda setting in health priorities, economic challenges, access issues, awareness, stigma and the cultural norms that impact their disease management (Ghose, Radhakrishnan, & Bhattacharya, 2019). These situations may sometimes overlook the needs of ethical oversight of cancer care research conceptualised or implemented in the same setting.

Research rigour and ethical responsibility rest heavily on the researchers conducting the study, especially in an international research study. Such research is accountable for establishing clear protocols with a complete understanding of the available standard of care for study participants (including control groups where applicable) along with clarity on applicability, relevance and use of guidelines that are directly translated from another research context (Ortega, 2013). Some of the ways in which this can be undertaken are with comprehensive reviews of the consent administration, sensitivity towards the decision-making context of participants and the perception and barriers to choice and withdrawal from participation in a study.

The reality of women accessing and negotiating healthcare in an urban setting in India is typically fraught with several layers of vulnerability that are interlinked with clinical hierarchy, sociodemographic factors that are disadvantageous, gender norms that are restrictive, the variance in public and private healthcare institutions, the norms surrounding patient care and perceptions surrounding healthcare (Raman, 2014). Additionally, cancer research in India is dynamic, complex and diverse thus making it essential for processes in research to be streamlined with care and caution (Sullivan et al., 2014). Though cancer research has increased significantly in the last few decades there is less emphasis on cancer epidemiology; and neglect of gynaecological cancers and palliative care in cancer. Most relevant is the much-needed qualitative research that highlights the cancer pathways and psychosocial aspects of cancer, especially women's cancer, which remains neglected and is an under-researched area.

3.1 Research Design and Methods

Use of Qualitative Case Study Methodology

This study used qualitative methods and was undertaken with Indian women affected by cancer, their caregiver and clinicians. The qualitative research design permitted for a rich understanding and in-depth exploration of cultural and the multiple complex issues impacting all the participants in the cancer care continuum (Liamputtong, 2019). Qualitative research encompasses the following: 'understanding research participants' meanings, investigating the influence of the specific contexts in which the individuals and activities studied are situated, elucidating the processes by which these meanings and contexts lead to features or outcomes, and explicitly incorporating the subjectivity of the researcher' (Maxwell & Reybold, 2015, p. 685). A descriptive case study approach because it is an "empirical method that investigates a contemporary phenomenon ('the case') in-depth, and within its real-world context" (Yin & Campbell, 2018, p. 15). A case is a situation, unit, or anything such as a person, a family, an organization, or a site which could be perceived as micro (individual), meso (an organization), or macro (community) (Schwandt & Gates, 2018).

Using an exploratory, qualitative case study approach in a real-world setting, the intent of this study was to give 'voice' to the participants especially the women. A case study approach was the methodology of choice as its main characteristics helped bring the realities of the participants' experiences to the reader and is a method now widely employed across disciplines (Noor, 2008). There are several key components of a case study approach. First, it taps into the viewpoints of participants (the women, their caregivers and those treating them); second, it allows participants to describe their multiple experiences in their own words. It is the preferred methodology when there is a need to ‘closely examine contemporary events’ (Yin, 2014).

The relativist ontological approach was also used for the study. Within relativist ontology, there is the understanding that reality is a subjective experience that is singularly associated with the individual, and their way of thinking, there is an overlapping of reality, and human experience, reality is human experience and human experience is reality. As there are multiple individual experiences, so there are multiple realties for the individuals, which was especially true for the women participants of this study (Levers, 2013). An emotionally demanding situation, such as dealing with cancer, can elicit responses or confidences that a woman may choose to refrain from confiding in a structured format. It becomes the responsibility of the researcher to foresee such situations while refining study instruments so that the line of questioning remains open and cognisant of the participants’ interests at the same time (Belotto, 2018; Guest, Namey, & Chen, 2020).

The methodology in qualitative health research can be a risk or a benefit depending on how a researcher administers consent and uses a particular technique in a setting. However, the other side of qualitative methods is the flexibility that allows the researcher possible advantage in gaining access to topics not typically permissible in a more structured method. Defining vulnerability of participants accurately and comprehensively in a research setting is the first step in ethical conceptualisation and design of a study (Mudur, 2010a). Semi-structured in-depth interviews were conducted with patients, personal caregivers and healthcare providers in this study. The rigor in this research was determined by the four criteria assessment “credibility, confirmability, dependability and transferability” which were critical vis-à-vis the depth of the data collected in this study rather than the sample size of the interviews (Forero et al., 2018).

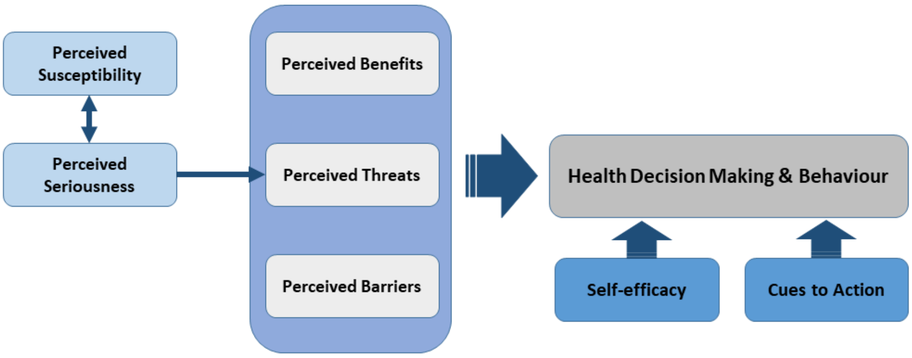
3.2 The Frameworks underpinning the Study

The health belief model (Rosenstock, 1974a, 1974b) and the theory of communicative rationality (Healey, 1992; Sheikh & Porter, 2013; White, 1995) were the theoretical frameworks used for this study. The former has been applied to study the perceptions of barriers and benefits in health decision-making. The latter has been applied to better understand the collaborative cues in such decisions and behaviour. The frameworks are presented below to illustrate the constructs that have been used subsequently to propose a collaborative efficacy of care model based on study findings (presented in chapter 8). Since these models have been discussed in the subsequent chapters only an overview of the frameworks is presented here. The next section will detail the theoretical underpinnings of the study and illustrate with examples their pertinence to the research methodology. The frameworks have been discussed with examples of their application in other research contexts to show the range of application they have.

The Health Belief Model

The health belief model (Figure 3.1) has been used across disciplines and contexts to study the cues for individual health behaviour change. The constructs of the model are predictive of behaviour and self-efficacy at an individual level which in turn are impacted by the contextual and external association of cues to action.

Figure 3.1. *The Health Belief Model*



After: Constructs of the "health belief model" (Rosenstock, 1974a, 1974b; Rosenstock, Strecher, & Becker, 1988)

Over the past two decades critiques have highlighted the limitations of the health belief model in terms of its applicability across health behaviours and context (Poss, 2001). Of these, one of the major limitations is the lack of focus on the inter-relationships between the constructs in the model because the functions are studied independently. In a health behaviour study of gynaecological cancers, the nature of associative relationships between the constructs in a framework is fundamental to understanding the journey of both the individual and the collective. Gynaecological cancers in India are about individual women dealing with cancers, but they are also very much about their stakeholders in the personal realms, the medical community and collectives of other women who are neither diagnosed nor in the current spectrum of study.

The health belief model proposes that the responsibility of health behaviour is solely on the woman, which is not the case in health decision-making in many contexts, including India (Tanner-smith & Brown, 2010). Yet, the health belief model is one of the most appropriate frameworks in its focused centrality of individual behaviour (Manasco, 2008; St Hilaire, 2016) to tap the conflicts a woman has in her journey through the cancer continuum with her perceptions of benefits and barriers that travel with her throughout the process of evaluation, decision-making and treatment.

The Communicative Rationality Framework

While the tenets of the health belief model have been very important in the study of disease management in the context of focus, they required a more cohesive theoretical underpinning to work with them. The communicative rationality framework serves that purpose very well. Again, in the present study it would be difficult for us to measure the role and influence of the “cues” to an individual’s actions and cultural hegemony (Poss, 2001) without the acknowledgement of the specific collective that the communicative rationality framework provides. The communicative rationality framework (Figure 3.2) is a behavioural paradigm that looks at individuals in synchronisation and connection with other individuals and collectives they are associated with.

Figure 3.2. *The Communicative Rationality Framework*

- *Acknowledgement* of the possibility of legitimacy of alternative “frames”.
- *Effort* to bridge communicative divides by conveying one’s own and listening to the other’s perspectives.
- *Deliberation* and *debate* of differences in rationales for action.
- *Openness* of the deliberations.
- *Inclusion* of different participant actors in deliberations.

After: Constructs of “communicative rationality” (Healey, 1992; Sheikh & Porter, 2013)

The communicative rationality framework is nascent in its application and has not been tested in multiple contexts. However, it has begun to be applied across a wide range of human behaviours that require collective action such as public policy, economic and social reform, and governance. Its significant relevance in health is beginning to be recognised globally since health action and interaction are now seen more from a collective/contextual paradigm than from the traditional top-down approaches of studying individuals in their contexts (Varghese, Kutty, Paina, & Adam, 2014). Health behaviours studied as interactive collectives also impact policy in a context better (Hodge, 2005). For this, the theoretical underpinnings need to offer platforms of focus on the collective while individuals traverse their health journeys (Bock, 2013). The framework also reveals that health decision-making does not occur in isolation but rather juxtaposed in knowledge pathways, medicalisation of care, information assimilation, social and personal beliefs, consensus forums and norms of rationalisation (Hodge & Perkins, 2007). The communicative rationality framework allows the study of collaborative, collective consensus and networks of interaction within disease identification, progress and treatment.

The health belief model focuses on the individuals grappling with the susceptibilities of health both at internal and external levels of cues, responses and decision points. Together, the two frameworks provide robust theoretical underpinnings and constructs that are pertinent and applicable for the study of gynaecological cancers in India which by itself is a less studied health behaviour.

These frameworks provide a foundation for understanding two important focal points of this study: 1) management of gynaecological cancers, which is an understudied area of behaviours, and 2) the role of collectives, networks and support systems in management of cancers in the Indian context which also forms an area with very limited data. The communicative rationality framework does not look at individuals separately from collectives in a context. Instead, it looks at behaviours that occur in a joint social space and framework and predicts how they get impacted at an individual level. Both the health belief model and communicative rationality framework are used to predict individual behaviour.

However, the former is used to predict individual health behaviour change with external cues and the latter is used to predict collective health behaviour expressed at individual levels of change. Both capture very different aspects of a context and behavioural prediction. In this research, the reason they play an equally significant role is because gynaecological cancers are both about self-efficacy at an individual paradigm and support from key stakeholders at an associative one. Together, these frameworks have been effective in capturing the perceptions, barriers, support networks, efficacy, cues and the methods of inclusion in health behaviour recommendations in this study.

3.3 The Research Journey - the Audit Trail

The study setting

The patients (*n* = 15) and personal caregivers (*n* = 10) were from one private tertiary referral hospital in an urban setting in South India offering subsidised care in the city. The healthcare providers (*n* = 35) were from three different tertiary hospitals (including the institution where patients and personal caregivers were interviewed), cancer support services and a community based organisation. The tertiary hospital where patients and caregivers were recruited caters to middle and lower socio income groups and is one of the leading specialty institutions for oncology care. It is accessed by patients across the region and country. The second institution offers advanced care among the private institutions in the region and the third one offers subsidised care and palliative care to patients across the region and is run with the aid of religious endowment and support. All three hospitals are leading institutions in advanced oncology care.

The researcher approached the heads of the oncology department of these institutions for approval to conduct the study in the hospital. A thorough review of the study documents were completed prior to approval being given to approach study participants by one institution (the first one described). The institution granted approval to meet women admitted in the oncology ward for long-term care. They however did not give consent to approach patients at the outpatient department. The reason they cited is women waiting for final diagnosis are already in a state of tremendous stress and that would not be an appropriate time to speak to them about cancers.

The head of the department identified key staff to be the liaison for the researcher during the recruitment process. At every stage of the study a staff person was available to consult with, or defer or refer to if there was any perceived need. At the same time, there was complete autonomy for the researcher to conduct the interviews with integrity and adherence to protocol. There was tremendous support from all the staff despite their own time and resource constraints. Some key issues were noted.

First, the liaison staff for the research played a critical role in managing all aspects of the recruitment. Cancer care has extremely stringent time requirements. When and whether a woman can be approached can be determined only by the insiders of a tertiary facility. The researcher worked with and around the timelines of the institution and women because that was the only way the study could proceed. This meant making multiple visits to recruit patients and sometimes stopping after consent or rescheduling at the last minute. Willingness to do all of this without losing focus was of paramount importance. Second, a thorough review of the documentation and ease of administration was another key factor. Women and their families are already in a compromised situation in terms of their attention to detail. Documents need to be simple and easy to understand. This rationale is also applicable to healthcare providers who are under high levels of stress and time constraints. Making the consent forms easily readable is a courtesy essential to these providers. Third, not falling into the "number trap" in participant recruitment process is essential. Even a few in-depth interviews are invaluable for the type of insight and relevance they hold. The thoroughness of the interviews is critical for data integrity. Body language, comfort and ease with which discussions occur made more of an impact during the exploration of interview themes.

Recruitment and training of the local interviewer and translator

Introduction of the researcher, interviewer and the study during the recruitment clearly will ensure that participation commencement is done with lucidity. The interviewer hired had worked with the researcher for several years on other research studies and was trained in conducting confidential, in-depth interviews in Kannada. It also sets the tone of the nature of interaction between the participant and the study. Clarity in study scripts and documentation for this purpose serves as a strong aid at different stages of introduction to participants.

Finally, a crucial support for an audit trail of such research is to have ongoing quality checks of the transcripts and study documentation. The researcher and the interviewer did this continuously so that there was an opportunity to correct or rectify omissions and missing data while the participant was still available for clarification.

3.4 Recruiting the Women Participants

Women diagnosed clinically with a gynaecological malignancy were approached for consent to participate after approval from the oncology department of the private tertiary referral hospital to conduct the study. The hospital caters to patients from lower socioeconomic groups both across the state in which it is located and from other states in India. It has a comprehensive specialty centre for oncology services and research, and is also a teaching hospital. The patients who had a gynaecological malignancy were recruited with the support of clinicians in the department. The researcher independently approached them for consent at times approved by the hospital so that there was no subtle encouragement or pressure perceived by patients due to the clinicians' presence.

Patients flagged as too ill or emotionally disturbed by the clinicians were not approached for consent in the study. At every stage the clinician and nurse in charge were consulted on the most convenient days and times to approach a patient. The department in the institution considered it appropriate that only the women admitted into their wards for extended durations of treatment could be approached for participation. Patients who were consulting providers in the outpatient departments of the oncology department were not contacted since clinicians assessed that they might be awaiting or undergoing investigative tests and perhaps experiencing high levels of emotional and psychological distress.

When prior approval was given by the clinician in charge of the ward, the interviewer first met the nurse in charge to confirm that she could go ahead and speak to women in the ward on that day, as per the pre-screened criteria was to ensure there were no other planned or unexpected medical appointments for the short-listed patients that could be disrupted by the research process. On occasion, cleaning in the wards or other inspections occurred at short notice and the researcher, along with the interviewer, waited outside the ward until the nurse in charge gave permission to continue the research.

After reviewing the list given by the clinician with the nurse in charge each day, the interviewer (who accompanied the researcher for all the Kannada and Tamil interviews and had also done the Kannada translations) and researcher introduced themselves to women in the ward individually. After introduction, the woman was first asked if she was willing and able to speak for a few minutes. If she agreed she was provided a brief study overview. It was clearly stated that the conversation was completely voluntary and separate from the clinical process in the hospital. At times a woman was willing to speak after the researcher’s introduction but the personal caregiver was unwilling for her to participate (due to either expressed or unspoken apprehensions). In such cases, the researcher and interviewer would respect the wishes and wait until a final decision on participation was made jointly by them. They were also advised specific questions or clarifications could be discussed further.

Once a woman consented to be interviewed she was asked after the interview if her personal caregiver may be approached for consent to participate. The consent process clearly delineated that responses of both the woman and the caregiver would be kept confidential and not shared with each other. If the woman refused permission to approach her personal caregiver they were not followed up by the researcher.

During all the interviews the patients were periodically asked if they felt well enough and comfortable to continue. If a patient indicated fatigue or need of a break or rest the interview was immediately concluded or rescheduled at the interviewee's preference. Similarly, during the personal caregiver interviews there were occasions when the caregivers expressed angst or need to return to the patient or attend to something related to her needs. The consent process comprehensively addressed the voluntary nature of participation and their ability to let the interviewer know any time they would prefer to stop or take a break from the interview process.

3.5 The Consent Process

The consent process was thorough and comprehensive but simple. It was designed to ensure that women, their caregivers and providers were able to make a fully informed decision about their participation even when in a state of ill-health, or when engaged in caregiving or urgent responsibilities that may cause them to have reduced levels of interest, attention or focus. There was ample opportunity for them to stop or question and clarify. The consent process also pre-empted any concerns they may have about privacy, confidentiality and respect for their responses and perspectives. In order to ensure clarity of the research purpose for the patients and caregivers (since the interactions occurred in the health institution where they also received health services) the consent process explained the independence of the research and that no clinical service was involved.

The consent process reiterated that participation did not have any impact on their existing services, benefits or relationships with the institution and providers. The researcher clearly explained to participants that any questions or enquiries beyond the jurisdiction of research or related to their health conditions needed to be directed to their physicians and nursing staff for appropriate responses and information. Participants could withdraw any time during the research process.

3.6 Conducting the Interviews

In all, 15 patient interviews, 10 personal caregiver interviews and 35 healthcare provider interviews were conducted. The recruitment of the participants was a multi-phased effort in order to make it least intrusive for them. The interview guide was used for the facilitation but equal importance was given to the issues participants were most comfortable to discuss. The context in India where the interviews were conducted had minimum resources in a tertiary hospital though it was comfortable and confidential to conduct the interviews in. The interviews with the patients and personal caregivers were conducted in a designated room of the department close to the ward so that the patient was able to walk there easily and independently. There were a chair for each person in the room and good ventilation due to a window. This was the research space allocated for the interviews by the hospital also because it was very close to the women’s ward. Women who did not feel well enough to walk to the research space were not included in the study even if they expressed interest and willingness to speak or be interviewed from their hospital bed in the ward. It was not feasible to conduct interviews in the wards for privacy reasons, and attendants were always present and within hearing.

Interviews with women and their personal caregivers were conducted in Kannada and Tamil languages and with healthcare providers in English, Kannada and Tamil. On average, the interviews with patients lasted between 20 and 30 minutes. If a patient showed any signs of mild tiredness or distraction but chose to continue, the interviews were concluded earlier. The interviews with personal caregivers ranged from 20 to 45 minutes.

Healthcare provider interviews were conducted in their offices and workspaces unless the staff had shared work spaces, and so interviews were conducted in another private room approved by the institution. The interviews with healthcare providers ranged from 30 to 60 minutes. This time range was for the actual interviews conducted. In addition, time was allocated on an individual basis for the rapport building prior to the interviews. Only post determining the comfort of the participants the interviews were begun. The interviewing technique gave primary importance to engage deeply and gather as many insights from the participants as feasible within the time allocated. One of the methods was to focus on subjects that each participant was most keen on sharing with the interviewer. Rather than focus on pre-determined guidelines of the interview guide the facilitation was largely determined by the participant's interest and engagement. The guide as a result served as means towards this end. At times the healthcare providers from support services were located in the hospitals but their institutional affiliations were to other organisations. In such cases the healthcare provider typically asked for time between the consent process and the interview in order to seek approval from the provider's parent organisation. This was duly respected and the consent form was left with the provider to consult further with a senior colleague and confirm the interview at a later time. Once the approval was received the consent process was repeated prior to the actual interview with the provider. If there were work follow-ups, interruptions or sudden calls that providers had to attend to during the interviews the interview was paused and only continued after the provider responded to that responsibility. When an unexpected situation required the provider to be away for an extended time, the interview was rescheduled to a later time and date of convenience for the provider.

All the English and Tamil interviews were conducted by the researcher who has been trained in health research and has experience in women's health research in the same setting. As detailed, Kannada interviews were conducted by a trained interviewer fluent in that language and who has worked with the researcher for several years. The researcher was present in every interview conducted by the interviewer.

There were 33 interviews conducted in English, 21 in Kannada and 6 in Tamil. Interviews in all participant categories were discontinued when there was data saturation and repetition. All interviews were audio recorded and did not include names or other identifying information such as the institution or department of the hospital. Participants who declined to have their interviews audio recorded were not included in the study.

The translations of the study materials and instruments were done by the researcher with the support of community translators who have worked with her for several years in community based research studies. The translations were thoroughly reviewed, piloted and back-translated to improve translation accuracy as well as contextual sensitivity. They were again reviewed after the first few interviews to determine clarity and authenticity of the consent form as well as the interview guide.

This dimension of the research showed that an appropriate contextual adaptation of study documents is fundamental to the integrity of the research process. Language is specific to a context and when we translate it outside the context the dynamic equivalence of the terminology need to be captured along with their meaning. If documentation adherence is restricted to language, we run the risk of increasing ethical gaps in interpretation and understanding.

3.7 Reasons for not participating in Interviews

Healthcare providers who declined to participate in the study gave their reasons as: time constraints, unwillingness to be audio recorded, or had no specific reason. Reasons patients gave for declining consent were: not feeling up to a conversation or discussion; feeling extreme fatigue or tiredness; did not want or were not interested to engage in any process not directly connected to their health service; not having anything to say or did not know what to say in a discussion; discomfort at being audio recorded; uncertainty about the reaction of family members; apprehension about whether they were giving appropriate responses; and not willing to give any reason for declining to be interviewed. Reasons given by personal caregivers for declining to participate were: too busy to give time for the interview; needing to focus on patient care; not interested; not wanting to be audio recorded; needing permission from some other family member; some other work or personal commitment

The interview guides had been developed and reviewed several times by the study investigators prior to the study commencement. After the first few interviews a comprehensive review of the guides was undertaken again to assess the preliminary emerging themes in the interviews. At this stage, additional probes and follow-up questions were added to explore thematic areas of specific interest and importance in the research.

All the English and Tamil interviews were conducted by the researcher who has been trained in health research and has experience in women’s health research in the same setting. As detailed, Kannada interviews were conducted by a trained interviewer fluent in that language and who has worked with the researcher for several years. The researcher was present in every interview conducted by the interviewer.

Patience and understanding by the research team are what will stand in good stead for the continuance of the interviews. The resource constraints in the setting sometimes hampered the availability of spaces in the hospital for the interviews to be conducted or space may be available only at specific times that are convenient to the staff. Those were times when the patients were sometimes resting or are not willing to consider participation. Such situations resulted in multiple visits to the hospital for a single interview. The visits and wait may not result in an interview since there is always the possibility a participant decides she is not up to participation or has another work commitment or simply does not want to share their time and thought. The researcher handled these problems as she was familiar with the larger challenges of the context in which patients are provided care and caregivers are struggling to ensure it helps them

In-depth interviews have been shown to offer increased scope for detailed and insightful information on varying aspects of cancer treatment-seeking, psychological and emotional angles in disease management, as well as access and equity issues. One helpful aspect to this process is the development and translation of the questionnaire by the researchers who will administer them to the participants. Rapport building in the setting, familiarity with the protocols specific to the institution, sensitivity to the environment and flexibility all aid the ethical conduct of the interviews. In a tertiary facility where oncology care is provided there are many emergency situations on a day-to-day basis. Research interests may seem secondary to the staff while they are managing such incidents.

Data Analysis

The interviews, were audio recorded, and were transcribed verbatim. Using the process described by Braun and Clarke (2013), the data was analysed using a latent approach, that identified and examined underlying ideas, and conceptualisations that informed the meanings of the interview data (Clarke & Braun, 2013). Thematic analysis of interviews was used and was informed by this process enabled identification of patterns drawn from the interviews. The process commenced with the verbatim transcription of interview audio files. The transcripts were read and re-read, notes were made, and initial codes were ascribed to meanings identified from the interviews (Hinton & Earnest, 2010). The data were examined under themes which were then underpinned to the two theoretical frameworks of the study.

After the data was analysed, the results were presented and share the results with the interviewer, research team and were used as part of member checking to share the results and recommendations from the research. And to determine whether the findings were accurate and to support validity and credibility of the findings

The research rigour was assessed through pilot testing of interview questions for refinement and finalization (Rogers, Sapkota, Dantas, 2019). The trustworthiness was maintained through ongoing review and interpretation of the data by the authors (Cohen and Crabtree, 2008; Graneheim & Lindman, 2004). An audit trail documented the study design, methods and analysis to allow for replication of the study (Maltrued, 2001; Rodgers & Cowles, 1993; Birt et al, 2016).

3.8 Ethics Approval

This study was reviewed and approved by the Curtin University Human Research Ethics Committee. All institutions that participated reviewed the study as per their institutional guidelines prior to their approvals for conducting the research.

Table 3.3 *Research stages and data points for Quality Control and Adherence*

Stages	Data point occurrence record	Staff responsibility	Quality control evidence point
Stage 1 Introduction and recruitment	Meeting the designated participant identified with the aid of parent institution	Self and study introduction. The staff (researcher or interviewer) conducting the interview will lead the introduction	Proceed to administer consent
Stage 2 Consent completion	Administration of the consent form	Staff (researcher or interviewer) conducting the interview will administer	Signature of the administering staff on the consent form
Stage 3 Preliminary demographic data	Written data on a demographic information form post consent by the participant	Staff (researcher or interviewer) conducting the interview will administer	Signature of the administering staff on the demographic form
Stage 4	Record the	Interviewer or	Post completion

Interview	interviewer from commencement post confirmation a second time after consent	researcher	replay briefly the interview to ensure that it is recorded accurately
Stage 5 Quality check 1	In participant’s presence	Interviewer	Initials in a study documentation record
Stage 6 Quality check 2 and completion	In the venue where participant was recruited	Researcher	Initials in a study documentation record

The participants did not receive any reimbursement or token of appreciation for their time as per the institutional guidelines of the tertiary hospital where the patient and personal caregiver interviews were conducted. In India, some health institutions regard that this as being a possible incentive or subtle encouragement for participation and guidelines vary between institutions as to whether a token can be given. In Australia, participants are reimbursed for their time with a small token that may be cash, gift card or a voucher or an offer to participate in a draw. This is an example of how specific settings might view the same event or act from a distinctly different perspective in terms of the ethical implications in research processes.

3.9 A Reflective Narrative of Research Ethics and Process

In this section I provide a first person understanding, experience and narrative of the researcher’s relevance in any health research and the ethical enquiry process at different stages of study execution. I narrate the subsequent ethical nuances I confronted and felt it was important to capture some of my individual observations, reactions and responses to perceived ethical dimensions in this particular research journey. I recognise my lens of ethics is guided by several direct and indirect factors. My education, gender, contextual realities, inherent discriminations that exist in the settings, personal experiences, and people I encounter and associate with were important consideration. The research protocols I practice and adhere to, situational analysis, life circumstances, recollection of previous research experiences—all of these and more have shaped my predispositions to study ethics.

The foremost perception I would like to record is that from study conceptualisation to the writing of this paper it has not been possible for me to make a complete and exhaustive list of the ethical questions, dilemmas and challenges pertaining to the research. In other words, the foundational ethical preparation for this research is the realisation that I could not stop or separate ethics from any part of the research continuum and my journey through it. The only preparation that was feasible in my experience was to never pause or stop the effort towards being more sensitive, deeply vigilant and constantly prepared. Perfect and impermeable ethical robustness in research, in other words, is an ideal that one may never reach. Yet the only way to conduct research is to strive to reach that destination.

To capture some of this perspective through specific instances from this research, the subject of gynaecological cancers in India by itself is about ethical considerations at several levels, be it the ethics of gender, mortality, access, neglected diseases, resource constraints or healthcare norms in the context. As a researcher, I encountered unexpected ethical quandaries when applying for institutional ethics approval for this study.

This journey has continued at all stages of the research and only when I stopped defining research ethics as only as a self-contained component of the research did I find harmony in both the collection and analysis of the data. The ethics review and approval for the research study was critical but equally important was my growing awareness that ethical outlook in every aspect of what I did as a researcher. It also helped to objectify my own (researcher) bias which exists between the spaces of research protocols and my research training, experience and intuition. My experience suggests that it is the balance of this objectivity that can strengthen methodology in health research, which is directly linked to the study of any human vulnerability in rigour, reflection and execution.

3.10 Institutional Approvals and Ethical Issues

The study received approval from the Human Research Ethics Committee at Curtin University, Australia prior to my return to India to approach the institutions for approval. In India, the guidelines for research with human subjects vary based on the subject of study, nature of collaboration, institutions engaged in the study and the risks and benefits of research proposed. Tertiary institutions approached for approval had different organisational structures depending on whether they were public, private or public private partnerships.

The ethics committees within individual institutions had specific criteria for review. One of the institutions approached was a public tertiary institution which is also a regional cancer centre offering advanced oncology care. Though the study received preliminary approval by the institution it did not receive approval by the ethics committee primarily due to concerns about data sharing. The feedback from the ethics committee was that the data collected from the institution should be under the supervision of the institution in India and not from a collaborating institution outside India (in this case Curtin University). The institutional and academic affiliation of the researcher in Australia (outside India) posed a constraint for ethics approval. I was a citizen of the country, and the research was being undertaken as part of my doctoral study but these did not suffice.

The Indian Council of Medical Research (ICMR) states that individual institutions may approve the research when an Indian citizen conducts research as part of their doctorate or master's degree. However, the grey area that potential researchers deal with in this guideline is individual institutions can make a decision to withhold approval due to inconvenience, resource availability for evaluation or supervision, and concerns regarding data sharing. Since ethics committees in hospitals in India are typically voluntary, they meet only bi-annually and tend to have a backlog of internal reviews. Accommodating external international research applications can be challenging which is why some applications are not considered.

Another significant issue that occurred during this process was the time investment required for the approval process and the related follow-up with one of the primary institutions we were seeking approval from. Between November 2017 and August 2018 there were multiple visits, presentations to committees, follow-up and paperwork with no transparency on either the process or the outcome. As the researcher I often had to travel to the institution at a few hours' notice to meet a departmental requirement or a committee process through these months with no clarity on the steps involved in review. During this period the heads of the committee changed twice, once due to retirement and the second time due to an internal staff change. Both times the study application had to recommence from the initial stages of review. While it is the independent decision-making authority of an institution as to whether or not to grant approval to a researcher from a foreign university, there are several ethical challenges in terms of transparency and operational aspects of committees for research review which are of grave concern.

This research confronted conflicting views among different members of the institutional committees due to different interpretation of clauses in their guidelines. Some members considered it critical to do research in this area and were willing to approve the study while others had a different stance. Standardisation in guideline interpretations is a serious issue. For instance, some of the internal committee members were of the view that supervision from the concerned oncology department in terms of the research process, informed consent and logistics were necessary for the research to be conducted in a rigorous manner. Others were of the view that after ethical review it would suffice for the researcher to be responsible for safeguarding the interests of the participants, if the study was already approved by another ethics committee in a reputed international academic institution.

A few members in the committee held a perspective that the institutional data ownership was more important to resolve than the actual conduct of an already-approved international research study. The main challenge confronted in this approval process was the severely divided opinion within institutional review board members which hampered the ethical review process significantly. The members in a public tertiary hospital asked me to present and defend the study during multiple sessions over a period of ten months till they made a decision to defer the study back to ICMR directly for approval. At this stage, in the interests of research timelines that were already considerably delayed the researchers decided not to continue investing further time into this approval process, a decision reluctantly made because data in India about the subject of study is scarce and there is a critical need for research with both public and private tertiary hospitals to provide evidence for future programs.. Although this situation is recognised by institutions, bureaucracy, varying interpretation of guidelines, concerns about data sharing, administrative burden and responsibility, and extended gaps between ethics committee review sessions result in rejection of research initiatives that would have significant outcomes.

3.11 Study Documents and Ethical Discernment

Two aspects of importance in the implementation of the study were the sensitive nature of the subject of study and the heightened vulnerability of patients undergoing treatment. Cancer is a word associated with deep fears of mortality in the Indian setting. Family members who played a critical decision-making role in gynaecological cancer care often do not share with patients that they have been diagnosed with cancer. As a result, some patients in a study were not aware that they are undergoing treatment for cancer. While there may be situations where the patient may guess the condition she is receiving treatment for, she would hold her silence in order to protect the emotional interests of the family. Healthcare providers cannot always have open discussions with the patient directly unless the patient herself discusses or questions them. These situations posed several ethical dilemmas for me as a researcher.

The informed consent process is one of the dimensions where this dilemma was considerable. Research ethics require the consent to be comprehensive and clear to participants so that they can make a fully understood decision about participation. However, in this contextual situation the documentation required transparency about the research without discussing the specific details of the disease itself. A fine balance was required to ensure that the research integrity is retained in both aspects. The study consent adhered to research protocol of ensuring that the participant made the most informed decision regarding participation. Concurrently, the researcher took care not reveal any information that may jeopardise the interpersonal relationships of the patient or her family. Research responsibility included ongoing focus on research and participation issues rather than disease discussion. Referral to clinician on site was made if there were queries or concerns beyond the purview of research.

In order to prepare for such situations during the study, a steering committee was formed to provide guidance on an ongoing basis in both the preparatory and implementation phases of the study. The committee was comprised of senior clinicians in the area of study, and health professionals in community based organisations working with similar populations.

3.12 Agency and Context

To ensure their best interests, agency of research participants needed to be understood concurrently with the cultural and social norms of the context. On occasion in this present study, the participants requested the consent process be explained to their personal caregiver to help make a decision on whether or not to participate. At other times, after the consent administration, patients said that would participate in the study after consulting their family members who were not present at the time of consent administration. One participant requested that her family member be present during the interview. Each of these circumstances were responded to with care, caution, sensitivity and understanding.

The responses in each situation were made with simultaneous consideration of the overall research protocol requirements. “Agency” in research participation cannot be separated from the setting in which the research is conducted. Research intent is to ascertain whether a participant is able to express their preference at all times in the participation process. Agency is likely to be secondary to their decision or preference. In some cases, there are ethical dilemmas because a participant sought assent or permission from her family on account of not being empowered in decision-making as happened in this. Or she could just be choosing to consult them. There were instances where a woman sought consultation with her family because she wants to be inclusive in her decision-making about participation. It was my ethical responsibility of researcher to sift through these nuances carefully. Consent administration had to be done sensitively and with vigilant awareness of the preferences of the women.

3.13 Gaps in Research and Ethical Queries

Treading in areas where limited research has been undertaken involves a far greater accountability because fewer guidelines and protocols have been measured or tested (Belotto, 2018). This brings up several ethical conflicts and concerns. The very limited gynaecological cancer research in India has rarely focused on the psychosocial aspects of the disease and clinical management. Institutional guidelines vary considerably and many of them have been developed for clinical trials and research. Development of the protocols needed to be done with insight and with the guidance of key stakeholders representing the interests of the populations under study. The steering committee of the study was established with this intent.

Some of the areas where such insights were essential was in recognising the differences between public and private tertiary care in India, such as centralised guidelines in care versus institutional guidelines in cancer care and approvals, and supervision requirements for research in an institution. In addition careful review should be made of: referral systems for health emergencies encountered during research participation; space and logistic arrangements for research; research conflicting with routine clinical operations and care of the participation; and the data sharing policies of institutions. Clarity is required before the implementation of the research. Some institutions that offer oncology care may lack research experience since their focus is on clinical care. The ethical responsibility in such cases is completely on the research study team rather than the collaborating institutions that participants are recruited from.

One of the biggest constraints in the present study was finding appropriate times when clinicians were available to be interviewed. They were sometimes available to speak only between patient visits. The ethical question on whether it was acceptable to keep a patient waiting during an interview came into consideration. Clinicians would sometimes make it clear that it was the only time they were willing to spare and that meant their patients must wait. Two issues were predominant in determining whether the researcher could proceed during such times. One was that the healthcare provider may be best placed to assess when and whether it was acceptable that a patient waits. The second issue was to discern when a healthcare provider may be consenting to give time due to courtesy or in response to the study being approved by the institution. As a precautionary measure the researcher clarified during each meeting that she was willing to come back at other convenient times or was willing to wait until all patients finished their appointments.

Some providers stated they had no time to spare except between patient visits. However, they also made it clear that they considered the research and findings important and relevant for cancer care management, therefore they wanted to participate. These were fine lines between patient care, clinician time, and research implementation that the researcher had to navigate.

Participant comfort with documentation, audio recording and face-to-face interviewing also cannot be predicted prior to the interview or during the consent process. The rapport that needed to be built with each participant in cancer care research was crucial to the integrity and ethical progression of the study. There were situations where participants grew uncomfortable with the audio recording once the interview started. In such situations, the recording was stopped to establish the participant’s comfort before proceeding. The focus on the comfort and convenience of each participant at an individual level was critical because the relevance of data had direct links to participants’ complete and informed willingness to share their stories.

3.14 Silent Concerns and Ethical Responsibility of Response

One of the most complex responsibilities in the present research setting was the ethical response to unexpressed questions and concerns related to the research and participation. In a tertiary institution for cancer care, research by itself can be seen as an intervention that will aid the clinical process. Patients could make a decision to participate based on their anticipation of an indirect adverse impact on their clinical status or treatment in the institution if they declined to take part. Their agreement may be linked to seeking the good opinion of the clinical staff or the self-induced pressure to cooperate since the research has been approved in their clinical context. Explaining to them that the research process is separate from the clinical context and had no positive or adverse repercussions was done not only at the time of consent, but on a continuing basis at different junctures of participation.

Such instances occurred when personal caregivers wanted to return to patients who were alone or when participants began to feel disinterest once the discussion began. Maintaining the balance in understanding and responding appropriately to the reasons why a participant may or may not want to continue (even though the reasons may not be explicitly stated) was a major research responsibility. Given the vulnerability of the participants in the clinical context, the balance also required the response to give greater priority to the participant’s preference and interests rather than the research interests.

3.15 Ethical Measures for Risks versus Benefits

Conducting cancer care research requires an ongoing and careful weighing of risks versus benefit. The patients, personal caregivers and healthcare providers in the present study were all stakeholders who engage with disease management daily. Pain, trauma, disappointment at treatment failure, fatigue with extended hospitalisations, and emotional burnout are common. Understanding that talking about cancer may be a different experience for each individual participating in the study was critical. It was essential for the researchers to be aware that a discussion may be cathartic or therapeutical for one person, but extremely traumatic and private for another person. Sensitivity to such individual reactions and an approach that does not assume them needed to be cultivated and practiced very early in the research process.

During the study, such differences emerged even at the stage of the institutional approvals when healthcare providers had very different reactions to the research and its aims. While some were of the opinion such research is vital for better understanding the challenges of cancer care management, others were of the view that patients and family members already undergo too much trauma about the disease and may not want to participate in research with such research focus. Understanding such views is important for the research to learn from and to respond to appropriately.

The underlying concerns institutions have are threefold. One is the concern that patients and their loved ones may undergo additional emotional distress due to a research process that can be avoided. Second: the apprehension that patients may feel pressured to participate in the research because they are in the clinical context where there is heightened vulnerability. Third: the concern of institutional liability for a research study that is not directly conducted or supervised by the institution. All of these concerns are legitimate.

At different stages in the implementation of this study, the researcher had to navigate through different kinds of ‘emotions’ that could not be predicted by protocol, including caregivers and senior healthcare providers breaking down to cry. While the focus of research protocols tend to be on how best to respond to such situations there is a missing link in recognising that mitigation efforts cannot be restricted to protocols. They need to be in spirit and inculcated in outlook, prioritisation and navigation of the research itself. In that process one of the primary issues is the acceptance that emotions are real and inevitable in qualitative research, especially when we conduct research on sensitive subjects among vulnerable groups and socio-cultural contexts.

There are multiple situations that call for the researcher to be a responsible human being first rather than hold on to a specified hat of a researcher with a checklist of responsibilities. What aided the researcher for this study were thorough reviews of study instruments, preparation and training for administering the interview, ongoing engagement with supervisors and senior professionals in the context, and cautious piloting that helped in accurate and culturally acceptable administration and terminology in translations. The research attempted neither to contain nor define every ethical challenge that could likely occur in the study.

At the same time, much importance was given to proactive measures that aided and ensured the ethical implementation at different stages of the study. Collaborations that draw on the expertise and experience of several individuals and institutions can help this. Steering committee's role was important since it has a sense of the pulse of a local context. Institutions that have an internal referral system are crucial in facilitating timely referrals when required and the institution was very supportive with this. Good rapport and relationships with these institutions are investments that were key for the research. Back-translation of instruments from a regional language to English was a useful aid to assess accuracy rather than literal translation from English. For the researcher and interviewer to deal with the emotional duress of a participant and to know how to refer internally was important. It was equally important to prepare that there will be situations where the participant may not want to be referred and simply require a human shoulder to lean on. We planned carefully for these scenarios. It also helped build trust with institutions while getting approvals to conduct the interviews.

3.15 Discussion

Understanding the interplay of research ethics and gynaecological cancer care in India was not about determining a complete or finite checklist of issues and ethical implications in the research process, since the management of cancer is demanding, organic and is required to adapt to dynamic and unexpected needs. Considering ethics as one important part of the research process runs the risk of it being encapsulated to a specified set of issues rather than the need to include it holistically in every step of its conduct. The recognition that research and ethics are neither separate nor different from each other was the first step in efficacious research in cancer care.

One of the reasons research on health inequities has gaps is because the perspectives and aims of research have been discipline specific and disjointed (Ravindran & Seshadri, 2018). It results in further division of agendas and priorities for policies, programs and guidelines that get informed by research. Ethical oversight suffers from several challenges such as multiple interpretations of guidelines, requirements that emanate from different epistemological positions of ethics committee members and the necessity for the varying state level gatekeeping, sanctions and permission seeking (Garimella & Josyula, 2018). Protocols and research methods time-tested in the West may have considerable inadequacies in their applicability in resource constrained settings where there are multiple factors such as impact of funders, internal resource distribution, political changes and training needs of health professionals, all of which determine the nature and execution of health research and its operationalisation (Sharma, Khatri, & Harper, 2016). Another pertinent recognition of our times is that ethics in health research is far more complex than feasible to be under the jurisdiction of review by institutional ethics committees, which are limited in scope, time and management (Posel & Ross, 2014).

Research uncertainty and “situational unpredictability” combine with regulatory limitations in an infinite set of ethical dimensions and dilemmas that affect ethical decision-making (Posel & Ross, 2014) that researchers need to make and confront, combined with credence that needs to be paid to the interests, preferences and actions of the research subjects a researcher works with. A coherent articulation of ethics in health research is also about consensus of research gaps and goals in such research. A focus on health equity, priority research areas to achieve it, and inter-disciplinary and collaborative networks, are all essential for a more robust research process in a context. Global literature highlights evidence of maximum value and relevance to multiple stakeholders in the context is key to enabling healthcare systems, their service delivery and ultimate outcomes (Sparring, Granström, Magna Andreen, Brommels, & Nyström, 2018). None of these interlinkages can show the complete picture independently in evidence gathering. Such associations are vital for one more purpose that can go undetected. In the zest for enabling vulnerable populations evidence can impel an overload of screening, preventive practices, treatments, intervention, and information exchange that are weighed separately from the risks and benefits of any desired outcome (Hersch et al., 2014).

There is little evidence globally that looks at the multi-layered associations between gynaecological cancers, fear, perceptions, barriers along with the influence and role of social support (Kissal, Vural, Ersin, & Solmaz, 2018). Gynaecological cancers are as much about psychosocial and cultural determinants as they are about clinical dimensions of care. In India, gynaecological cancers have the additional challenge of silences around many of these subjects due to cultural norms, the importance given to women’s reproductive roles, and the stigma associated with cancers. These are combined with severe resource constraints in access and care seeking behaviour. Decoding these silences comprehensively and accurately is possible only when research does not separate or distance itself from any factor in a research context, whether it seems relevant or not. The responsibility of research cannot be adequately met with drawing boundaries along with the study plan. It continues and covers areas deemed essential by both process and progress.

In the Indian context research responsibility in gynaecological cancers is juxtaposed with the ambiguity that surrounds standards of care and services available to women (Srinivasan, 2016). There are situations where no form of care is the standard, and research that views legal and local guidelines independent of ethics, would be free to adhere to the same standard in care provision. The recognition that absence of guidelines does not translate into irrelevance of the same is vital. A person’s distress in the cancer care continuum may be impacted by several factors in the social context that care seeking occurs (Gangopadhyay & Nath, 2018). Women in India are further affected in this scenario by the economic, social, educational and cultural inequities they face. The cancer care continuum in which they seek care needs to be holistic as a result rather than divided into sectors and networks through which women access and connect with the health system.

3.16 Conclusion

Currently, there are divisive forces between the health institutions, personal networks, health policies and the community based supports that operate within the Indian health system. For a woman to circumvent these divisions and access care in an enabling manner, research that records and reveals these gaps is of paramount importance. It becomes the ethical responsibility of research undertaken in this realm to articulate these issues with coherence so that it paves the way for better integration between health systems, research, communities, patients and their families in the gynaecological cancer pathways to care. The research accountability increases by leaps and bounds when the primary participants are not in positions of power to make truly informed decisions about aspects of the research process (Kadam, 2017).

The ethics of research and the ethics of communication are inextricably linked due to this. The authenticity of the evidence gathered is equally proportionate to the comfort, clarity and comprehension experienced in research. Hierarchy in the research process exists in visible, invisible, direct and indirect ways. Anticipating this in conceptualising, conducting and completing research will be a valuable move in preparedness for unconscious ethical violations, dilemmas and ambiguity. Ultimately, how steadfast the ethical accountability of research is depends on how self-reflective the research and researchers themselves remain.

3.17 Summary

This chapter has presented the importance of how ethics remains integral to the entire research process and ethical sensibilities are not only evoked at specific points of approval, consent data sharing or adverse events. This chapter has described some of the dimensions of research where such ethical engagement can be articulated and even measured. The next chapter considers the narratives of one of the main stakeholder groups and participant categories in this study—the healthcare providers.

Note

The next four chapters present the analysis and findings in the form of four articles to be submitted for examination. The university encourages students to submit articles for publication:

Article 1: *Gynaecological cancers in India: The less heard perspectives of Healthcare Providers.*

Article 2: *Unravelling partial silences: The limits of language and communication among women with gynaecological cancers in India*.

Article 3: *Beyond money matters: The hidden costs of gynaecological cancer care in India.*

Article 4: *Undiagnosed burdens in care: Gynaecological cancers and the lonely challenges of personal caregivers in India.*

Chapter 4

Gynaecological cancers in India: Perspectives of Healthcare Providers

The chapter is the first in the thesis to capture the perspectives of one of the participant categories in the study: healthcare providers. It explores the previously unheard barriers and challenges faced by a group of professionals traditionally considered to be in an advantageous role in the health system. The role of the healthcare provider is typically one of power and autonomy and considered to elicit respect and consensus from patients and the larger social reality in India. However, the data gathered from this study has revealed that behind the exterior of this hegemony is a complex set of issues that providers face in their roles and responsibilities. This article portrays these less-known sides to care provision with an intent to address the assumption that power is synonymous with agency. Responsibility in cancer care impacts agency on an ongoing basis within care provision. The chapter is sequentially placed after the ethical enquiry in the methodological section as the providers are the first point of reference in the health system. The key perspectives of the healthcare providers undergoing this journey as captured in this chapter.

This chapter will be submitted for publication to the ***BMC Journal of Public Health*** with the title: *Gynaecological cancers in India: The less heard perspectives of healthcare providers*.

Abstract

There has been mounting evidence on the role of healthcare providers in chronic illnesses such as cancer. The specific complexities in their roles to enable health are less heard. Gynaecological cancers have several undercurrents beyond the obvious. The data discussed in this article were collected in the period 2018–2019 as a part of a larger study on the role of communication in the management of gynaecological cancers in India. Patient numbers, cost, time, cultural norms, context and institutional constraints in cancer care provision are just some of the factors impacting care provision. Healthcare providers are typically acknowledged for the criticality of their roles in the continuum of care. However, our research suggests that the psychological harm and challenges they themselves may face in providing that care are severely neglected. Through listening to some of their voices, clear doorways emerge to better support the practice of those who are responsible for cancer care.

Keywords: Healthcare providers, provider burden, patient provider communication, provider burnout, provider responsibility

4.0 Introduction

Severe resource constraints in a health setting like India bring ongoing challenges and ethical dilemmas for healthcare providers responsible for cancer care management (Ghose et al., 2019; Kedar, Kannan, Mehrotra, & Hariprasad, 2019; Victor, George, Inbaraj, & Norman, 2018). The primary clinical focus in the care continuum may be on cure and recovery of the patients but the process and responsibility in the care continuum, especially in gynaecological cancers, requires further investigation and interventions informed by such evidence (Desai, Mahal, Sinha, Schellenberg, & Cousens, 2017). Issues such as stigma, difficulties in conducting screening programs, cultural norms in discussing side effects of treatment and the burden of costs are not separate from the other day-to-day logistics of healthcare provision. They interplay concurrently with the routine of professionals providing care. Outcome related dimensions such as health promotion for screening, alleviating psychological distress and preventive practices will be more effectively addressed if this interplay is understood better.

One of the aspects complicating healthcare provision in India is the collusion that exists in cancer care (Victor et al., 2018). Families and personal caregivers are more often than not reluctant to disclose the disease status to the women they care for, and healthcare providers are often unwillingly drawn into this conspiracy of silence which the patients themselves may not desire (Sushmitha Dharani et al., 2018). It places high levels of strain on the healthcare providers who tend to feel divided between what may be in the best emotional interests of the patient and the expectations from family to protect the woman from her own health condition. The cultural norm places the family in a role of significance in such decisions, making situations strenuous specifically for healthcare providers. Such norms both enable and challenge people depending on the context of care in the cancer continuum. Women are likely to benefit and choose this norm whereas health care providers might be in circumstances where they are forced to give the family more importance than they would prefer while rendering their services.

Training needs of young aspiring healthcare professionals to address requirements of cancer care continuing is another area full of limitations in India (Bhatnagar, Patel, & Raja, 2018). Similarly, there is insufficient capacity and time for providers to implement screening (Patil et al., 2019). Perception and recognition of cancer risks in a timely manner is a key factor in physician training especially at the primary level of care globally (Samimi et al., 2019). However, coping and dealing with the uncertainty in a chronic illness is tough on healthcare providers themselves, who have the task of communicating that uncertainty effectively to patients and personal caregivers (Etkind & Koffman, 2016). Uncertainty permeates many aspects in the care continuum such as prognosis, patients' and caregivers' psychological trauma, the efficacy of provider communication and the patients' cooperation and compliance, and the knowledge and emotional resilience to fight the disease (Crew et al., 2019). Awareness and knowledge levels in nursing play a crucial role in cancer care management and are likely to impact the communication with patients that occurs in different stages of screening and care (Jain, Bagde, & Bagde, 2016; Shekhar, Sharma, Thakur, & Raina, 2013; Singh, Seth, Rani, & Srivastava, 2012).

In short, there are several distinct dimensions in the cancer care spectrum that span negotiations of treatment, space, interpersonal communication and availability of services (Macdonald, 2016). A chronic illness like cancer also needs to factor in the role and importance of support services, trained paramedical staff and community health workers who through their liaison and integration can be powerful allies for providers in the health system (Jiang et al., 2018; Kaasa et al., 2018; Mudur, 2010b). There is an urgent need to find innovative methods of gaining support to overcome the resource constraints and the training limitations.

Provider communication is important in chronic illnesses such as cancer when the prognosis or information can vary for a patient across the continuum and stage of care. Patients' understanding of such information is equally vital for all steps forward (Brandes & van Weert, 2017). Breaking bad news is never easy and even with the best of experience and intent the provider may find times when they might have difficulty when faced with patients who react with deep emotional trauma and distress (S. D. Singh & Demkhosei, 2018). Those situations require the support of auxiliary and support services such as social workers and psychologists, which most tertiary facilities in India do not have.

Evidence from an online survey shows that the job satisfaction in cancer care, specifically that of medical oncologists, is poor in most countries of the world (Raphael et al., 2019). Countries with resource constraints are likely to benefit from collaborative ties with frontline workers who have strong ties to the communities from which patients seek care (Scott, George, & Ved, 2019). The stress and burnout health practitioners deal with in their work is considerable (Bhutani, Bhutani, Balhara, & Kalra, 2012; A. Kaur, Sharma, & Chaturvedi, 2018; Subramanian, 2012). There are complex multi-layered issues in the cancer care spectrum for women that are arduous to negotiate.

The literature highlighted in this chapter is aimed to serve a two pronged purpose. The challenges and barriers of healthcare providers are often hidden in the importance they are typically accorded in the health spectrum. The vulnerabilities such challenges create for them in addition hamper their well-being directly and possibly their responsibilities indirectly. The literature seeks to show between its lines the lives of these professionals are difficult and need to be understood better.

This article aims to examine and bring forward day-to-day complexities in cancer care dealt by healthcare providers in India who manage gynaecological cancers. Through listening to the perspectives of healthcare provider perspectives there is scope to better understand the support systems required for this critical group of professionals in the continuum of cancer care.

4.1 Methods

Study Design

The data were collected between April 2018 to April 2019 as a part of a larger qualitative and exploratory study focused on gynaecological cancers and the role of health communication in risk-reduction in an urban setting in southern India. The geographical location was chosen for the availability of tertiary specialty hospitals offering care for gynaecological cancers, and women who come from different parts of the region and nation.

Since the topic is sensitive in nature and required access to women in advanced stages of illness, the methodology was qualitative. A case study approach was used since it helped bring the participants’ experiences to the reader and is a method now widely used across disciplines (Noor, 2008).The viewpoints of the participants and bringing them forth in their own words was feasible. The relativist ontological approach captured the intimately subjective experience which bridges human and individual experience together. As there are multiple individual experiences, so there are multiple realties for the individuals, which was especially true for the women participants of this study (Levers, 2013). Using an exploratory, qualitative case study approach in a real-world setting, the intent of this study was to give ‘voice’ to the participants especially the women. A case study approach was the methodology of choice as its main characteristics helped bring the realities of the participants’ experiences to the reader and is a method now widely employed across disciplines (Noor, 2008).

Frameworks Underpinning in the study

The research was underpinned by two conceptual frameworks, that is, the health belief model (Rosenstock, 1974a, 1974b) and the theory of communicative rationality (Healey, 1992; Sheikh & Porter, 2013; White, 1995) that have aided the unravelling of complex nuances in health decision-making in cancer care.

The communicative rationality approach has shown the factors impacting ongoing decision-making in health among stakeholders (patients, personal caregivers and healthcare providers), while the health belief model has helped reveal perceptions, triggers and benefits influencing those decisions. Both these approaches have constructs that highlight the complexity in the consensus, priorities and approaches among different stakeholders. Communicative rationality reveals the process of agreement among people “living together differently through struggling to make sense together” (Healey, 1992) with sustained initiatives towards consensus in spaces that enable expressing views and respecting another’s.

The health belief model has been applied in health systems for decades since its development to better understand predictors health behaviour (Guvenc, Akyuz, & Açikel, 2011; Rosenstock, 1974a, 1974b; Sohler, Jerant, & Franks, 2015; Tapera, Senabye, Mhaka-Mutepfa, January, & Apau, 2019; Yoo, Kwon, & Pfeiffer, 2013). The model is relevant to decode the beliefs, barriers, risks and benefits that influence the perceptions in health behaviour. It also aids the assessment of the self-efficacy of women, their providers and personal caregivers in the healthcare spectrum. Most importantly, the two models reveal when decisions are made by the participants individually or jointly, and where they disagree or disassociate with each other in health decision-making. In this paper the perceived risks and susceptibilities are constructs that are particularly relevant, since healthcare providers deal with them at different stages of the disease in the continuum.

Themes and Study Instruments

Interviews: Semi-structured in-depth interviews were conducted with patients, personal caregivers and healthcare providers in this study. The main themes for the patient interviews were around identification of disease, treatment and institutional decisions, communication in treatment trajectory, self-efficacy and health management. Caregiver interviews explored responsibilities in caregiving, norms in caregiving, communication and information sources; healthcare provider interviews were on experiences with care provision, communication with patients, internal communication and referral services.

The interview guides were developed drawing on the experience of the researcher in consultation with her supervisors who were experienced in qualitative women's health research studies in international settings, including India. The guides were translated into Tamil and Kannada by the researcher and two interviewers she has worked with previously when researching women's health in India. The interviewers were from communities in the same urban setting where the study was conducted.

Consultations were done with a study steering committee comprising health professionals from both clinical and community health settings in the context, on both the identification of study sites and the implementation of the study. Questions were reviewed by the study investigators and translators after the first few interviews to ensure that they adhered to the thematic focus of the study and ensured clarity for study participants.

Study setting, Recruitment and Ethics

Purposive sampling was used to recruit participants and healthcare providers were recruited from three tertiary hospitals offering advanced cancer care in southern India, cancer support services and one community based organisation for cancer care. One tertiary care hospital caters to patients from lower socio income groups, another is a private hospital with a comprehensive specialty centre for oncology services and the third caters to low- to middle-income groups and has the largest palliative care network for cancer care across the region. Healthcare providers approached included physicians, surgeons, nurses, dieticians and nutritionists, counsellors, psycho-oncologists, patient coordinators, ASHAs (Accredited social health activists), social workers, cancer registry staff, organisational heads, and administrative and institutional reception staff. A total of 35 healthcare provider interviews were conducted.

The study received human research approval from the ethics committee of the institution the researcher is affiliated with. The study also received permission as per the institutional guidelines of the hospitals and organisations healthcare providers were recruited from. The participants did not receive any reimbursement or token of appreciation for their time as per institutional guidelines.

Healthcare provider interviews were conducted in their offices and work spaces. If the staff had shared work spaces the interviews were conducted in another confidential room approved by the institution. At times the healthcare providers from support services were located in the health institutions but their institutional affiliations were to other organisations. In such cases, the healthcare provider was allowed the opportunity between the consent process and the interview in order to seek approval from their parent organisation. Once the approval was received the written consent process was repeated prior to the actual interview with the provider. If there were work follow-ups, interruptions or sudden calls that providers had to attend to during the interviews the interview was paused and only continued after the provider had responded to the situation, even if the interview had to be rescheduled to a later time and date. The interviews with healthcare providers ranged between 30 and 60 minutes.

All healthcare provider interviews were conducted by the researcher. The healthcare providers were in a range of roles in the health institutions that provide tertiary oncology care for women with gynaecological cancers, and were directly engaged in providing service or care for women diagnosed with gynaecological malignancies. For their convenience, interviews were scheduled at times that were most convenient for them in the course of their professional responsibilities.

Table 4.1 portrays the range of roles healthcare providers had as well as the number of them designated for each role. It also illustrates the type of institution in cancer care management they were affiliated. All the organisations providers were affiliated to provide some form of advanced oncology care for gynaecological cancers. If a healthcare provider declined participating in the interview, the contact information of the researcher was left with the provider so that they could contact the researcher any time in the future if they changed their mind. The researcher ensured the health care provider could engage in the consent process voluntarily and without the pressure of their responsibilities. All interviews were audio recorded and did not include names or other identifying information such as the participants' institutions or departments. Participants who declined to have interviews audio recorded during the consent process were not included in the study.

Table 4.1. *Institutions and Roles of Healthcare Providers*

Type of institution	**Role of healthcare provider**	**Numbers**
Tertiary subsidised hospital	Head: Oncology	1
	Oncologist: Radiology	4
	Oncologist: Surgery	2
	Nurse: Oncology outpatient	2
	Nurse: Oncology ward	2
	Patient relations: Front desk	2
	Counsellor	2
	Dietician	1
	Head: Cancer registry	1
Tertiary private hospital	Head: Gynaecological	1
	Service Line Manager	1
	Patient Relations: Front desk	1
	Psycho-oncologist	1
Tertiary missionary hospital	Palliative care: Head	1
	Palliative care: Home care physician	2
	Palliative care: Nurse	4
	Oncologist: Radiology	1
	Oncologist: Surgery	1
	Counsellor	1
Support services	Senior counsellor & founder	1
Community based organisation	Founder & director	1
	Medical director	1
	Community health worker	1
	Total Providers	**35**

4.2 Analysis

The interview data analysis followed several steps including 1) reading of the transcripts and translations to ensure rigour in the data capture; 2) identifying main themes and subthemes in the data; 3) developing a codebook with a list of coded themes; 4) triangulation of data from different categories of respondents in the main study (patients, caregivers and providers) during analysis to enhance validity and identification of themes. The health belief model and the theory of communicative rationality were the theoretical frameworks used for this study. The former has been applied to study the perceptions of barriers and benefits along with risks and susceptibilities and seriousness of conditions that impact - health decision-making. The findings of this chapter specifically related to barriers in interpersonal relationships between provider and patients and the flow of information exchange have been understood better with the aid of the health belief model. The need for consensus and collaborative action as evidenced by perspectives from providers has also shown the tenets of collaboration that the communicative rationality framework provides. The latter has been applied to better understand the collaborative cues in such decisions and behaviour. Determination of data saturation was made when repetitive themes were assessed to occur and for each participant category interviews were stopped when data saturation occurred (healthcare providers n=30, patients n=15 and personal caregivers n=10); while other factors such as content validity and quality assurance and rigor of the data were determined with the different study processes including development of study codebook with joint consultation and review of the questionnaires by the steering committee. (Belotto, 2018; Guest, Namey, & Chen, 2020; Roberts, Dowell, & Nie, 2019; Waldherr et al., 2019; Yang et al., 2018)

The demographic background detail is available in the previous chapter of the thesis. The interview data required deep engagement with not only what was articulated by the providers openly but dimensions they hinted at or suggested subtly. It was critical to evaluate whether such interpretations were accurate and sensitive and whether they may have been impacted by researcher bias. Rigour in the study was ensued through ongoing dialogue and clarifications, evaluation of the major themes and subthemes, refinement of the codebook and adherence to the research questions. Transcripts were periodically visited to confirm the authenticity of not only the translation but the implications of what was interpreted. To maintain the confidentiality of the participants none of the quotes from providers are identified by institution, department or an individual's role.

4.3 Results

Coping with a Diagnosis Called Cancer

Providers highlighted a difficult dimension of healthcare provision as facing questions for which they have no answers. These questions are about recovery and survival, both of which are often uncertain in cancer care. Fears are expressed by patients about costs, physical pain, duration of treatment, side effects and death. Providers find the balance between being truthful and simultaneously encouraging about treatment is never easy.

Many healthcare providers said that there are no clear universal guidelines on how a provider can deal with these case by case uncertainties with patients and their caregivers. Each one has their own personal code as a result. The trust of patients and failed treatments imposes a heavy emotional burden.

> *Every oncologist goes through this (fatigue) . . . You are dealing with death and suffering the whole day.*
>
> *When a patient receives a diagnosis of cancer it is almost to her like receiving a penalty or sentence. Whether it is a life sentence or not it is still a sentence.*
>
> Participant ID_Onco_1
>
> *Praying for patients is something that staff often do here. Being there for them and doing something to help. An injection, two words of prayer – we seem to make a difference even with this*
>
> Participant ID_Palliative_Nursing_2

Providers who have the rare opportunity to find peer support from colleagues are fortunate. It is a safe space for them and reduces emotional burnout and decision-making burden since it is a joint presence and perspective in difficult situations. Providers are referring to a deep sense of aloneness in care provision and colleagues can be an antidote to a sense of personal responsibility when treatments fail.

> *Learning to understand it is not my fault; it is the nature of the disease and working with a colleague with whom you can counsel [a patient]. This way you can share the responsibility and it really brings down the stress levels. ... the work used to weigh down on me a lot. Having one more person to share the responsibility helps.*
>
> *Participant ID_Onco_1*

The Truth That Stays Hidden

Collusion is an area that poses challenge and ethical conflict for healthcare providers. Families repeatedly request them not to share with the patient about her condition. Family plays a vital role in the treatment of a patient and they tend to lead discussions, make decisions and manage logistics of treatment, sharing of information or discontinuance (Van Hollen 2018). The family as a result usually decides to protect the patient from the truth about her health and diagnosis. This situation is often in direct conflict with the provider's need for transparency, especially if the patient wants to know about her status.

The association with the word "cancer" holds high levels of stigma and fear in people's minds. Providers say that the word cancer is rarely uttered in common parlance in a hospital setting. Rather they use words such as tumour, biopsy, malignancy, growth or infection spread to describe the condition to patients. Only when a patient asks her physician directly if she has cancer do they talk about it to her fully or openly. Even in private hospitals where patients can read signboards and readily available printed information, families ask providers not to share the patient's condition with her. For a provider to accurately gauge what a woman may prefer in this scenario is filled with risk. They speak of instances when a woman agrees to a treatment preference to the provider in front of her family but, subsequently reveals in private that her family is coercing her agreement, and requests the provider not to reveal to her family about what she has just shared. The provider is placed in an extremely difficult position to negotiate with the family on the patient's behalf without revealing that the patient herself has stated her real preference in confidence. It sometimes results in families getting angry with providers, refusing to cooperate and blaming them for any non-cooperation from the patient. Unless handled extremely cautiously, families may discontinue treatment or seek care elsewhere.

> *One of the biggest challenges is dealing with differences in what the patient wants and the family wants.*

Participant ID_Psych_1

> *Making calls to a patient - one has to be very careful since family may have hidden from her about the disease (from the patient undergoing treatment). The word cancer is usually not mentioned at all unless the family and patient openly mentions it we cannot either… Nursing staff are usually respected a lot in palliative care – often doctors ask for inputs from them on which patients require what kind of specific support…*

Participant ID_Palliative Nursing_3

Patients and families share confidences with their primary physician provider about personal problems. These tend to be about finances, which may be awkward for a clinician who is both an institutional representative and the primary healthcare provider for a patient. Providers try their best to facilitate available discounts and financial schemes but coordination is a strain when combined with demanding clinical responsibilities and other patient needs. However, patients are somewhat forced to depend on clinicians for emotional support, because there is a significant gap in the availability of administrative, counselling and other support services and the numbers of patients who need such support. Many counsellors in such hospitals are volunteers and their time is limited and as equally stretched as that of physicians and surgeons.Relationships with families can be complex and not easy to manage during clinical interactions.

> *Higher income groups don't need much coaxing. The minute they know it is cancer they begin treatment. For women in lower income strata finance is the biggest issue. Social support is a problem – the husband can be very unsupportive… He will have to spend money and she may not be useful at home or sexually inactive. We do see women isolated at home, husband doesn't care, in laws will stigmatize, money is a huge burden along with this… Sometimes they come alone or with their neighbours – without family*

> *members. The family may even draw them away from going to the hospital if they confide about problem*
>
> Participant ID_Radiation Onco_1

There are many times when providers know that the patient is well-aware of her illness since her body is giving her cues to her condition. Many patients also keep up the pretence of not knowing for the sake of their family's peace of mind and do not ask questions. This complicated collusion places a patient in a position of high emotional responsibility for others when she needs to focus on her own wellbeing. It places the providers in an additional uncomfortable role, since they are drawn into and become unwilling participants in family dynamics. However, most of them are motivated by what they discern as a patient's real apprehensions.

> *They will start with complaints and then their worries. You just need to listen to them. Reveal the result in stages. They will know since it is their body. Patient will hide this from family and family will hide it from patient. Patient will act as if she doesn't know. It can be revealed to the patient slowly. We cannot give false hopes. Oncology can never give false hopes.*
>
> *Participant ID_Onco_2*

> *We shouldn't be interfering to prove a point. They have to live with their families.*
>
> *Participant ID_Pysch_1*

There are other instances when psycho-oncologists and counsellors play a pivotal role in family negotiations when there are differing views among the family. A patient can express preferences to providers that she is unable to express to families and directly requests the provider to open negotiations on her behalf. When counsellors intervene in this way, it can result in the families better understanding the patient's perspective, particularly so when patients do not want to undergo further treatment in very advanced stages and want a peaceful end without intervention.

> *Patients have died in the space they want to since we push for internal communication between families.*
>
> *Participant ID_Psych_1*

Familial tensions can result in a woman being left in a situation where she has no recourse to treatment since she is financially dependent. There are also situations where she is partially or fully abandoned post-diagnosis and has to manage her own health care. Access to short-stay homes is extremely limited and women sometimes have no place to turn to when such situations occur. Women are highly vulnerable when abandoned by a spouse and left with dependent children. Providers then become a primary point of contact and facilitators of aid when this happens. Several providers spoke about a lack of adequate service in this area and stressed that it is one of the most urgent requirements in care management.

Each family reacts differently to the final adverse event of death. Additionally, each institution has its clinical guidelines and protocols on the processes following a patient's death. Bereavement formalities are mainly handled by the primary physician of the patient along with counselling, where available. Providers expressed the view that while they want to be there for the families through this period the demands of time and emotion are stressful.

> *An oncologist is a friend for life. The day a patient is diagnosed with cancer the oncologist is a permanent person to them. It is a life-long follow-up and association. The door is open even after the loss has happened.*
>
> *Participant ID_Onco_1*

When a patient is from outside the geographical location of the service, decisions need to be made about transport of the patient's body. In some cases providers need guidance about last rites or funeral practices according to the patient's religion and faith. There are instances where caregivers request that the body not be kept in a hospital mortuary until they can arrange for transport. Such coordination requires empathy, sensitivity and understanding. Providers also play the role of negotiators between the institution and family for logistics without mitigating the magnitude of the moment for families.

A Limited Luxury Called Time

A recurring theme among the providers was about severe time constraints for cancer care. Trained staff in gynaecological cancers are few. Most women seek care in an advanced stage of the disease, and the complexity of the condition requires extended time to be invested in each patient and her family at diagnosis and at subsequent and different stages of care. However, providers also deal with several patients in their outpatient departments and follow-up stages simultaneously.

> *When we handle a new patient with the diagnosis for cancer definitely no doctor or oncologist can just sit for 5 to 10 minutes and talk about treatment. We sit for a much longer period with them discussing the disease.*
>
> *Participant ID_Onco_3*

Providers explained they are not in a profession where they can switch their mobile phones off. A few providers talked about understanding of their families being the reason they are able to handle the pressures of their jobs. They acknowledged that family support was given despite their own inability to invest equally in their personal lives.

Due to low literacy levels among patients, administrative staff spend several hours coordinating documentation and basic aspects of care to the patient and family. Apart from treatment, insurance and financial schemes that are available to lower-income patients also requires extensive paperwork and approval-related follow-up. Linguistic barriers routinely occur since tertiary care is clustered in urban settings, and many patients who are from other parts of the country may not speak the local language.

> *Patience is very important in this job. Patients may cause a lot stress but we need to deal with them patiently. This job simply cannot be done otherwise.*

Participant ID_Admin_1

The Silences in Communication

Awareness of risks and the importance of follow-up are two of the most urgent needs in internal communication in a health institution. Providers try to improvise and create their own communication modules and innovate methods to reach their patients more effectively.

> *I tell my patients, "Don't talk about whether you have had your lunch or breakfast. Start talking to one another [other women] about whether you have had a pap smear or breast scan . . . talk about your health".*
>
> *Participant ID_Gyn_1*

> *Patient remembers the first day and which doctor explained the treatment the first day. Everything matters on that first day. If you can create confidence then they will be there for the treatment long-term and they usually look for you [whenever they visit hospital].*
>
> *Participant ID_Onco_4*

Interpersonal communication and health information for patients should be customised significantly by providers based on individual understanding, needs and receptivity of patients and families. Lack of context specific data increases this load on providers.

> *Unfortunately, in India we don't have data, we don't have statistics on outcomes of disease or treatment; we follow American or European guidelines [in practice].*

> *Most of the literature is from the West. The tumours and our patients are both different; race, nutrition, finance, social codes are all also different.*
>
> *Participant ID_Onco_1*

Patient referrals from doctors is essential for counselling support to be provided in a timely manner but referrals are often made based on symptoms or complaints from a patient. Counsellors discuss the needs their colleagues themselves have for counselling support. Palliative care providers speak about the problems with their services being the last point of referral when all other options are closed. The unspoken interpretation that palliative care is end-of-life care hampers patient openness to seeking it.

A patient is not referred immediately for counselling support since emotional trauma and physiological symptoms are considered natural and normal during the treatment period. Hospitals focus on patient diagnosis, care and treatment plans and there are no avenues to talk about difficulties in treatment due to constraints of time, confidentiality and limited institutional resources. There is also the silent expectation for the providers to be strong, courageous and confident under all circumstances.

Grief, Fear and Mortality

Gynaecological cancer care is interconnected with apprehensions about mortality. Most patients and families respond to a diagnosis as the commencement of a ticking clock against them regardless of the stage of the disease. Providers acknowledge that even where there are good prognosis and treatment outcomes, their experience suggests that one can never guarantee complete cure. Women are additionally concerned about the impact of the disease and treatment side effects on their roles as wives and mothers. Patients are willing to take high risks and discontinue treatment in order to preserve their reproductive organs, especially younger women yet to have children. The negotiations providers have with patients and families are extremely sensitive, since treatment side effects could have severe implications on the marital life of a woman. Sometimes these decisions become a complex weighing of the risk to a woman’s life vis-à-vis the risk to her sexual activity, marriage and acceptance by those closest to her. Providers have to deal with such issues with tremendous thought since a recommendation for treatment despite opposition from family could elicit strong resistance and may even push a woman or her family to discontinue treatment.

> *I get very upset when surgeons or oncologists say we will "cure" cancer . . . we are fooling ourselves and fooling everybody else.*
>
> *Participant ID_Onco_2*

Mortality due to gynaecological cancers is high in low- and middle-income countries due to poor screening efforts, sociodemographic factors and access to advanced radiotherapy facilities (Chopra et al., 2019). India recorded 97,000 cases in terms of the global burden of cervical cancer and 60,000 deaths in 2018 (Arbyn et al., 2019). Providers are the primary people to manage grief from the patients and the family at all stages of treatment. Grief could also manifest itself in a variety of other ways like anger, fear, depression, silence and non-cooperation towards the providers. The treatment for gynaecological cancers in advanced stages is long and typically patients and their caregivers are in the hospital for at least 6 to 8 months. Both families and providers face ongoing uncertainties of prognosis. An ethical dimension enters the situation when financial instability occurs. Families seek answers on whether or not they should continue spending for treatment if there are no positive outcomes. Providers deal with both harsh realities: patients and families who simply cannot accept failed treatments with no options left, and those that insist on continuing even when the prognosis is very poor and they cannot afford the costs.

By the time a patient reaches palliative care, pain management and acceptance from the patient herself become crucial. Providers are called upon to manage pain, be an emotional confidant or just pray, depending on the requirement for the day and time. The relationship becomes very personal for the family, and providers in this study discussed the strenuous responsibility of maintaining their professional equanimity and emotional distance as needed. Delayed referrals accentuate these issues a great deal.

> *It is important not to come in for support when death is right there.*
>
> *Participant ID_Psych_1*

In home-based palliative care, providers sometimes see their patients being poorly treated, neglected or verbally abused by families that are too exhausted themselves and are no longer able to care for the patients. Basic access to hygiene that is fundamental for preventing infections or relapse may be missing in resource-limited homes. However, any intervention or feedback may adversely impact the relationships for the patient in the household and worsen her condition.

> *In the hospital it can be mapped, but once you enter a village several issues need to be understood. We have to follow them till death.*
>
> *Participant ID_Palcare_2*

Treatment Failure, Burnout and Self-doubt

Losing a patient is personal for each healthcare provider though the way they cope, address and respond to it may differ. Many of them talk about the helplessness of failure and the guilt of not having met the main responsibility a patient and family trusts them with—cure and life extension. While they rationally recognise variables determining outcomes, there is a deep sense of personal guilt providers carry.

> *I get very involved with patients . . . my mentors over the years have had a lot of influence on the way I deal with patients.*
>
> *Participant ID_Onco_2*

> *It is emotionally draining. We see death. We see a lot of suffering. Not just physical but psychological, spiritual distress and we see social distress.*
>
> *Participant ID_Palcare_1*

Patients and families often ask providers to make most decisions on their behalf since they rely on their expertise and experience. While on the one hand this creates a veneer of authority and confidence in healthcare provision, below the surface are the lonely pressures of decision-making that could go very wrong. Some providers try to lessen these pressures by not getting involved with the patients' and families' emotional trauma. Emotional burnout early in their careers is something they learn from and try to avoid repeating in their careers. The constant need for reassurance places a huge weight on the already overworked doctors, nursing staff and counsellors. Many acknowledge that though they try, long-term associations make it impossible to completely disassociate from the personal reactions, ongoing fear and anguish of patients and families.

> *If I try to manage caregiver burnout we ourselves will also have burnout so I have stopped doing that.*
>
> *Participant ID_Onco_5*

As there is a shortage of trained nurses and staff in the specialty of gynaecological cancers, staff are required to increase their responsibilities. Providers express their awareness of burnout, stress, and unmanageable workloads even though a smile from their patients makes everything worthwhile. Experienced providers were seriously concerned about apathy among young providers because of a lack of training and the increasing commercialisation of medicine. Empathy and compassion, according to many providers, are as important as the medical training received for cancer care.

> *They will hear half, do half, understand half and patient will be treated half or zero [about trainings conducted with junior colleagues].*
>
> *Participant ID_Nutri_1*

Most of the providers acknowledged intermittent or an ongoing sense of burnout that they experience in their work. Their methods of coping were different and practiced by trial and error at an individual level.

> *I just shut down and not talk to anyone, compassion fatigue is high in the work and it is important to de-stress . . . Don't hide the stress; face it and acknowledge it and be mindful.*
>
> *Participant ID_Psych_1*

> *I have not got to the stage of figuring out how to de-stress myself [when a patient has poor outcomes]. I have noticed one way that helps me is to move on to the next patient.*
>
> *Participant ID_Onco_2*

A Space Called Spirituality

Where all hope is lost some providers say that spirituality tends to provide the maximum solace and comfort to people. Other providers expressed how they themselves faced existential crises that question their faith due to the pain and loss they deal with routinely in their work. Healthcare providers in palliative care are particularly articulate about the role spirituality plays in their day-to-day lives. Several of them mentioned faith as a source of strength to cope with pain, suffering and loss.

> *I got more compassion [for patients] after I began actually experiencing God's love. I started feeling peace.*
>
> *Participant ID_Palcare_3*

> *Some oncologists put their reliance in God. I have actually questioned my belief in God after being in oncology. If we pray or do something does someone really listen to all this? I have had my own spiritual challenges when dealing with patients with cancer.*
>
> *Participant ID_Onco_1*

Nursing staff also explained that spirituality teaches them to bear and be respectful of high degrees of physical suffering their patients and families undergo. The word "healing" was used by many staff when speaking of the nursing care that patients need, and that they coped with this responsibility only with the aid of their personal spiritual faith. Some providers said spirituality gives them solace and meaning especially when they reach internal spaces of hopelessness.

4.4 Discussion

The research has shown that healthcare providers are adversely impacted by the challenges of time constraints, limited support services and emotional burnout. This is consistent with global literature that highlights the importance of responding to provider perspective and burnout in chronic illnesses and end of life care (Harrison et al., 2017; Murali & Banerjee, 2018). The literature highlights how support services and models of care integrated services to assist healthcare provision should be evaluated thoroughly to understand if their efficacy is context specific and that the services need to be tailored appropriately with the views of key professionals (Baker, Hoffman, & Fenlon, 2019; Ignatowicz et al., 2014; Northfield et al., 2019). While individual providers talk about different dimensions of support, the recurrent theme among them is the hardship of managing their responsibilities alone while handling varying demands in care management. They are united in the view that cancer care management is extremely challenging, emotionally arduous and fraught with guilt, burnout, loneliness and self-blame. The social and cultural complexities in care provision require collaboration between providers, institutions, patients, families and allied services.

Evidence suggests that major illnesses have complex expectations in health-seeking behaviours, and these negotiations about illness and wellness impact relationships between providers and patients (Garrino et al., 2015; Mattsson et al., 2018). The research shows that these relationships are further aggravated and distressed due to a dearth of resources and a lack of open forums to discuss these issues. There is a general consensus among providers that even when they run out of all options and have no assistance they would never choose to give up on a patient.

The frameworks of communicative rationality and the health belief model underpin the findings that there are several barriers both for their work with patients and their own inner wellbeing. For interventions to be of relevance the interplays of perceptions of patients, personal caregivers and institutions towards cancer care need to fully decipher since they directly affect the context of providers. The decisions that providers make in cancer care are surrounded by uncertainties that span a range of issues such as patient communication, prognosis, role of personal caregivers and institutional guidelines (Shelton, Brotzman, Crookes, Robles, & Neugut, 2019).

The health institution is still the central variable of care provision and experience for a patient and her family while the provider is in many ways the epicentre in that decision-making process. While this perspective might seem patronising towards patients and their families, it is the harsh reality in the care spectrum where these groups engage with each other. The provider being an important point person is not about placing him or her higher in the hierarchy. It is about recognising the power they wield just by the nature of their responsibilities. This inference certainly does not imply that this is ideal or desirable in the health spectrum, simply that this is the reality in a context like India for many women. The interventions or support services that are activated to enhance their work should enable providers in the health system, rather than act as external problem solvers. For this, a thorough and well-informed understanding of providers' needs is essential.

An area where allied services can offer definitive support in the existing scenario is in increased counselling support for patients and in organising patient centric events in the hospital. This can also be combined with health information both in the health institutions and in local communities. Clinicians reiterate that the persons or groups involved with such engagement need to be trustworthy and credible. Appropriate services that institutions endorse and collaborate on may be the solution. An objective review by individual institutions on how joint or collaborative care can be provided by multiple providers in patient interactions and treatment follow-ups especially the challenging ones, is essential.

The other area that requires investment is counselling and professional support for providers themselves. An internal referral system that makes periodic counselling mandatory for all providers in cancer care may be an approach to consider. Alternatively, easily accessible and informal confidential counselling support outside the institution or through a reliable helpline may also be an option that will help providers significantly.

A key aspect such interventions and support services need to recognise is that they cannot add to the existing workloads of healthcare providers. The conflicting emotions and apprehensions that a provider faces in disease management are rarely shared. There is the requirement for the health system to recognise this and make available supports that anticipate providers' needs before they themselves do.

Neutral and enabling spaces where providers can just sit and recharge or heal by themselves and sometimes with each other, may be another dimension of physical and psychological benefit. Institutional boards for case management can also convene sessions to discuss provider burnout, stress and other individual or collective concerns. The silences that surround provider needs have to be broken without fail from within institutions.

The recommendations of providers are clear and categorical. Support from colleagues to handle difficult conversations including treatment failures and end of life care is necessary. Time allocation in clinical care can be improved with well-functioning support services to handle the secondary needs of patients such as administrative and funding support, health information modules, patient counselling and personal caregiver services. Internal coordination between clinical care and palliative care within institutions will also aid patient care far better. Work in the community in the form of preventive care support and screening can benefit more with the involvement of community based organisations. The need for more holistic education about patient care is imperative. It can be better synchronised in the current academic curriculum so that there is necessary sensitisation and capacity building before the careers of health providers commence. The study findings strongly suggest that the neglect of these key professionals can aggravate challenges severely for them and those they care for long-term.

4.5 Conclusion

With this research we contribute to alleviating some gaps in the literature about the challenges healthcare providers face in India in the management of gynaecological cancers, especially in relation to the conflicts within their professional responsibilities vis-à-vis their own wellbeing. Providers of care in gynaecological cancers have major unmet needs. Their perspectives reveal how the gaps in allied personnel support, information dissemination and confidential emotional support affect their responsibilities. These individuals bear tremendous responsibilities to help and heal others. It is imperative to hear the perspectives of healthcare providers managing gynaecological cancers in India, along with a focused intent to alleviate their problems.

4.6 Summary

This chapter has revealed the perspectives of a group of professionals who are considered powerful and empowered in the gynaecological cancer care spectrum. The findings document that healthcare providers suffer from emotional burnout and the loneliness of their competing responsibilities of their daily work through patients, families, institutions and policies for care provision. The next chapter focuses on the women patients interviewed in this present study. The theoretical frameworks used in the study are applied in these two chapters specifically in the study of barriers health care providers and patients face in the care continuum. Both these chapters portray aspects in care seeking and provision that require better internal communication, coordination between stakeholders and systemic issues that require support. The frameworks highlight both the pathways to care and the deterrents in the same.

Chapter 5

Unravelling the Silences of Women with Gynaecological Cancers

The findings of this chapter are from data collected from interviews with women patients admitted to a tertiary facility for treatment of gynaecological cancers.

The chapter commences with an introduction to the literature about women and gynaecological cancers in order to highlight the study-specific findings. The study focus is on enabling the care continuum for women patients as they form the primary protagonists in the health narrative in gynaecological cancer management. Their emotions, perspectives, angst, networks of support, financial burdens, quality of life, fears, spiritual support and crisis are all reminders of the many needs that exist in care negotiations in cancer management. The interviews were conducted by the researcher and a Kannada-language speaking interviewer. The reviews were conducted by the second and third authors and the thematic analysis for the article was undertaken with consultation of all three authors. All of patients recruited have been diagnosed with a gynaecological cancer. This article finds that the issues impacting their health behaviour and decision-making are not only what they mention but those they refrain from speaking about.

The chapter will be submitted for consideration to be published in the journal, ***Healthcare for Women International*** with the title: *Unravelling partial silences: The limits of language and communication among women with gynaecological cancers in India*.

Abstract

Women who are cancer patients deal with issues and emotions that are rarely expressed openly. The limitations of language need to be carefully understood in the attempt to unravel conversations about gynaecological cancers in India. This article is part of a larger qualitative exploratory study on the management of gynaecological cancers in India applying the health belief model and the theory of communicative rationality. Drawing on data collected through in-depth interviews conducted from 2018 to 2019 in a tertiary hospital in southern India, the participants revealed what existing communication does not express about their experiences of gynaecological cancers. In the attempt to listen to and unravel their silences, this article presents some critical directions that are most acceptable to Indian women in interventions designed to enhance their health. The challenges to women's communication are several. Stakeholders and interventions in the cancer care continuum need to recognise that management of physiology, finance and access is one part of gynaecological cancer management. The other side is about the impacts it has on their roles in family and society. This recognition will pave the way to addressing both expressed and unexpressed concerns women have. Research that focuses on women's perspectives, concerns and needs have to be subtly integrated in the care continuum rather than as sporadic or intermittent efforts. The social stigma women face with a diagnosis of cancer requires coordinated holistic efforts by institutions, the health system and communities to create ongoing awareness. The key role of community health organisations is to be acknowledged and their liaison with health institutions for joint efforts can set the tone for this initiative.

Keywords: Indian women, patients, gynaecological cancers, silences, gynaecological cancers, tertiary.

5.0 Background

The more recent projections (2020) for cancer incidence among patients in India is 98.7 per 100,000 which translates into 1.4 million patients (P. Mathur et al., 2020). India has seen a steadily increasing cancer incidence and burden without signs of reduction over the past few years (Gandhi et al., 2017; Krishnaveni et al., 2018; M. R. Mathur et al., 2014). India's contribution to information and data on chronic illnesses is limited and incomplete due to its reliance on self-reported data for chronic conditions, a situation further exacerbated by inaccessible data of undiagnosed populations (Arokiasamy, 2018). Cervical cancer, which has a heavy global burden as the second most common cancer, is the leading cancer among women in India where there complexities hamper risk-reduction and preventive strategies (A. Sharma et al., 2017). The cancer burden estimate suggests that the incidence in India will not see any mitigation in the years to come with current trends projecting 132,000 cervical cancer cases and 77,000 deaths every year, and future trends projecting a fast growing incidence of 226,084.

Gynaecological cancers not only suffer from the tremendous challenge of late diagnosis and presentation of disease but result in a high proportion of mortality in India (Sundar et al., 2018). In addition to this, incomplete cancer registries of rural populations in India may be showing lower estimates than what the reality is. Longitudinal and comprehensive data collected through cancer registries of different regional populations, changing lifestyle changes, disease patterns, treatment outcomes and behavioural patterns are rarely available in India (Mathew et al., 2019). Of data that is available, mortality from cervical, breast, uterine and ovarian cancers have not shown a reduction despite positive outcomes in life-expectancy in the country. The fact that tertiary cancer care is overburdened, poorly regulated and clustered in urban settings further aggravates the burden (M. R. Mathur et al., 2014).

The gynaecological cancers scenario in India is bleak and the research that can create a better understanding of them is sporadic and limited. Inadequate attention has been given to understanding the incidence and records of cancer since national registries of populations are largely from urban settings. These registries hold records of tertiary facilities that cater to people from both urban and rural settings. Further they may not give the complete picture of deaths at home and deaths occurring without medical intervention, a picture which is crucial for a real understanding of gynaecological cancers (Dikshit et al., 2012). Women’s inequities in health need to be understood from varying interplays of urban versus rural residence, social norms and belief systems, delivery of healthcare where there is access, and behavioural factors that impact diagnoses of the disease (Mahajan et al., 2019). The data from rural India about the prevalence and incidence of cancers continues to be extremely limited in availability (Kinra et al., 2010) and complicates the accuracy of estimates as well as linkages with sociodemographic factors. This in turn leads to skewed insights about programmatic outcomes or success in screening for gynaecological cancers. Many of them are only partially successful because other than the barriers of geography, economics and management of such interventions, they are largely adapted from developed countries and not necessarily culturally appropriate (Nene et al., 2007).

Gynaecological cancers cannot be examined from the boundaries of access or affordability alone since these have complex interplays with gender, social roles of marriage and fertility choices as well as cultural codes (Namasivayam, Osuorah, Rahman, & Antai, 2012). Dialogues and interventions on pregnancy, spacing or contraception are not the only enablers of reproductive wellbeing for women in a context where the same socioeconomic factors may impact other aspects of their health and wellbeing (Mishra & Lohiya, 2016). Conversations around gynaecological cancers that look at very specific issues such as stakeholders’ role, capacity and training in prevention programs and data collected directly from women that reveal their preferences are dire needs in India.

They need to be studied prior to implementation of programs for disease management and research adapted from contextual realities (Suba, 2014). Reproductive organs in the context of women are strongly and symbolically associated with a woman’s fertility, role in a familial setting and sexual relations with her partner (a husband for the women) in the Indian cultural context. The loss and impairment of reproductive health during cancer treatment has emotional ramifications that are neglected (Khan, Bahadur, Agarwal, Sehgal, & Das, 2010). The stigma associated with gynaecological cancers is significant and cancer care may be sought only at a very advanced stage despite awareness and symptoms due to the social ostracism women fear with diagnosis ("The secrecy and shame around women's cancers", 2018). Understanding the impact of stigma in cancer care and its association with gynaecological cancers is imperative in designing efficacious interventions for cancer prevention, awareness and behavioural change (Nyblade, Stockton, Travasso, & Krishnan, 2017). Studying gynaecological cancers is not only about research on gynaecological cancers as a generic condition but rather about how specific cancers affect women's lives and health in particular. The literature is only just beginning to explore the quality of life for a woman that is associated with not only her survival after cancer but about her life prior to and after diagnosis and treatment (N. Kaur, Gupta, Sharma, & Jain, 2018).

Restricted access to facilities may prevent behavioural change translating into effective seeking of care. Thus, the feasibility of screening and prevention in India needs to be looked in relation to other variables of capacity, treatment options and geography rather than unilaterally as efficacious interventions to facilitate access ("Bridge gap between evidence and policy in tackling women's cancers: Global cancer expert", 2018).

This article aims to address the gaps in the literature through experiences, perspectives and unexpressed challenges in the care continuum among women diagnosed with gynaecological cancer in India. It presents opportunities and implications for interventions, programs and research in the gynaecological care spectrum. The objective in this process is to unravel issues and silences in women's cancer care that currently block such opportunities.

5.1 Methods

Setting and Recruitment

The data for this paper is drawn from a larger study on gynaecological cancers and risk-mitigation efforts through communication conducted between 2018 to 2019. Interviews were conducted with women patients (*n* = 15), personal caregivers (*n* = 10) and healthcare providers (*n* = 35). This article focuses on the interviews conducted with women patients (*n* = 15) diagnosed with gynaecological cancers. Participants in the research were recruited from a private tertiary referral hospital in an urban setting in South India. Located in southern India, the institution offers advanced and subsidised oncology care to economically disadvantaged populations across multiple regions of India, both within and outside South India. Following institutional approvals being granted, women diagnosed clinically with a gynaecological malignancy were approached for consent to participate. Interviews with women were conducted in local languages (Kannada and Tamil).

Frameworks underpinning the study

Semi-structured in-depth interviews were conducted with women either by the researcher or by an interviewer in the researcher's presence.

The main themes and subthemes for the patient interviews were around identification of disease, treatment and institutional decisions, communication in the care trajectory, barriers to care and follow-ups, self-efficacy, experience of disease and treatment, support networks, spirituality, collusion and health management. The themes and subthemes for the research have been identified both inductively and deductively. While the interview guides had broad themes the interviews were kept open to capture emerging themes.

The research was underpinned by two conceptual frameworks, that is the health belief model (Rosenstock, 1974a, 1974b) and the theory of communicative rationality (Healey, 1992; Sheikh & Porter, 2013; White, 1995), which have aided the unravelling of complex nuances in health decision-making in cancer care.

The communicative rationality approach has been used to identify the factors impacting ongoing decision-making in health, while the health belief model has helped reveal perceptions, triggers and benefits influencing those decisions. Both approaches have constructs that highlight the complexity in achieving consensus as well as the variances in priorities and outlook among different stakeholders. Specifically, with the health belief model cues to action and self-efficacy reveal the triggers to women's individual actions and decision-making in the cancer care continuum. Communicative rationality reveals the process of agreement among people "living together differently though struggling to make sense together" with sustained initiatives working towards consensus in spaces that offer scope for expressing one's view and respecting another's (Healey, 1992). The collaborative aspects of behaviour are captured in the care continuum through this construct.

The health belief model has been applied in health systems over several decades since its development to better understand predictors of health behaviour (Guvenc, Akyuz, & Açikel, 2011; Rosenstock, 1974a, 1974b; Sohler, Jerant, & Franks, 2015; Tapera, Senabye, Mhaka-Mutepfa, January, & Apau, 2019; Yoo, Kwon, & Pfeiffer, 2013). The model supports unravelling beliefs, barriers, risks and benefits that influence the perceptions of health behaviour, as well as perspectives and self-efficacy of women in the care trajectory.

Study Setting

The interview guides were developed based on existing literature, drawing on the experiences of the researcher and informed by the two theoretical frameworks. The guides were translated into Tamil and Kannada by the researcher and two interviewers she has worked with previously on women's health research in India. The interviewers were from communities in the same urban setting where the study was conducted. Consultations were done with the study steering committee comprised of health professionals from both clinical and community health settings in the context, on both the identification of study sites and the implementation of the study. Questions were reviewed by the study investigators and translators after the first few interviews to ensure they adhered to the thematic focus of the study with consistent clarity.

Participant Profile

Participants in the study were aged between 30 and 60 years. Among those women who were working, occupations and sources of income were mainly from agriculture, coolie work (coolie refers to daily wage earners who typically belong to the unorganised labour sector), domestic house cleaning and *anganwadi* school (subsidised educational and child care centres). Most women were either illiterate or have had 5 to 6 years of schooling. Only one participant attended pre-university college (high school equivalent). Some women lived with their husbands while others were either widowed or separated from their husbands. None of the women lived alone, all of them resided with others in the house, either those from their marital or natal families. The cancers that fifteen women in the study were diagnosed with were ovarian cancer, uterine cancer and cervical cancers. When women spoke about their experiences of cancer they spoke about symptoms and experience rather than identifying disease and type of cancer. Depending on their response, the information exchange was tailored and where they did not refer to the disease directly no mention was made by the researcher either. Women undergoing treatment typically stayed in the hospital between 3-6 months at a minimum and the types of treatment they underwent included invasive surgery, radiation and chemotherapy. Overall women were happy with the care and treatment and spoke positively about the staff especially the doctors. Some referred to specific nursing staff as well and in general were fine with the facilities available in the hospital and wards.

Consent and Participation

Women were approached for consent after the healthcare provider identified them as having been admitted for a gynaecological malignancy in the institution. There was a first level of screening by the provider if a woman was considered too ill to participate in the research. Patient interviews were conducted in a room within the hospital designated and approved by the institution. The space was private and confidential and the patient was able to walk to it from the ward and speak to the interviewer without being overhead by others, including her family members. The interviewer periodically enquired about the comfort of the patient in continuing with the interview and also if she would like a break or rest between the conversation. All interviews were audio recorded and did not include names or other identifying information such as the names of the participant, their healthcare providers, family members, date, address or hospital. If a patient showed any non-verbal signs of disinterest, mild tiredness or distraction but chose to continue, the interviews were concluded earlier. Participants who declined during the consent process to have interviews audio recorded were not included in the study.

Coding and Thematic Analysis

Transcripts were transcribed and translated and the codes were refined based on themes and subthemes that were jointly finalised by the researcher in ongoing consultation with the other two study investigators. The patterns and data trends were used to identify directions using thematic analysis as the analytical approach (Gower, van den Akker, Jones, Dantas, & Duggan, 2016; Parkinson, Eatough, Holmes, Stapley, & Midgley, 2015; Rogers, Sapkota, Tako, & Dantas, 2019).

Ethics

The study received Human Research Ethics Committee approval from Curtin University, Perth, Australia. Separate approvals were received in India for approaching women patients recruited from the tertiary hospital as per their institutional guidelines. The participants did not receive any reimbursement or token of appreciation for their time as determined by institutional guidelines. The study rigor was ensured and practiced with adequate supervision and engagement in terms of the research process, informed consent and logistics with the hospitals managed by the researcher.

5.2 Findings

The study findings are voices of the women related to different aspects of care. They speak of the conflicts in emotion and pain. Women also highlight support of different kinds and ways from fellow patients and their personal caregivers, that is their own families specifically men.

The Words Waiting to be Spoken: Emotions

“Why me?” is a question women ask. A few women said that they did everything right with their lifestyles and were shocked to be affected with the disease. A recurrent view was that women “felt absolutely well”. Despite symptoms like excessive bleeding women did not consider themselves to be ill except for the “nuisance” with their periods. The symptoms were bearable in their opinion. The need to seek health intervention came only when it became impossible to continue with one’s daily work and routine. Most women found it embarrassing to talk about such issues with their husbands and families. Not having a woman that they could trust in the family or circle of friends (a sibling, mother, sister, friend or daughter) is a major deterrent for a woman’s openness about her condition.

> *In my village they told me, “During menopause it [symptoms like excessive bleeding] will happen to everyone . . . so you don’t worry”.*
>
> *Patient_ID_001*

> *I went back and forth [to the hospital] when there was back pain for three months in my village. I didn't get better. It would get better for a few days and then worsen. I didn't tell anyone at home. Just went to the hospital by myself.*
>
> *Patient_ID_003*

Cancer is perceived as a punishment, penalty or curse since women speak about not understanding what they have done to "deserve the disease". Women also shared with hesitation that they felt cancer was a result of one's fate and destiny. Stigma is another strong adverse experience women face due to cancer and the need to hide their health status stems from the feeling of how people will treat them knowing that they have the disease. What commences as not being able to care for children because they are unwell, can result in families keeping the children away from them due to fear of cancer being contagious. This is one reason why women are not allowed to return to their post-treatment routines though families might not openly state the reason. Women dread this possibility and prefer to hide symptoms as long as they can to prevent such circumstances.

The Networks of Support

The degree of physical pain that women go through is immense in cancer treatment. Since many of them seek care at an advanced stage there is often an emergency at diagnosis. Invasive surgery, extended radiotherapy and hospitalisation for 6 to 8 months are all too common. Women talk about symptoms such as loss of hunger, severe pain, reduced mobility, nausea/vomiting, and dizziness due to weakness during these months of treatment at the hospital. While women do not directly express going through emotional trauma, they discuss fear of side effects, concerns of being a burden, and of guilt regarding the workload of the primary caregiver. Support of family is a recurring theme in all of these issues. Those who do not directly discuss neglect from family talk indirectly of feelings of loneliness and being a burden to family.

Women use the expression that their families ask them to "sit quietly and not do anything" with the result that they feel left out, or confined within the walls of home because of this. While most do not openly accuse the family of keeping them out of routine life, they express discomfort with not being "allowed" to do any work or be engaged in routine household chores. A woman continues to feel a patient long after hospitalisation and her discharge, and the silent pointer is towards the family and its reactions to her.

Older women indicate conflicting emotions of feeling pride that children care enough to incur debt for hospital bills, however they also regret that the children need to struggle for money. Women who do not have spousal support indicate feelings of loneliness, meaninglessness of their lives and a sad resignation about their health, though they speak about marital issues in general terms rather than about their lives specifically. Having a supportive sibling, child or parent mitigates their suffering but there is a recurring self-enquiry on whether it is worthwhile to fight the disease and recover.

> *It is enough for me [life], I am ageing . . . this much of life is enough for me. I do not like to apply any pressure on my children's lives. However long God grants as life that's enough.*
>
> *Patient_ID_004*

> *My daughter-in-law said should we go to the hospital. I refused. Why give trouble to the children?*
>
> *Patient_ID_013*

Close bonds develop among other patients and personal caregivers in a ward. Women talk about such support. The type of support may range from assisting one another with buying medicines or food when their own families are away, or having conversations where emotional support is extended. Most women speak highly of these interactions and mention significant emotional support from others but do not specify the nature of the conversations they have with other patients. There are critical implications in these bonds, which are shared journeys occurring in a cancer ward that few can fathom from the outside. Such kindred spirit and togetherness among patients in cancer specialty institutions can also be considered a pivotal channel for health information exchange that occurs (Van Hollen, 2018).

> *Everyone here in the ward is my friend. There are people here who will help me if I need it.*
>
> *Patient_ID_007*

Women feel a kindred spirit with other women, either those who have been diagnosed with cancer or those who may need information about services and preventive measures to undergo screening.

> *I feel the need to help others [women] because I have also suffered.*
>
> *Patient_ID_004*

Support from men (husbands, brothers and sons) is often seen as willingness to spend on treatment and hospital costs. When men assure them that they are willing to take care of costs for their health, women feel encouraged and perceive that their life is important to the men.

> *My husband said to me, "Your recovery is most important. I will take care of everything"*
>
> *Patient_ID_012*

Men stating directly or indirectly that the burden of costs is less important than a woman's health is vital in her perception and valuation of her own health. The role of the natal family is accentuated further if she does not have support from her spouse and the marital family. Women who share positive relationships with their natal family are able to cope better with the indifference from the partners or other marital family members.

> *If husband doesn't help the natal family should be the ones to help women. Women can talk to their natal family.*
>
> *Patient_ID_012*

Women experience tremendous support from their families when they tell them to “not worry about anything”. These words indicate support at several levels: financial, emotional, physical and spiritual. They are words of protection. They are words of hope. They are words that show the availability of unconditional support. Similarly, family anger because the woman did not share the symptoms earlier is perceived by the woman as love and care in the guise of anger. Women talk about such anger with mild amusement or even happiness at the rage of children and family who reprimand them because it shows they care for the women. Such a reaction also means that the family would have liked to have facilitated the treatment earlier. This gives a great deal of strength for a woman especially during extended treatments where she may worry about being a burden on the family.

Women repeatedly talk about not wanting to worry their families being the reason they do not talk about their illness or symptoms of poor health. Literature, even in economically advanced contexts, shows that late presentation of symptoms is common among women in gynaecological cancer management, with women showing a tendency to normalise their symptoms (Low, Whitaker, Simon, Sekhon, & Waller, 2015). Women who are fortunate to have families able to sensitively gauge this conflict, get necessary reassurances from their families.

> *My daughter-in-law does not have a mother so she takes care of as if I am her mother.*
>
> *Patient_ID_004*

Women's willingness to undergo treatment is directly proportionate to the willingness of caregivers to articulate and show their support for the treatment.

> *Medicine is not a support. Visiting family members and friends are the support for a patient.*
>
> *Patient_ID_004*

Cancer is as much about family acceptance and coping as it is about the patient's coming to terms with her condition. Families or personal caregivers play a vital role in the context and their feelings and reactions are strongly interlinked with the patients' emotions towards her health. They are support systems and powerful channels who can either facilitate or completely block health information from a patient. Since it is culturally and socially acceptable for a family to have precedence in making decisions in healthcare, even when a woman wants information she is shielded and protected from it.

Personal caregivers discuss this directly with healthcare providers and often request them not to share any information with women. Healthcare providers cannot mitigate or disregard the importance of the caregivers' presence every step of the treatment pathway. Even those providers who believe that the patient's right to information is of topmost priority state that it can be enforced only with some level of cooperation from the family. Patients also express in direct and indirect ways that the journey of their care is as much about their caregivers' wellbeing, collaboration and consent as it is about them.

> *Even if I ask they [family] say, "Don't be afraid we will deal with it" [the family not sharing details]. Even if I want to know I don't get to know much information about what the doctors say.*
>
> *Patient_ID_002*

Women articulate that they do not share their apprehensions with family since that would worry them. Women also express knowledge about their condition though families tend to tell themselves that the information is hidden from the women. This conspiracy of silence and partial sharing can complicate treatment decisions significantly.

> *Doctors didn’t tell me anything during treatment. My brother talked to them directly. When I asked he said, “Don’t be scared. We will discuss everything with the doctors. This is not necessary for you. You will be scared. You will cry. Leave it.” Even now when I ask my brother doesn’t share anything with me.*
>
> *Patient_ID_002*

> *Doctor will visit and inform my daughter-in-law and she will take care me. I don’t know anything.*
>
> *Patient_ID_013*

Life and Living Post-Diagnosis

While the primary concern during treatment is survival, life post survival is a mixed experience for many women with its own set of challenges and pain. Of these the foremost is worry and apprehension of loved ones suffering due to their illness.

Many women became extremely emotional as they began speaking about their children. The concerns ranged from whether their children were eating regularly, their education, weddings (if they were older children), physical safety and emotional wellbeing. Women expressed and indicated guilt for not being there to take care of their children for an extended period, despite the fact they were away because of a major illness. Help related to children is perceived as the most critical support that they can receive from someone. Women with younger children openly stated they were forever indebted to family members who cared for their children.

> *I feel upset . . . pain during treatment is very challenging . . . going through this is very difficult if you have young children [who require care].*
>
> *Patient_ID_012*

The challenges of not having education or information place tremendous burden on women in ways that may not be fully expressed or understood, which hinders their access to basic services, knowing what questions to ask, where or when to seek help and tapping of support networks in the health setting. Women also do not know whom to turn to or how to seek such information

> *Educated people will see [information] through TV or radio and they will come for check-ups. Uneducated people like us how they will come here? If they have a pain in their stomach what they will do? They will just go to the medical shop and take tablets [over the counter painkillers] that's all. After that they will go back to their work.*
>
> *Patient_ID_011*

> *People like you [referring to interviewer] and hospitals can help. You should recommend that women go for check-ups, recommend the hospital and say that they will take care of us there. Somebody should tell us that way.*
>
> *Patient_ID_012*

Many women do try alternative medicine and home remedies prior to seeking treatment. A few said they will try alternative medicine after surgery if they do not recover fully. Though there is limited evidence on the efficacy of alternative medicine and gynaecological cancers in India, women in the study have expressed the belief that they know and practice different home remedies. This is especially applicable for symptoms and pain management with knowledge from their personal networks. Women do not discuss openly about these medical options since they are seeking care in a hospital that provides Western medicine, but the familiarity and trust in alternative medicine is common among women. This is consistent with literature in other contexts where home remedies and self-medication and management are tried at different stages by women with gynaecological malignancies prior to seeking medical treatment or even when they are undergoing treatment (Keene, Heslop, Sabesan, & Glass, 2019; Low, Whitaker, Simon, Sekhon, & Waller, 2015; Zeller et al., 2013).

> *Nowadays no one wants to listen. There is good Indian medicine available in this country. But people believe only Western medicine is superior.*
>
> *Patient_ID_004*

Most women seek healthcare at an already advanced stage of the disease when the situation is urgent and sometimes the tumours inoperable. Feeling “upset” or “sad” or “guilty” because the family is upset on their behalf is a common reaction from women and a trigger to hide pain and symptoms both in the beginning and through treatment.

> *I don’t tell my family when there is a problem. Their hearts will hurt won’t they? So I don’t say anything. No peace of mind for them and no peace of mind for me. So I say nothing. Even if I have pain I will tell them that I am fine.*
>
> *Patient_ID_005*

> *Women should have the courage that we should take care of ourselves and be well. It should come from within. I tell my daughter-in-law, “Don’t expect your husband to take care of you. You take care of yourself if there is a health problem. We should take care of ourselves. Not depend on others”.*
>
> *Patient_ID_004*

The other side of this outlook is the high level of dependence and expectation women have on the family members, especially husbands and brothers to help solve their health issues. Some women do not consider it necessary to engage with the health system in any way and have a silent expectation that everything should be dealt with by the family. This dependence poses a high degree of responsibility on the caregivers to frontend all the decisions in the care continuum without having adequate support for themselves.

> *I didn’t tell the doctor any of my symptoms. I told my brother and he told the doctor.*
>
> *Patient_ID_002*

A major side effect to treatment is the loss of appetite and poor digestion. Women mention fatigue combined with worry due to loss of appetite. The major tertiary institutions typically have only one dietician or nutrition specialist responsible for all patients in the hospital. The patient and caregiver meetings are done on the basis of referrals from primary physicians though ward visits are made periodically to meet the patients. This is insufficient interface for the women who may need comprehensive nutritional advice at different stages of their treatment based on side effects and requirements. Economic constraint results in unhygienic food bought from inexpensive eateries since it becomes impossible to source home cooked food when they are so far away.

Challenges, pain and trauma are sometimes perceived as a natural part of life for many women. There is also a self-initiated pressure due to this to remain strong and silent when there is pain.

> *Being a woman itself is suffering . . . from when she is born there is suffering . . . the same after marriage . . . at every stage, everything is difficult.*
>
> *Patient_ID_010*

> *The support my family is extending for me now during my illness is enough . . . I really don't want to ask them for more than this.*
>
> *Patient_ID_010*

Coming to Terms with Fear

Fear is a common reason for women not expressing to their families their fears about ill-health or symptoms. The association of cancer with death and hearing about women not surviving treatment are common reasons for hiding symptoms until it is too late. A few women said they feared talking about their condition because voicing fears made the problem more real for them. These fears continue during hospitalisation and treatment. Many families extend themselves a great deal and women do not like to discuss with family the psychological trauma they face. Secondly, families do not openly acknowledge to women that they are undergoing treatment for a major health condition. This puts the woman in a situation where she cannot express her knowledge about the seriousness of her condition and fears that she will not survive the treatment.

The silent yet contradictory expectation from families that a woman should be strong but stay unaware of the magnitude of her condition complicates issues at multiple levels. It results in the woman camouflaging her most fundamental fears related to survival and mortality. If there is no one in the family they can confide in or if they feel the need to protect the primary caregiver emotionally, women tend to be secretive, and this is one of the harshest secrets they carry quietly.

Financial pressure is the second most challenging fear a woman negotiates in her journey to survive. Younger women patients fear that money required for children is spent on treatment and older women fear that there is burden on their offspring to spend on treatment. Most importantly, fear of financial difficulties resulting in delays or discontinuance of treatment is a trepidation that runs across conversations with women. This is something they find hard to express since it would make them appear selfish to the family, which is struggling with treatment expenses. Women are emotional when they speak about the urgent need for financial help from support organisations and knowledge about government schemes that can help them and their families with medical expenses.

> *We have money problems at home so I did not talk to anyone at home. I went to the medical shop by myself and got some medicines to eat . . . When there is pain I would lie down and when there is relief I would continue with all the work at home. This is what I would do without telling anyone. My neighbour said 'go to the hospital where they will do all check-ups…otherwise you will die' [so she decided to tell her family].*
>
> *Patient_ID_011*

Pathways to care

Ovarian cancer was the most common cancer among women in the study followed by cervical and uterine cancers. The women were admitted in the gynaecological ward for long-term care. Their stay in the hospital for the surgery, radiation and treatment ranged anywhere between 3-8 months. Since the treatment weakened them considerably it was essential for them to have an attendant on a full-time basis staying with them. Women typically expressed satisfaction with the treatment and their experience in the hospital though they looked forward to getting discharged and returning home. Many of them adverse experiences prior to reaching the hospital for long-term care. They had had consultations with general practitioners or smaller clinics which had resulted in delay in seeking necessary treatment. They spoke about undergoing some medication or treatment by themselves because they did not want to share their problems with the family. Women who did not have another female family member close by tended to hesitate sharing the health issue with their partners or sons. There were adverse experiences in the pathway to care that the women had experience though this was not the case with all women. Some had good referrals to tertiary care from general practitioners or gynaecologists that they had consulted. One of the reasons some women finally reached the destination in the pathway to care was two-fold a) they did not get better with previous treatments elsewhere, b) someone reliable in their personal network gave them suggestion to seek care in the hospital where they were currently undergoing treatment.

Faith and Prayers in Healing

Prayer is a form of support that women perceive to be of tremendous benefit. They talk about children, spouse, siblings, friends and in-laws praying on their behalf for their welfare. They also discuss prayers of family members to offer something in kind or as service in return for their good health. Coping with the aid of prayer and spirituality, when confronted with a major chronic illness, is common in India since there are multiple layers of support through emotions, belief systems and joint coping in a setting of otherwise limited means (Jagannathan & Juvva, 2009).

> *My daughter has prayed to Tirupathi to offer hair [tonsure] if I get better. I too will offer my hair there as well as in Maruvathur [another temple].*
>
> *Patient_ID_008*

Women seem to have varying relationships with God, religion and spirituality when handling their health in the cancer spectrum. Evidence shows that culture, religion and belief systems interplay with several aspects of self-efficacy, choice and behaviour change in gynaecological cancers (Dareng et al., 2015) as does spirituality with a definition of wellness and quality of life (Rannestad, 2010). One of the responses from women is a quiet yet potent anger towards God and a refusal to talk about spirituality and faith because they state they are too angry with God. Women have talked about how faith has let them down despite the fact that they had a close association with their favourite deities. While for some it is God that has let them down badly, for others the same God is a source of immense solace, strength and hope. The journey is personal and subjective in spirituality but a force that is palpable.

Women talk about continuous prayers that have helped them since being diagnosed with cancer and their prayers range from requests for a full recovery to managing pain on a day-to-day basis. A couple of recurring prayers are to take care of their children and desiring an extension of life in order to go back to their routine lives. Women express a sense of happiness when they talk about their family members having prayed on their behalf, especially with the promise of certain rituals and offerings if they should recover. These promises and negotiations in prayer seem to be tangible ropes of connection and hope between their lives and the perceptibly "higher realm" of spirituality.

The question of whether God is punishing them by giving them a life-threatening disease is expressed by the women with some trepidation. The query is often followed by the silent implication that they have done nothing to deserve the illness and they do not understand why God is testing them. Women ask the question "Why me?" and "What have I ever done?" in this context. While they do not directly acknowledge that there may be a reason for a punishment they acknowledge that the thought has crossed their minds if the disease is a punishment. Why the thought has entered their minds is something they do not discuss.

> *I work inside the temple, help with the cleaning and maintenance. I am doing this work since it is good for me to work in the temple. I pray, 'Keep me safe*

> *Oh Mother. That's it. I feel that God has taken care of me . . . I don't know how it will be moving forward. Till I pass on help me at least as much as you have done till now Mother—that's enough.' I have prayed this way.*
>
> *Patient_ID_010*

> *I used to pray to every god so often. Being in the hospital for eight months now I have not prayed . . . no god has taken care of me (when the disease struck).*
>
> *Patient_ID_011*

> *I pray to this god and that god. I pray to Jesus. I pray to all gods possible.*
>
> *Patient_ID_008*

5.3 Discussion

Women's experiences show how cancer care is fraught with several complex issues that affect them. This is why they maintain several silences in the cancer continuum. There are boundaries in health settings that prevent an open discussion of the fears they grapple with and the resolutions they seek. Those who care for them are dealing with their own challenges in the continuum of care (Teskereci & Kulakaç, 2018). In order to fully understand the problems of women dealing with cancer, screening programs and interventions need to be longitudinal and proactive rather than reactive and with short-term goals.

Gynaecological cancer has long-term effects on the quality of life, requiring efforts to understand and cater to them appropriately (V. L. Beesley, Chalachew, & Webb, 2019). For a woman to be upfront with her personal trauma and fears, support networks need to also evolve with readiness prior to care and be by her side through her treatment and follow-ups. Better bridges are required in healthcare for women to feel comfort to access the health system and healthcare providers in an enabling manner for themselves (Sumiko Oshima, Kisa, Terashita, Kawabata, & Maezawa, 2013).

Women try and focus on the positive aspects of their care since there could be a sense of obligation to their caregivers and providers who help them during an extremely challenging time. To point out personal or professional inadequacies is culturally deemed ungrateful when others extend themselves with limited resources and constraints. Yet cancer survival is a journey as hard as the treatment trajectory itself (Abbott, 2016). It would be of great benefit if there is opportunity within the health system to create a separate space for the patient to articulate her fear, worry and needs and such conversations are periodically facilitated by a counsellor. Evidence over the past two decades shows that health care providers and support services that cautiously and sensitively aid a woman's emotional resolutions are critical in the cancer care continuum (Buckley, Robertson, Wilson, Sharpless, & Bolton, 2018; Rieger, Touyz, & Wain, 1998; Thygesen, Pedersen, Kragstrup, Wagner, & Mogensen, 2012). In many ways such services are the only windows of hope for women who are negotiating several issues internally and with their loved ones. With such services there is likely to be much more of an open forum for women to confide on issues that directly impact their psychological wellbeing.

Apprehension about upsetting the family and personal caregivers was a recurring theme across many interviews. Evidence shows that the lives, emotional wellbeing and workloads of caregivers are significantly impacted when they care for women with gynaecological cancers (Seven, Yilmaz, Sahin, & Akyüz, 2014). The dependence on the family in turn for the women may not be completely by choice. Some say that their families do not share information with them (though they want to know their own health status) and others share that they route questions through their families from the commencement of treatment. None of the women state their actual preference in this. This is a sensitive and complex realm since the health system is reluctant to intrude in the personal relationships of their patients. Working with the patients is essential to find viable and acceptable approaches for women to articulate their preferences in cancer care. A possibility is for healthcare providers to strengthen their internal referral network. Another is for the primary clinician to invite a counsellor to be periodically present during patient discussions.

The family is the vital support for a woman after treatment completion as the institutional health setting in India is already overburdened. However, the healthcare providers are the best facilitators for critical health communication when the woman is in the institution and when she is ready to return home for post-operative or treatment care and recovery. This is consistent with global evidence that suggests that while there is much room for improvement in provider patient communication in varying social contexts, the role and access of healthcare providers continue to be of significance in gynaecological cancer care (Loehberg et al., 2020; Marcusson-Rababi et al., 2019; S. Oshima et al., 2011).

Cultural sensitivity becomes paramount in this facilitation since even a strong recommendation or firm reaction in support of a patient's perspective that is contrary to family's can result in interpersonal problems that have serious consequences. Worse, at times the family can decide to discontinue her treatment and go elsewhere. It is imperative to gauge what subtle or blatant pressures from her loved ones are being experienced by the woman along with her self-induced pressures. Where there is reluctance to go and see a counsellor alone, the counsellor could be in an adjoining room or participate in physician conversations with her jointly, because a woman is likely to be more forthcoming than in the direct presence of family. Since this is a difficult process to practice consistently, it is necessary for healthcare providers who interact with her to consider all conversations as their windows of opportunity to understand her unvoiced preferences. The routine clinical meetings are the most easily available platforms for providers to get a sense of a woman's mind and her emotions about an extremely intrusive and intensive treatment. In addition, providers can ask a woman to step aside with them when they are on their outpatient ward rounds since there are confidential spaces available in the ward that a woman can walk in to for exams. Having such conversations during routine patient interactions is acceptable both for the patients and their caregivers and the caregivers would be willing to wait in the ward while this happens. Providers can also spend a little time post radiation sessions in the radiation therapy rooms since the caregivers are usually asked to wait outside during the sessions. Having fixed times where they are on call with a patient is also a feasible method. Speaking to the woman on the phone and giving her such access increases comfort for a woman to interact with her provider.

Women's self-efficacy can take a step back in cancer treatment which has harsh physiological side-effects. Losing organs, and having chemotherapy side effects such as hair loss, post-surgical pain, loss of libido, poor digestion and nausea are common. Extreme fatigue also prevents them from contributing to household chores following treatment and surgery. Misconceptions of the disease in turn can make families keep children away from women when they return from the hospital. Most women hear or see side effects experienced by other patients in the wards; if it is the only preparation for them it serves to increase their fear. As a result of severe time and resource constraints in a tertiary health facility that caters to high numbers of disadvantaged women, there are few opportunities to clarify their concerns openly right from the onset. Evidence strongly suggests that a well-planned woman-focused clinical approach that is aware of factors that invade her self-efficacy is key to management in gynaecological cancers (Manne et al., 2020; Sandsund et al., 2020). The emotional strength and courage a woman needs for the treatment is heavily impeded by her separation anxiety or worry about whether her health is placing a heavy burden on her children. Health institutions need to include this subject in their preliminary history taking when a patient seeks care. Awareness of this dimension's impact on a woman's health is essential for health institutions to recalibrate their interactions appropriately.

The matter of finance is a double-edged sword since it causes extreme stress to the both the women and the caregivers. Communication interventions that address families of patients to explain what the treatment costs are, prepare them for financial responsibility, length of treatment and eligibility of public grants are needed. They should be tailored sensitively and in a proactive manner to ensure caregivers' clarity on long-term costs without jeopardising their emotional wellbeing. Evidence shows that resource-constrained settings suffer from the double burden of presentation and diagnosis at an advanced stage translating into fewer chances of good prognosis and higher costs of treatment (Bibi et al., 2016). It may also be a reason why treatment is often discontinued mid-way.

The issue of mortality is a constant undercurrent in everything women express. Fears related to mortality are expressed as angst or anger against God, worry about who will care for children in their absence, yearning to recover, emotional trauma about disease and unwillingness to share with others that they have cancer. Fear of death requires urgent focus from support networks. Literature from other contexts show that fears of dying, thoughts about death and emotions about mortality are common among women (Williams et al., 2018). Death and dying are not easy subjects to discuss in many cultures. The cultural importance of acceptance and fatalism in India imposes subtle expectations on the women to be brave. It is why women with cancer need a proactive support network to talk with about her unwillingness to die, and to help her deal with this intense suffering. The combination of physiological pain with fear of mortality is one of the loudest silences many women live with in cancer care.

Very few studies have looked at collusion and its direct impact on patients and families (Victor et al., 2018). Women second-guessing about what their families want them to know, do, say and feel is a consistent undercurrent in the interviews. This is different only if they have an enabling relationship with the primary decision-maker who might discuss situations with them openly, or if women themselves feel empowered in their family settings. Collusion also poses instances where there is stringently monitored time, space and conversation with their healthcare provider, even when patients or providers desire separate time. Families do intervene in decision-making powers of women as this is culturally acceptable in healthcare and women themselves typically participate in it to avoid the risk of hurting their families. To consider this a loss of agency may be looking at just one side of the issue from a Western paradigm and it does not reveal the full or real picture of the cultural context.

A woman’s emotional conflicts in this scenario may arise from the need to protect the emotional interests of her loved ones who in turn attempt to protect her interests. To understand intent and intrigue have the purpose of protecting a loved one requires knowledge of a social structure where health decisions are largely collective in nature. Cultural norms may consider revelation of the health condition to be more emotionally and psychologically harmful to women than withholding information (Van Hollen, 2018). Women tend to respect and value that intent in their families. As a result, non-disclosure of health information in cancer care cannot be interpreted with didactic or simplistic conclusions about a woman’s loss or lack of agency.

Periodic and brief time slots for healthcare providers to engage with their patients without the presence of family members is the most pressing need for women. Since this is a culturally sensitive issue have time alone with their healthcare provider needs to be handled with thought, presence of mind and in innovative ways that do not threaten the women or caregivers. The research interviews in this study themselves proved to be such an avenue with a few women openly expressing their angst and conflicts about collusion with the interviewer. For healthcare providers, trust-building becomes crucial for this purpose from the commencement of the association. At the same time, such efforts should not jeopardise the interests of the healthcare providers who are themselves dealing with time pressures, negotiations and responsibilities in the care spectrum.

5.4 Conclusion

Women with gynaecological cancers in India are negotiating through multiple silences in their experiences with cancer care. Many of these silences interplay with well-meaning intents of care, compassion and concern from their personal caregivers and healthcare providers. These silences are laced with tiered complexities that require time, understanding and contextual sensitivity to be decoded accurately. Such unravelling is a precursor to the conceptualisation of appropriate responses and interventions that address their health needs with their participation and consent. The network the woman has in her care trajectory with providers, families and health institutions needs to be accepted as her strongest ally despite its many shortcomings and limitations. A woman’s health, wellbeing and mortality are tied to the acknowledgement of her as one of the active agents in cancer management. For this to be achieved, the media, individuals, institutions and women themselves need to recognise women’s agency in the cancer care spectrum and consciously stop viewing or projecting them as victims of gynaecological cancer (Allen & Roberto, 2014; Grimsby, 2015; Weiss, 2012).

Lastly, an important point to note is that none of the women discussed sexual dysfunction, concerns or challenges common in gynaecological cancers. That silence is resounding since it is also tied to the stability of marital relations, spousal negotiations and childbearing options. The silences of Indian women are not an indicator of powerlessness nor without self-efficacy. These silences are considerable and complex and require urgent and unbiased attention. Such effort will aid in providing a more lucid picture of how and why women exercise certain choices in cancer care, including where they may step aside quietly in the decision-making spectrum. This important recognition will be the first step for voices to break the silences in gynaecological cancer care in India and for stakeholders to support a woman’s efficacious journey towards wellbeing in the cancer care continuum.

5.5 Summary

The article in this chapter has presented and discussed the risks of assumptions about women’s challenges in the cancer care trajectory. More research is required to understand not just what women express about their problems in access, seeking and receiving care but about what they choose not to express. The next chapter presents the dimensions of finance in the lives of stakeholders in the cancer care continuum.

Chapter 6

Beyond Money Matters: The Hidden Costs of Care

This chapter focuses on data that captures the perspectives that reveal the dilemmas, challenges and situations related to financial transactions and needs in cancer care management.

The chapter commences with the evidence on affordability and payment of hospital bills. The study findings show that cancer care management is far more than affordability and economic viability of care. Money and financial transactions during treatment and after are about life and living. The patients and their caregivers deal with many aspects of survival that are interlinked with money. This article highlights their struggles and trauma and the risks of assuming that care issues are primarily about hospital bills. It builds on the previous chapter that makes known the perspectives of women patients. Through participant voices the limitations of considering finance as a finite boundary around affordable healthcare are explored.

This article will be submitted to the ***Indian Journal of Medical Ethics*** with the title: *Beyond money matters: The hidden costs of gynaecological cancer care in India.*

Abstract

Challenges of affordability of care have been an important area of research in the management of cancer. However there has been far less focus on finance and its interplays beyond monetary transactions. This missing lens can better reflect the financial constraints that practically translate into people's lives in non-monetary terms. Drawn from research done in India from 2018 to 2019 this article brings attention to the perspectives from three stakeholder groups in the cancer care continuum: patients, families and healthcare providers. The economic affordability of healthcare in chronic illness is important and has been given due acknowledgement in multiple health programs and interventions. However, the emotional, psychological and social dimensions that determine decision-making related to money tend to get neglected. The perspectives show that the discussions on affordability are entangled in related factors like conflicting financial pressures, willingness to spend, relationship of the patient with key decision-makers, self-efficacy and agency. Financial schemes and programs that work with a causal link between affordability and care may be missing other links as a result. The objective of this paper is to gain a better understanding of how these translate into day to day challenges in cancer care seeking and access. This understanding is likely to illustrate ways to respond effectively to address such gaps.

Keywords: women's health, gynaecological cancers, India, affordable healthcare, finance, family

6.0 Introduction

Cancer’s adverse impact on the economic health of individuals and households in low- and middle-income countries is well established (Chopra et al., 2019; Engelgau, Karan, & Mahal, 2012; Gelband et al., 2016; Pramesh et al., 2014). In a context like India the burden of expenditures due to non-communicable diseases is likely to skyrocket with the dual needs of prevention and care costs that increase concurrently (Engelgau et al., 2012). The mortality burden from gynaecological cancers is extremely high in the country and despite the advancements of medical science to improve women’s health globally, the incidence of death from cervical cancer (a leading cause for mortality) is estimated to increase (A. Sharma et al., 2017). Late presentation of gynaecological cancers, large population, urban versus rural residence and age impact on surviving the disease are common characteristics that affect disease progression (Dikshit et al., 2012). Research shows the possibility for financial viability and disease management to work together if some of these factors are addressed appropriately (Sankaranarayanan & Swaminathan, 2012). What research does not adequately discuss is the role of the factors that possibly create economic inadequacy in health decision-making to begin with.

Women affected with cancer continue to form one of the most vulnerable and affected sections of society and their situation worsens if they live in low- and middle-income countries (Bachelet, 2017; Ginsburg, Bray, et al., 2017). Much of women’s health and mortality vulnerability in gynaecological cancers in such countries has been correlated to gender disempowerment, global inequities, out of pocket expenses, socio-cultural disadvantages and contextual challenges in resource allocation to disease management and wellbeing of women (Ginsburg, Badwe, et al., 2017). There is strong evidence correlated with delay in seeking care or diagnoses and incurring out of pocket expenses (Nebiyu et all, 2020)

The complexity of care costs is further aggravated with non-viable insurance schemes, disproportionate out of pocket expenses, discordant regulatory practices within public and private sectors, and regional variances of medical systems (Pramesh et al., 2014). While the private sector has grown steadily in the country it has been largely restricted to the urban areas of India (Holdaway, Levitt, Fang, & Rajaram, 2015), which twists the "affordability" paradigm incorrectly when any financial lens is used in healthcare. Research has slowly but surely begun to call out the gaps in the current literature in which the focus continues to be on the disparities in health expenditure rather than the underlying causal links to it (Saikia, Moradhvaj, & Bora, 2016). For instance, evidence suggests there are disparities for women in care seeking as well as expenses incurred for care, even before their actual access to tertiary care (A. Mukhopadhyay, 2014). Such disparities in finance management may well commence long before a woman's disease diagnosis and entry into a health institution. A woman's autonomy over earnings or control over financial decision-making in a household may not be only about less power but equally about many other aspects of the relationship, therefore such hasty and incomplete conclusions propel the dangers of generalising gender inequities (Namasivayam et al., 2012). Changes in the economic context within India have had some adverse effects on the health access to women in India (K. Mukhopadhyay & Pallab, 2018). The increasing growth of the private health sector or the power of the pharmaceutical industry have not translated into efficaciously bridging any of the gender gaps. Rather, they seem to further aggravate the existing and unmet needs of women for treatment access, money and timely interventions for their health challenges.

While literature on financial schemes specific to gynaecological cancers in India is not available literature on general gynaecological services suggests that only a small percentage of women have health insurance (Desai, Sinha, & Mahal, 2011). The study however suggests that women who are insured tend to undergone treatment more than those who don't have insurance. This implies financial burdens impacting decisions on whether or not to take treatment. Evidence on health insurance has mixed reports in India and there is no clear correlation that enrolment in such schemes translates to lower out of expense for people seeking care (Prinja, Chauhan, Karan, Kaur, & Kumar, 2017). Similarly, under universal health coverage there are gender variances in actual utilisations of hospital services and schemes even under universal health coverage with women seeking less utilisation (Shaikh, Peters, Woodward, Norton, & Jha, 2018).

People have less familiarity and knowledge about the availability of public or government sponsored insurance schemes that can help alleviate cost of tertiary service in India (C. Chatterjee, Joshi, Sood, & Boregowda, 2018). Such information gaps are heightened due to low levels of literacy and the geographical residence or location of the patient seeking that advanced care. These challenges are heightened by a preference for the more expensive private sector due to concerns about the quality of care in the public sector. Women who are already at a disadvantage for health care access may still not receive such information in a timely or useful manner.

The usage of public insurance schemes may also vary considerably in urban versus rural households in diagnosis, detection and treatment outcomes (Azam, 2018). The experience of utilisation and benefits of a national health scheme vary in households and there is little evidence of a significant reduction of out-of-pocket expenditures for patients despite such schemes.

There are risks in excluding individuals, especially family, when deciphering issues related to cost management in women's cancer care (Alexander et al., 2019). Non-communicable disease management is not exclusively to patients but are also about their personal caregivers, the families, friends and stakeholders in private spaces. The context in which a patient is dealing with her cancer costs has to be deciphered in many ways: social, cultural, regional and familial. This consciousness at the individual and collective levels is necessary for cost effective measures to actually be of more holistic benefit to patients and their personal caregivers.

Gynaecological cancers in India have the dual challenge of less research and data on themas well as too few women being identified at risk in a timely manner through screening (Gandhi et al., 2017). Evidence suggests that several factors like nulliparity, age of the woman, education, geographic residence, marital status, usage versus non-usage of contraception, number of pregnancies and experience of previous health services impact receptivity and willingness to participate in screening and preventive programs (Nene et al., 2007). Cancer estimates suggest that nearly 30% of gynaecological cancers in India will be gynaecological malignancies by 2020 (Barman et al., 2017). Cervical cancer mortality is the third among causes of cancer deaths in India and late diagnosis is common (Narayana et al., 2017).

Tertiary institutions providing care in India suffer from many problems as do other low- and middle-income countries. These could be related to costs, funding sources, quality, access, training, research and infrastructure (Sirohi et al., 2018). Largely restricted to urban settings these institutions deal with extremely high patient numbers, which delays timely treatment especially for those living in rural India. Majority of expenses for patients in cancer care is out of pocket and most hospitals that have access to public financial schemes do not offer multidisciplinary care that is required to manage cancers (Caduff, Booth, Pramesh, & Sullivan, 2019). In the context of high complexity in care management, affordability cannot be reduced to match patients' ability to pay for the health care expenses alone. This article seeks to argue how the discussion on affordability needs to go considerably beyond such a naïve if not limited understanding, to include the deeper perspectives and experiences of individuals, families and health care providers that undergo, pay and manage their health care.

6.1 Methods

This article is drawn from a larger qualitative study on cancer care conducted in 2018 and 2019. The study examined the barriers related to care seeking and provision in gynaecological cancers in India and the role of health communication in risk-reduction strategies. This article discusses the implications of money in gender, familial power, and social networks that impact the complex planning and decision-making in cancer care management.

The research was underpinned by two theoretical l frameworks, the health belief model (Rosenstock, 1974a, 1974b) and the theory of communicative rationality (Sheikh & Porter, 2013; White, 1995) that have aided the unravelling of complex nuances in health decision-making in cancer care. The communicative rationality approach has shown the factors impacting ongoing decision-making among stakeholders in health, while the health belief model has helped reveal perceptions, triggers and benefits influencing those decisions. Both frameworks have constructs that highlight the complexity in the consensus as well as the variances in priorities and outlook among different stakeholders (patients, healthcare providers and personal caregivers). This duality requires deep understanding in the care continuum which is fraught with the challenges and changes of a life threatening disease. Communicative rationality reveals the process of agreement among people "living together differently through struggling to make sense together" (Healey, 1992).

The health belief model has been applied in health systems over several decades since its development to better understand predictors health behaviour (Guvenc, Akyuz, & Açikel, 2011; Rosenstock, 1974a, 1974b; Sohler, Jerant, & Franks, 2015; Tapera, Senabye, Mhaka-Mutepfa, January, & Apau, 2019; Yoo, Kwon, & Pfeiffer, 2013). The model is relevant not only to decode the beliefs, barriers, risks and benefits that influence the perceptions, but also perspectives and self-efficacy of women, their providers and personal caregivers in the care spectrum. Most importantly, the two models reveal when the participants decide jointly and where they disagree or disassociate with each other in health decision-making. This is significant for proposing any response interventions that accurately address the groups of participants.

Semi-structured in-depth interviews were conducted with patients (*n* = 15), personal caregivers (*n* = 10) and healthcare providers (*n* = 35) in this study in an urban setting in the south of India. The patients and personal caregivers were from one private tertiary referral hospital and the healthcare providers were from three different tertiary hospital settings (including the institution where patients and personal caregivers were interviewed). Healthcare providers from cancer support services and a community based organisation were also interviewed.

Women diagnosed clinically with a gynaecological malignancy were approached for consent to participate in the study with the support of clinicians in the department. The hospital caters to patients from lower socio-income groups from many regions of India. It has a comprehensive specialty centre for oncology services, research and is also a teaching hospital. Patients whom clinicians considered and flagged as too ill or emotionally disturbed were not approached for consent in the study.

Once a woman consented to be interviewed she was asked (post interview) if her personal caregiver may also be approached for consent to participate. The consent process clearly delineated that her responses in the interview would not be shared with her personal caregivers and vice versa. If the woman declined permission to approach her personal caregivers they were not contacted further by the researcher.

During the interviews, patient participants were periodically asked if they felt well enough and comfortable to continue and the interview proceeded as per the patient’s response. Similarly, interviews with personal caregivers were rescheduled or concluded when the caregivers expressed angst or needed to return to the patient or attend to something related to her needs.

Interviews with women and their personal caregivers were conducted in the Kannada and Tamil languages. The interviews with healthcare providers were conducted in English, Kannada and Tamil. The English and Tamil language interviews were conducted by the researcher, the lead author. The Kannada interviews were conducted by an interviewer trained by the lead author and with research experience.

Data was managed and aggregated as themes and subthemes after multiple reviews by the researcher and then checked with her supervisors. The main subthemes explored in the first level of analysis included cues for decision-making, collusion among participants, communication, hospitalisation experiences and institutional dimensions in cancer management. The findings for this paper have been aligned using a comprehensive set of themes related to finances and cost-related subthemes underpinning the frameworks used in the study. The application of the theoretical frameworks in this paper have been particularly related to the cues to action in both the health behavioural spectrum and collaborative realms. The cues have interlinkages with financial decisions, affordability, out of pocket expenses and concerns about long-term care costs patients and their caregivers have. These are further impacted by perceived threats due to the disease and the perceived benefits of adherence or taking a line of treatment. The communicative rationality framework has underpinned final decisions that are taken collectively about treatment costs, though the primary decision-maker may be one person who pays for the costs. Inclusion of multiple players in the familial decision making spectrum and often the patient herself is another aspect that can be studied better by the application of this tenet.

All interviews were audio recorded and did not include names or other identifying information such as institution or department. Participants who declined to have their interviews audio recorded during the consent process were not included in the study. This study was approved by the Curtin University Human Research Ethics Committee. All institutions that participated reviewed the study as per their institutional guidelines prior to sanctioning their approvals to contact and approach the participant categories for consent.

The study has used the guiding principles of contribution, rigour and credibility (Northcote, 2012) as quality criteria. Research that focuses on the non-clinical dimensions of non-communicable diseases such as cancer, especially gynaecological cancers, is limited in India. Thorough and periodic review of study design, methods and guides were undertaken by study investigators and a steering committee comprised of professionals with expertise in clinical, social and research angles in health were routinely consulted.

6.2 Findings

Financial need acquires many layers of power and vulnerability for people dealing with cancer as patients, personal caregivers or healthcare providers. These may change organically with the progression or regression of the disease itself. They also work differently with specific individuals, institutions and groups of people. Relationships between costs and care have to be fully unravelled to see the subtlety of such interplays.

Money and its Role in Survival

One of the main characteristics of understanding money in cancer care is to listen to who is talking about it at a given point in time. Its implications tend to vary accordingly.

> *"I spent so much, I have done so much . . . how can you [Doctor] say she may not survive?" is something family feels.*
>
> *(Healthcare provider: Oncologist)*

Healthcare providers say that when a personal caregiver speaks about money it is also in the context of angst, of confronting negative outcomes despite the costs they have borne. Similarly, the "approval process" for funding means different things to them compared to what it means to the patient herself. For the personal caregivers, financial support translates into a reduction of the cost burden. The patient on the other hand considers the approval process more an administrative hurdle as the clock ticks on her health and wellbeing.

Among siblings who are caregivers, talk of money differs based on who is the primary financial provider for the treatment costs. Costs escalate with time and there is lack of clarity on when they will end. The combination of factors are a severe pressure on the person who pays the bills. For the patient herself there is also the pressure of being a burden on the personal caregivers along with the urgent need for survival, and her desire for quick and pain-free treatment.

Among patients, when an older woman speaks about money her stance may vary from a woman who is younger with multiple familial responsibilities. For the older woman the perception of whether her life is worth the costs incurred becomes a traumatising internal enquiry. Cues from the family's reactions, especially to costs, may be watched carefully.

> *Enough. The years that God has given is enough. I don't want to see my children suffering [because of me]. If my remaining time is okay that is sufficient.*
>
> *(Patient)*

Money as a Complex Decision-making Process

Older women's emotional loneliness in dealing with financial uncertainty and pressure is an area surrounded by silence, particularly the silence related to the supressed emotions as to whether their lives ahead are considered necessary as contributing members of family. A recurrent theme of hope occurs among patients when they are given the reassurance from personal caregivers that their recovery and lives are worth the costs incurred or what will recur in the future. Reassurance may be directly articulated by the personal caregivers or it may be sensed by a patient in the countless ways that a caregiver may facilitate or be engaged with her care. If the communication channels and exchanges that occur between patients and their families help a patient perceive this willingness in her personal caregivers, she also perceives a greater value for her life and wellbeing.

> *How they [family] take care of me now—that's more than enough for me. I don't want anything other than that.*
>
> (*Patient)*

Expenditure towards treatment and money spent on care may be perceived in multiple ways by a patient. In some cases, although large amounts are spent on her she may sense "financial fatigue" from a family member, slight or open resentment from an in-law or resignation from a dear one, when money is taken away from other planned expenses in the household. In some cases, the person who pays the bills may have little choice and may do so out of duty or for familial or social expectations. At a time of deep vulnerability and heightened sensitivity towards her condition, a woman may be well aware of these dynamics even as she confronts her illness.

> *Doctors need to tell patients upfront about the cost of treatment, charges and stay at the hospital. Very often this is not done. Lack of funds will make the husband take the wife away midway and this will create several problems [later]. Another reason is women may feel symptomatically better when they start treatment and they will just decide to leave without telling the doctor. They will have recurrence [due to this] and return.*
>
> *(Healthcare provider: Oncologist)*

The priority list in resource allocation suffers a severe blow in cancer care. No family is prepared for this eventuality and even those most willing to invest in care suffer under the shock of the ongoing costs. Many costs such as medication, specific treatments, nutrition supplements or travel are unclear in the beginning since the level of treatment or intervention a patient may need during care is not evident to anyone. Nor is there clarity on the duration a woman may need to take a break from her own economic productivity or other responsibilities in the family. Managing care costs with other financial commitments is an arduous task for families. However, there is little social leeway to express this worry openly. The traditional approaches and norms expect families to set aside other priorities to handle the larger health emergency.

> *We never expected things to be serious. We thought we could go back with medication and injections. Only after coming here we realised it was this serious. We have relatives for support. But if we borrow we have to return that money.*
>
> *(Caregiver-Daughter)*

Money: Where and When it is Needed in the Care Continuum

Where people live may also influence their financial options in cancer care. The tertiary hospitals are typically in the cities of India so referrals require patients and caregivers outside cities to relocate for long periods. During those months they lack access to basic life conveniences since they either live with relatives in the city or in paid accommodation, which add to their expenses. Transport during care is an ongoing expense and the farther away one’s geographical residence, the greater the financial strain on a day-to-day basis. Dependence on extended family and friends also creates emotional stress and guilt and, in some cases, deep sadness when the support is unwilling.

Distress due to financial duress is common among participants. There are situations where the personal caregivers have to give up a job or take unpaid leave in order to be able to care for the patient. The caregivers and patients have shared that this creates a lot of challenge for them manage the caregiving along with related care costs. One caregiver (son) and had quit working to care for his mother, one caregiver (husband) had reduced workdays at loss of pay and one caregiver (daughter) had several days of loss of pay due to caregiving responsibilities. Two patients shared that there were treatment delays due to costs and the approvals coming through for the scheme payments. Not many patients know about the availability of the government schemes which can aid prior to admission. Those who mentioned the schemes have all shared that the details become available to them through the hospital at the time of admission. The hospital where the patients and families are recruited has played a pivotal role in such information dissemination.

Health care providers shared that families residing at a distance from the hospital may choose to identify a hospital that provides less advanced care but is closer to their homes. This may result in an abrupt decision to move there and so discontinue treatment, which is very risky for the woman's health. There are also situations where care facilitation may happen through a local agent who accompanies them from their place of abode and might expect a financial commission through the care process, which further jeopardises the financial stability of families while undergoing care.

> *Money is a problem. . . . It is difficult . . . the interest on loan itself takes up the entire salary . . . She [the patient] doesn't eat much because she is unwell. So with one plate of food that they give in the hospital we both manage to eat.*
>
> *(Caregiver: Sister-in-law)*

In addition to willingness a difficult issue personal caregivers may face is sustainability of care. Along with physical and psychological efforts, they are required to manage unpredictable and ongoing expenses. Gynaecological cancer care runs into several months of treatment with multiple radiation sessions, surgery and investigations. Most women are admitted into the hospital during this time and require a caregiver to be physically present with them throughout this period. In the cancer caregiving context in India a family member typically accompanies the patient throughout as a caregiver.

> *When they spend 6 to 8 months in the hospital they [caregivers] lose their jobs.*
>
> *(Healthcare provider: Support Service)*

Health care providers in the present study revealed from their experience some critical insights on how financial stress impacts daily life of families. While the available financial schemes may cover some or much of the actual treatment all other expenses such as travel, personal caregivers being in the hospital, food, medicines and tests are likely to be additional expenses. Since the woman typically plays an important role in household responsibilities external support for those responsibilities is needed, with the resulting cost of money and time for coordinating and providing such support.

The prolonged nature of treatment and demands on financial resources have a critical impact on palliative care which is vital in cancer care. Healthcare providers say that most health institutions do not have their own palliative care departments and the few that do are severely overworked and strapped for cash. Palliative care professionals in the study said that by the time patients reach them the families have already spent everything they have on their treatment options. This service currently functions with little or no financial stability even in the best of hospitals.

Money and Social Norms

Social and gender norms in the context of the study tended to place most of the financial burden on male members of the family. There might be instances when the only role a man is expected to play in caregiving is payment of the hospital bills. Despite it being the primary role, the strain is considerable since there is little support from others.

> *Finance is a big problem. There are recurring expenses which run in thousands; my income is in hundreds every day.*
>
> *(Caregiver Husband)*

> *Money is the support caregivers most need and they need help with. With that they can do everything else.*
>
> *(Caregiver Husband)*

There is a hierarchy of costs in the care spectrum. Hospitalisation and treatment (radiation, surgery, investigative tests- may be considered more important and critical in terms of investment vis-à-vis other kinds of costs such as long-term nutrition, support services, rehabilitation, palliative care and follow-ups. Healthcare providers are of the view that this may trigger patient relapses since the investment is in hospitalisation, whereas the main recovery may occur outside and beyond the hospital.

The power a woman wields in her family at a point in time may be directly proportionate to the amount of time and emotional investment a family readily makes even prior to her treatment costs commencing. A willingness to pay for diagnostic treatment itself could be connected to the status of her relationship with the spouse or other primary members in the family.

> *Some husbands are alcoholic and do not care. Others have extramarital relationships and do not love their wives. So the wife might think, "What kind of a life is this, how many days should I tolerate it . . . I might as well die and be with God".*
>
> *(Patient)*

Older women with daughters in a supportive marriage have a helping hand from their sons-in-law but this support is less common. A woman with recourse to her own finances feels a much higher degree of confidence about her treatment and is also far more engaged in treatment decisions, prognosis and interactions with the healthcare providers. Similarly, women who have been in positions of individual responsibility such as being a single parent are more likely to be consulted during their treatment trajectory since the family is used to their agency in financial decision-making in other decisions. Women who have difficult relationships in their marital home may hide symptoms since they fear reactions from family members. This is one of the strongest reasons for barriers in acknowledging their health condition and treatment seeking.

> *My mother-in-law said, "From the time you came into this house as a daughter-in-law, all the time you have been having some health problem or the other". When she says such words I do not eat and get upset . . . Because of this scolding from my mother-in-law I did not share my symptoms.*
>
> *(Patient)*

Significant financial vulnerability arises in situations where the spouse is the primary personal caregiver and both partners are aged. The husband may have retired or may not have his own source of income due to his age. There could also be a circumstance of not having people to turn to for such support during his wife's treatment.

> *I told my daughter-in-law about my symptoms but not my son since he may feel sad. There are financial problems at home so I did not share things with my son. My daughter-in-law asked me to go to the hospital soon but I delayed from my side due to these money problems.*
>
> *(Patient)*

Dependence combined with expectation is usually placed on the sons for money. Levels of support from a son may be determined by the proximity of his residence to where treatment is being provided, the relationship he has with parents, his own financial stability, other commitments, and the role his partner plays in the decision. These situations create tremendous pressure on the ageing caregiver husband since he feels a divided responsibility towards his ailing wife and his son who is struggling to provide financial support.

> *All the family members go for coolie work and give the money to my eldest son and he manages. It is difficult for one person to manage is it not? I am*

> *already old. I don't know when I am going to go . . . Why should I trouble them like this? It would be ok if I had this problem when I was middle aged. I am now old.*
>
> *(Patient)*

Expressing financial need seems an easier feat for caregivers if the support is from impersonal sources such as institutions, healthcare providers and employers. A need to maintain "self-respect" by not asking family and friends was a recurrent theme in the interviews. "I will not ask anyone" was expressed with determination and pride even in instances when there is urgent need for support and no options left.

> *My daughter, my son and I. That's it. No need for other support.*
>
> *(Caregiver: Mother)*

Money and Healthcare Providers: Expectations to Serve

> *Money and health information are linked here.*
>
> *(Healthcare provider: Nurse)*

The primary healthcare provider plays the most important role at this stage since they are the person the personal caregivers usually turn to as a primary contact to resolve all their problems. The healthcare provider is seen to be on "their" side despite being a representative of the health institution or hospital.

Patients and families find it difficult to navigate the systems in a tertiary health institution. On the practical side the health institutions struggle to give realistic estimates of costs given the unpredictable nature of the disease. Disease progress and recovery cannot be homogenously predicted among individuals because patients respond differently to treatment and intervention plans may vary in stages based on recovery. The institution is the facilitator and provider of care in critical ways. However, it also determines the range of experiences in the cancer care continuum and their associated financial costs that a patient and personal caregivers will be responsible for. A deep insecurity that the health institution can create for patients and families is related to the quality or refusal of care due to their limited financial means.

> *Most of the patients who come to the hospital after discussing treatment options will say, "We will arrange the money and come back because we are not ready financially". Some will not return. When we follow-up they will usually say they couldn't arrange the money.*
>
> *(Healthcare provider: Patient registration/Admission)*

Many patients stop their treatment midway or do not return for follow-ups since they are unable to pay for the treatment. Healthcare providers feel deeply responsible and troubled with this reality especially when they know there are sound chances a woman may recover if she completes the treatment. They also grieve when they know that discontinuation can have adverse consequences on the patient's prognosis. While they individually attempt to negotiate and dialogue to provide options to their patients, they must work within the guidelines and limitations of the institutions. The grief and pain health care providers experience are heightened in this dimension of care and discontinuance.

The cost of treatment when entering the institution at a later stage of the disease brings many financial implications for the patients and their families. Advanced treatment requires not only invasive surgery and extended admission but multiple sessions of chemotherapy and radiation. The procedures span over anything between 3-8 months averaging to about 6 months per patient. Multiple patients and caregivers spoke about costs already incurred ranging between 1 lakh to 2 lakhs despite having access to government schemes and discounts from the hospital. Having situations where they cannot pay immediately is common and the personal caregivers talk about tremendous stress when that happens. Treatment can be delayed considerably if the patient depends solely on the financial schemes from the government. The paperwork takes time and the patients have to wait till the approval is in place. Non-awareness of how expensive the treatment is and applying for schemes post getting an estimate from the hospital is a very common phenomenon. Most patients and families are completely unprepared for the costs for treatment as well as what is required to apply for schemes. They depend on the hospitals for assistance for both. The hospital on its side is overburdened with this time consuming additional responsibility and does its best. However, the delays all around occur because of this complicated situation. There is no clear evidence that there is a reduction in out of pocket due to the access of schemes. Most patients speak about the financial burden for themselves or their personal caregivers due to the disease.

> *Primarily we try to help them financially since that decreases a lot of their stress. We sometimes raise lakhs per patient . . . When they voice financial stress it causes us [doctors] burnout. Clinical care is my passion and I am happy doing it. Financial stress from patients bogs [traps] us down.*
>
> *(Healthcare provider: Oncologist)*

The more money people spend (usually beyond their means) the greater they feel comforted that they are working towards helping a person dear to them. The hope is that the money spent may result in a slightly longer lease of life or bring better quality to the final days even when there is no hope of recovery. That is also the reason why there is a sense of satisfaction at having spent large amounts of money in treatment costs even if prognosis is poor or when it is completely unaffordable for the family. The language used by families and patients to define financial requirement is always prefixed with a need they have for some “help”. Rather than seeing costs as responsibilities, they see them as problems that require support and aid from others.

One of the most complex interplays of money highlighted by the study findings is with healthcare provision. Medicine, healthcare and alleviation of illness are traditionally attributed to selfless service, intent and a philanthropic attitude among the providers. Healthcare providers face these expectations constantly. In addition, in a chronic illness such as cancer where fear of death is constant, discussions and problems related to money are perceived as mundane and even blasphemous. Healthcare providers are expected to navigate through patient numbers and expectations from them and their families. They do this along with handling patients’ treatment management and follow-ups.

> *Taking money for end of life support is very difficult from people who don't have any more and are in debt.*
>
> *(Healthcare provider: Palliative care)*

> *Even if from a higher income group or middle class they have the same financial constraint at their different levels . . . because it is an expensive treatment.*
>
> *(Healthcare provider: Support service)*

The interviews repeatedly highlight an almost passive surrender of the patient and families to the health institution in the hope and expectation that the support of the healthcare providers, institution and system may get them through the continuum and treatment costs. Responsibility for paying bills and cost management becomes a difficult subject to discuss with patients and families in this scenario. As they reel under their own worries, patients and their caregivers do not recognise the financial concerns related to their care that burden providers.

6.3 Discussion

Accepting that affordability of medical expenses is not the only challenge in expenditure management seems to be vital in cancer care for women. This acceptance introduces several insights into patient care, follow-ups and decision-making in treatment trajectories. The discussions on finance and money are entangled in a complex decision-making process. These complexities are often tied to specifics of care costs such as the patient's role in the family, the one responsible for the costs incurred, at what stage of disease they need the money, and how resources are allocated at different stages of the disease progression. There are other layers to the burden of costs in a social economy influenced by norms associated with the woman who is a patient, norms that are pervasive through practices of medical treatment, personal help, duty and obligations of both the personal and professional care providers. In addition, there is uncertainty of information, health outcomes, and current expenses to pay and the duration of recurring costs. An entire range of stakeholders are implicated in this multi-layered negotiation in their roles as personal caregivers, patients, health care providers or support networks.

As a first step, a deeper understanding of affordability offers scope to customise conversations according to the nature of a specific patient's needs. It also helps decide who would be the most appropriate communicator and facilitator in such conversations. Small tokens of support such as reimbursement of travel, food coupons or a subsidy for accommodation options can go a long way in supporting patients and families who do not reside in the same geographical location as the tertiary referral institution. Such tokens serve as an ice breaker for support services to understand the extent of financial need people actually have.

Prior to discontinuation of treatment is the crucial stage when affordability challenges or barriers can be perceived and anticipated by the health institution. A staff member designated to liaise with patients and their families can assess the financial circumstances at that time and in an ongoing manner. Potential flags for concerns about cancer care costs may be present when patients begin enquiring about a subsidy, asking for a time leeway for paying bills, choosing a less expensive treatment option, discussing with the healthcare provider about their financial worries, availing of a scheme, or residing in a different geographical location.

It is necessary to understand the very critical role of palliative care in finance since cancer continuum decisions are synonymous with palliative care. The palliative care sector in Kerala has developed better compared to any other part of the country(Vijay & Monin, 2018). The role that the community has played in this is immense. Kerala has shown evidence that when the community plays a role in palliative care the indicators of well-being are superior for patients (Kiirii & Jona, 2019). The intrinsic interlinkages between care, out of pocket expenses, community, cancer are illustrated in such initiatives. The space and scope of alternative therapies with cost saving measures, the engagement of healthcare providers in a more systemic way, the role of NGOs in such measures and meeting of the psycho-social needs of patients are all more feasible when there is a conscious development of palliative care in cancers (Lijimol, Krishnan, Rajagopal, Gopal, & Booth, 2020).

Creating a forum or peer support group among personal caregivers for information exchange will help new patients and personal caregivers entering a tertiary facility for cancer care. Personal caregivers mention extended periods of time on their hands while they are in the hospital and not attending the family member who is the patient. A few willing ones can be trained to be patient and family navigators who assist in care coordination and access in the cancer care spectrum.

Conversations related to finance require some level of customisation according to the education, role and decision-making capacity of the person engaged actively in the patient treatment process. There may be multiple stakeholders in a woman's life who want a voice in the treatment plan. Sensitive understanding and accurate decoding of such responses mean the health institution should have a designated staff for such conversations. Identifying who is the key decision-maker in each patient's care is of utmost importance in this.

There is a need for sensitive, culturally safe and clear health promotion and communication that preventive measures are financial investments rather than a harbinger of illness. In gynaecological cancers, decisions on treatment, non-surgical and minimally invasive procedures, number of radiotherapy sessions tend to vary according to the stage of treatment. This information is not known to most women and families and only after the treatment do they realise they could have prevented invasive surgery and extended treatment cycles with earlier care seeking. In a context where womanhood is linked strongly to roles of mother and wife, preservation of reproductive organs hold a certain importance even after completion of families, and past one's youth or middle age. However, the fact that such procedures in advanced stages also cost far more would be a message that patients and families are likely to be receptive to.

Healthcare providers consistently expressed during the interviews that the first day in the hospital is the most unforgettable experience for a patient and family and is also the day to build the strongest rapport with them. Discussions about financial costs need to be factored into this day's discussion to alleviate fears about treatment not being forthcoming due to affordability. The focus on the institution being ready to facilitate care for the patient and willing to work with any financial challenges will go a long way to ensuring that the cost of care is not kept hidden until the payments become due. It also gives the institution some time to evaluate options for financial management with each case. Hearing other patients and families speak about how they have traversed and overcome their own financial struggle is also a good way of boosting morale in financial uncertainty. A module of patient or family endorsement can be included in these sessions.

In an overburdened health context it is essential that palliative services offer home-based care. They can support personal caregivers with hands on training for pain management and care during the final stages of a patient's life. The patient herself might be a silent participant in this scenario if financial impediments determine her journey towards health and wellbeing. Low- and middle-income countries face immense pressures in cancer management and there is growing recognition of the criticality of patient navigation through access, fund flow, treatment trajectory and implementation of all aspects of cancer related support and service (Dalton et al., 2019; Farmer et al., 2010; Prager et al., 2018). It is important to understand that a woman patient's journey is fraught with the juxtaposition of the value of her life vis-à-vis the value of the treatment she requires that is seemingly measured in monetary terms. It is a traumatic conflict, and better addressed with a heightened sensitivity to pre-empt this challenge. The woman patient needs assurance that every dimension and person in the care spectrum is working to give precedence to her life and health.

6.4 Conclusion

Cancer care costs highlight complex shortcomings of health systems by their sheer magnitude and non-affordability for most patients (Pramesh et al., 2014). However, we as a global society are at risk of an error if we conclude that this financial lens alone is an adequate interpreter of challenges that are also human, changing and—as a result—less than obvious. The evidence offered about the affordability of cancer care tends to focus on lack of availability of cost effective drugs and related therapeutics along the treatment continuum, political economy of drug discovery and availability (Cazap, Magrath, Kingham, & Elzawawy, 2016; Gyawali & Sullivan, 2017; Ruff, Al-Sukhun, Blanchard, & Shulman, 2016). The affordability and expense of cancer care is understood but far there needs to be further exploration about what it means for people in actual decision-making, care seeking and treatment completion. An enabled sensitivity will help tailor solutions that are not only about enhancing affordability in cancer care but also understanding that affordability has undercurrents that have massive impacts on care.

It is important to first focus on the many psychological, social and emotional dimensions of money in chronic illnesses. These findings bear additional significance in the current scenario of a public commitment in India for United Health Coverage. The *Ayushman Bharat*, a program designed to provide holistic health cover for secondary and tertiary hospitalisation specifically for economically disadvantaged people, is aimed towards more inclusive and accessible wellness (P. Chatterjee, 2018; Lahariya, 2018). Such programs can bear fruition when access is studied carefully along with the levels of care: the media attention, public private care regulation, rural versus urban residence and how money impacts everything will equally impact the lives of patients and other stakeholders (P. Chatterjee, 2018; Gopichandran, 2019; Lahariya, 2018). There is a global opportunity through the sustainable development goals and WHO's commitment to cancer prevention. While there is increased attention on these, the distinct opportunity needs to be taken seriously to comprehensively understand what affordability and cost entail (Prager et al., 2018).

The time is now and the time is right for the recognition of the urgent need to call for actions and to assess effectiveness of strategies in the country that address cancer care in developing countries (Akashdeep Singh et al., 2020, Farmer et al., 2010). Clearly, decoding affordability and money matters are vital for this effort. If we miss this opportunity, the decisions in health economics will continue to be made with the best intentions that misinterpret, misunderstand and misrepresent affordability. Such risks will mitigate the scope for a necessary and well-informed sensitivity towards existing problems in cancer care cost management, efficacious responses to them and timely prevention of future problems.

6.5 Summary

This chapter has identified the risks of partial perspective when affordability and expenses dominate the financial dimensions of cancer care. Reading between the lines can better inform dialogue about economics in gynaecological cancer management. The people who matter in the process and costs of care cannot be neglected or sidelined. It is necessary for medical expenses are not looked at as hospital bills only towards this. In the next chapter, the less celebrated heroes, the personal caregivers in cancer care in India, are the study focus.

Chapter 7

Undiagnosed Burdens of Personal Caregivers

The paper presents the limited evidence available on caregiving pressures in cancer care for women and focuses on the pressures that caregivers face. The role of a caregiver makes a difference in the type and level of pressure they experience. Personal caregivers in gynaecological cancer care in India, typically family members, bear high levels of burden and responsibility. Personal caregivers in cancer care share some of their perspectives and experiences in this article. Through their narratives we strive for the less focused stakeholders in cancer care to be brought to the centre stage. Their stories merit specific attention both for their quiet heroism and unmet needs. The objective of the paper is to illustrate the challenges of those providing care in the personal realm in the cancer spectrum. Since the focus in cancer care tends to be on patients this is a group that is much neglected and requires to be highlighted. The primary intent of this article is to understand the neglect that personal caregivers suffer in gynaecological cancer care, both unintentionally and intentionally in the health setting. The broad stage for this discussion was set in the previous chapter when caregivers' financial responsibilities were mentioned as one of the acute problems in caregiving.

This chapter features a paper written to be submitted to the journal ***PLoS One*** with the title: *Undiagnosed burdens in care: Gynaecological cancers and the lonely challenges of personal caregivers in India.*

Abstract

Personal caregivers in the cancer continuum are acknowledged as an extremely important group of stakeholders in facilitating cancer care. However, the context of specific challenges and burdens in caregiving is understudied. Resource constraints in India have kept the focus on cancer research in the clinical dimensions of care giving, access to health care and affordability. The psychosocial barriers of Indian women with gynaecological cancers are rarely considered. The hardships faced by their personal caregivers receive even less attention.

Semi-structured in-depth interviews were conducted with 10 personal caregivers of patients diagnosed with gynaecological cancers in a tertiary hospital offering advanced oncology services. Personal caregivers were approached for consent if women patients diagnosed with a gynaecological cancer consented for their caregivers to be contacted after undergoing a research interview themselves. The interviews were part of data collected in 2018 and 2019 as part of a larger study on the role of health communication in mitigating risks in gynaecological cancers in India.

In India, family plays a crucial role in cancer care starting from symptom identification, diagnosis, investigations, treatment and follow-ups. Often, the time of treatment and decisions on treatment options are as dependent on the personal caregivers as they are on patients themselves. Additionally, in gynaecological cancers dimensions of gender and familial roles are as relevant as are the financial, social and emotional dimensions of the disease and its management. The nature of the relationship the personal caregivers share with patients impacts health decision-making at multiple levels.

Financial burdens and feelings of guilt towards patient suffering leads to significant emotional burden for caregivers. Personal caregivers who have accepted the prognosis and failed treatments are able to find peace for themselves and support the patients find their own. The lengthy duration of treatment as well as other life commitments that take a secondary position during caregiving place a severe practical burden on caregivers. Collusion and the burden of bearing the prognosis alone also have adverse effects on the personal caregivers. There is limited evidence on the role and challenges of personal caregivers of women with gynaecological cancers in India. Understanding the roles, decisions and the pressures of such personal caregivers is imperative for clarity on the complex interplays in the cancer care continuum spanning across illness and wellness.

Keywords: Personal caregivers, family, caregiving responsibility, caregiver stress, caregivers support, psychosocial support

7.0 Background

Family plays an important role in the decision-making process, care and support of health and illness in India and this is evident in the cancer care continuum (Alexander et al., 2019). Indian women dealing with cancer rely on their families tremendously at different stages of the disease management ranging from decisions related to treatment seeking, the provision of care, as well as financial and emotional support. The recognition that a woman cannot be considered in isolation in the cancer continuum, but rather as a person with strong affiliations and co-dependence in the family unit, is imperative for the improvement of services that impact both her recovery and those that support her in the process.

7.1 Global Perspective

Evidence across the world shows that women with gynaecological malignancies have care needs that are not restricted to physiological care (Williams et al., 2018). The literature clearly suggests that anticipation of care needs to be inclusive and holistic, not only for the purpose of providing the best care options for a patient but also to reduce the burden on the health services provided to them. Holistic support in cancers include the vital support patients receive from their personal networks through the duration of treatment, recovery or adverse outcomes.

Dimensions of Care

One of the less spoken dimensions of caregiving in the cancer continuum in India is the fluidity of time demands it poses. This is especially so in palliative care needs which is often a full-time responsibility for a caregiver with no form of physical or psychological respite (Antony, George, & Jose, 2018). In order to fully assess the levels of stress on caregivers in meeting this responsibility, several factors should be understood. They include their own personal access to support networks, financial stability, relationship with the patient, occupational demands, conflicting responsibilities, duration of caregiving, coping mechanisms, the specific caregiving the patient requires, as well as the quality of life of the caregivers. There is a considerable variance and an urgent need for better models that look at the linkages between adverse emotions, caregiver need, preparedness, outcomes in caregiving responsibilities and the burden they deal with on a routine basis(Schumacher et al., 2008).Evidence also suggests that there is considerable distress in the marital context when a spouse is confronting terminal cancer in the relationship and factors that aid or support resilience in caregiving require better understanding (McLean & Jones, 2007; Sun, Qin, & Hengudomsub, 2021).Such dyadic relationship require careful and sensitive consideration in order to have a real understanding of caregiver stress.

Evidence shows that caregiver burden is extremely high in cervical and breast cancers with the burden being more if the caregiver is male and when from a lower income household (Srinivasagopalan, Nappinnai, & Solayappan, 2015). Disclosure and non-disclosure in cancers typically had similar reasons among caregivers though there was a strong consideration of why they would or would not disclose to their loved ones (Chittem, Norman, & Harris, 2020).This suggest that collusion is a culturally complex occurrence to be viewed with sensitivity and real understanding. The burden that caregivers face routinely in caregiving for cancers is a subject that requires far more research and insight. Currently, the levels of burden combined with the lack of adequate tertiary care increases the impact on them heavily (Lukhmana, Bhasin, Chhabra, & Bhatia, 2015).Another aspect that needs to be considered in caregiving in cancers is that perceptions of caregivers in terms of how they consider the burdens they bear (Unnikrishnan et al., 2019). While the load of caregiving may be considerable their perceptions may vary due to a variety of reasons. Looking at various parameters that help assess burden is required for an accurate scale of well-being of the caregivers. Lower income levels and financial stress seems to play a definite role both in expression and assessment of caregiving burden (Vashishta et al., 2019). One of the major challenges in evidence on caregiver depression and burden is that there are few directions for interventions and programs designed to support caregivers. In other words while the literature clearly highlights the problem of psychological burdens on caregivers the context specific solutions that need to be considered do not get clearly drawn direction (Awasthi and Kuhu 2017). There is the necessity to retain neutrality when developing measures for caregiver burden in cancers. A study has shown that hope and positivity did not show variance in types of cancer and age but there was a variance based on socio-economic status (Sunkarapalli et al., 2016). Such evidence reiterates that engagement and understanding of caregiver role and responsibility requires the need to have no pre-conceived notion of how we definite burden or stress.

Definition of care determines specific responsibilities in cancer care directly impacting the “sense of self” and “self-care” of caregivers themselves because of the burden of responsibilities (Shilling, Starkings, Jenkins, Cella, & Fallowfield, 2019). Such definitions are not easily measurable and as a result the degree to which caregivers face adverse impacts in caregiving can get easily underestimated. There are also interplays of gender, age and social norms with these realities that create imbalances in the type of work, time allocations and responsibility of a caregiver.

Complexities of Caregiving

While the literature consistently shows women do better with familial support than those who have none, there are fewer studies on how such social support affects the perception and experience of the woman in her illness trajectory. Hierarchies in relationships, both in the personal realm and the health context, further complicate this scenario and impede accurate interpretation of self-reported data.

Literature in India has only recently begun to explore the possible association between the quality of life of the patients in the cancer spectrum and how it directly affects the quality of life of their caregivers (Padmaja, Vanlalhruaii, Rana, Tiamongla, & Kopparty, 2017). It requires in-depth study because the quality of life of a patient typically tends to be correlated with variables in the health system like access, treatment or relationships with healthcare providers, and not of personal caregivers. The reason this is not prioritised is that caregivers themselves are a neglected group of stakeholders in the cancer care spectrum. Data that focuses on this group and looks at correlational angles of quality of life is hard to come by in India.

A significant challenge in cancer care is when the primary caregiver is also the primary breadwinner of the family (Sivakumar, 2017). This could be further exacerbated in gynaecological cancers which require not just long durations of caregiving but with physically debilitating conditions (e.g., extreme fatigue, nausea, food intolerance, loss of hair, loss of libido) that require ongoing attention and physical assistance from the caregiver. In such circumstances the pressures on the caregivers are manifold. They must balance financial commitments of treatment versus familial expenses along with emotional support requirements, physical support for the women, and coping with their own psychological pressures of caregiving.

Some of the very specific challenges caregivers deal with are related to physical strain and financial responsibility. Finance is a burden they bear better if there is some kind of support from family and friends. Caregivers talk about different aspects of support they receive such as having some to talk to, ability to take a break for basic needs when someone handles the caregiving and knowing there is someone to go to even if they choose not to. There were seven women who were caregivers and three men. Relationships ranged from husband, son, daughter, daughter-in-law, sister-in-law and mother. Regardless of the gender the caregivers spoke about similar aspects of caregiving and responsibilities. Their occupations ranged from farming, house-keeping, driving and coolie work. Some of the physical challenges of caregiving were related to gender since men could not sleep in the women's ward at night. They slept in the open courtyards or verandas which was ridden with insect bites and inconvenience. Access to clean and hygienic bathrooms were also a difficult issue. Having access to clean food and going to a good restaurant were challenges since they could not leave the patient for long. Overall the physical strain was far greater on the male caregivers in this study than the female caregivers.

The complexity of unmet needs and the unvoiced expectations in the relationships between cancer patients and their personal caregivers makes understanding difficult (Chawak, Chittem, Butow, & Huilgol, 2019), and it is a difficult area to research because very personal realms of emotion and values determine behaviour. The cancer trajectory has challenges related to collusion where families cannot express problems they themselves face in caregiving. Similarly, patients are often not given any option to express their own preferences in care seeking. The communication channels in personal caregiving are rarely transparent in cancer care thereby making it additionally complex to understand the precise needs and expectations both groups have of each other.

Supports for Caregiving

An area requiring further enquiry is the strength caregivers receive from Indian spirituality at the face of adversity, including chronic health conditions and pain of their loved ones (Hebbani & Srinivasan, 2016). In a context like India where faith and spirituality define important aspects of day-to-day living, support that a caregiver receives could be in the form of worship, practices, rituals and prayers conducted in the course and trajectory of caregiving. Assumptions that aid is only facilitated through other human beings disregards this important dimension which is directly linked to the self-efficacy and enablement of the caregiver. Measures for such support perceptions are important in order to evaluate the ways in which caregivers can allocate time for their own wellbeing and support systems.

Similarly, robust measures for quantifying the stress and burden of caregiving in the context of cancer care are missing in India (Kulkarni et al., 2014). There is little known about how they cope, including their spirituality and faith practices that form important parts of everyday lives in India. Simple measures that can capture the difficulties of caregivers need to be administered in a time-efficient manner to understand caregiver stress. Some areas in which such quantifiable measures would help understand this better are health of the caregivers, time allocation to caregiving, facilities and infrastructure available at home for caregiving, support systems of the caregivers, mobility and access to health institutions, other dependencies on caregivers such as children or livelihood, psychological pressures in caregiving, and relationships and roles vis-à-vis patient and the demographic status of caregivers.

Literature in India shows evidence of psychological and emotional repercussions of dealing with cancer. However, there are several gaps in the literature about the psychological harm and adverse effects of ongoing caregiving in cancer care. These gaps are accentuated by a twofold neglect. There is a lack of research into the unmet needs of patients in resource constrained settings and the collection of data or evidence is difficult because caregiving tends to largely occur quietly and in the personal settings of patients. This paper attempts to reveal some of the long-term risks of neglecting this critical group of people who are not only caregivers to women but valuable allies of the health system in managing chronic illnesses.

7.2 Methods

This paper has drawn from data from a larger study on gynaecological cancers in India and risk-reduction strategies through health communication. Semi-structured interviews (*n* = 10) were conducted with the personal caregivers of women diagnosed with a gynaecological malignancy from a tertiary specialty hospital providing cancer services in an urban setting in South India. The study was approved by the Curtin University Human Research Ethics Committee. The tertiary hospital in India that participated reviewed the study as per their institutional guidelines prior to sanctioning their approval for the researchers to contact and approach the participants for consent. The caregivers were approached for consent to participate only after the women they were providing care for were interviewed and had given their consent for the caregivers to be contacted.

After informed consent, interviews with the personal caregivers were conducted in the Kannada and Tamil languages. The interviews lasted from 30 to 45 minutes (Appendix J – O) and were held in a confidential space designated by the hospital. The interviews explored responsibilities in caregiving, identification of disease and care access, social and norms for caregivers, burden and burnout, networks of support, experiences and exposure to mass media and interpersonal communication within the health system. Interviews were of shorter duration if personal caregivers requested they be conducted quickly because of their caregiving responsibilities. Ten caregiver interviews were conducted in the study. All interviews were audio recorded and did not include identifying information such as names or contact details of participants. The two conceptual frameworks of the health belief model (Rosenstock, 1974a, 1974b) and the theory of communicative rationality (Healey, 1992; Sheikh & Porter, 2013; White, 1995) were used as theoretical underpinnings in the research.

The researcher has considerable experience in women's health research in both Indian and international settings and developed the interview guides, translated them with the assistance of two Indian translators who had worked with her previously on women's health research in India. The guides were further reviewed after the initial interviews to ascertain participant comfort, clarity of translation, ease of administration and adherence to the research process and questions. The researcher conducted the Tamil interviews and the Kannada interviews were conducted by one of the translators in the researcher’s presence. A study steering committee comprised of senior healthcare professionals (both clinicians and community health specialists) in the setting provided advice and guidance on an ongoing basis.

7.3 Analysis

Thematic analysis of the data in this study identified directions in the data distinct to each participant category and those that were similar (Gower et al., 2016; Parkinson et al., 2015; Rogers et al., 2019). Themes and subthemes in the data were identified by the authors after transcriptions and translations of the interviews. Emerging themes and a codebook were finalised based on research questions of the study with collaborative dialogue among the study investigators (Belotto, 2018). The respondent categories in the main study (patients, personal caregivers and healthcare providers) were triangulated for validity. All translations were reviewed for accuracy to the original interviews. Interview quotes are used to support the themes and none of the quotes in this article have been linked to any identifying information about the caregivers. The emerging themes have helped develop a proposed framework for the gynaecological cancer continuum, which will be presented in chapter 8.

Two constructs have been widely applied to better understand the findings of this paper. “Perceived threats” from the health belief model and “acknowledgement” from the communicative rationality framework offer maximum scope for this analysis. The threats related to the disease and the consensus that occurs post acceptance are the recurring theme in the study findings. Fear pertaining to the future, disease prognosis and the support required to handle the disease are some of the strongest points of distress for both patients and their families.

7.4 Findings

The Challenges of Giving Care

Personal caregivers experience an ongoing helplessness with the many aspects of caregiving. Some of these were short-term and practical related to pending accounts to be paid, delays in treatment due to non-payment of charges and expenses, and loss of job or salary as a result of caregiving responsibilities. They also deal with several intangible long-term difficulties related to the woman hiding her symptoms, chances of her finding out about her condition, her mental and emotional health due to her illness, the reactions of children and other dependent members of family, and treatment failures that might result in death. The caregivers have no control over any of these situations yet these factors impact their decision-making in ways that might differ considerably from their normal routines, roles and responsibilities. Caregivers appear to have few options or solutions to the relief of psychological pressures, loss of faith and emotional exhaustion they bear as a result of their caregiving role.

> *I was upset and asked her "Why have you not told us your symptoms? Why did you hide them?"*
>
> *Daughter: Relationship of caregiver*

Caregivers' roles and investments in the care continuum varied significantly based on the nature of the relationship they shared with the woman. A woman with a good relationship with the primary breadwinner for the family or the person primarily responsible for the payment of bills has a good chance to receive the maximum amount of support. Both men and women extend themselves significantly in caregiving when they share a close and strong relationship with the woman. Caregivers articulated that they contribute high levels of financial, emotional and physical resources to ensure the recovery and wellbeing of the women. As detailed earlier, there are times when sons or husbands of women live in the hospitals for months at a time, sleeping outside the ward at nights (men are not allowed to sleep inside the women's ward at night) and eating in small unhygienic eateries close to the hospital. Caregivers must sometimes give up their jobs in order to support the women patients during the treatment period. Others travel long distances from different parts of the country multiple times to ensure a steady income from jobs they hold in their residential regions, for the treatment costs.

Most caregivers endure difficult conditions because the resources available in a general ward of a subsidised health service are scarce and the wards poorly maintained. Yet, none of them complained about these issues in their interviews conducted for the study, because their priority was the woman undergoing major treatment. The general and silent consensus is that the caregivers must put first the interests of the woman undergoing the actual trauma. While this fundamentally is commendable, the emotional ramifications are strong. Caregivers are in positions where they cannot share their burdens with their loved ones since the women themselves are not in circumstances to support them. Also, the nature of the relationship they share with the women determines whether or not they are able to openly articulate some of their concerns and communicate with them. Some caregivers share their feelings while many do not discuss matters they think might disturb the women.

Partners who are the primary caregivers have an extremely difficult role if they do not have adequate support from others in the family. Similarly, if the woman has had a financial responsibility in the family, the loss of income combined with her illness makes the burden very severe on her primary caregiver. More than financial or family support, the positive relationships a woman shared determine how much caregivers extend. It means that if she has an empowered relationship with the primary earning member in the family, that person may in turn influence other family members to support her. For instance, a son who had a strong relationship with his mother would ensure that his wife supported his mother in the hospital or during her recovery, even though the daughter-in-law herself may not share a good relationship with the woman.

> *During my first pregnancy my mother died in an accident. My mother-in-law took care of me like a mother. From that day both of us did not hide anything from each other. She is not like a mother-in-law. I am more attached to her than her daughters. I don’t have a mother.*
>
> *Daughter-in-law: Relationship of caregiver*

> *It is difficult but we have to take care of her. She is more important than us right now.*
>
> *Sister-in-law: Relationship of caregiver*

> *She first shared about her symptoms with me. I then shared with her two daughters.*
>
> *Daughter-in-law: Relationship of caregiver*

> *If I have concerns about her then I share them with her daughter [her sister-in-law]. I tell her because my mother-in-law listens to her. She will then talk to my mother-in-law.*
>
> *Daughter-in-law: Relationship of caregiver*

Confronting Mortality

The word cancer is linked to risk and threat to life and is the first emotional upheaval that caregivers face when confronted with the diagnosis of a woman they care for. The association of cancer with mortality is a burden most of them bear throughout the treatment period even when prognosis is good. Cancer progression is unpredictable and even in best case scenarios healthcare providers cannot ensure recovery is complete or for how long a woman may be in remission. Relapses can occur at any stage of the treatment period or in the future. There are many situations when partial or complete treatment failures occur that caregivers are called on to make decisions that can impact life and death. Emotional exhaustion is aggravated with a need to be courageous for the sake of the patients. In many instances a caregiver does not even share the diagnosis with the woman, and so they bear the pain alone even when encouraging the woman consistently. Those caregivers who have access to their own emotional support systems are less burdened by this reality. Some have accepted the situation, made peace with it and are able to focus only on providing support to the women.

> *If the difficulty is for the mother everyone gets affected don't they? I am very affected.*
>
> *Daughter: Relationship of caregiver*

Caregivers rarely receive the emotional support they themselves need. An additional dimension of their responsibility is preparation for palliative support for the women when treatments fail in an advanced stage of the disease. Palliative care and end-of-life support occur in most cases when all options run out. At the stage of palliative care for the women, caregivers have a need for emotional support and frequently suffer severe stress, in part because it is a stage when they no longer have financial resources since everything has been spent on treatment options. Caregivers require in-depth counselling and therapy when the patients reach the palliative care stages for women, however there is a far greater demand for this service than can be made available in a resource constrained setting like India. As a result, although death is typically seen as an end in terms of care, it is the beginning of a new challenge for the caregivers. They are left to deal with not only the loss of a loved one, but emotional and physical exhaustion, despair, lack of coping mechanisms and even financial bankruptcy. They are in extremely vulnerable positions during these times and unless they have access to some form of steady support are likely to undergo long-term psychological distress and harm.

The inter-relational and co-existing nature of relationships need to be understood in caregiving. The concept of mutuality clearly delineates the possibility, enablement, joy, dependability and “mutual” nature of a symbiotic relationship which sees oneself in relation to another and vice versa (Jordan, 1986). The theory also suggests that existing factors such as demand for something, inter-relational mutuality between caregivers and patients and the preparedness for the requirement or need can predict several outcomes in caregiving(Schumacher et al., 2008).In gynaecological cancers it is necessary to study the impact on both the woman and others she shares a mutual relationship with since they play a very critical role in her care, caregiving and decisions related to both. The association of mutuality with caregiver well-being has been widely studied and is particularly relevant in chronic illnesses. Some factors that get impacted by this phenomenon include relational dimensions between people, the construct of time in illness and care giving, cultural applicability of mutuality which includes the co-existing nature of individuals who do not see themselves separately from the relationship and the interventions that enhance mutuality (Park & Schumacher, 2014). Caregiving challenges as well as recommendations in chronic illnesses can be best determined with this. Literature on cancer and mutuality look at specific issues such as 1) whether spouses require a different support mechanism due to the current distress of caregiving responsibilities,

2) the role of gender in coping as well support provided to cope with cancer (Baider, Kaufman, Peretz, Manor, & et al., 1996) Mutuality can also help predict the factors that can impact the dyadic resilience and strength-sharing in these relationships. This can also aid the providers from aiding and encouraging aspects that help patients as well as their caregivers to cope with the nature of disease and build their resilience (Gibbons, Ross, Wehrlen, Klagholz, & Bevans, 2019) Mutuality is a fundamental construct in dyadic relationships and this was seen in many of the relationships between women and their caregivers. Intimate in nature the relationship does not tease itself out as two separate beings or individuals in the caregiving spectrum. Rather it expands itself as one situation in which inter-connected people are functioning, deciding and deriving the consequences of a range of actions.

Faith and spirituality tend to give hope to caregivers when they confront the mortality of their loved ones and many of them spoke in the interviews of varying offerings and forms of worship that strengthened them. They turn to their personal form of deity and practices to pray, ranging from seeking the acceptance of death to wanting a pain free end for the woman or wishing for her acceptance of her own condition. Some spoke of praying for their personal fortitude to deal with the situation and to be of help to others in the family coming to terms with the loss. The acceptance of death seems easier for those caregivers who perceive that they have done everything possible to save their loved one. Treatment options, duration of disease from diagnosis to treatment and coping of the woman herself are important. Such factors play a role in caregivers accepting and moving towards the end-of-life decisions when treatment fails, however most have long-term issues since self-neglect is common in caregiving both during the treatment and in their responsibilities that follow treatment.

> *I used to do puja [prayer] for her but now since I am here whenever I go downstairs I do a namaskar [greeting] to the deity in the prayer hall within hospital downstairs.*
>
> *Mother: Relationship of caregiver*

> *God just needs to give me courage and the strength to work and manage this. That's all I ask of him. On Fridays I stop and light camphor in every temple that I pass by ever since she became ill.*
>
> *Husband: Relationship of caregiver*

Responsibility without an End Date

The timeline of cancer care is possibly one of the toughest uncertainties to deal with. Caregivers deal with several responsibilities in the form of treatment facilitation in the hospital along with physical, financial, and emotional care during treatment. Caregivers are also responsible for psychosocial rehabilitation for the patient after treatment. The practical feasibility for the caregivers to take on and maintain the responsibilities is a major challenge. A woman having a positive relationship with a partner, children or natal family may have access to greater emotional support from them.

It is essential to understand that these variables have several permutations and combinations in support giving and receiving in cancer care. For instance, although affordability may be a problem, a good relationship with a woman may result in the caregivers incurring a large debt for treatment and care. Or the emotional support a woman receives from her family may impact her willingness to accept or fight her disease. Simplistic conclusions that affordability independently translates to access or that knowledge translates to access of care are risky. They run the risk of not interpreting recognising the influence of these nuances over behavioural outcomes.

Most caregivers do not have access to professional services and support to deal with their grief, problems and setbacks in caregiving. Gynaecological cancers create heightened degrees of vulnerability in women in India not only as a result of the disease but also the social norms of marriage and motherhood that are threatened by their illness. In hospital settings where there is considerable dearth of resources and services are stretched, the focus is only on the recovery and rehabilitation of the women. As a result, the available counselling support tends to focus on the women rather than include efforts to address the needs of caregivers. The need that families have for support is either not prioritised or tends to fall through the cracks because of multiple demands on their time and resources.

Emotional pressure only increases for caregivers and many would benefit from guidance or professional intervention in a timely manner. One additional factor that aggravates this issue is the critical role that caregivers have to play well after the women are out of the treatment cycle in the hospital. Care will continue long-term since most women have serious interventions that debilitate their physical independence and normal routines. Relapses can occur any time. This common scenario is explained by care being sought by women when in advanced stages of a cancer. For caregivers who play the crucial role of supporting them after professional care in the hospital, the road is not only long but uncertain in terms of when and whether caregiving responsibilities will conclude. Caregivers acknowledge varying feelings like severe emotional burnout, grief, anger and guilt and are quick to add that they recognise the top priority is their loved one, however the brushing aside of their own feelings and unmet needs suggests the likelihood of psychological harm and adverse effects. Self-effacing caregiving is the greatest harm for caregivers.

> *We manage ourselves since to care for others we should be strong. Only then we can take care of her well. Our own problems—we will somehow manage them.*
>
> *Daughter-in-law: Relationship of caregiver*

> *I married my wife and I should take care of her . . . it is my responsibility however difficult it is for me.*
>
> *Husband: Relationship of caregiver*

Peace in Acceptance and Collaboration

There is a strong linkage between the acceptance of the disease and condition by caregivers and the woman herself. When a woman perceives her caregivers accept her condition or the stage of her disease she is more likely to accept it herself. This works the other way as well where children, partner and siblings of a woman make greater peace with and among themselves and accept her illness when they see that she does.

Families that come to terms with the situation are in a position to offer significant support to patients. They are also able to spend quality time with a woman even during treatment, help her better and come to terms with the magnitude of impact in a healthier way for themselves. Women who accept their condition either through the support of their families or with the knowledge that their families are able to cope, are also able to be at greater peace in such situations. This interdependence of emotional acceptance is a key factor in the health and healing of personal caregivers during caregiving responsibilities and after the loss of a loved one.

> *I have friends who will help with money. I can talk to my friends as well. My older brother earns more than I do. So we decided he can earn for the treatment and I will stay in the hospital and take care of her. I know she is upset when she simply sits and thinks of something. I have been very concerned. I want her to get better. There is a caregiver here in the hospital for another patient that I am close to. We are of support to each other.*
>
> *Son: Relationship of caregiver*

> *We need family support. If one person stays in the hospital during treatment and other family members take turns and visit and she too feels happy. Mentally that is very important for a patient.*
>
> *Husband: Relationship of caregiver*

> *Whatever her luck is that is what will happen. I have left it. I have a lot of courage. I have seen many illnesses. I have taken care of many relatives who have been ill. I am the one who usually attends to them. So my courage is high, since I have seen all this before.*
>
> *Mother: Relationship of caregiver*

Silences of Fear and Guilt

A frightening emotional burden that caregivers share with healthcare providers is the responsibility they bear when treatment decisions go wrong. While healthcare providers experience this at a professional level, personal caregivers experience this at a personal level. The decision-making responsibility on caregivers is very heavy in the cancer continuum in India since most patients are involved in their own treatment decisions either minimally or not at all.

Collusion is common as a result of which patients either do not know about their health condition or even when they do, they tend to protect their family members by pretending they do not (Victor et al., 2018). Consequently, caregivers make all decisions from the stages of diagnosis to follow-up. When treatment fails in some way, caregivers experience tremendous grief, self-blame and guilt. Keeping up a front to the patient takes a huge emotional toll on caregivers.

Families that hide the health status and do not share it with the woman are forced to maintain hope on an ongoing basis. They must facilitate and negotiate all discussions with healthcare providers in order to ensure that the providers do not reveal any aspect of the woman's condition to the patient herself. This situation is hard for the family which is now in a self-orchestrated silence, but could have emotional solace if transparency and open communication was practiced. It also complicates their relationship with the healthcare providers who disagree with this pressure to keep information from a patient. Counselling needs for families become extensive in this context since personal caregivers experience stress and psychological harm due to collusion and the need to protect their loved ones from the truth. At times this dimension in caregiving also affects their relationship with the woman who either suspects or knows the truth with clarity. Yet, she is under pressure to maintain the illusion that she knows nothing about her health in order to protect the role played by her caregivers.

> *Cancer is big right? There might be some kind of terror in my mother so we haven't shared with her that she has cancer. We just told her that she has a problem in her uterus.*

Daughter: Relationship of caregiver

> *She hides symptoms from us thinking we would be upset or afraid. It is better not to discuss with her what the condition is. Better not to talk unless she wants to talk. I don't discuss it much and I just listen to her.*

Sister-in-law: Relationship of caregiver

> *I don't discuss her health with her since she will feel bad. I don't ask her much . . . not even about her pain since she will feel upset and I will feel upset too. She doesn't speak much to me . . . she doesn't speak much to others either.*

Mother: Relationship of caregiver

Personal caregivers experience a deep sense of guilt in the journey of care. These could be related to a range of aspects in caregiving. Challenges include inadequacy of finances to support the woman, not identifying her health issue in a timely manner, decisions in treatment options, relationship problems with the woman, past reactions towards her or being a witness to her suffering and pain and being unable to help her. Such guilt can translate into the following different responses: the need to protect her from any adverse emotion; to take on all responsibility related to her physical and emotional wellbeing; making compromises on other commitments; neglecting one's own health and wellbeing; and incurring huge debts. The burden of guilt that caregivers experience may not be articulated but they bear a heavy load that is interwoven with multiple complex interplays of the relationships shared.

One of these dimensions is unlike the burden of the healthcare provider, which typically occurs during the treatment and follow-up trajectory; the responsibility that caregivers hold is throughout the illness, commencing from the stage of symptom identification and continuing well beyond post treatment discharge. Caregivers experience the need to protect their loved ones long-term which could be an extremely extended timeline through recovery or death. Most of them also tend to put their own needs last in this endeavour.

The Rolling Impact of Debt

The financial aspect involved in caregiving is the most practical example of continuous strain on caregivers. Cancer treatment is lengthy and expensive and most women do not have adequate personal resources to cover the treatment costs. Caregivers incur severe financial pressures to support the women. Male members of the family, typically the husband or the son, are expected by society to meet the payments. In cases where the husband is retired or too old to have his own source of income their dependence typically falls on the sons. For women who do not have sons, the dependence could turn to brothers or sons-in-law (if the daughters are in supportive marriages). The men in the family tend to struggle to bear the burden of expenses. Cancer treatment costs are high and although middle-income groups are rarely prepared for meeting the costs, economically-disadvantaged families suffer tremendously.

The expectation that men take care of the expenses is strong even in relationships where the woman does not have a good relationship with them. Financial responsibility poses recurring problems. In some cases they are unable to meet other pressing financial needs such as mortgages or interest payments on loans, education of their children or household expenses. In other cases, for those families that do not have support from multiple members, the men have to juggle both the financial pressure along with providing physical and emotional caregiving for the women. While this is the scenario for men, there are also situations where there is absolutely no support for a woman from the men in her family and she must rely on her own resources or on support from her mother, mother-in-law, sister or daughter. In situations where women are responsible for the costs of care, the burden is twofold since they simultaneously bear the financial burden as well as some or all household responsibilities, which are in addition to being there to support the psychological and emotional needs of the woman.

The high costs of the treatment and its duration impact the availability of adequate resources for post treatment care, thus creating a dearth in nutritious food options, hygienic conditions at home, and the availability of care so that the woman does not exhaust herself with post treatment household responsibilities. There is also debt repayment that many caregivers suffer, which may eventually impact treatment decisions in a direct way, often in the form of the woman not continuing with treatment or follow-up. The emotional strain of repayments for high debt is because caregivers feel the need to bear expenses at all costs in order to save their loved one even when treatments show poor prognosis or fail. At this juncture, the health system and providers play a crucial role in explaining to the caregivers the actual chances for recovery. Providers are in the difficult position of weighing the chances of recovery with the financial ramifications in a family's life and not all of the choices are categorical. There are shades of grey in prognosis as well as how certain patients and their caregivers feel about ongoing treatment. Where decision-making may become the primary responsibility of the providers the ethical dilemmas are constant and difficult.

In contexts where there is less clarity about the woman's condition, caregivers can incur insurmountable debts in continuing treatment that could fail. Caregivers also tend sell their land, assets and jewellery to pay for treatment costs. The participants in the study belong to a lower socioeconomic group in India where any unplanned expense is difficult and unmanageable. They require some form of support or need to take loans to manage treatment costs. Though the hospital from where they were recruited for this study offers considerable subsidised care to its patients, even that is too high for many who live below the poverty line. Most of them expressed worries in their interviews with the researchers about how they would face the future since they were already in some form of debt for hospital expenses.

> *My elder son-in-law has given me 10, 000 rupees for treatment. For other expenses my son takes care but I have no idea how he manages.*
>
> *Husband: Relationship of caregiver*

> *Money for cancer treatment is the main support caregivers need. We are managing with some loans but people are in worse situations. Some people will know nothing about the disease and not have money.*
>
> *Sister-in-law: Relationship of caregiver*

> *Caregivers need money. With that they can do everything else. Before anything else, they need that help.*
>
> *Husband: Relationship of caregiver*

Circles of Trust, Sharing and Support

Those caregivers with access to support of some kind from other members of the family or friends are able to manage caregiving with far greater calm and equanimity. Some speak about talking to these networks on an ongoing basis and of feeling better after getting assurances of someone's support during the journey. These networks tend to be siblings, children or partners of older caregivers, and siblings or friends of younger caregivers. The caregivers did not mention seeking support from parents, which is in keeping with the cultural reality that younger people are usually expected to support the elders financially rather than vice versa. Others talked about the relief when siblings, partner, children or friends come to their assistance or when hospitals help them to receive government financial assistance. The network of family and the caregivers of other women also undergoing treatment in the same hospital is a great source of support to caregivers.

The caregivers in the present study spoke of support within the cancer ward which makes them feel better emotionally with the knowledge they can request someone to take care of their loved one briefly, when they step out for something urgent or on an errand. The reassurance they receive from other caregivers was a recurring theme in many of the caregiver interviews. Even verbal assurances of willingness to share small responsibilities brings a lot of hope. A significant amount of the strain is psychological. Hearing others express their solidarity and having shared experiences assures them they are not alone as caregivers. It also lessens their exhaustion because of being constantly available to the women, who may not be in a position to even notice their stress or burden. Sharing of small joys and hopes in caregiving also becomes a more routine and comforting discourse to what is a most significant dimension of life. Yet, here too are exceptions who prefer bearing the burdens alone and in silence, their grief and responsibility remaining private.

> *I talk to friends often, that's the only support. They are away but I discuss everything over the phone. I talk a lot to my friends.*
>
> *Daughter-in-law Relationship of caregiver*

Redefining Life

One of the hardest challenges for caregivers is role revision with other responsibilities that conflict with their caregiving duties. Michael Bury's concept of biographical disruption explains the power that "chronic illness has as a destructive event" in a person's life because of its negative power to impact, change and create unplanned repercussions in all aspects of life (Bury, 1982). While the advent of disruptive change is significant and real for patients with chronic illnesses such as cancer, they have an equally disruptive effects on the lives of caregivers supporting those patients. When caregivers spend several months in the hospital with the woman, they are away from their homes and their roles there. For those families who seek care from other towns or faraway regions this translates into not meeting their families for many months.

Caregivers who have children suffer emotionally and worry about them ceaselessly, albeit quietly. Where there is inadequate support, the children and families are inconvenienced greatly. Some caregivers are forced to give up their jobs due to caregiving needs, which has implications on both their present and future financial stability. Being in the hospital for months at a time has different challenges for women and men. Women have access to a sleeping area within the cancer wards but are apprehensive and restricted in terms of mobility, especially if they are from another town and do not know the language. Men do not have access to the wards during the nights and will attempt to sleep in insect-ridden open corridors or outside the hospital entrance in unsafe conditions, perhaps under tree cover only. Caregivers have no access to convenient and hygienic toilet and bath facilities.

> *I have four children. One is in my brother-in-law's house, one with my sister, one with my in-laws and one child is with me. I am struggling this way, leaving them in different places.*
>
> *Daughter: Relationship of caregiver*

> *My husband takes care of some responsibilities. I have two children. My mother takes care of one and my mother-in-law takes care of the other. Finance is a problem. It is difficult but we have to take care of her. Right now she is more important than we are.*
>
> *Sister-in-law: Relationship of caregiver*

7.5 Discussion

Our research confirms there are unaddressed needs that personal caregivers have in the gynaecological cancer care spectrum in India. This is consistent with the evidence in global literature that reveals gaps in unmet needs of families in gynaecological cancer care and data that explore the complex nuances of the relationship between women and their caregivers (V. Beesley, Alemayehu, & Webb, 2018). Research that address these issues are urgent for several reasons. Such research is currently not available or prioritised in India. Women may already be in underprivileged circumstances and there may be cultural factors that influence personal caregivers from not revealing their challenges. Considering the women and their personal caregivers as dyads rather than separately offers better scope to look at cancer care and related problems holistically. The patient centric focus of health systems overlooks the psychological aspects of care and wellbeing that are inextricably linked to people a woman is strongly associated with.

Literature documents that perceived benefits of outcomes and psychological wellness in cancer care vary based on several factors that impact a patient's experience of disease and care (Manne et al., 2018). Our findings suggest that the relationship between the women and their caregivers has a significant role in determining how a woman deals with her disease as well as how a caregiver extends support to her. In addition, the findings suggest that the wellbeing of the caregivers are bound to the wellbeing of the women themselves. The linkages may be social, emotional, financial or all of these together affecting the psychological wellbeing of both parties. Many of the reasons why caregivers make the decisions they do show this mutual and symbiotic association in the care trajectory. This being revealed, it follows that interventions and efforts that focus on both the woman and her family concurrently have a much better chance of improving outcomes, rather than those that look at them as mutually exclusive categories of people in gynaecological cancer management.

The psychological harm of dealing with cancer has been explored in great depth but the harm in caregiving in cancers and for caregivers has barely been explored. The data show that regardless of the nature of the dyadic relationship and the supports caregivers may have, the adverse effects of caregiving are emotionally exhausting, burdensome, and long-term. This is in keeping with data across the world that show caregivers in cancer care experience a heavy workload, that their ongoing needs for psychological support are usually unmet, and that the scope for them to cope and focus on their own being is extremely limited (Lund, Ross, Petersen, & Groenvold, 2014).

This research demonstrates that caregivers find an informal and support through spirituality and personal faith, an avenue for doing something for their loved one when adverse events occur or all options cease. Spirituality in caregiving merits in-depth study since faith, prayer and spirituality could be a common source of support for women and family to unite and deal with cancer and its outcomes. The juxtaposition of caregiving vis-à-vis other life commitments determine a caregiver's longitudinal response and reactions to it. Cancer is an illness that alters life and life experience significantly. Evidence shows that experiences of cancer and the needs it creates in people have to be "analysed holistically" in conjunction with several factors: social structures, individual responses to disease, life narratives and individual perceptions of need. (Joanne, Mari, Sheila, & Christopher, 2010). Such analyses would be considerably incomplete if we conclude the narratives and experiences are restricted to patients. In illnesses such as cancer those experiences are as much about the significant others who are present in patients' lives as they are about the patients themselves. Evidence also suggests that the patient's spiritual identity can be pivotal in providing hope, and aid caregivers' coping and wellbeing in the cancer care trajectory (Tan, Lim, Kuek, Kua, & Mahendran, 2015). Again, it reiterates that the hope and hopelessness that patients experience are enmeshed with those of caregivers and those close to them.

The study findings show that the responses of caregivers depend on the nature of conflicts in caregiving, and range from hope to exhaustion to desperation and a frantic search for help. The long duration of caregiving accentuates the stress on caregivers, and the ways in which they delineate their responsibilities to themselves depend on their relationship with the patient, the responses and other responsibilities they have. This is concordant with the literature in cancer care which shows that the load of caregiving experience is heightened by the other stress-inducing factors in a caregiver's life even if they are considered secondary to caregiving (Stamataki et al., 2014).

As for partners, the study results highlight the tremendous levels of stress that are present if the partner has to multi-task with different aspects of caregiving. Caregivers talk about the physical and financial strain of multi-tasking. However, the nature of the relationship has other unarticulated ramifications such as the contributions of the woman in the household in routine times or her emotional and sexual association with her partner. These losses are not mentioned or easily measurable between people. The literature shows that longitudinal effects such as psychological trauma, body imaging due to treatment-related changes, and loss of reproductive parts in women with gynaecological cancers due to invasive surgery, have direct implications in women's sexual functioning. These problems could be further exacerbated by the gaps in communication between three vital groups traversing this path together: women, their partners and the healthcare providers (Dariusz, Katarzyna, & Natalia, 2016).

Research shows that male caregivers are affected by barriers in communication and intimacy with women following treatment or surgical interventions, and they have problems identifying coping mechanisms and support networks for themselves in the caregiving process (Mazanec, Reichlin, Gittleman, & Daly, 2018). The study findings echo these issues at multiple levels since partners openly expressed the difficulty in expressing their personal concerns to their wives, fearing the emotional impact on them. They also express difficulty in talking to others about support they need, since their wives have been their primary emotional supports for several years. Men say that while they may seek general companionship and talk to others for a relaxation, they are less likely to seek support openly. Partners who are primary caregivers to women dealing with the multiple demands. They are required to provide consistent support to their wives, deal with their own lonely psychological distress, try to meet the social expectations of bearing all costs of treatment and be responsible for their wives wellbeing in ways that make them neglect their own needs. Understanding the problems of partners is of great importance in a context like India where the institution of marriage plays a significant role in a woman's and family's wellbeing.

In a context where gender inequities abound it is not the norm to expect a man's wellbeing may be jeopardised. Assumptions would be that the man takes good care of himself, which would mean that support extended to others may not be extended to him. It is sensitive line to tread, but the study findings clearly show evidence of men compromising on their own interests heavily because of their caregiving responsibilities. Guidelines to healthcare providers on these unmet requirements of personal caregivers can address major gaps in the existing communication between caregivers and care providers.

Data from other contexts show that the measurement of caregiving burden is highly subjective since the way a caregiver experiences time or responsibility in caregiving is strongly influenced by the relationship with the patient, stage of the disease and the caregivers' own network of support (Seven et al., 2014). The respondents in the study who have had strong networks of support have been more likely to focus and make decisions regarding the wellbeing of the patient versus the caregivers who have primary responsibility and less support. Those with less support have been more likely to speak about the pressures, challenges and loneliness in caregiving. Loneliness is an experience that requires in-depth study in cancer caregiving since there are so many reasons for a person's loneliness being triggered, ranging from not being able to be transparent with a patient, financial distress, not being able to turn to anyone, emotional and physical exhaustion and not having access to necessary information. The feeling of not having someone to "turn to" is lonelier for caregivers than the responsibility of bearing everything alone

Literature emphasises that among the several factors that affect cancer caregivers the context of caregiving plays an important role due to its interplays with sociodemographic realities (Gaugler, Eppinger, King, Sandberg, & Regine, 2013).

This directly supports the central theme of this article that context specific and culturally appropriate understanding is fundamental to holistic interventions that respond to caregiver needs. Culturally in India, although there is social expectation that a patient's interests and needs are prioritised and there is the recognition her pain is paramount, there is no acknowledgement that caregiving brings is own set of trials and tribulations. This cultural hierarchy works against personal caregivers when they grapple with and are burdened by the challenges of care. An important dimension to understand in cancer caregiving is non-disclosure to the patient. While western paradigms tend to analyse this from the frameworks of self-efficacy and autonomy it is essential to understand the cultural context in which this occurs. For instance non-disclosure is as aptly recognised is not an absolute but an organic reality between concealment and revelation (Banerjee, 2019). The reasons given my caregivers for non-disclosure tend to be a collaborative decision not to worry the patient or burden her (Chittem, Norman, & Harris, 2020). Literature clearly suggests that non-disclosure needs to be studied vis-à-vis the culture and social norms of a context in which it occurs (Chittem et al., 2020).

Caregivers share that they can make decisions independently and be less exhausted about the process with the simple assurance that when necessary there are support networks they can access. Assuming that caregiver loneliness is always about handling responsibilities is an incorrect assumption because loneliness has many related emotions surrounding it. Respondents in the study spoke very differently of the same responsibilities based on whether or not they perceived they would have supports for themselves if they reached out for help. Those who knew they could did not express loneliness even if they bore the caregiving responsibility alone.

Caregivers have discussed prayer, worship and a patient's recovery almost synonymously with treatment. The responses suggest that for most people dealing with the magnitude of diagnosis and disease, they benefit from the aid of a higher force that helps them cope internally with the uncertainties of the situation. This is reflected in the literature which shows that coping with caregiving, especially in the final or advanced stages of disease is better among those caregivers who have spirituality as a means and mechanism to cope (Paiva et al., 2015). The responses from caregivers show that seeking the aid from “God” or through “faith and spirituality” helps them accept that there are limits to what they or healthcare can do in the treatment process. Recovery and positive outcomes are unpredictable in gynaecological cancers and the ongoing uncertainties can bring heightened grief, stress and feelings of severe inadequacy among caregivers who do not have internal mechanisms to deal with them. Spirituality plays a key role in that acceptance and for forgiving oneself for not being able to rectify the situation.

Despite deep fears about survivorship of the women they love, the caregivers in the study focused on current caregiving needs rather than those that may occur after the patient is discharged. Information and planning after care is essential in cancer care where recurrence, long-term emotional distress and infection susceptibility are high. Preparedness is key for caregivers who already suffer burnout through the hospital treatment. These issues are further accentuated by the socioeconomic disadvantages the women and their caregivers in the study have. Most women had severe financial constraints in managing their healthcare. Studies show that post-survival care planning helps caregivers a great deal both practically and emotionally to prepare for what awaits after the treatment process (de Rooij, Teresa Hagan, et al., 2018).

Participants in the study did not discuss their relationship with healthcare providers extensively. While they said that there was a contact person in the health setting such as a nurse or primary physician that they could seek for questions, most of them said that there were given information on a need to know basis. This meant information was shared at the time and stage of treatment rather than proactively or with adequate time leeway for them to process or make financial and logistic preparations. The other aspect caregivers talk about is that of health care providers repeatedly asking them to think, focus and attend to the woman and give unwavering attention on their needs. While caregivers do not state this openly there is the implication that providers ask caregivers to temporarily suspend self-care and attention. This is in keeping with literature that suggests communication between caregivers and healthcare providers has information deficits, uncertainties about treatment progression and the providers’ non-recognition of caregiver responsibilities and stress (Lund, Ross, Petersen, & Groenvold, 2015). When asked about support for themselves, most caregivers shared that they did not have the luxury to focus and think about oneself, even periodically.

The need to prioritise the woman in cancer care is imperative. However, there is a serious risk in not recognising the fundamental role her caregivers have in her wellbeing, during every step of treatment and after her move back to her personal context, be it to recover or to succumb to the disease. In the dangers of viewing a woman as an isolated individual and the family as a separate entity in her life expected to care for her, we miss the critical truth that several aspects of her wellbeing are interwoven with those dear to her. The first step towards alleviating this gap is to stop looking at women and their caregivers separately.

While we need individual perspective, we equally need better insights into the dyadic relations a woman shares with her caregivers at every stage of gynaecological cancer care. This will pave the way to establish systems in the care continuum that are conducive to enabling her wellbeing in a more holistic manner. Women's care in gynaecological cancers in India cannot be understood without a far better appreciation of the critical role played by caregivers. Care for a woman cannot occur in a sustainable manner at the expense of her family's wellbeing. The means to enable and enhance current realities in the cancer care spectrum is to design responses and support services in ways that include and embrace both caregivers and the women patients. The protagonists of this chapter article are in many ways the lifeline of support in the cancer continuum. Their caregiving responsibilities typically begin before a woman enters the tertiary care services and continue well after she completes her treatment. The tireless stories of the caregivers deserve much attention.

7.6 Conclusion

The study concludes that the caregiving burden is extremely complex since it is fraught with aspects like guilt, responsibility, self-expectation, norms of caregiving and perceptions of support for oneself. All of these are factors that influence self-efficacy. Of these, culture shapes a caregiver's journey from commencement to completion in several ways, not all of them evident or measurable. While it is rarely articulated as an influencer its presence is consistent in all the listed factors that become determinants. Culture’s role from the perspective of caregiving is not understood. It also harbours several silences. The responses from caregivers reflect the pressure to meet perceived social norms and expectations.

The next chapter presents a discussion of the thesis, which leads to the thesis’s conclusion. There, a model of care is proposed that has been adapted with the help of the theoretical underpinnings of the study, the health belief model and the theory of communicative rationality. The chapter will also present recommendations based on study findings for research, practice, community organisations and institutions.

Chapter 8

Discussion, Intervention Proposal and Conclusion

8.0 Introduction

This chapter concludes the thesis. It summarises and discusses the results of the entire thesis and makes recommendations as a result of the study findings. The recommendations are made for community organisations, community health workers, policy and practice, and future research. This chapter also details the significance and the limitations of the study, which reveal directions for future research in this area. The chapter then proposes a communication intervention model adapted from the theoretical underpinnings of the study and from the study findings. The applicability of the collaborative model is explained and illustrated in the context of the study. A rationale for the efficacy of the model and its possible replicability in other contexts is provided. The chapter concludes with the possibilities for future directions and scope of research.

8.1 Overview

Globally, gynaecological cancers have risen steadily over the past few decades. Even economically advanced countries continue to grapple with challenges in early diagnosis, access, information and enabling decision-making in gynaecological cancers. In resource-constrained settings the problems are accentuated by economic, social and cultural challenges that often create barriers in a woman’s journey of care seeking and receiving. Women’s gynaecological cancers in India is an area of work that has several complexities since the neglect that is rampant in the context is twofold in nature: (a) cancers are prioritised less than other non-communicable diseases that are considered more urgent in the country, and (b) gynaecological cancers and patient care suffer from deficits such as gender inequities, social norms and contextual barriers. The management of gynaecological cancers in the cancer continuum thus leaves much to desire despite the best efforts of the health system, individual tertiary units and healthcare providers serving women against all odds. What currently exists is dedication and resources that are extremely limited, stretched, and not fully able to serve the purpose.

In a scenario where resources cannot be replenished overnight, sound insight on how to deal with what is lacking is most valuable when it comes from people who are at one or the other end of care-giving or receiving. The recommendations and suggestions of the three primary stakeholders (women diagnosed with gynaecological cancers, their personal caregivers and their healthcare providers) have consequentially been the focus of this study. Their voices are vital since they have not been heard often or considered as a cluster of stakeholders in the Indian setting. The scarce literature that is available briefly touches upon the barriers of women or the economic problems in care management. We need more in-depth perspectives on the interplays that occur in gynaecological cancer care. Access to such perspectives in a research setting where non-clinical data remains scarce is the foundation for finding long-term solutions to enhance cancer care services. From such cues, this study has sought to explore possible remedial measures for the current barriers and gaps in the care continuum for women in India.

8.2 Reflections on the Research Design

The two frameworks that formed the theoretical underpinnings of the study are the health belief model and the theory of communicative rationality. The constructs of the health belief model are most applicable for individual efficacy in health behaviour and the communicative rationality framework emphasises collective efficacy. Even though these frameworks have helped shape the study's deductive approach, the study findings have helped shape the inductive approach and inform the proposed care framework presented later in this chapter.

Participants

The study had three participant groups: women diagnosed with gynaecological cancers, their personal caregivers (typically family members) and their healthcare providers. Women in the study were recruited from a tertiary oncology hospital's gynaecological specialty ward. They were all diagnosed with a gynaecological malignancy and seeking long-term care in the hospital. All of them were admitted for extended treatment for their cancers. Women were above 18 years of age, able to speak either the Kannada or Tamil language, and were able to provide informed consent. Those women identified by healthcare providers as too ill to participate or who were considered emotionally disturbed were not included in the study.

Personal caregivers of the women were above 18 years of age and were approached for recruitment after the women completed their interviews and consented for the researcher to contact their caregivers for participation. Personal caregivers spoke either the Kannada or Tamil languages, able to provide informed consent, and had accompanied the woman to the hospital to provide care during their treatment.

Healthcare providers were recruited from three tertiary hospitals providing advanced oncology care (including the one where women patients and their caregivers were recruited), one support service organisation and one community health organisation. All organisations were in the same urban setting in southern India. The healthcare providers were above 18 years of age, able to provide informed consent and spoke in English, Kannada or Tamil.

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Semi-structured in-depth interviews were conducted with the participants. In all, 35 healthcare provider interviews were conducted as well as 15 women patient interviews and 10 personal caregiver interviews. All interviews were audio recorded and if potential participants declined to have their interview recorded they were not included in the study.

The analysis was of themes and subthemes identified for each participant group and the codebook was finalised in consultation with the supervisors. All data (both recorded and documented) were not linked to any identifying information and all the study documents were assigned a delinked numerical code.

8.2 Discussion

In response to the research objectives of the study, the in-depth interviews sought to better understand four aspects of the cancer care continuum:

1. the communication processes among and between the participant categories
2. the challenges and barriers confronted by participant groups and its impacts on access, care seeking, interpersonal communication and care provision
3. the decision-making that occurs in the cancer care spectrum by different stakeholders and factors that affect them

4. the directions of the study which in turn has aided the proposal of a collaborative model of care in the cancer spectrum.

With regard to the first objective, identification of the types of communication that occur in the cancer care continuum was a revelation. The communication that occurs among women, their caregivers and healthcare providers needs to be viewed in unison with dimensions in the cancer care continuum such as the stage and phase of disease, life factors that impact care seeking, and prognosis of the disease. To isolate aspects of this communication as if related to illness alone gives only a partial and limited picture of the realities. The life of a woman in the cancer care spectrum is affected by every independent and related aspect such as hospitalisation, caregiving, finance, interpersonal relationships, side effects of treatment, familial responsibilities, agency in care, caregivers' support, perceptions of treatment success and spiritual solace. Accordingly, every communication she has with others is affected and influenced by realities that may not be obvious. The most important aspect that contributes to a better understanding of the communication is the researcher's willingness to suspend pre-conceived notions, judgement and assumptions of her journey in care.

The inquiry for the second objective, to understand challenges and barriers that women, personal caregivers and healthcare providers handle in the care continuum, unearthed several dimensions that lay beneath the surface. Most participants were very willing to share their stories and the burdens they bore at an individual and collective level, despite the personal nature of them. This research found that the participants did not have enough listeners to hear their perspectives. It is an area of work that requires much more attention since many of the answers for the next steps in care management lay within this group of people. No resolutions are possible in disease management challenges without their cooperation, engagement and insight.

The findings of the study into the third objective revealed many nuances and subtleties in the decision-making process between women and their personal caregivers. The cultural reality of collusion, in which women and their caregivers protect each other from different aspects of information, has required careful consideration. When confronted with collusion it is typical for researchers to make an assessment of subterfuge or disempowerment unless the cultural context in which the reality of people in the care continuum is understood with empathy, focus and openness. Significant decision-making occurs in these interactions, which have many accompanying complexities. Understanding why collusion occurs and how decisions and consensus are reached through them rather than despite of them should be the mandate of future programs and research.

The decision-making process is complex not because of collusion only but because of constraints women and their personal caregivers constantly deal with as they manoeuvre and manage life in cancer care. This present research found that decision-making processes cannot be polarised as being of those with agency or a lack of agency. Decisions occur in an organic manner as health options occur in consonance with life, opportunities and deficits. Women choosing to let their families or providers make all decisions is a decision they make with agency. It can often be as active a choice as it would be if they made all the health-related decisions themselves. Similarly, the caregivers who promote collusion cannot be assumed to be uncooperative beings who hide information from women who seek it and may be dying due to a major disease. Caregivers are also likely to be caring human beings who choose this complicated route to protect their loved ones to the best of their abilities. Some of them succeed in their intent and in such cases collusion actually works. The question on whether this is ethical, or simultaneously promotes disempowerment and debilitates the agency of a woman, should be the aim of a separate study. The fact that others might override the autonomy of the woman and make decisions for her is something most of them do not even consider or evaluate, just as she herself may not.

The final objective of this study was to propose a more inclusive model of care based on the findings and theoretical underpinnings of the study. The primary issues that aided the development of this model are that (a) the cancer care continuum is organic and not separate from health decision-making and health behaviour, which occur together and collaboratively in an ongoing graph of time; (b) the care continuum cannot look at the women patients in isolation either in terms of decision-making or behaviour because their travel through the spectrum is enmeshed with the travels of their caregivers and providers on the same platform; (c) the care continuum does not have a concluding date or timeline because of the nature of the disease and the kinds of management it requires through the life-time of a woman. As long as there is life there is some form of management that the three participant categories are required to do, alone and together. Once a woman enters the trajectory of gynaecological cancer care she stays and strives through the highs and lows of ill-health, reclaims of good health and for the duration of her life.

8.3 Recommendations from the Study

Recommendations for Community Organisations

There are four recommendations for community organisations.

1. The study findings revealed that although community based organisations have excellent reach, access and respect within their communities, they are under considerable strain to manage their overhead costs. It takes a long time before they are trusted both within communities and by the hospitals or health institutions they liaise with. The credibility they build with their work requires financial support for long-term effort on their side to continue in a sustained manner. Although it is a challenging situation for most organisations there are some ways in which they can work around such obstacles. Investing in collaborative initiatives with such organisations is mandatory. This will ensure that the staff who are directly engaged in the work are those who do not require special training for knowledge of the community where they facilitate movement towards health institutions.

2. Hiring volunteers or part-time peer educators from the community is an effective way of reaching people. Such staff are well-versed with community dynamics and are also more willing to give back to their settings through volunteering or lower salaries. They are aware of how to negotiate or whom to approach when adverse events occur in the community. They are also capable of identifying others with similar interest in community work. The recommendation is to focus on community based recruitment so that there is both familiarity and efficiency among the staff as they conduct their

responsibilities.

3. Some remote services such as a helpline or telephone counselling support would help reduce costs. At the same time, however, it is an opportunity to have round-the-clock support available for emergencies. Some women may be more comfortable accessing remote support first, rather than in a face-to-face discussion or consultation regarding their health problems. Measures need to be in place concurrently so that women can act as per preference.

4. Efforts that will help community organisations gain legitimacy within health institutions are a necessary area of focus. Appointing to the board of trustees a clinician who is like-minded and supportive of the work, are ways in which the clinical hierarchy within the hospital can be approached. Currently, organisations invest tremendous amounts of time trying to gain access to clinicians at tertiary institutions. Their willingness will be so much the greater if they are approached with community based data and with the support of another clinician who has aided the work and believes in it.

Recommendations for Community Health Workers

Community health workers in many ways are critical frontline service providers who have a hand directly on the pulse of the community. These individuals over time almost become like family members to women undergoing treatment since they are likely to be the first points of contact for preliminary screening, follow-up reminders and the liaison with tertiary care at times when independent entry of a woman is arduous due to some reason. Many of them see women through the care journey from start to finish and accompany them routinely, especially when there is little support from family. It would not be incorrect to view their service almost as surrogate family support for women, with intimate knowledge of the woman’s personal and health situations. The biggest challenge for community health workers is that they are poorly paid, lack organised supervision and are overburdened with work. Three recommendations are aimed at enabling their services.

1. Efforts at the grassroots level are currently dispersed and specific, which makes the work of community health workers physically strenuous. Planning

the locations for their job responsibilities around the places they reside can aid them tremendously since they can access these by foot and in far less time. Transport to work locations can be physically strenuous because of traffic congestion in urban India. This mobility issue impacts the functioning of dedicated personnel and needs to be addressed immediately. Currently, they function in sub-optimal conditions which impacts the level of support they can provide.

2. Better salaries or at least consistent incentives for screening, identification and follow-ups are missing or sporadic. Many community health workers are not regularly paid, but despite that continue their work out of commitment to the women who rely on their support. However, a lack of recognition demotivates these tireless workers. Directing savings in transport costs towards incentive is one method of addressing this problem. Another is to consider including a nominal amount in the service charges of patients at the hospital which is routed towards the work retroactively. This will also ensure that the woman cancer patient or family are not indirectly pressured to pay the health workers since that cost will be included in invoices issued to patients by their organisations.

3. There is a need to clarify who community health workers are professionally accountable to. There is a lack of clarity regarding this. Those affiliated with community health organisations are able to function better. However, those who offer their time and service on a voluntary basis without affiliation to any organization operate in a grey area. A designated professional in the clinical setting or a community based organisation needs to be available for such support and leadership. Since this is missing for many community health workers, challenges occur in the form of decision-making and giving correct information in the community. Existing services can easily accommodate this chain of communication and benefit from all sides.

Recommendations for Policy and Practice

There are serious gaps between policy and practice in India related to gynaecological cancers. First, it is necessary to understand and accept that for a country with a large population below the poverty line, the government cannot be held solely accountable for screening or opportunistic practices within the public health system. Policy, practice, public-private partnerships and health agendas in gynaecological cancer management in India are not independent entities since none of them can function in a linear fashion without affecting each other. Setting priorities without each discipline consulting the other can jeopardise the interests of both. Any health priority for management needs to be located within an agreed time-bound and outcome-based plan of action. India already suffers from insufficient, incomplete and inaccurate health data that impedes understanding of health issues (Kamath & Kamath, 2020). Four recommendations are intended to improve policy and practice.

1. Awareness and education of screening related to gynaecological cancers requires the effort of collaborative forces. Frontline health workers, and elected representatives of women in peri-urban, rural and urban settings need to join hands to translate any policy on gynaecological cancer management into implementation (Vallikad, 2006). Cost is a major factor that impacts preventive measures and screening in gynaecological cancers. Public-private partnerships that include cost-effectiveness in their models are necessary, and more research that looks at the viability of such measures is urgently needed (Akashdeep Singh et al., 2020).

2. The diversity and population of India can be deeply affected in their health choices by prevailing issues. There is evidence that the COVID 19 pandemic has affected oncology services in India as it has in other countries. Hospitals and tertiary facilities continued to provide care but with new rules and changes that impacted patients considerably. Online consultations, postponements of non-emergency procedures and moving patients to waiting lists based on priority allocations (Sultania et al., 2020) have long-term policy and practice ramifications. It is necessary to be in tune and for health services to adapt their provision according to the larger impacts and changes at systemic and policy levels.

3. With reflection on gynaecological cancer management vis-à-vis the COVID 19 pandemic revisions are needed in protocols and implementations that are

fully understood by women and their families. Such efforts should sufficiently guide women towards accessing care in an even more changed health context. The current scenario is intimidating for patients to access care in which access has already been affected with new rules and apprehensions: everything related to care seeking is less than ideal. It is also a reality that simply cannot be neglected by anyone directly or indirectly determining care.

4. Women who are already grappling with access issues in care will need specific policies that enable them to seek care. Once again, collaborative efforts at the grassroots level by community health organisations, frontline health workers and government protocols that are standardised in public private care institutions are required. Innovative ways of reaching women to reassure them about safety measures and to concurrently educate them on steps required from their side are necessary for follow-ups and visits to tertiary centres. This is more so for patients to seek care from outside the geographical area or locality. A multi-tiered approach is required for follow-ups which will vary according to the levels of education, awareness and stage of disease among women.

   Efforts by clinicians to promote well-woman clinics and health promotion from their institutions will be an effective way to both create awareness and to do opportunistic screenings. However, it is imperative that policy makers and administrators are not separate or distant from clinicians. An inclusive environment is needed in the care provision scenario where each stakeholder is seen to have an important role to execute. Better liaison with community health workers by tertiary care will ensure that the first step of the journey from community to institution is enhanced and occurring routinely. Similarly, the institution should be connected to the stage of health policy that influences the health system. At a most preliminary level to reflect this, funds that can provide standardised incentives for workers is an urgent necessity for the government to help create. With this activation of flow through the health system in frontline work, there will be positive impact on the woman's readiness to reach the care context.

Recommendations for Future Research

Important research insights are available into the clinical dimensions of gynaecological cancers, across the world. There are also studies that look at the psychosocial aspects of caregiving in the cancer continuum. However, much of this research is done in contexts that are economically advanced and socially different, meaning that many of them already having better healthcare availability, access and different norms in health-seeking and receiving. The applicability of the findings of such studies to resource constrained settings is partial at best, because of the variance in several dimensions of care combined with the diversity in culture, social norms and beliefs that impact health decisions. Accordingly, this present research suggests five areas for future research in India.

1. There is a need to tease out replicability from research that cannot be adapted. The trend to follow the West in imitating their success stories in healthcare is not helpful. Investigations in India would benefit from research that is located in not just the context but in the long-term relevance within it. For this, looking at India based studies across disciplines and allied fields such as women's studies, economics, health systems, policy research and anthropology is the most fundamental need. Instead of only looking at Western literature, there is a need to look at local literature which can give a distinct lens into some of the specific challenges that impact healthcare. Cancer care is not an isolated field, it is impacted by several human experiences that are captured by these allied fields. Such knowledge will aid the process of what needs to be the realm of focus and what else needs to be explored, unearthed and understood via research.

2. Training and capacity building of health researchers is a critical need in India. Currently, several cancer studies are conducted by medical students or researchers who are supervised by medical practitioners. While this is an important capacity for health research, training in social science research with a knowledge base in varying branches of health (medical anthropology, public health, health systems and policy research) is important. Senior professionals in India are required to train, mentor and guide new researchers in order to add pertinent and robust literature in the field that will aid their learning and

train them to create more relevant research as they proceed with determining the nature of subsequent practice.

3. The type of research most needed in the cancer care continuum of gynaecological research is multi-pronged. Research that looks at the longitudinal trajectory in gynaecological cancers and care needs of women (including palliative and end-of-life perspectives) is necessary. Though such research is difficult to collect it can inform the context of interplays between prognosis, support services, caregivers support, women's roles within family and demographic factors. Coordinated efforts with health institutions will help to conceptualise and implement such work.

4. Research that focuses on women who are not captured in the health setting, who adopt alternative medicine and home remedies is equally essential since they will not get covered in the umbrella of allopathic services that is tied to tertiary care in India. It is of paramount importance to capture the voices of women and caregivers who access palliative care in order to understand the challenges surrounding the mortality linkage to gynaecological cancers. There is little data in India on caregiver stress and their psychological support needs. There is even less data on women who have absolutely no caregiver support.

5. Last, research focused on offspring of women who have gynaecological cancers is likely to reveal important insights. This study has found that children play a significant role in a woman's life. Knowing what children undergo in the family setting and life when a woman is diagnosed with gynaecological cancer is likely to throw light on critical aspects of health, decision-making and wellbeing for both women and their familial networks.

8.4 Significance of the Study

This study has made a genuine attempt to listen to what 60 individuals have said and to listen to their silences. Therein lies its core significance, however there are a number of other aspects to this study that are significant.

1. There is little data in India on the psychosocial aspects of women diagnosed with gynaecological cancers. Those that look at dimensions beyond clinical

care tend to focus on the economic challenges in accessing care. Studies such as the present one that focus on psychosocial aspects of cancer care are rare. Additionally, there are no other studies that have looked at the care trajectory in gynaecological cancers from the concurrent perspectives of the three critical stakeholder groups (women, personal caregivers and healthcare providers).

2. The communication chain that occurs in the cancer continuum between the three stakeholders can be better understood when their independent challenges are understood. Since these three stakeholder cohorts participated in in-depth interviews independently (rather than as dyads with simultaneous participation) there is scope to focus on their perspectives separately as well.

3. The qualitative exploration with semi-structured interviews allowed many insights from the health care providers in a range of roles in healthcare to be tapped. Typically, providers are looked at as those exercising hierarchical power and advantages in the health continuum. This study has revealed, however, how difficult their day-to-day lives are and how vulnerable they themselves can be. Many are overworked and emotionally affected, yet remain deeply dedicated to their professional roles despite requiring support and sensitive understanding themselves.

4. This study has revealed insightful directions in what can be done for women if palliative care has better investment and focus. Despite the critical nature of palliative care it has low priority because its association with end-of-life care tends to push it back to a secondary position in the care continuum. However, cancer care is also about acknowledging death and dying which is best supported in palliative care. The perspectives of healthcare providers have shown how important are their roles in cancer care, especially for women who have less support in advanced stages of the disease. These findings have reiterated the need for health institutions to incorporate providers in mainline service in gynaecological cancers. Palliative care is still rarely available as a service in southern India. The present study was fortunate in being able to interview some of the few individuals trained and providing the service. Their

insights are invaluable records of the important issues surrounding this essential service.

5. Another contribution of this study is to recognise that as important as the holistic nature of care and its challenges are, the commitment of individuals must be acknowledged also. The nature of services (community, institutions, departments and referral organisations) is largely determined by individuals who remain sincerely committed despite all odds. There are possibly no studies into how such individuals manage to cope with the constraints surrounding cancer care in this context.

6. Several studies have examined the economical aspects of cancer care. However, this present study has shown the emotions, challenges and complexities at work below the surface of financial and health transactions in healthcare. The findings reiterate the limitations of looking at financial aspects as merely affordability and costs when other dimensions of finances determine decision-making. In addition, such limited research focus risks looking at relationships that occur in the continuum as transactional.

7. The study has identified specific results relating to collusion and the cultural sensitivity surrounding them. Assuming that agency is an individual measures checklist is risky in a cultural context where information does not always translate into power. Families play an important role not merely as a result of social structures but also due to consent and volition from women who are in the caregiving spectrum. Understanding these nuances is essential to see that collusion is not necessarily what occurs against the woman all the time. It may be occurring with both her consent and silent preference. This finding is an important contribution of the study.

8. Tertiary care and its burdens are not what gets attention in research. The challenges and inadequacies in care tend to get precedence in research interest. While the burdens of care seekers gets focus, rarely does the problems of tertiary service get an equal stand and say. This study’s intent provides that platform.

8.5 Limitations

The study findings have the possibility where they are affected by the study limitations. We live in times where health institutions in India are apprehensive of legal action from patients who are reluctant to share personal health information. External research is rarely encouraged due to this. Insights from patients and caregivers from multiple hospitals would have made this study even more enriching.

Unlike the providers who were recruited from multiple institutions, the patients and personal caregivers were recruited from one hospital providing advanced oncology care with hospitalisation in the private sector and these may not be representative of experiences women have in other tertiary facilities, especially public institutions. Permission was given to access only one community health worker since most hospitals did not have routine contact with community health workers who visited their premises to liaise with women from the community. Also, as such frontline workers visit the hospitals when women attend the hospital for the first time, they are not available for research purposes. More interviews such frontline workers from the community would give far more insight into the challenges related to community work in cancer care awareness.

The hospital in the study permitted access only to the women admitted post-diagnosis because they assessed women who were awaiting investigations and final diagnoses would be emotionally disturbed. However, the latter is an important cohort of people who are in the first stage of the care continuum which is likely to have issues that would add to the findings of this present study. Personal caregivers at the hospital tend to be family members. However, over time other networks and support systems such as friends and neighbours play a critical role. Accessing such people for the purposes of research such as the present study are best done in a community setting rather than in a hospital-based setting which prioritises the family as carers due to the nature of care required.

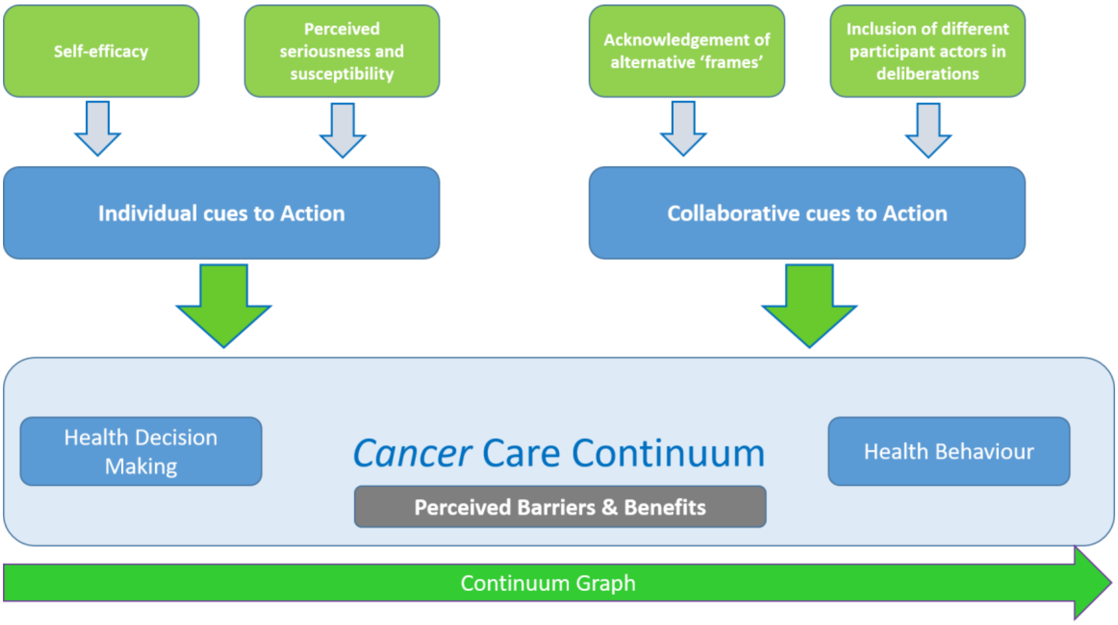
In a hospital setting there may be subtle pressure to cooperate and to respond in a socially desirable manner in an interview. This is probably less likely in a community setting or in interviews conducted in participant homes. The one hospital that gave permission to approach their patients for consent to participate in the study had a profile of diverse participants from a wide range of geographic regions. A wider representation of other socioeconomic groups would have been available to the study had permission been given by other hospitals. This situation revealed there is much more to be understood of the research process in India as well. While this research can record its own experiences in implementation, the ethical implications of how and whether such research gets support from the health system needs far greater study.

8.6 Proposed intervention

Models of health behaviour are typically applied to individual health behaviour change. The findings of the present study suggest that such models are somewhat limited because they do not adequately recognise and include the collaborative nature of decision-making in health behaviour. Stakeholders are involved in all aspects of an individual's behaviour change. In India and possibly other such collectivist societies where decisions are joint experiences, a culturally appropriate model to predict health behaviour would be useful. First, there is a need to predict the interplay of cues, spaces and directions for all stakeholders. Second, is the requirement to recognise that a woman's decision-making and behaviour in the gynaecological health spectrum needs not be linear or progressive but rather organic. What enables action and behaviour in that spectrum is both symbiotic and multi-dimensional.

This study proposes a collaborative efficacy of care model with the aim of supporting the inclusion of primary stakeholders in the gynaecological cancer care continuum. The model depicted (Figure 8.1) is intended to make optimal use of resources to enhance self-efficacy, decision-making and behaviour, as well as better health outcomes in gynaecological cancer care. Its constructs are possibly applicable to other chronic conditions in settings where collective and collaborative decision-making determine health behaviour and outcomes.

Figure 8.1 *Proposed Intervention: Collaborative Efficacy of Care Model*



Adapted from two frameworks of this research detailed in chapter 3: the health belief model (Rosenstock, 1974a, 1974b; Rosenstock, Strecher, & Becker, 1988) and communicative rationality (Healey, 1992; Sheikh & Porter, 2013).

This proposed model has adapted constructs from the health belief model and the communicative rationality framework that underpin this study in addition to the new constructs it proposes as relevant.

A woman seeking care for gynaecological cancers commences her journey in the cancer care continuum at different stages and states of readiness, dependant on multiple factors she has to deal with. The primary factors are individual factors that determine her decision to seek care such as her self-efficacy, her perception of the seriousness of her health condition or symptoms, and her perception of the degree or level of her susceptibility to the health risk or disease. Each of these, independently or in some form of combination influence her willingness to enable her health. This enablement occurs when she seeks care personally and directly, or after eliciting help from others to aid her process of care seeking. This process, in short, leads her to enter the care continuum. The cues to action at an individual level and the collaborative level connect in the behavioural spectrum which deals with the barriers and benefits of care.

Even before she considers seeking help, the commencement towards care is open to the possibility of impact and influence from other stakeholders in her life who play a critical role in facilitating her journey towards the continuum. They could be her family, well-wishers, healthcare providers, health system that directly reaches her in her community through proactive, preventive or responsive measures. In other words, her access to healthcare occurs primarily due to the influence of one or more of these stakeholders who guide her care seeking and who play an important role in addressing existing barriers that challenge or prevent her from care seeking.

Barriers and benefits in healthcare do not occur only prior to or during a particular phase in a woman's care process, but are ongoing realities through the care continuum of, for example, illness towards wellness or through relapse and recurrence. Accordingly, the care continuum must be inclusive of all stakeholders and the woman at any given point in her journey. Even if she is by herself, she is never fully alone in her care journey. Barriers and benefits that accompany the woman throughout the continuum might cease, reduce or increase and make way to new barriers and benefits along the way. At every step of this process others such as caregivers, well-wishers and health providers support the woman as she faces the realities of her experiences. As a result this model suggests barriers and benefits need to be integrated into the continuum. They cannot be left behind at any stage since we cannot predict when or whether a woman's experiences and perceptions of barriers and benefits actually cease in care.

Consequentially, the continuum graph is a time momentum in which women, providers, caregivers and others concurrently engage in health decision-making and behaviour that continuously impact on a woman's health. However, this does not imply that a woman is a passive recipient or cannot enable her own health. Rather it shows that if we look at a woman's behaviour as an independent occurrence in the spectrum, we see only half of her reality by separating her from those stakeholders who are involved in her continuum. Recognition of both the individual and joint processes can help to avoid misleading and misrepresentational assumptions or decisions made with regard to the woman, and can aid the health system to pre-empt decisions or behaviour and anticipate a necessary and appropriate response.

To illustrate this model: depending on the stage of the malignancy a woman and a caregiver may need to stay in the hospital for 6 to 8 months. The health system and institution can show immediate readiness to handle issues this situation can trigger: financial distress, personal challenges such as childcare or travel for women from other regions or nutritional challenges since home cooked food is difficult to organise if the woman is from a faraway place. At this stage the providers are prepared to impart information or engage with appropriate and timely referrals.

Another example is if a woman is diagnosed with a gynaecological malignancy during a community health camp organised by a health institution. The community health worker who has played a vital role in screening participation, and who probably undertakes the follow-ups and referrals should continue liaison through the care journey, at least until follow-ups occur with the parent health institution and the woman has developed a trust relationship with her health care providers at that institution. This model shows that many or all of these impacts and interventions are with the woman before and through her care seeking and health behaviour. To expect her to make decisions or show behaviour by herself at a specific juncture of care fails to recognise that the cancer care continuum is a collaborative space at every single stage.

The model also suggests the continuum graph does not have an end date which will most certainly vary for each woman’s situation. It might be impossible to predict an end date for some women. Women who complete their care and treatment may yet be required to continue self-monitoring for a potential relapse or recurrence, at which point they may stay in the care continuum albeit inactively. Some women may seek palliative care due to failure of treatment or lack of other options and that aspect of care can continue till death.

For other women, care provision could be an ongoing process with different treatment trajectories that are tried and tested in an ongoing manner with intermittent gaps and spaces. Some women may discontinue because of their challenging situations, but it cannot be predicted if and when they will re-enter the continuum with a different set of stakeholders. The presence of these women remains in the care continuum in some form for as long as disease and life outcomes specific to their cases. Even when the end of the care continuum may be death for some women, their providers and caregivers may continue the care experience for other patients that commence or continue their journey. It is essential to recognise the cancer care continuum as one that is organic without an end date.

In summary, gynaecological cancers in India is both a collaborative and a continuous process for women and stakeholders in the care trajectory. Any intervention or program can benefit with this fundamental insight and avoid one or more the major pitfalls such as excluding one or more stakeholders, and conceptualising outcome-related efforts that target women exclusively rather than inclusively. Best efforts to improve outcomes need to feature consensus and collaborative processes not only at the programmatic or systemic level but also at the individual level. These are foundational precursors for relevant and empowering health promotion and choice for all women at risk of gynaecological cancers in India.

8.7 Concluding Comments

The care continuum in cancer is a continuum of hope. Although this thesis has reported research that focused on barriers and challenges that women face in their journey through the cancer care trajectory, advantages, opportunities and hopes abound in that same space.

First, although tertiary care in India is extremely burdened, it has the advantage of being already set up to care for patients who might access it in the most advanced stage of the disease with very limited means. In other words, institutions and providers are geared to respond to women in need of different types of support—financial, emotional and familial. Prepared for this advanced stage, providers can battle along with women patients for a lease of disease-free life. The willingness and preparedness of tertiary carers can be of greater benefit if women seek care earlier or undergo age-appropriate preventive measures routinely. Every provider interviewed in the current study displayed high levels of commitment, sincerity and willingness to go the extra mile for their patients despite the problems, inadequacies, bureaucracies and psychological pressures of work. Not one was willing to give up on their patients however hopeless the situation seemed. If women and their families approach their wellbeing with a little more awareness, self-evaluation and self-responsibility, the tertiary carers and providers can work with them for improved prognosis, disease management and recovery rates. This step can be taken with simple awareness promotions, integrative measures with community based organisations and preventive measure promotions, led by frontline workers from the government and communities, working together rather than in isolation.

Second, the invaluable presence, influence and support from the families of women who have gynaecological cancers cannot be emphasised enough. The family is with a woman from the start of her journey in the care continuum through every point in that trajectory. These personal caregivers undermine their own interests to be of complete support to women. Interventions that address core challenges that caregivers face, such as finance, time management and emotional burnout, will go a long way in facilitating sustainable care and support. Culturally, this aspect is one of the greatest strengths in the care continuum in India, whose women have their families with them through the ups and downs of their battle with gynaecological cancer.

Last but not least, the *protagonists* of this research, the women who are diagnosed and deal with the disease called gynaecological cancers. What does the continuum hold for them? Several enabling possibilities that are obvious and not so obvious do exist. Stigma, shame and fear have hidden the multiple efficacious realities that frequent the cancer spectrum they deal with. Despite the lack of resources at different stages of the journey, there is some help if they choose to seek it. Subsidised care options are available if women know where to go to receive it. Community initiatives and medical camps (temporary organised medical services in designated areas offered within communities) focus on women of the reproductive age groups, to screen for gynaecological problems so that preventive measures can be taken early. If there is a willingness among women to undergo screening (even when they think they do not have a problem) there are many enabling opportunities for a woman to take early charge of her health when a problem occurs. Such initiatives also make attempts to reach women and families in their own homes with information on where and when they can access care.

The process of writing this thesis showed how little data and how few open perspectives exist about this subject in the context of study. On the one side are the steady silences of the stakeholders and on the other side are the missing links of information that are critical to care management. Data scarcity and absence of voices on the care continuum has shown that the neglect is deep-rooted. The reasons for such silences could be many, a primary one perhaps being a focus on clinical management with minimal resources for care. The health system, institutions, individuals and services are striving to improve, however there is much room for doing better. Yet, none of them attend to the ignored voices and the perspectives to be heard that might illuminate issues that have existed for some time. This study has sought to bring the readers' attention to some of them.

In conclusion, and with a distinct ray of light and hope, this research shows it would be a mistake to consider women as disempowered in gynaecological cancers management, because of the many problems they deal with. There are individuals, institutions and initiatives who are working with those women towards their enablement in the cancer care continuum. The success and relevance of these ventures are certainly important to evaluate. Equally important is the recognition that women have committed supporters for their care. It is vital for women themselves to acknowledge their existing support systems and to work with them for greater benefit. The barriers, challenges, pitfalls and fears women face when confronted with a diagnosis of gynaecological cancers are overwhelming, but they become considerably more manageable with support systems and networks that are willing to come together and function optimally with investments, but most of all in the form of recognition from women.

As proposed by the collaborative efficacy of care model, conscious and collaborative health promotion and communication in gynaecological cancers will play a pivotal role in the Indian context. Isolating communication to activities or events related to interpersonal communication or merely initiatives to promote awareness or gain media exposure runs the risk of the discipline further distancing itself from mainline cancer care.

Communication and health promotion exist in some form in every aspect of service in the cancer care spectrum tied to health behaviour since the very essence of care provision is the promotion of health. It can be most effectively harnessed through (a) awareness building, (b) integration of services, (c) interpersonal communication processes between the health system and the individual, (d) referral networks, (e) an increasingly active role of support services, (f) social responsibility of media, (g) more enabled conversations between women and providers, women and caregivers, and caregivers and providers, (h) and integrated networks between community health workers and health institutions. Each of these are avenues where communication enhancement can and should occur in the gynaecological cancer care continuum in India. What it primarily requires is multiple stakeholders in the cancer care spectrum to acknowledge each other’s contribution and the interdependent nature of their responsibilities.

All of these networks already exist but the health professionals tend to work independently and in isolation. Such integration will pave the way to address barriers identified in this study. Action can be taken with only a little investment and costs that not will pose an unmanageable burden on the resource providers. All that is required is a recognition of the cohesive nature of tertiary care provision and a willingness to implement simple steps to reflect it. Women dealing with gynaecological cancers in India face much hardship in dealing with multiple challenges and barriers in overcoming their disease. However, in this arduous journey, they are not alone.

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Appendices

Appendix A. Participant Information Statement (Women)

HREC Project Number:	HRE2017-0739
Project Title:	Managing care in gynaecological cancers: Role of health communication in enabling women's hea choices in India
Chief Investigator:	Professor Jaya Dantas, Professor of International Health & Director of Graduate Studies, Faculty of Health Sciences
Student researcher:	Kalyani Subbiah
Version Number:	2.0
Version Date:	October 14, 2017

Study introduction: Hello! My name is Kalyani Subbiah and I am a PhD student at the Curtin University in Australia. I am conducting this study to better understand issues related to gynaecological cancers in India. Findings from this study will contribute to future research and programmes designed to reduce women's risk towards cancers and to improve women's health in India. The PhD research is funded by the Australian Government with some funding from Curtin University.

Reasons for speaking to you: We are speaking to you about this study because you are seeking care in this hospital. If you consent to participate in this study we will have a personal interview with you.

About the interview: This interview will be about 60 to 90 minutes and will take place here in the same hospital where you are seeking care. It will be done confidentially and in a quiet place so that no one can hear us. There will be no costs to you for participating in this project.

We will do an audio recording of the interview so that we do not miss anything you might share with us. The recording will not include any information about you such as your name or the name of this hospital. When we write down the interview too, we will not add such details about you. All your responses are valuable to us.

At the end of the interview, if you are happy to do so we will ask you to introduce us to a family member or friend who supports you as a personal caregiver and accompanies you to the hospital. We would also like to understand their views also in a separate interview. None of your responses will be shared with them and similarly their responses will also be kept confidential. We will not contact your personal caregivers if we do not have your permission.

Benefits to participation: We hope the results of this research will help us to promote health for other women who are currently at_risk for cancers and those who may be at risk in the future.

Risks to participation: If you feel tired or need a break any time during the discussion feel free to let us know. If you would like some clarification about a question or more information from us you can stop us any time. If you feel anxious or upset about any of the questions or topics please do stop us any time and we will be happy to address your concerns. You do not need to answer any question you do not want to answer.

Access to your medical records: Your medical records will be accessed if you are a patient here only to confirm your illness through your doctor. Your health information will not be used for another purpose than this research.

Your information: Your name or other identifying information about you will not be linked to the information you share with us in this study.

Research findings and information safety: Information collected in this study will always be kept in a secure a cupboard and will be destroyed after 7 years.

The results of this research will be presented at conferences or published in scientific journals. Your name will not be shared in any results.

Voluntary participation and withdrawal: Your participation in this study is completely your choice and is voluntary. You can decide to not answer any question or to withdraw from the study without giving us a reason. Your decision will not affect any of the services or relationships in this hospital. We will not share with anyone in this hospital whether or not you choose to participate. Similarly, your decision will not affect your relationship with the Curtin University, staff or colleagues. If you want to stop the interview midway we will destroy any information (including the recording) of you may have shared with us till then.

Thank you very much for your time and participation in the interview. It is much appreciated.

Contact Information

You can contact me, Ms. Kalyani Subbiah to obtain further information or answer questions or concerns regarding the research. My contact number is 98458 34947 and my email is kalyani@postgrad.curtin.edu.au.

Or you may contact my associate supervisor Dr. Arima Mishra in Bangalore if you have any questions about the study. Her phone number is + 91 97403 80808 and her email address is arima.mishra@apu.edu.in

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number 2017-0739). If you would like to have a confidential discussion or make a complaint to someone not associated with the study, you may contact the Ethics Officer on +61 8 9266 9223 or the Manager, Research Integrity on +61 8 9266 7093 or email hrec@curtin.edu.au.

Appendix B. Participant Consent Form (Women)

I………………………….. consent to participate in the study titled: *Managing care in gynaecological cancers: Role of health communication in enabling women's health choices in India aka* ***Wellness and Empowerment with Communication (WE.com Project)***

- The information sheet about the study has been given to me to read and the details in it explained.
- The purpose of this research is clear to me.
- I have understood the possible benefits and risks of my participation in it.
- I have thought about whether I want to participate in this research. I have had an opportunity to ask questions. I know that I can withdraw from this study any time I want to without any problem to me.
- I voluntarily consent to participate in this study.
- I understand that this project has been approved by Curtin University Human Research Ethics Committee.

☐ YES	☐ NO	consent to being audio-recorded

☐ YES	☐ NO	consent to the access of my hospital medical records for verification

☐ YES	☐ NO	consent to be contacted about future research projects that are related to this project

Participant Name	
Participant Signature	
Date	

- <u>Low or non- literate participants:</u> I have read to me in Kannada or Tamil the information statement version listed above and I understand its contents.
- <u>Witness for low or non- literate participants:</u> I have witnessed the reading of the consent form, opportunity for the participant to ask questions. I confirm that the participant has voluntarily consented to participate.

Participant Thumbprint	

Witness Name	
Witness Signature	
Date	

Declaration by researcher: I have supplied the study information and consent form to the participant who has signed or placed her thumbprint above. I have also explained the possible risks and benefits of participation and believe that the participant has understood them.

Researcher Name	Kalyani Subbiah
Researcher Signature	
Date	

Appendix C. Participant Information Statement (Physicians)

HREC Project Number:	HRE2017-0739
Project Title:	Managing care in gynaecological cancers: Role of health communication in enabling women's hea choices in India
Chief Investigator:	Professor Jaya Dantas, Professor of International Health & Director of Graduate Studies, Faculty of Health Sciences
Student researcher:	Kalyani Subbiah
Version Number:	2.0
Version Date:	October 14, 2017

Study introduction: Hello! My name is Kalyani Subbiah and I am a PhD student at the Curtin University in Australia. I am conducting this study along to better understand issues related to gynaecological cancers in India. Findings from this study will contribute to future research and programmes designed to reduce women's risk towards cancers and to improve women's health in India. The PhD research is funded by the Australian Government with some funding from Curtin University.

Reasons for speaking to you: We are speaking to you regarding this study because you are a physician providing health care in this hospital for gynaecological cancers. If you consent to participate in this study we will have a personal interview with you.

About the interview: This interview will be about 60 to 90 minutes and will take place here in the same hospital where you are providing care. It will be done in a quiet place so that no one can hear us. There will be no costs to you for participating in this project.

We will do an audio recording of the interview so that we do not miss anything you might share with us. The recording will not include any information about you such as your name or the name of this hospital. When we write down the interview too, we will not add such details about you. All your responses are valuable to us.

Benefits to participation: We hope the results of this research will help us to promote health for other women who are currently at_risk for cancers and those who may be at risk in the future.

Risks to participation: If you would like some clarification about a question or more information from us you can stop us any time. If you feel uncomfortable or upset about any of the questions or topics please do stop us any time and we will be happy to address your concerns. You do not need to answer any question you do not want to answer.

Your information: Your name or other identifying information about you will not be linked to the information you share with us in this study.

Research findings and information safety: Information collected in this study will always be kept in a secure cupboard and will be destroyed after 7 years. The results of this research will be presented at conferences or published in scientific journals. Your name will not be shared in any results.

Voluntary participation and withdrawal: Your participation in this study is completely your choice and is voluntary. You can decide to not answer any question or to withdraw from the study without giving us a reason. We will not share your decision about whether or not you choose to participate with any other health care provider or patient in this hospital. Similarly, your decision will not affect your relationship with the Curtin University, staff or colleagues. If you want to stop the interview midway we will destroy any information (including the recording) of you may have shared with us till then.

Thank you very much for your time and participation in the interview. It is much appreciated.

Contact Information

You may contact me Ms. Kalyani Subbiah to obtain further information or answer questions or concerns regarding the research. My contact number is +91 98458 34947 and my email address is kalyani@postgrad.curtin.edu.au.

Or you may contact my associate supervisor Dr. Arima Mishra if you wish to speak to someone in Bangalore about the research either now or in the future. Her contact number is + 91 97403 80808 and email address is arima.mishra@apu.edu.in

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2017-0739). If you would like to have a confidential discussion or make a complaint to someone not associated with the study, you may contact the Ethics Officer on +61 8 9266 9223 or the Manager, Research Integrity on +61 8 9266 7093 or email hrec@curtin.edu.au

Appendix D. Participant information statement (Auxiliary & Support service)

HREC Project Number:	HRE2017-0739
Project Title:	Managing care in gynaecological cancers: Role of health communication in enabling women's hea choices in India
Chief Investigator:	Professor Jaya Dantas, Professor of International Health & Director of Graduate Studies, Faculty of Health Sciences
Student researcher:	Kalyani Subbiah
Version Number:	2.0
Version Date:	October 14, 2017

Study introduction: Hello! My name is Kalyani Subbiah and I am a PhD student at the Curtin University in Australia. I am conducting this study to better understand issues related to gynaecological cancers in India. Findings from this study will contribute to future research and programmes designed to reduce women's risk towards cancers and to improve women's health in India. The PhD research is funded by the Australian Government with some funding from Curtin University.

Reasons for speaking to you: We are speaking to you regarding this study because you provide care or support service in this hospital for gynaecological cancers. If you consent to participate in this study we will have a personal interview with you.

About the interview: This interview will be about 60–90 minutes and will take place here in the same hospital where you are providing care or support service. It will be done confidentially and in a quiet place so that no one can hear us. There will be no costs to you for participating in this project.

We will do an audio recording of the interview so that we do not miss anything you might share with us. The recording will not include any information about you such as your name or the name of this hospital. When we write down the interview too, we will not add such details about you. All your responses are valuable to us.

Benefits to participation: We hope the results of this research will help us to promote health for women who are currently at risk for cancers and those who may be at risk in the future.

Risks to participation: If you would like some clarification about a question or more information from us you can stop us any time. If you feel uncomfortable or upset about any of the questions or topics please do stop us any time and we will be happy to address your concerns. You do not need to answer any question you do not want to answer.

Your information: Your name or other identifying information about you will not be linked to the information you share with us in this study.

Research findings and information safety: Information collected in this study will always be kept in a secure cupboard and will be destroyed after 7 years. The results of this research will be presented at conferences or published in scientific journals. Your name will not be shared in any results.

Voluntary participation and withdrawal: Your participation in this study is completely your choice and is voluntary. You can decide to not answer any question or to withdraw from the study without giving us a reason. We will not share your decision about whether or not you choose to participate with any other health care provider or staff or patient in this hospital. Similarly, your decision will not affect your relationship with the Curtin University, staff or colleagues. If you want to stop the interview midway we will destroy any information (including the recording) of you may have shared with us till then.

Thank you very much for your time and participation in this interview. It is much appreciated.

Contact Information

You may contact me, Ms. Kalyani Subbiah to obtain further information or answer questions or concerns regarding the research. My contact number is +91 98458 34947 and my email address is kalyani@postgrad.curtin.edu.au.

Or you may contact my associate supervisor Dr. Arima Mishra if you wish to speak to someone in Bangalore about the research either now or in the future. Her contact number is + 91 97403 80808 and email address is arima.mishra@apu.edu.in

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2017-0739). If you would like to have a confidential discussion or make a complaint to someone not associated with the study, you may contact the Ethics Officer on +61 8 9266 9223 or the Manager, Research Integrity on +61 8 9266 7093 or email hrec@curtin.edu.au

Appendix E. Participant Information Statement (Community Health Workers)

HREC Project Number:	HRE2017-0739
Project Title:	Managing care in gynaecological cancers: Role of health communication in enabling women's hea choices in India
Chief Investigator:	Professor Jaya Dantas, Professor of International Health & Director of Graduate Studies, Faculty of Health Sciences
Student researcher:	Kalyani Subbiah
Version Number:	2.0
Version Date:	October 14, 2017

Study introduction: Hello! My name is Kalyani Subbiah and I am a PhD student at the Curtin University in Australia. I am conducting this study to better understand issues related to gynaecological cancers in India. Findings from this study are planned to contribute to future research and programmes designed to reduce women's risk towards cancers and to improve women's health in India. The PhD research is funded by the Australian Government with some funding from Curtin University.

Reasons for speaking to you: We are speaking to you regarding this study because you provide support as a community health worker for women seeking care in this hospital for gynaecological cancers. If you consent to participate in this study we will have a personal interview with you.

About the interview: This interview will be about 60 to 90 minutes and will take place here in the same hospital where you are providing care or support service. It will be done confidentially and in a quiet place so that no one can hear us. There will be no costs to you for participating in this project.

We will do an audio recording of the interview so that we do not miss anything you might share with us. The recording will not include any information about you such as your name or the name of this hospital. When we write down the interview too, we will not add such details about you. All your responses are valuable to us.

Benefits to participation: We hope the results of this research will help us to promote health for women who are currently at risk for cancers and those who may be at risk in the future.

Risks to participation: If you would like some clarification about a question or more information from us you can stop us any time. If you feel uncomfortable or upset about any of the questions or topics please do stop us any time and we will be happy to address your concerns. You do not need to answer any question you do not want to answer.

Your information: Your name or other identifying information about you will not be linked to the information you share with us in this study.

Research findings and information safety: Information collected in this study will always be kept in a secure cupboard and will be destroyed after 7 years. The results of this research will be presented at conferences or published in scientific journals. Your name will not be shared in any results.

Voluntary participation and withdrawal: Your participation in this study is completely your choice and is voluntary. You can decide to not answer any question or to withdraw from the study without giving us a reason. We will not share your decision about whether or not you choose to participate with any other health care provider or staff or patient in this hospital or the community. Similarly, your decision will not affect your relationship with the Curtin University, staff or colleagues. If you want to stop the interview midway we will destroy any information (including the recording) of you may have shared with us till then.

Thank you very much for your time and participation in the interview. It is much appreciated.

Contact Information

You may contact me Ms. Kalyani Subbiah to obtain further information or answer questions or concerns regarding the research. My contact number is +91 98458 34947 and my email address is kalyani@postgrad.curtin.edu.au.

Or you may contact my associate supervisor Dr. Arima Mishra if you wish to speak to someone in Bangalore about the research either now or in the future. Her contact number is + 91 97403 80808 and email address is arima.mishra@apu.edu.in

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2017-0739). If you would like to have a confidential discussion or make a complaint to someone not associated with the study, you may contact the Ethics Officer on +61 8 9266 9223 or the Manager, Research Integrity on +61 8 9266 7093 or email hrec@curtin.edu.au

Appendix F. Participant Information Statement (Ayahs)

HREC Project Number:	HRE2017-0739
Project Title:	Managing care in gynaecological cancers: Role of health communication in enabling women's hea choices in India
Chief Investigator:	Professor Jaya Dantas, Professor of International Health & Director of Graduate Studies, Faculty of Health Sciences
Student researcher:	Kalyani Subbiah
Version Number:	2.0
Version Date:	October 14, 2017

Study introduction: Hello! My name is Kalyani Subbiah and I am a PhD student at the Curtin University in Australia. I am conducting this study to better understand issues related to gynaecological cancers in India. Findings from this study will contribute to future research and programmes designed to reduce women's risk towards cancers and to improve women's health in India. The PhD research is funded by the Australian Government with some funding from Curtin University.

Reasons for speaking to you: We are speaking to you regarding this study because you provide support in this hospital for maintenance and care for women seeking care in this hospital for gynaecological cancers. If you consent to participate in this study we will have a personal interview with you.

About the interview: This interview will be about 60 to 90 minutes and will take place here in the same hospital where you are providing support service. It will be done confidentially and in a quiet place so that no one can hear us. There will be no costs to you for participating in this project.

We will do an audio recording of the interview so that we do not miss anything you might share with us. The recording will not include any information about you such as your name or the name of this hospital. When we write down the interview too, we will not add such details about you. All your responses are valuable to us.

Benefits to participation: We hope the results of this research will help us to promote health for women who are currently at risk for cancers and those who may be at risk in the future.

Risks to participation: If you would like some clarification about a question or more information from us you can stop us any time. If you feel uncomfortable or upset about any of the questions or topics please do stop us any time and we will be happy to address your concerns. You do not need to answer any question you do not want to answer.

Your information: Your name or other identifying information about you will not be linked to the information you share with us in this study.

Research findings and information safety: Information collected in this study will always be kept in a secure cupboard and will be destroyed after 7 years. The results of this research will be presented at conferences or published in scientific journals. Your name will not be shared in any results.

Voluntary participation and withdrawal: Your participation in this study is completely your choice and is voluntary. You can decide to not answer any question or to withdraw from the study without giving us a reason. We will not share your decision about whether or not you choose to participate with any other staff or patient in this hospital or the community. Similarly, your decision will not affect your relationship with the Curtin University, staff or colleagues. If you want to stop the interview midway we will destroy any information (including the recording) of you may have shared with us till then.

Thank you very much for your time and participation in the interview. It is much appreciated.

Contact Information

You can contact me, Ms. Kalyani Subbiah to obtain further information or answer questions or concerns regarding the research. My contact number is +91 98458 34947 and my email address is kalyani@postgrad.curtin.edu.au.

Or you may contact my associate supervisor Dr. Arima Mishra if you wish to speak to someone in Bangalore about the research either now or in the future. Her contact number is + 91 97403 80808 and email address is arima.mishra@apu.edu.in

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2017-0739). If you would like to have a confidential discussion or make a complaint to someone not associated with the study, you may contact the Ethics Officer on +61 8 9266 9223 or the Manager, Research Integrity on +61 8 9266 7093 or email hrec@curtin.edu.au

Appendix G. Participant Consent Form (Health Care Providers)

I………………………….. consent to participate in the study titled

Managing care in gynaecological cancers: Role of health communication in enabling women's health choices in India aka

Wellness and Empowerment with Communication (WE.com Project)

- The information sheet about the study has been given to me to read and the details in it explained.
- The purpose of this research is clear to me.
- I have understood the possible benefits and risks of my participation in it.
- I have thought about whether I want to participate in this research. I have had an opportunity to ask questions. I know that I can withdraw from this study any time I want to without any problem to me.
- I voluntarily consent to participate in this study.
- I understand that this project has been approved by Curtin University Human Research Ethics Committee.

☐ YES	☐ NO	consent to being audio-recorded

☐ YES	☐ NO	consent to be contacted about future research projects that are related to this project

Participant Name	
Participant Signature	
Date	

Appendix H. Participant Information Statement (Personal Caregivers)

HREC Project Number:	HRE2017-0739
Project Title:	Managing care in gynaecological cancers: Role of health communication in enabling women's hea choices in India
Chief Investigator:	Professor Jaya Dantas, Professor of International Health & Director of Graduate Studies, Faculty of Health Sciences
Student researcher:	Kalyani Subbiah
Version Number:	2.0
Version Date:	October 14, 2017

Study introduction: Hello! My name is Kalyani Subbiah and I am a PhD student at the Curtin University in Australia. I am conducting this study to better understand issues related to gynaecological cancers in India. Findings from this study will contribute to future research and programmes designed to reduce women's risk towards cancers and to improve women's health in India. The PhD research is funded by the Australian Government with some funding from Curtin University.

Reasons for speaking to you: We are speaking to you regarding this study because you are providing personal care to a woman seeking care in this hospital. If you consent to participate in this study we will have a personal interview with you.

About the interview: This interview will be 60 to 90 minutes and will take place here in the same hospital. It will be done confidentially and in a quiet place so that no one can hear us. There will be no costs to you for participating in this project.

We will do an audio recording of the interview so that we do not miss anything you might share with us. The recording will not include any information about you such as your name or the name of this hospital. When we write down the interview too, we will not add such details about you. All your responses are valuable to us.

Benefits to participation: We hope the results of this research will help us to promote health for women who are currently at risk for cancers and those who may be at risk in the future.

Risks to participation: If you would like some clarification about a question or more information from us you can stop us any time. If you feel uncomfortable or upset about any of the questions or topics please do stop us any time and we will be happy to address your concerns. You do not need to answer any question you do not want to answer. We will not share any of your responses with anyone in this hospital including the woman you are providing care to who introduced us to you.

Your information: Your name or other identifying information about you will not be linked to the information you share with us in this study.

Research findings and information safety: Information collected in this study will always be kept in a secure cupboard and will be destroyed after 7 years. The results of this research will be presented conferences or published in scientific journals. Your name will not be shared in any results.

Voluntary participation and withdrawal: Your participation in this study is completely your choice and is voluntary. You can decide to not answer any question or to withdraw from the study without giving us a reason. We will not share your decision about whether or not you choose to participate with any health care provider or patient in this hospital. Similarly, your decision will not affect your relationship with the Curtin University, staff or colleagues. If you want to stop the interview midway we will destroy any information (including the recording) of you may have shared with us till then.

Thank you very much for your time and participation in the interview. It is much appreciated.

Contact Information

You may contact me Ms. Kalyani Subbiah to obtain further information or answer questions or concerns regarding the research. My contact number is +91 98458 34947 and my email address is kalyani@postgrad.curtin.edu.au.

Or you may contact my associate supervisor Dr. Arima Mishra if you wish to speak to someone in Bangalore about the research either now or in the future. Her contact number is + 91 97403 80808 and email address is arima.mishra@apu.edu.in

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2017-0739). If you would like to have a confidential discussion or make a complaint to someone not associated with the study, you may contact the Ethics Officer on +61 8 9266 9223 or the Manager, Research Integrity on +61 8 9266 7093 or email hrec@curtin.edu.au

Appendix I. Participant Consent Form (Personal Caregivers)

I………………………….. consent to participate in the study titled

Managing care in gynaecological cancers: Role of health communication in enabling women's health choices in India aka
Wellness and Empowerment with Communication (WE.com Project)

- The information sheet about the study has been given to me to read and the details in it explained.
- The purpose of this research is clear to me.
- I have understood the possible benefits and risks of my participation in it.
- I have thought about whether I want to participate in this research. I have had an opportunity to ask questions. I know that I can withdraw from this study any time I want to without any problem to me.
- I voluntarily consent to participate in this study.
- I understand that this project has been approved by Curtin University Human Research Ethics Committee.

☐ YES	☐ NO	consent to being audio-recorded

☐ YES	☐ NO	consent to be contacted about future research projects that are related to this project

Participant Name	
Participant Signature	
Date	

- <u>Low and non-literate participants:</u> I have read to me in Kannada or Tamil, the information statement version listed above and I understand its contents.
- <u>Witness for low and non- literate participants:</u> I have witnessed the reading of the consent form, opportunity for the participant to ask questions. I confirm that the participant has voluntarily consented to participate.

Participant Thumbprint	

Witness Name	
Witness Signature	
Date	

Declaration by researcher: I have supplied the study information and consent form to the participant who has signed or placed her thumbprint above. I have also explained the possible risks and benefits of participation and believe that the participant has understood them.

Researcher Name	Kalyani Subbiah
Researcher Signature	
Date	

Appendix J. In-depth Interview Guide (Women)

PARTICIPANT CODE :
HEALTH FACILITY CODE :
DATE :
INTERVIEW START TIME :
INTERVIEW END TIME :
INTERVIEWER INITIALS :

As we discussed we will now start the interview which will take approximately an hour and a half of your time. Please feel free to stop me at any time if you would like to ask questions or have clarifications. If you need to stop for a few minutes at any time because you feel tired please feel free to let me know.

These responses will be kept confidential. Your responses will not be identified and they will not be shared with others in this facility.

We sincerely appreciate the time you are making for us. Can I start the recording?

Interviewer Instruction: Wait for the participant to say YES and then start recording.

Identification of disease

1. Guideline questions: Can you tell us a little about your family and home?
2. Can you talk about the time when you first started feeling unwell? What did you do about it?
3. Where there specific symptoms that you can remember?
4. Whom did you first talk to about it? What were their responses?
5. Can you discuss whether you discussed or tried to find out more about your symptoms before going to a doctor or hospital?

Treatment and facility decisions

1. Approximately how long was it from when you first felt unwell and when you decided to consult a doctor?
2. What are all the decisions you had to make before seeking treatment at this hospital?

Communication and treatment

1. Can you talk a little bit about your current health and treatment?

2. What kinds of information have been most helpful for you in your treatment?
3. Approximately how many times have you been visiting the hospital for treatment since you first began including admissions?
4. How far do you have to travel for your treatment? Do you live in the same city?
5. Does someone usually accompany you to the hospital for treatment?
6. Is there any information you understood incorrectly or was not clear to you in the course of your treatment? Can you speak about this?
7. Are there times when you miss your treatment or hospital appointments? What are the reasons for this?

INTERVIEWER INSTRUCTION*: Ask "Do you want to drink water or do you feel tired? Can we continue? Do feel free to stop me if you need to."*

Health impact

1. Can you talk a little about your family and friends and the type of support you receive from them during your illness?
2. Can you talk a little about treatment costs and managing family responsibilities at home?
3. Can you talk a little about managing other responsibilities outside home along with your health and treatment?

Self-efficacy and disease

1. Can you talk a little about how you feel currently about life, health and making decisions?
2. Can you talk about what you may like to change and what you may like to keep the same way?

Recommendations

1. Are there suggestions you have on information that can help women such as you who seek health care for cancer?
2. What are the most effective ways to provide this information to women?
3. Where or which places do you think such information can be given to women?
4. Who are the best people to give information to women?

These are all the questions that I have today. Do you have any questions for me? Please feel free to ask me. INTERVIEWER INSTRUCTION. Wait for the participant to ask questions and respond as needed. All your opinions and suggestions are important to us. Thank you very much for your time and support towards this research.

Appendix K. In-depth Interview Guide – Health care providers (Physicians)

PARTICIPANT CODE :

HEALTH FACILITY CODE :

DATE :

INTERVIEW START TIME :

INTERVIEW END TIME :

INTERVIEWER INITIALS :

As we discussed we will now start the interview which will take approximately an hour and a half of your time. As a reminder, please feel free to stop me at any time if you would like to ask questions or have clarifications.

We are most interested in all your responses, opinions and suggestions and there are no right or wrong answers in this discussion. These responses will be kept confidential. Your responses will not be identified and they will not be shared with any other staff in this facility.

Our aim is to better understand existing services for women in cancer care in India. We hope this research will do that and your responses are valuable towards that aim.

We sincerely appreciate the time you are making for us. Can I start the recording?

Interviewer Instruction: Wait for the participant to say YES and then start recording.

Work history and role

1. Can you tell me a little bit about your role and responsibilities in this hospital in providing care for women with cancer?
2. How long have you been in this role?
3. Approximately how many women with cancer do you provide care to on a monthly basis?
4. Of these how many are gynaecological cancers?

Experience with care provision

1. Can you talk a little about the problems in providing care for women with cancer?
2. How do you respond to them?
3. In your view what are the challenges women may have in seeking care for cancer?
4. What is the information they already have about health and what stage how they usually decide to seek care here? Do you see any typical pattern in treatment seeking?
5. Are there specific issues related to gynaecological cancers that need to be addressed differently in care provision compared to other cancers? What are they?
6. What are some of the important supports that you have in this hospital to provide care?
7. What are some of the challenges to providing care?

Communication and experience with other staff in facility

1. What are some of the most important aspects of communication between staff in a hospital like this?
2. What are the specific or special issues when providing women's cancer care? For example types of referral internally or follow-ups you may want done?
3. In addition to you who would be the key people in a hospital to give information to a woman and what type of information would that be?
4. In large health facilities with high patient numbers what are some of the challenges related to confidential information sharing and communication? How are these managed?

Communication with patients

1. How would you assess the patient provider relationship in women's cancer care?
2. What are some of the problems you have to manage or handle in talking to patients?
3. What are the thoughts or possibly incorrect information that women come to you with about their health condition?

4. What are some of the institutional guidelines available in this hospital for patients (example treatment guidelines, care facilities, referral support and networks, inter departmental and specialty related, administrative etc.) -
5. What are aspects related to treatment that they are worried or fearful about?
6. What are the guidelines or information that is given to women usually about sexual problems they may have due to their health?
7. What are the time constraints that you have for patient interaction along with your other busy treatment responsibilities?
8. Can you talk a little about the decision-making process for a woman seeking care for gynaecological cancer treatment? Her challenges and dilemmas…
9. What is the role of the family in treatment decisions?
10. In your experience how do costs influence treatment decisions in gynaecological cancers?
11. What are the rates of follow-up to treatment? Can you talk a little about treatment and patient's regularity with check-ups and follow-ups?
12. What are the typical referral and support services that women with gynaecological cancers need? Are the services provided here or elsewhere? Can you talk about these?
13. What is the preferred mode of communication with women? In addition to your one on one communication do you recommend they carry any written information such as pamphlets or brochures or watch any media material on their health condition?
14. Are there any ways in which you think this communication can be improved? What would support your work in this?

Communication with family and personal caregivers

1. In your experience which members of family and personal attendants usually accompany the patients?
2. What are your views on the challenges and benefits of communicating with personal caregivers?
3. What are the situations where the personal caregivers may pressure or coerce a woman to make a decision on treatment? Can you talk a little about this and how you handle such situations?

4. What are the support services in this city for personal caregivers and family members coping with cancer?

Recommendations

1. Are there suggestions you have on specific information that can help women better in seeking health care for cancer?
2. What is the best way to provide this information to women?
3. Is there anything that can be done better in existing services? If yes, what?
4. What in your view is the most important information women need to get about preventive measures such as screening?
5. How can we make them better available to women?
6. Where do you think such information can be given to women?
7. Who are the best people to talk and give information to women in addition to you?
8. What are the ways in which we can ensure that this is made available to them?

These are all the questions that I have today. Do you have any questions for me? Please feel free to ask me. INTERVIEWER INSTRUCTION. Wait for the participant to ask questions and respond as needed.

All your opinions and suggestions are important to us. Thank you very much for your time and support towards this research.

Appendix L. In-depth Interview Guide – Health Care Providers (Auxiliary & Support Staff)

PARTICIPANT CODE :

HEALTH FACILITY CODE :

DATE :

INTERVIEW START TIME :

INTERVIEW END TIME :

INTERVIEWER INITIALS :

As we discussed we will now start the interview which will take approximately an hour and a half of your time. As a reminder, please feel free to stop me at any time if you would like to ask questions or have clarifications.

We are most interested in all your responses, opinions and suggestions and there are no right or wrong answers in this discussion. These responses will be kept confidential. Your responses will not be identified and they will not be shared with any other staff in this facility.

Our aim is to better understand existing services for women in cancer care in India. We hope this research will do that and your responses are valuable towards that aim.

We sincerely appreciate the time you are making for us. Can I start the recording?

Interviewer Instruction: Wait for the participant to say YES and then start recording.

Work history and role

1 Can you tell me a little bit about your role in this hospital?
2 If you were define your routine day-to-day responsibilities what would they be?
3 How long have you been in this role?
4 Approximately how many women do you provide some form of care or support to in this hospital on a weekly basis?

Experience with care provision

1 In your work how often do you speak to patients who seek some kind of treatment or support for gynaecological problems?
2 At what stage of their visit do you typically get introduced to them?
3 Who introduces you to them?
4 In your opinion, what do you think women find most useful about talking to you?
5 In your view are there challenges during these discussions?
6 How do you manage them?
7 What are some of the important supports that you have in this hospital to provide care?
8 What are some of the challenges to providing the needed service?

Communication and experience with other staff in facility

1. How many people do you work with routinely in this hospital – for example is there a team or group within the specialty that you are a part of?
2. What are the aspects you enjoy most about team work in providing care?
3. Are there any special issues when providing women's cancer care? For example types of referral internally or follow-ups you may want done?
4. What are your thoughts about these interactions? What is most beneficial to women? What can be improved in your opinion?

Communication with patients

1. What do patients ask you about usually?
2. What are the myths or misconceptions, if any, you have to typically manage when talking to patients?
3. In such instances do you respond to them with the appropriate information or do you ask them to speak to someone else in the hospital?
4. What is the process of referral you follow? Can you talk a little about the different steps in it?
5. What are the typical referral and support services that women seeking treatment for gynaecological cancers need? Are the services provided here or elsewhere? Can you talk about these?

Communication with family and personal caregivers

1. Do most women come to the hospital by themselves or with someone?
2. Who are the people who typically accompany women to the hospital?
3. In your opinion, how critical is the role of the personal caregivers in treatment decisions?
4. In your opinion, how do costs influence women and their personal caregivers in coming to the hospital?
5. How often do personal caregivers interact with you? What are the subjects of these interactions?
6. Do such interactions usually happen in the patient's presence or separately?
7. Are there misconceptions and incorrect information that personal caregivers come to you with about their health condition? What are they and where do they get such information from?
8. Are there situations where the personal caregivers pressure or coerce a woman to take or not take treatment? Can you talk a little about this and how you handle such situations?

Recommendations

1. Are there suggestions you have on specific information that can help women better in seeking health care for gynaecological cancers?
2. What is the best way to provide this information to women?
3. What in your view is the most important information women need to get about services in the hospital or about their health?
4. How can we make them available to them better?
5. Where do you think such information can be given to women?
6. Who are the best people to talk and give information to women in addition to you?
7. What are the ways in which we can ensure that this is made available to them?

These are all the questions that I have today. Do you have any questions for me? Please feel free to ask me. INTERVIEWER INSTRUCTION. Wait for the participant to ask questions and respond as needed. All your opinions and suggestions are important to us. Thank you very much for your time and support towards this research.

Appendix M. In-depth Interview Guide – Health Care Providers (Community Health Workers)

PARTICIPANT CODE :

HEALTH FACILITY CODE :

DATE :

INTERVIEW START TIME :

INTERVIEW END TIME :

INTERVIEWER INITIALS :

As we discussed we will now start the interview which will take approximately an hour and a half of your time. As a reminder, please feel free to stop me at any time if you would like to ask questions or have clarifications.

We are most interested in all your responses, opinions and suggestions and there are no right or wrong answers in this discussion. These responses will be kept confidential. Your responses will not be identified and they will not be shared with any other staff in this facility.

Our aim is to better understand existing services for women in cancer care in India. We hope this research will do that and your responses are valuable towards that aim.

We sincerely appreciate the time you are making for us. Can I start the recording?

Interviewer Instruction: Wait for the participant to say YES and then start recording.

Work history and role

1. Can you tell me a little bit about your role in this hospital?
2. If you were define your routine day-to-day responsibilities what would they be?

3. How long have you been in this role?
4. How frequently do you interact with women who come to seek care in this hospital?
5. In a week, approximately how many women do you provide some form of support in the community to encourage visits to the hospital or to seek care?
6. Of these will you be able to estimate how many are for gynaecological cancers?

Experience with care provision

1. In your work how often do you speak to women or families who seek some kind of treatment for gynaecological cancer?
2. Where in the community do you usually interact with them?
3. In your opinion, what do you think women find most useful about these interactions?
4. In your view are there any problems women face in these interactions? How do you manage them?
5. What are the health needs women usually speak to you about?
6. Are there specific issues they usually discuss or ask about when they first meet you? What are they?
7. Are there any problems related to confidentiality when you speak to women in their community? If yes, how do you manage them?
8. What are some of the important supports to your work?
9. Can you discuss if there are problems in doing your work in the community?

Communication and experience with other staff in facility

1. On a routine day how often do you need to either coordinate or work with other staff in the hospital?
2. How many people do you work with routinely in this hospital – for example is there a team or group within the specialty that you are a part of for information giving, follow-up etc?
3. What are the challenges of community work and cancer care information?
4. What are the follow-ups in your work that you are able to manage better with the help of your colleagues in the hospital?

Communication with patients

1. What are some of the doubts or misconceptions women talk to you about in your work?
2. How often do women come to you directly with problems and how often do you need to refer them to someone else?
3. Usually what steps do you follow to encourage women to access services and follow-up in the hospital?
4. How do you manage confidentiality and privacy issues in the community?
5. What are the specific or special issues when providing information on women's cancer care?
6. What are your thoughts about these interactions? What is most beneficial to women? What can be improved in your opinion?

Communication with family and personal caregivers

1. How often do personal caregivers interact with you? What do they usually talk about?
2. Do such interactions usually happen in the patient's presence or separately in the community?
3. Can you talk a little about the role of family in a woman's decision to visit the hospital or take treatment?
4. Are there any support services in this city for personal caregivers and family members coping with cancer? What are some of the challenges they face in your view?

Recommendations

1. Are there suggestions you have on specific information that can help women better in seeking health care for gynaecological cancers?
2. What is the best way to provide this information to women?
3. How can we become information for women more easily available in communities?
4. Where do you think such information can be given to women?
5. Who are the best people to talk and give information to women in addition to you?

These are all the questions that I have today. Do you have any questions for me? Please feel free to ask me. INTERVIEWER INSTRUCTION. Wait for the participant to ask questions and respond as needed.

All your opinions and suggestions are important to us. Thank you very much for your time and support towards this research.

Appendix N. In-depth Interview Guide – Health Care Providers (Ayahs)

PARTICIPANT CODE :

HEALTH FACILITY CODE :

DATE :

INTERVIEW START TIME :

INTERVIEW END TIME :

INTERVIEWER INITIALS :

As we discussed we will now start the interview which will take approximately an hour and a half of your time. As a reminder, please feel free to stop me at any time if you would like to ask questions or have clarifications.

We are most interested in all your responses, opinions and suggestions and there are no right or wrong answers in this discussion. These responses will be kept confidential. Your responses will not be identified and they will not be shared with any other staff in this facility.

Our aim is to better understand existing services for women in cancer care in India. We hope this research will do that and your responses are valuable towards that aim.

We sincerely appreciate the time you are making for us. Can I start the recording?

Interviewer Instruction: Wait for the participant to say YES and then start recording.

Work history and role

1. Can you tell me a little bit about your role in this hospital?
2. If you were define your routine day-to-day responsibilities what would they be?
3. How long have you been in this role?

4. In your work how frequently do you interact with women seeking care in this hospital?

Experience with care provision

1. In your work do you know how often do you speak to women or families who seek some kind of treatment for gynaecological problems?
2. What are these interactions usually about?
3. Do families speak to you about anything routinely? What are such interactions about?

Communication and experience with other staff in facility

1. On a routine day how often do you need to either coordinate or work with other staff in the hospital? What is the nature of that work?
2. How often do you have to work alone and what are those responsibilities?
3. Who are the people you work with routinely in this hospital – for example is there a team or group within the specialty that you are a part of?
4. What are the important supports you have in your work?
5. Are there any challenges in your work?
6. How do you manage these situations?

Communication with patients

1. Do you usually know when a woman is seeking treatment for gynaecological cancers?
2. In your view are there any problems you have to typically manage when talking to such patients?
3. Can you talk a little about what women talk to you about?
4. Are there problems they discuss related to their health condition?
5. How do you respond to them when they share such problems?

Communication with family and personal caregivers

1. Do most women come to the hospital by themselves or with someone?
2. Who are the people who typically accompany women to the hospital?

3. How often do personal caregivers interact with you? What do they usually discuss?
4. Are there times when you may not know how to respond to their questions? How do you manage these?
5. Do family interactions usually happen in the patient's presence or separately?
6. Do you have thoughts or suggestions on how health services can better serve women with cancer?

Recommendations

1. Are there suggestions you have on specific information or service that can help women better in seeking health care for gynaecological cancers?
2. Is there anything that can be done better in existing services in this hospital or other hospitals? If yes, what?
3. Are women receiving important information easily? How can we make them available to them better?
4. Who are the best people to talk and give information to women in addition to you?

These are all the questions that I have today. Do you have any questions for me? Please feel free to ask me. INTERVIEWER INSTRUCTION. Wait for the participant to ask questions and respond as needed.

All your opinions and suggestions are important to us. Thank you very much for your time and support towards this research.

Appendix O. In-depth Interview Guide – Personal Caregivers

PARTICIPANT CODE :
HEALTH HOSPITAL CODE:
DATE :
INTERVIEW START TIME :
INTERVIEW END TIME :
INTERVIEWER INITIALS :

As we discussed we will now start the interview which will take approximately an hour and a half of your time. As a reminder, please feel free to stop me at any time if you would like to ask questions or have clarifications.

We are most interested in all your responses, opinions and suggestions and there are no right or wrong answers in this discussion. These responses will be kept confidential. Our aim is to better understand existing services for women in cancer care in India. We hope this research will do that and your responses are valuable towards that aim.

We sincerely appreciate the time you are making for us. Can I start the recording?

Interviewer Instruction: Wait for the participant to say YES and then start recording.

Responsibilities in caregiving

Guideline questions: Currently, do you live in the same home with XXXX (use the role such as sister, wife, friend etc.) you have accompanied to this hospital? If no, how far away from her do you live?

1. When did you first get to know that she was unwell?
2. Were there specific symptoms that you can remember that she discussed with you?
3. Are there people or support services you contacted to find out more about her condition? If yes, who were they?
4. How did you hear about this hospital?

INTERVIEWER INSTRUCTION: If participant is not the husband of participant ask,

1. How often do you get to meet XXX?
2. What are the ways in which you have had to support her since she has been unwell?

Norms in caregiving

1. In your view what are some responsibilities you have after she became unwell?
2. How often are you able to accompany her to the hospital or seeing the doctor?
3. Can you discuss how you manage other responsibilities so that you have time to provide care to her? Example your work…
4. Can you discuss if there are challenges you face since XXX has been unwell?
5. How do you manage them?

Communication and experience in hospital

1. Please discuss your experiences as a family member/personal caregiver *(change address according role person has to XXX)* when you first visited the hospital.
2. How many people have you interacted with in this hospital during the treatment and follow-up? Who are they?
3. Can you discuss if there was any information was not clear to you about XXX's treatment?
4. As a personal caregiver do you think that your XXX is getting the best treatment and service possible in your opinion? Can you discuss this in a little detail?
5. How can such services be improved even more?
6. Can you talk about the services you find most beneficial about this hospital?
7. Can you discuss if there are any challenges to seeking treatment in this hospital?

Communication with patient

1. How often do you talk to XXX about her health condition?
2. What are some of the issues related to her treatment and health that she is able to discuss openly with you?
3. In your view are there issues about her health that she is not able to discuss?
4. Can you discuss her illness or treatment with anyone who supports you? Can

you please talk about what kinds of support you get from them?

5. Can you discuss any other help or support from others to help manage her illness?

Other information sources

1. What did you know about gynaecological cancer before XXX was started seeking care here?
2. Whom or where did you get or hear this information from?

Recommendations

1. Is there any support that will be helpful for you or others like you who take care of women who seek treatment for cancer?
2. How can we make such information available and accessible?

These are all the questions that I have today. Do you have any questions for me? Please feel free to ask me. INTERVIEWER INSTRUCTION. Wait for the participant to ask questions and respond as needed.

All your opinions and suggestions are important to us. Thank you very much for your time and support towards this research.