Baseline Assessment for Mental Health Needs among Women Facing Cancer, Their Families and Healthcare Providers in Uganda

Final Report, September 2023

conducted with support from VOICE

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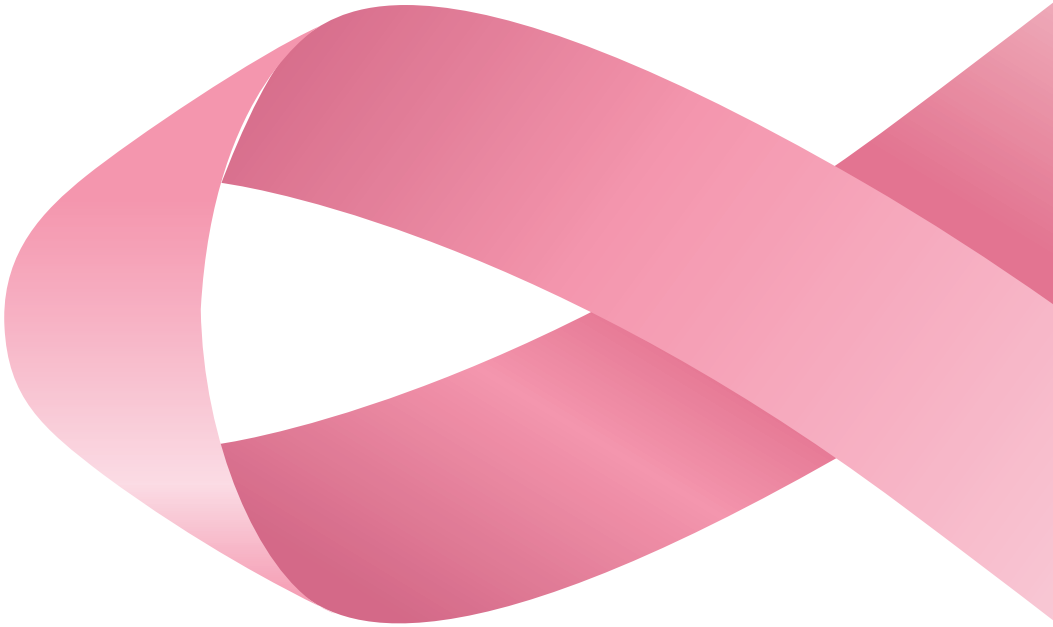
I. ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
BUHOPE	Buwaya Hope Project
GLOBOCAN	Global Cancer Observatory
HIV	Human Immunodeficiency Virus
IHME	Institute of Health Metrics and Evaluation
KI	Key Informant
UCI	Uganda Cancer Institute
UWOCASO	Uganda Women Cancer Survivors Organization
WHO	World Health Organization



II. ACKNOWLEDGMENT

Ayinza Consults was contracted by Uganda Women's Cancer Survivors Organization (UWOCASO) to conduct a Baseline Needs Assessment on mental health challenges among women facing cancer, their families and health care providers. Ayinza would like to acknowledge the support provided by all stakeholders who were involved in this Needs
Assessment. We are grateful to all the key informants and respondents who spared their valuable time and provided information for the Assessment.

Our appreciation goes to UWOCASO leadership, staff and partners including Uganda Cancer Institute for providing not only the necessary resources and guidance for the baseline but also their participation during the interviews. Special thanks go to the women cancer survivors and their care givers for their availability during the consultative meetings for the assessment; providing and sharing invaluable insights, experiences and perspectives, without which this baseline would not have been possible.

Special gratitude goes to the consulting team for the tireless effort put in to undertake the Needs Assessment. We believe this report will go a long way in guiding various stakeholders to initiate, improve and/or scale up interventions aimed at addressing the mental health challenges among women facing cancer, their families and care providers.

III. SUMMARY

By 2040 it is estimated that the 5-year prevalence of all cancers will become 50.5 million people across the globe. The Uganda Cancer Institute estimates that 33,000 Ugandans are diagnosed with cancer every year. In terms incidence, cervical cancer presents one of the highest incidences, with over 20.5% of new cases reported in 2020; projected to increase to 66.1 per 100,000 population by 2030. Among women, new cases of cervical and breast cancer in 2020 stood at 35.7% and 13.5% respectively. Cancer is a chronic illness and the profound psychological impact of a cancer diagnosis and the accompanying treatments often cause severe long-term physical sequelae, suffering and affect one's mental health.

UWOCASO commissioned a Needs Assessment to create visibility of mental health needs and challenges among women cancer patients, survivors, their families and healthcare providers; with an objective of positioning mental health as central in their lives. Specifically, the assessment sought to ascertain mental health challenges and causes among women cancer patients and /or survivors, families and health care providers; to identify the copying techniques currently used to solve mental health challenges and to provide recommendations to alleviate the mental health challenges identified.

The Needs Assessment was largely qualitative and information was obtained through interviews and consultative meetings with key informants; that is, people with specialized knowledge including professionals working in care cancer and treatment in Uganda; but also, with women cancer survivors and their care givers; who shared their lived experiences. The KIs were identified through purposive, snowball sampling and on judgement basis, that is selecting respondents most appropriate for the assessment.

Findings of the assessment revealed that participants had knowledge of mental health challenges and could point to some of the symptoms faced including having why me thoughts and their inability to concentrate. Anxiety and Depression were pointed out as the most common mental health challenges faced triggered by diagnostic, treatment, social support issues, stigma, beliefs and society related factors. In terms of copying mechanisms, participants pointed out prayer and spirituality; seeking support from individuals, support groups and peer groups; self-education regarding cancer; selling personal property and borrowing money to meet care related expenses; and maintaining direct contact with their doctors for real time support. Some survivors reported becoming advocates for their own rights as survivors and for others facing similar challenges in a way that built their confidence and ability to cope with their own mental health challenges.

The Assessment established that the Mental Health needs of women cancer survivors are multi-faceted and require comprehensive support. Participants reported the need for social support; financial, psychoeducation and information needs; and the requirement for uninterrupted, continued treatment, care and rehabilitation. More importantly, the need for professional mental health care, treatment and therapy during their treatment and in the survivorship period was raised as a critical need particularly as such services are largely lacking at different levels.

Based on the findings of the assessment, key recommendations with potential to address the mental health challenges faced by women facing cancer and their families are made. Prioritization and increased budgetary allocation towards mental health to ensure staffing and training on mental health of professionals specializing in cancer care; ensuring effective integration of mental health in cancer care for women through development of an integrated psych oncology model focusing on a holistic approach; undertaking a robust targeted awareness and public education campaign about cancer and its impact on mental health; providing more support to civil society organisations to undertake cancer support and psychoeducation interventions for women cancer survivors; and guaranteeing increased access to cancer medication/treatment for women are major recommendations.

IV. INTRODUCTION

This report presents findings of a Baseline Needs Assessment commissioned by Uganda Women's Cancer Survivors Organization (UWOCASO) to create visibility of mental health needs and challenges among cancer patients, survivors, their families and healthcare providers. This assessment aimed to identify gaps and challenges in mental health services and to guide future interventions focused on improving the mental well-being of this population.

Following the acknowledgement, summary and this introductory section, the overall structure of the report takes the form of five sections including the broader context; the background and rationale for the needs assessment as the fifth and sixth sections respectively. The seventh section is concerned with the methodology for this assessment. Section eight of the report presents the findings of the assessment with a focus on five key sub sections as follows: the cancer experience; knowledge and recognition of mental health challenges; attributions of mental health challenges; copying mechanisms; mental health needs; and efforts to integrate mental health care. Drawing upon the entire assessment, the report concludes with key recommendations section.

V. CONTEXT

1.1 Cancer in Uganda

Worldwide rates of cancer occurrence continue to rise to the extent at by 2040, the 5-year prevalence of all cancers is estimated to become 50.5 million people across the globe (Sung, et al 2021)[i] . Recent statistics indicate that there were an estimated 18.1 million cancer cases around the world in 2020; of which 8.8 million were in women[ii] .

In Uganda, cancer has increasingly become an important health problem; contributing to the health burden in the country both socially and economically yet reports of rapid increase in its annual incidence abound. The Uganda Cancer Institute estimates that 33,000 Ugandans are diagnosed with cancer every year (UCI).[iii]

According to The Global Cancer Observatory, there were 34,008 new cancer cases[iv] in Uganda in 2020. The most common types of cancer are: cancer of the cervix, cancer of the breast, cancer of the prostate, Kaposi's sarcoma, cancer of the ovary, cancer of the colon and cancer of the liver[v] .

In terms incidence, cervical cancer presents one of the highest incidences, with over 20.5% of new cases reported in 2020 (WHO 2021)[vi] i.e. 52.6 per 100,000 population and this is projected to increase to 66.1 per 100,000 population by 2030 (Asasira, et al 2021)[vii]. Breast cancer at 7.8%; Kaposi sarcoma 11.3%; Prostate 7%; Non-Hodgkin lymphoma at 6.9%. Among the women, new cases of cervical and breast cancer in 2020 stood at 35.7% and 13.5% respectively.

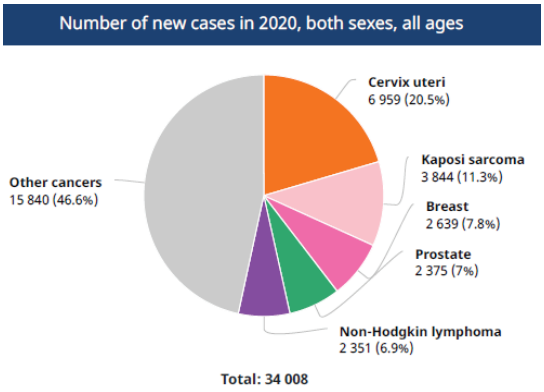


Figure 1: Number of new cancer cases in Uganda in 2020 (Source: Globocan 2020)

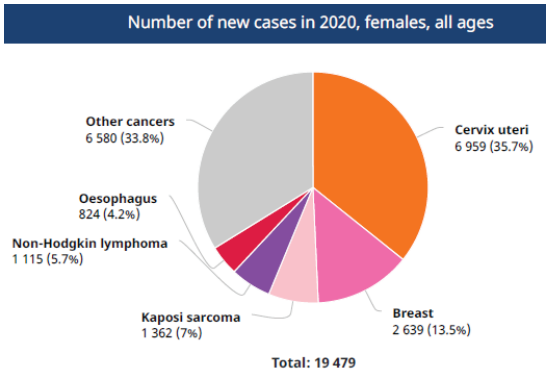


Figure 2 Number of new female cancer cases in Uganda in 2020 (Source Globocan 2020)

1.2.
Mental Health in Uganda

At the same time, mental health continues to be a public health challenge in Uganda. The World Health Organization defines mental health as: ***"..a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community."*** At the opening of mental health month in May, 2022, Ministry of Health in Uganda and Uganda Counselling Association revealed that about 14 million people of the 43.7 million population have a mental illness and these, according to experts are people who reported to health facilities. A 2022 review of 24 prevalence studies in Uganda found that 24.2% of adults were suffering with a mental illness (Opio et al., 2022).[viii] Depression and anxiety were the top two most common mental health conditions, with approximately one in four Ugandans being affected by these mental health conditions.

1.3.
Cancer and Mental Health

Psychological disorders are strong predictors of the development of communicable and non-communicable diseases (Prince et al., 2007; Sweetland et al., 2014).[ix] Risk factors associated with high prevalence of mental disorders include high HIV and malaria prevalence rates, community history of war and political violence, the increased burden of non-communicable chronic diseases including cancer (Dalal et al., 2011)[x] , and poor/under-resourced healthcare systems (Kaggwa et al., 2022)[xi] . Conversely, individuals with physical health conditions - especially chronic illnesses such as cancer - are at an increased risk of developing a mental disorder (Patel & Kleinman, 2003; Menil et al., 2012).

Left untreated, mental disorder can negatively impact physical health mainly through negative health-related behaviours (Sweetland et al., 2014)[xii] . Both physical and mental health interacts in a bidirectional manner where the aggravation of one type of condition can deeply impact the other. Cancer is a chronic illness that leads to profound and long lasting physical, social, emotional, and spiritual changes in those diagnosed with it (Kim, et al. 2015)[xiii] .

A cancer diagnosis may have a profound psychological impact and cancer treatments often cause long term physical sequelae, potentially one's mental health. Many women find the diagnosis a traumatic experience (Lee V. 2008)[xiv] , and the usual reactions include anxiety, hopelessness, anger and negative and suicidal thoughts (Schubart, et al.2014)[xv] . Some of the treatments can also cause severe long-term suffering. For example, in the case of breast cancer, surgery usually results in a lifelong scar and may cause breast shape alteration and persistent pain. The diagnosis and treatment of the breast cancer might also affect the woman's family, including intimacy with their partners (Kim, et al. 2008)[xvi] and relationships with their children. Moreover, women who return to work may also face new challenges, not only in the relationship with their work colleagues but also in their cognitive functioning (Carlsen, et al. 2009).[xvii] Women must also deal with the fear of cancer recurrence and death (Koch-Gallenkamp, et al. 2016)[xviii] . At the same time this situation is often exacerbated by various forms of exploitation these women face such as violence and abuse within intimate relationships or families; financial exploitation where their limited financial resources are taken advantage of by others.

These certainly have significant consequences on their mental health.

Recent advances in cancer treatment has led to increased survival rates among cancer patients yet less effort has been placed on psychological and mental health aspects of care for cancer patients/survivors and care givers. Therefore, an understanding of the mental health challenges and needs of women facing cancer, their families in Uganda is crucial to facilitate and inform powerful interventions at all levels for directing deliberate effort, strategies and solutions towards integration of mental health services into routine cancer care.

VI. BACKGROUND AND RATIONALE FOR THE NEEDS ASSESSMENT

Uganda Women's Cancer Support Organization (UWOCASO) is a membership organization founded by breast cancer survivors. The organization is undertaking its independent mandate to mobilize cancer survivors to help women and their families cope with the challenges of cancer treatment; empower communities with information about risk factors and causes of cancer; benefits of screening and early detection and importance of adherence to the full course of treatment prescribed for the disease. Through a partnership, UWOCASO and Buwaya Hope Project (BUHOP) are piloting "Mentally Cancer free & Thriving" intervention in Wakiso District with an objective of positioning mental health as central in the lives of women cancer patients, survivors and their families whose mental health is grossly affected by the lack of basic needs such as food, transport to health facilities, free cancer treatment and support from spouses and family during cancer treatment and survivorship. UWOCASO is cognizant of the fact that interventions will only achieve that much without attention to the mental state of their beneficiaries. It is against this background that the organization sought to undertake a baseline needs assessment of mental health challenges and needs for women facing cancer and their families.

1.1
Purpose and Objective

The purpose of this baseline needs assessment is to gather information on the current state of mental health support for women with cancer their families and health care providers in Uganda. The assessment aims to identify gaps and challenges in mental health services and to guide future interventions focused on improving the mental well-being of this population. The central objective of the needs assessment is ***to create visibility of mental health needs and challenges among cancer patients, survivors, their families and healthcare providers*** whilst supporting coordination and scaling up advocacy for integration of mental health services into routine cancer care. Specifically, the assessment was guided by the following objectives:

(i) To ascertain mental health challenges and causes among women cancer patients and /or survivors, families and health care providers;
(ii) To identify the copying techniques currently used to solve mental health challenges and
(iii) To propose solutions to alleviate the mental health challenges identified

VII. METHODOLOGY

The Needs Assessment was qualitative in nature with information obtained through interviews with people specialized knowledge including professionals working in the cancer treatment and care field in Uganda; who together with women cancer survivors and their care givers constituted the key informants for the assessment. Key Informants (KIs) were identified to provide expert insights on mental health challenges. They were identified through purposive, snowball sampling and on judgement basis, that is selecting respondents most appropriate (Fetterman 2010)[xix] for the assessment. The KIs were purposively selected based on among others; their experience in implementing cancer programmes and involvement in mental health.

Table 1: Category and number of Key Informants Interviews with KIs were conducted using an interview guide and the questions explored areas of particular relevance to the needs assessment including: general experience with cancer; mental health challenges; perceptions of their causality; copying mechanisms; mental health needs and recommendations. The interview guide was open ended to allow for KIs to provide detailed personal insight and share without any restrictions but guided to keep focus on the issues under discussion. The guide enabled prompting and probing for clarification of issues and allowed KIs to freely share their experiences and perspectives which the needs assessment sought to explore. Prior to the interviews, the KIs were briefed on the purpose and objectives of the assessment and the potential use of the findings. Consultative meetings were also conducted particularly with women cancer survivors

Group	Number
Women cancer patients/survivors	19
Family Care Givers	20
Oncologists	4
Psycho Oncologist	2
Mental Health Experts	2
Psychiatrists	5
Mental Health Advocates	2
Counsellors Psychotherapist	3
Nurses	3
Clinicians	2

Table 1: Category and number of Key Informants

and their care givers. the meetings consisted of open-ended questions and discussions exploring perspectives on cancer in women, knowledge about mental health, causal attributions and copying mechanisms.

Interviews and consultative meetings took no longer than 30 minutes and half day respectively and were conducted from 25th August to 1st September 2023. A total of 60 key informants were reached for the Needs assessment and these included women cancer patients/-survivors; psychiatrists; psych-oncologists; mental health experts; mental health advocates; oncologists among others (see Table 1). These were identified from different organisations including Uganda Cancer Institute (UCI), Uganda Cancer Society, Butabika Hospital, Hospice Africa Uganda, Cancer Charity Foundation, UWOCASO, Nsambya Hospital and Cancer Aid Organisation. Email, telephone calls, and WhatsApp messaging were used to reach the KIs. Through its network, UWOCASO identified women cancer patients and survivors who were requested to participate together with their care givers. UWOCASO obtained informed consent from this group before any interviews and consultative meetings were held. The identified care givers and survivors were met separately. While the survivors collectively participated in the consultative meetings; the lead consultant and her assistant also had a one on one interview with each survivor to follow up on the discussions in the meetings. The assessment did not take into account specific demographics of the KIs but the inclusion criteria included being women cancer survivor; and either involved in the care and treatment of women with cancer/survivors.

Utilizing the hermeneutic qualitative approach, the lived experiences of cancer survivors and their care givers were assessed (Richards & Morse, 2007)[xx] . The primary objective aimed at understanding how mental health had affected their lives and contributed to psychological distress. More importantly, comparative, content and thematic review and analysis of literature was undertaken to assess existing knowledge on mental health challenges and causes among women cancer patients and /or survivors, families and health care providers; and the copying techniques currently used to solve mental health challenges.

VIII. FINDINGS

a. The Cancer Experience: From Diagnosis; Treatment and Post Treatment

There is real potential of creating effective interventions including systems of support from an understanding of the lived experiences of people affected by cancer (WHO)[xxi] . The needs assessment sought to understand the broad and general perspectives of patient/survivors, caregiver/family and the health care providers in regard to cancer; drawing on their
relevant experiences. For the patients/survivors and their care givers, ***"going through cancer is a devastating experience". "Cancer is a long journey from diagnosis stage to even after cancer as a survivor. "It is an expensive illness. "You learn the importance or not of your family members and friends. "You can never be the same with cancer, I continue to worry and fear"***. Many participants in this needs assessment reported suffering cancer as ***"traumatic experience"*** that triggers a broad and profound effect on the health and wellbeing of everyone involved. Comparing the illness to other chronic diseases some survivors and care givers preferred to ***"suffer with HIV/AIDS than cancer"***. Care givers reported that for one to play the role of care take for a cancer patient they ***"have to be a strong person"*** - in the sense that they endure a lot during the long journey of care including ***"exhaustion"*** as they are usually the ***"only care giver"*** or the ***"preferred"*** one by the patient. It was observed during the assessment that most care givers started playing the caring role for patients at a young age. Out of the 20 care givers that participated in this needs assessment 11 i.e. 55% were between 19 to 25 years of age; and each had provided care to their relative for over 10 years. The youngest care giver at the time of the assessment was 19 years and she recalled having started caring for her mother at 8 years. ***"I was in primary school at that time and I was the only one to care for her..... issues of handling vomiting, changing the catheter and more were too much for me as a young care giver"***. The care takers also reported that even at a later stage in survivorship, caring continues. Wondering whether it is the side effect of treatment or advancement in age of their loved one; they reported that the issue of ***"forgetfulness"***

among survivors demands that ***"one is alert and always available to support and remind" the patient. On the other hand, while health care workers also reported that the experience of cancer among their patients is "often distressing for them"***; they mentioned that ***"this perhaps is due to many factors including limited knowledge of the disease"*** and the fact that ***"indeed some cancers are curable".***

b. Knowledge and Recognition of Mental Health Challenges

The assessment set out to establish whether participants had knowledge, awareness and recognition of mental health challenges. Mental health in cancer survivors is defined by the presence or absence of distress as well as the presence or absence of positive well-being and psychological growth (Andrykowski, et al., 2012)[xxii] . The assessment found that all the participants had knowledge and would recognize mental health problems. They reported a number of mental health challenges including anxiety, severe stress (both emotional and financial stress), depression and stigma. All cancer survivors could relate to these challenges in their cancer journey. In terms of recognizing mental health symptoms participants reported "inability to concentrate", making of ***"irrational decisions", having "why me thoughts", "suicidal thoughts",*** feelings of fear, anger and wanting to be alone; being ***"too sensitive to what people say"; "denial";*** attribution of illness to ***"witchcraft"*** by people from their work places and families including ***"from the other wives of the husband"***; as some of the symptoms. It is worth noting that some mental health symptoms may overlap with symptoms related to cancer or side effects from treatment including appetite, weight loss and sleep changes as well as changes in concentration and motivation. (Allison 2021)[xxiii]

i. Most common mental health challenges identified

For any patient, a cancer diagnosis can be overwhelming with profound psychological impact. Many women find the diagnosis a traumatic experience (Lee 2008)[xxiv] , and the usual reactions include anxiety, hopelessness, anger and negative and suicidal thoughts (Schubart, et al. 2014)[xxv] . This assessment sought to ascertain the most common mental health challenges:

Anxiety

was reported as one of the most common mental health challenges among women facing cancer. Anxiety is a disorder that causes feelings of worry, tension and intrusive thoughts (GU 2021)[xxvi] . The cancer survivors testified that in their journey, "anxiety started right at the stage of diagnosis and went through the treatment." They reported having "uncontrolled restlessness, anger and outbursts; trembling and shaking among others". Anxiety was also singled out as common by health care providers: "In my experience…. anxiety is most common among women with cancer"- Oncologist, UCI. In 2019, 301 million people globally were living with an anxiety disorder (IHM 2020).[xxvii] In 2017, Uganda ranked high in Africa in rates to anxiety disorders at 2.8%(WHO 2017).[xxviii]

Depression

was also reported as most common among women with cancer and survivors. It is a mental health disorder characterized by extreme sadness, feelings of emptiness, and/or irritable mood, accompanied by somatic and cognitive changes that significantly affect the individual's capacity to function (American Psychiatric Association 2013)[xxix]. Cancer survivors and their care takers in this study reported experiencing feelings of sadness, loss of interest in activities they once enjoyed, and in some cases, had thought of suicide during their cancer journey. Globally, nearly 280 million people are affected by depression with profound effect on their lives including compromised relationships with family and friends and decreased ability to engage in the community (WHO 2021)[xxx]. While Africa alone had 29.19 million cases of depression; that is 9% of the global burden (WHO 2017)[xxxi], the general population prevalence in Uganda was reported to be 4.6% (WHO 2017)[xxxii]. . It should be noted that while there are many factors that cause depression and hence the statistics, the specific statistics of depression due to cancer need further study.

This baseline established that anxiety and depression are the two very real and common consequences of a cancer diagnosis. This finding tallies with results of different studies in which depression and anxiety were reported as the most common mental health problems (Prince, et al. 2007)[xxxiii]. Data from such studies show that the prevalence of depression and anxiety among cancer patients is up to 20% and 10% respectively, regardless of the treatment phase or point in the disease trajectory. (Pitman et al 2018)[xxxiv] Some studies have also found that female cancer patients may be more susceptible to anxiety and depression (Arvanitou, et al. 2023; Wen, et al. 2019)[xxxv,xxxvi], during their cancer journey. At the family/care taker level; care taker participants reported experiencing high levels of burden. Mental health challenges in this group relate to both the activity of care and the impact caring has on their own health (Northouse, et al. 2012; Stenberg et al 2010)[xxxvii,xxxviii],

c. Casual attributions of Mental Health Challenges

The assessment established that causes of mental health challenges among women facing cancer and their care givers were to a greater extent due to diagnostic, treatment, social support, stigma and society related factors:

The Diagnosis: Beyond the burden of living with cancer and its treatments, receiving a cancer diagnosis can be a severely stressful event (Zhu, et al. 2017). [xxxix] The diagnosis may have a profound psychological impact on the patient's mental health. An excessive psychological reaction may itself lead to psychiatric disorders (Mitchell, et al. 2011).[xl] Many women find the diagnosis a traumatic experience. Participants reported an overwhelming trauma and emotional impact on receiving a positive cancer result and for some, the way this information was communicated by the doctors only worsened the situation. It was reported that both survivors and care givers had to put up with a certain portion of the trauma at the of the news of a cancer diagnosis. Beyond the initial diagnosis news, participants reported having developed anxiety and fear for subsequent diagnostic procedures. Care takers also reported of denial among survivors as a major problem. They reported that in the initial stages, women facing cancer suffer mental health challenges as a result of denial. Below are some excerpts from the participants to demonstrate the impact:

"Imagine I was in the taxi when the doctor called me and informed me of the results, I just shut down" - Survivor.

"My sister had been in denial yet she knew she had cancer and kept quiet. She even separated from her husband without reason which threw the entire family in total confusion. As a family we indeed almost forced her to go for a checkup. When the results came out positive, she was extremely resentful, angry and annoyed with all of us – Care giver"

"When my mother was told she had cancer, she came home told me about it, she was unsettled and even showed me her photo portrait that we shall use at her funeral" – Care giver.

"I got a call from UCI that "there was an emergency", I could hear a lady crying, wailing loudly in the background. The doctor told me to hurry as the situation was going out of hand..... but the issue was that the lady had just found out that her husband had stealthily left and abandoned her in hospital and went back to Kabale, following the diagnosis – Counsellor

Treatment: A cancer diagnosis is often accompanied by swift and aggressive treatment and it is all but expected that a person will be overwhelmed, worried, fearful and anxious while doctors focus on their medical well-being. Some of the treatments including chemotherapy or radiotherapy and their side effects cause severe long-term suffering potentially affecting one's mental health. In the case of breast cancer for example, breast removal/surgery "was extremely traumatic and the stigma around it". The surgery usually results in a lifelong scar and may cause breast shape alteration and persistent pain. The diagnosis and treatment of the breast cancer might also affect the woman's family, including intimacy with their partners[xli] and relationships with their children.

"I know of a lady I counselled. Her husband just walked out of the home following breast surgery; he has never returned" – Counselor

"My daughter who was the care taker developed depression due to the side effects of the treatment"- Survivor
"The Cancer Institute itself is another place that causes fear – every time I took the patient, I would fear and feel depressed, seeing all the sick people" - Care giver

Participants reported having lacked relevant information about cancer and its treatment and the side effects whose consequences including hair loss, progressive physical deterioration led to increased anxiety and depression.

"I had no information about the disease.....only saw changes....it was my first time to see hair falling off from a person" – Care taker

In addition, they reported having fallen prey to misinformation about the effectiveness of alternative medicine that led them to use local and Chinese herbal medicine which in due course proved ineffective.

"I remember a nurse told me that chemotherapy kills and this drove me to a herbalist" - Survivor

Such misinformation brings confusion and gives false hope hence worsening the mental wellbeing of survivors and care givers upon realizing that eventually the herbals were ineffective.

The fear of cancer recurrence: It should also be noted that at a later stage after treatment, survivors must also deal with the fear of cancer recurrence (Koch-Gallenkamp, et al 2016)[xlii] . Even though this fear declines slightly over time, it is still a common mental health problem for survivors even 10 years after cancer diagnosis (Heide, et al. 2019)[xliii] . Indeed, both survivors and their care givers reported a constant fear of recurrence of the cancer - which causes ubiquitous emotional challenges. Review medical visits, unexplained pain, any signs associated with previous treatment trigger anxiety and fear as those they faced at diagnosis and/or during cancer treatment.

"Any illness now even if its headache brings fear" – Survivor
"The doctor told us that if our mum gets any sickness, the first hospital we take her go to is at the Cancer Institute" – Care taker

Social Support issues: Social support is help provided by social relationships such as family, friends, and significant others, and plays an important role in directly and indirectly reducing uncertainty (Lien, et al. 2009)[xliv] . Lack of social support especially for women facing cancer is a serious driver of mental challenges during their cancer journey. Some participants reported being the bread winners for their families before cancer set in; others noted that they are single mothers, unemployed with no stable income yet are faced with rent, school fees their children and meeting costs of basic necessities. They opined that since cancer is a long one journey, family and social support withers along the way if one is lucky to receive it in the initial stages of the disease. They observed that along the cancer journey, "money becomes everything at some point".

Treatment: A cancer diagnosis is often accompanied by swift and aggressive treatment and it is all but expected that a person will be overwhelmed, worried, fearful and anxious while doctors focus on their medical well-being. Some of the treatments including chemotherapy or radiotherapy and their side effects cause severe long-term suffering potentially affecting one's mental health. In the case of breast cancer for example, breast removal/surgery "was extremely traumatic and the stigma around it". The surgery usually results in a lifelong scar and may cause breast shape alteration and persistent pain. The diagnosis and treatment of the breast cancer might also affect the woman's family, including intimacy with their partners and relationships with their children.

They noted that even when women facing cancer realize that they need hospital care, they have low financial capacity to access the care and this results into cancer related stress, worry, anxiety and distress. Due to financial constraints and impediments, many times treatment plans are affected as they patients are unable to afford the required medication.

"A few months into my mother's cancer treatment, our father lost his job and we could not afford money for treatment. He had to explain the situation to the doctor who was treating her but the doctor developed an uninterested attitude towards us whenever we would go there. It was our mother's women community groups that started supporting us." – Care taker.

At the same time this situation is often exacerbated by various forms of exploitation women face such as violence and abuse within intimate relationships or families; financial exploitation where their limited financial resources are taken advantage of by others. Mental health problems could result from gender specific factors such as isolation, powerlessness, domestic violence, low education levels and economic dependence (Moultrie & Kleintjes, 2006)[xlv] .

"There was no money and everyone seemed fed up with me. Some family members suggested that I sell my house to get money for treatment....I will never forget that day. In my mind I just gave up; and was ready to die than selling my house I had built as s single mother." - Survivor

facing cancer suffer at the lack of support from their partners and at the same time also have to suffer the fear of rejection by the same partner hence contributing to their poor mental health.

Stigma.

It was reported during the assessment that "stigma is real and wide spread" women facing cancer. From diagnosis to the life of survivorship, women suffer different forms of stigma. Changes to a woman's body due to cancer treatment such as breast loss, scarring, hair loss, weight loss, and others can lead to a negative body image and perceived loss of femininity. A recent study published showed that 92% of female cancer patients experienced body image disturbances (Monika, et al. 2022)[xlvi] .

"My doctor referred me to another lady whose breast had been removed. I was to go there to talk her about her experience before I would have my own surgery. Upon meeting the lady, she completely denied she was the one I was referred to and having had her breast removed. She asked me to leave"- Survivor.

Stigma and attitude especially at the work place, from carers/family, women membership groups and in society generally was also reported as a major cause of poor mental health for women facing cancer. Participants reported feeling judged or stigmatized because of their mental health challenges.

"Work colleagues became insensitive and impatient of my absence from work yet I was receiving treatment. I would be told of them saying "she is going to die"- Survivor

Society and Beliefs:

Societal attitudes and and beliefs surrounding cancer impact mental well-being. It was established that cultural beliefs and people's perceptions contribute to mental health challenges especially among women facing cancer.

The *"initial belief that the disease is caused by witchcraft has led many women facing cancer to suffer untold mental illness"- Health expert.* Participants reported that *"some women believe that their co-wives are the cause of the illness and resort to witchcraft and visiting traditional doctors.....others believe it's their fellow workmates bewitching them"*. These traditional doctors end up worsening the cancer with improper treatment. They extort a lot of money from the already financially constrained patients and often sexually abuse and rape the patients. In addition, these beliefs and perceptions have led to *"family breakdown as family members accuse each other of witchcraft meanwhile the disease spreads in the body."* Other general wrong society perceptions regarding cancer including *"being incurable"* impact on mental health for survivors and care takers: *"Nze bangamba nti cancer tawona; omulwadde omukuumako bukuumi."* (I was told there is no cure for cancer; I just have to wait by keeping company to the patient) - Care taker.

At the care takers level, denial by the patient; being a young carer and alone with no one to consult; lack of information about cancer its treatment side effects; failure to go back to work/school; thoughts of possible imminent death of a loved one; issues to do with personal future; loneliness (with the patient at all times), sleepless nights; lack of family support; having to take difficult decisions on behalf of the patient; poor communication by the doctors; among others were reported to contribute to their own poor mental health as care givers.

From the health care provider perspective, oncologists interviewed during this assessment reported that major underlying factors affecting the mental health of women cancer patients included treatment side effects, physical deterioration and concerns of their bodily image, anxiety, socio economic and family related stress. These observations are in tandem with different studies in this area (Granek, et al 2019)[xlvii].

Coping techniques

Coping mechanisms have been categorized as problem-focused and emotion-focused coping strategies (Antony, et al. 2018; Rahmani, et al. 2019)[xlviii xlix]Problem-focused or active coping approach is aimed at finding solutions to challenges, while emotion-focused or passive or avoidance coping approach is aimed at managing emotions. The assessment set out to identify copying mechanisms used to mitigate the mental health challenges faced. A number of strategies were reported by the participants:.

Prayer and spirituality were identified as one of the copying mechanisms. Participants noted that having strong faith in God during their cancer journey helped calm down their mental health challenges. They found solace in religious beliefs and engaged in prayer. They reported having family prayers and some identified pastors, priests and individuals or prayer centers to go to for healing and support prayers.

"We were not religious before but began prayers when cancer came in; and these prayers they helped" – Survivor.

This finding is in sync with other studies that also identified religion as an important coping mechanism for cancer patients (Distelhorst et al, 2015)[l]. In Uganda, some studies have revealed that when Ugandans face mental health challenges, they are more likely to seek complementary help from religious leaders as their first line of support (Mugisha et al., 2013[li]).

Seeking support and relying on individuals, social support groups, peer groups, networks and family friends was reported as a key copying mechanism. Survivors reported getting counselling and mental health support from friends, family and *"rarely from a professional therapist"* as a way to cope with cancer. Survivors and care givers noted that such groups provided a wide-ranging scope of support including financial, empathetic environments and enabling of sharing of experiences, emotions and challenges with others that faced similar situations. Support groups provided an understanding of the challenges faced and allowed survivors to feel loved and less isolated.

"I joined four others to start a peer group through UWOCASO and this has greatly benefited us" - Survivor

"We would regularly receive support visits and some financial help from members of community groups where my mother was a member" – Care taker

"I had a friend who knew navigation in the hospitals and she supported me every time" - Survivor

Self-education and a deliberate effort to seek and search for correct information regarding cancer was identified as a copying approach to among others; dispel the wrong societal attitudes and perceptions about the disease but more importantly to understand the illness, the basics of the disease - the type of cancer, treatment options etc. This information helps to nurture acceptance, positive thinking about their condition and a belief in their ability to cope.

"The Survivor Magazine at the Cancer Institute was very helpful and I was confident it had correct information" - Survivor

"...by God's grace we had a Doctor in the family... we didn't know what to do" – Care giver

To address financial constraints especially at times of reduced support from family and relatives, participants reported of resorting to selling personal property and borrowing money to meet care related expenses. Some care takers reported to borrowing money *"without informing the patient for fear of causing them more stress".*

Different organizations were also approached for financial support:

"We got support from the Catholic Sisters which helped to pay for part of my treatment" - Survivor

Some survivors reported becoming advocates for their own rights as cancer patients/survivors and for others facing similar challenges. Different organizations and organized groups including UWOCASO were reported to having been started by survivors and continue to demand for better cancer care for women. Survivors reported being called upon by different people and organisations to raise awareness about cancer and share their personal experiences which indirectly helps them to cope with their own challenges through such conversations; and builds more confidence in them making them feel they still have a purpose in life.

Survivors reported having a "direct line*" with their doctors as a copying mechanism. "My doctor allowed me to call any time I needed to consult him during my treatment....many doctors eventually became my friends for allowing this open communication."* Oncologists, counsellors interviewed for this assessment agreed to this; that maintaining an open communication with a patient is a source of relief to them as it dispels any fears they may have at that time.

e. Mental Health Needs

Social support needs: Participants in the assessment reported that facilitating connections and networks between patients/survivors and individuals can help combat social isolation. They recounted the different support groups with peers who had similar experiences with cancer were of extreme help in mitigating their mental health challenges. In addition, they note that, family members and friends should be encouraged to participate in the support process to help create a stronger and more supportive network. Support groups provide a nurturing environment for women to share their experiences and receive hope and emotional support.

In addition, financial needs were also highlighted by participants to help cope with financial stress that cancer elicits among women and their families. Mental health problems amidst cancer as noted above were attributed to financial stressors such as unemployment and the pressure of providing for children and paying school fees, which were noted as particular stressors for women especially single mothers. Addressing financial support and security needs is key not only to facilitate access to treatment of both cancer and mental health challenges but also to help minimize the anxiety associated with such insecurity.

Psychoeducation and support needs: Participants in the assessment reported a number of issues that collectively pointed to psychoeducation needs to help them overcome mental health challenges. Issues raised included need for receiving basic information about cancer, its treatment, coping with the disease, nutrition aspects, social support and sharing of their experiences and emotions about concerns in their cancer journey; were raised during the assessment. Psychoeducation refers to strategies that involve information giving and receiving, discussion of concerns, problem-solving, coping skills training, expression of emotions, and social support (Barsevick, et al 2002)[lii] . It has emerged in practice as an adjunctive psychosocial intervention for cancer for both patients and families (Lukens, et al 2004)[liii] .

Information needs: Beyond psychoeducation, provision of regular and accurate information about their diagnosis, treatment options and potential side effects of chemotherapy treatment and management was reported as crucial and a constant need. Participants in this baseline narrated how information about their illness including survival rates; helped them alleviate anxiety and empower them to make informed decisions. They reported that correct and timely information from health care providers helped them to avoid health decisions based on myths and side track herbalists

Uninterrupted, continued treatment, care and rehabilitation needs were reported as important right from diagnosis to survivorship. Survivors opined that having living with cancer is a long and difficult journey during which treatment, care and counselling are critical all the way. The breakdown of the radiotherapy machine at the Cancer Institute for instance often caused nervousness and anxiety to them. Rehabilitation needs including counselling services for instance that address issues of body image concerns and relationships with partners – such as exploring alternative forms of intimacy and pleasure were singled out to be helpful in rebuilding confidence to navigate the changes survivors face due to treatment.

Professional mental health care needs: Beyond the counselling, it was reported that women facing cancer require professional mental health care and therapy during their treatment and in the survivorship period. Participants observed that professional mental health care services were lacking in their cancer care yet mindfulness-based stress reduction and other evidence-based interventions with tools for managing anxiety depression and other mental health challenges women may face can help them cope with the emotional distress associated with cancer. Survivors noted that some doctors only attend to the cancer treatment aspects and "have no time for our mental concerns during the visits". An oncologist in the study also reported that "it would be a good thing to integrate these matters for us not to concentrate on treatment only but also psycho-oncology". At the same time another had the view that "addressing these psychosocial issues takes time; and amidst the number of other patients one has to attend to; you are better off creating a referral system where patients are referred to for such specialized care."

IX. RECOMMENDATIONS

1. There is need for increased Budgetary allocation to mental health in Uganda if mental health interventions are to be effectively implemented. Mental health currently takes up less than 1% of the total budget allocated to Ministry of Health. Despite some effort to integrate mental health in the primary health care, the primary health care system remains poorly resourced, inadequately funded and ill equipped to address mental health concerns (Kigozi et al, 2010)[liv]. Recognition of the increasing burden of mental health in the country is critical to addressing substantial gaps in mental health services. This recognition entails among others appreciating the importance of psychological and mental health aspects of cancer care; undertaking targeted investments and more importantly prioritization of resources towards mitigating mental health challenges at all levels including providing staffing of mental health professionals specializing in cancer care and space for mental health in hospitals.
2. Effective integration of mental health in cancer care is critical. This can be done through development of an integrated psycho oncology model of care that incorporates mental health services within cancer care facilities and settings targeting women cancer survivors to ensure that they receive comprehensive mental health support. Integration should focus on a holistic approach that recognizes that cancer survivors deal with various challenges processing diagnosis, treatment decisions and side effects. Mental health support should be integrated to address these holistic needs. All cancer treatment units and centres should have a referral system that connects women patients/survivors to appropriate mental health professionals
3. Relatedly, in addition to increasing knowledge of mental health among practitioners; training of these health care providers to enhance their capacity in identifying and addressing mental health issues related to cancer is paramount for them to handle mental health challenge among women with cancer. Routine medical and mandatory education about the treatment of psychosocial and psychiatric conditions; psychiatric patient care including among others education on the psychology of cancer communication skills and evidence-based approaches to psychological care should also be considered. Ultimately, health professionals should be able to adopt a palliative and remedial approach to the psychosocial needs of patients, which will enable them to face the disease and uncertainty, to overcome difficult experiences associated with the disease and to adjust to living with cancer. It is important to note however that healthcare providers who are often at the forefront of providing support to women cancer patients may also be susceptible to mental health challenges that too may need redress.

4. Undertaking tailored women cancer patient/survivor psychoeducation interventions. As noted earlier, psychoeducation is a specialized education that consists of educational and psychosocial endeavors with an aim to create behavior change in patients and their families. Such interventions will assist women facing cancer and their families to cope with and adapt to the difficulties associated with the disease. It goes beyond information about their illness - clinical stage and grade and any information relevant to their particular condition such as likelihood of survival; but also, and more importantly the associated mental health challenges. Accordingly, this education should focus on allowing patients to recognize mental health and psychological issues during their cancer journey. In the same vein, similar education should be provided to caregivers and families for them to undertake this role with the requisite information.
5. Cancer awareness is crucial for cancer care and prevention. However, cancer awareness in Uganda is still low given the stigma, beliefs and societal perceptions about the disease; and more importantly its nexus with mental health. A robust targeted cancer awareness and public education campaign (akin to the HIV/AIDS awareness campaign in the early onset of the disease) at all levels to raise public knowledge about cancer its self and its impact on mental health is key. The campaign should target among others men (and their involvement), religious leaders and traditional healers who are identified to oscillate around mental health of women. The campaigns should also target rural areas to engage communities in promoting mental health through challenging stigma and establishing local support groups for women with cancer. Local languages should be used to effectively communicate messages to the population.
6. Civil society groups including Non-Governmental Organisations, Community Based Organisations, recognized cultural and religious institutions should be supported to scale up their work of supporting women cancer patients/survivors and their care givers. The assessment revealed that it is such groups that have provided the much-needed support during the cancer journey of survivors in terms of providing counselling services specifically tailored for women with cancer. Civil Society groups should be supported to undertake community mobilization and empowerment of women in such areas as financial security and planning amidst cancer.
7. Increased access to cancer medication/treatment for women: Access treatment is a major burden for women cancer patients/survivors especially in view of their roles and responsibilities as women and gender considerations. Travelling far distances for treatment and having to spend days away from their homes is not only a barrier for their treatment but also increases domestic challenges especially among in rural settings. A drug delivery service would for instance reduce transportation costs. Access to more cancer screening and treatment facilities for especially for women will go a long way to address their treatment needs.
8. The national health insurance scheme for Uganda is a welcome initiative and its implementation should be expedited. It is envisaged that the scheme will ensure that undergoing long term treatment does not throw the patient and their family into dire financial stress but provide health care for all at an affordable cost. The scheme should prioritize special support towards women with cancer.
9. More research on mental health in cancer care in Uganda should be supported to generate further evidence to inform undertakings and subsequent improvements in ensuring a holistic approach for cancer treatment and care particularly for women facing cancer and their care givers.

X. Future Research

This baseline needs assessment could obviously not cover the issues in detail. A major survey on the mental health challenges and needs of women facing cancer and their families to ascertain the magnitude and impact on cancer care for women is recommended. However, findings herein provide an important insight into what interventions must be prioritized; and some key facets that need further study.

XI. Conclusion

The Baseline Needs Assessment highlighted the significant mental health challenges faced by women cancer survivors and their families/care givers. The findings underscore the urgent need for targeted interventions to address cancer related mental health challenges among women facing cancer; including improving their access to services and promoting holistic care that integrates mental health support within cancer care. By implementing the recommended approaches and interventions, it is hoped that a significant step shall have been taken towards ensuring comprehensive and holistic care for women affected by cancer.

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