

Research Article

Developing a Hardiness assessment scale for Informal caregivers of patients with cancer in Uganda

Rachel Kansime^{1*}, Simon Kizito², Paul Bartone³

¹Uganda Cancer Institute, Paediatric Haematology-Oncology service Mulago specialised Hospital

²Pincer Training and Research Institute, Makerere University, school of psychology; College of Humanities

³Uniformed Services University of the Health Sciences, Department. of Psychiatry

*Corresponding Author: kansimerachel@yahoo.com , Tel.: +256789412139

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Abstract— Cancer is becoming an increasingly prevalent illness in low-income and middle-income countries (LMICs) with Uganda not being exceptional. The study aimed to validate an adapted version of the Dispositional Resilience Scale in a sample of 426 Ugandan cancer caregivers. The study was conducted at the Uganda Cancer Institute in Kampala and the Mbarara Regional Cancer Centre in Uganda. The study used a cross-sectional design. Study participants were consenting adult caregivers (aged 18 years and older) of cancer patients. The study included caregivers of patients diagnosed with cancer at any stage, regardless of cancer type, and treated at the Uganda Cancer Institute and Mbarara District Hospital. Convenience sampling was used in this study. A composite index developed through structural and internal consistency reliability tests was used to generate scores for each respondent. A total of 436 caregivers participated in the study. The male to female ratio was 32%:68%. The mean age of males was 37.3 SD = 12.2 years and the mean age of females was 33.5 Sd = 34.7 years. The age difference was significant ($t = 3.181$ & $P\text{-value} = 0.002$). There was a significant difference in the occupation of the caregivers (test statistic 19.1, $P = 0.014$). There was no difference in income level by gender. There was a gender difference in the religious affiliation of the caregivers, which was significant between male and female caregivers, and there was also a significant difference between the means and standard deviations of male and female caregivers of the Anglican faith (62(44.30 and 87(29,9). In conclusion, the adjusted Dispositional Resilience Scale (DRS) was shown to be a reliable and valid tool for assessing resilience in the cancer caregiver population. Through rigorous testing and validation procedures, this scale has demonstrated strong psychometric properties, making it suitable for use in research and clinical settings.

Keywords— Cancer, Coping, Hardiness, Caregiver, Composite, Indices

1. Introduction

Introduction In Uganda, the responsibility for caring for sick relatives at home falls primarily on family members, particularly female relatives. The lack of palliative care services in the country means that caregivers face the difficult task of managing their relatives' symptoms with little access to professional health care providers. This is likely to be a source of great stress and psychological burden in a culture where people have a moral obligation to care for sick relatives at home throughout their lives. Uganda faces a particularly serious problem related to cancer, a disease that until recently was not recognized as a major health problem in the country [1].

In a context already burdened by HIV/AIDS, malaria, and tuberculosis, the rising incidence of cancer is likely to further strain health care resources [2]. Due to limited cancer screening and treatment options, the majority of newly

diagnosed patients in Uganda have advanced, incurable diseases. This often means that patients suffer from pain and other unpleasant symptoms due to their disease. Cancer is an increasingly common disease in low- and middle-income countries (LMICs) like Uganda. It is estimated that by 2020, LMICs will account for two-thirds of the global cancer burden. More than 80% of the world's population lives in countries classified as LMICs. In this context, temperamental resilience (or trait resilience) can be defined as the stable ability to maintain healthy levels of psychological and physical functioning in the face of adversity, to recover effectively, and to experience minimal stress without burdening the individual. Some people are assumed to have a set of personality traits that serve as protective factors against the detrimental effects of exposure to a variety of adverse life events. Measures have been developed to assess this globally and for specific populations, and it has been suggested that a greater understanding of those with high temperamental resilience may provide a resource for interventions targeting those with low temperamental resilience. The term

"resilience" originated in the field of physics (syntropy) and was introduced into social and psychological psychology by Norman Garmezy as a counterpoint to the developmental deficit model [3]. It was originally used to describe the relatively unusual phenomenon in which individuals exposed to severe adverse life experiences were able to maintain competent functioning and positive feelings about themselves. Since what distinguishes resilient from non-resilient individuals is not the way they face major stressful events, but rather the way they cope with them, it is now more often defined as a trait that describes differences between people exposed to similar stressors. Today, resilience is an important component for research on the well-being of people facing chronic adversity and is associated with positive psychological and health-related outcomes such as better quality of life and successful coping.

This paper is organized into several sections. Section 1 provides background information on the study, definitions of key terms, and the organization of the paper. Section 2 includes related research by other scholars and elaborates on the research problem statement and research objectives. Section 3 contains detailed information on the steps taken to conduct the study, including the research design, study area, study population, sample size, sampling method, and data analysis. Section 4 presents the results of the study in tables and also includes a discussion of the results. Section 5 contains the conclusions and also details the recommendations of the study. Other sections include conflicts of interest, funding sources, author contributions, acknowledgments, and references cited in the study.

2. Related Work

Resilience is a psychological construct that has been shown to be a protective factor against psychological illness. Studies on resilience training have shown that it reduces depression and anxiety and increases positive emotions in diverse groups of participants who face different types of adversity [4]. However, these interventions have been shown to be ineffective for those with low temperamental resilience [5]. In Uganda, there have been no interventions targeting resilience in cancer caregivers. High dispositional resilience is defined as a stable personality trait associated with using mental processes to promote positive adaptation in the face of adversity [6]. The Dispositional Resilience Scale (DRS) is a 15-item self-report measure of this concept. It has demonstrated good internal consistency and test-retest reliability and has been shown to predict depression, anxiety, and stress in both student and patient populations [7].

Unfortunately, the DRS has not been validated in a caregiver group. This means that it remains to be determined whether caregivers understand the DRS questions, interpret them in the same way as students and patients, and accurately measure levels of dispositional resilience. For these reasons, it is important to test the DRS before attempting a resilience training intervention targeting cancer caregivers in Uganda. It is also important to assess the level of resilience in this population and whether they differ from other populations.

We hypothesized that cancer caregivers in Uganda would have higher resilience scores than the only other group of caregivers assessed using the DRS. In a pilot study of caregivers of children with Down syndrome in Greece, the mean resilience score ($M = 85.93$, $SD = 14.06$) was significantly higher than the DRS norming sample [8]. [8] found that the mean resilience score for stroke survivors was $M = 85.14$ ($SD = 20.71$). The high resilience of stroke survivors is consistent with the theoretical assumption that adversity promotes resilience [8].

[9] compared a sample of parents of children with cancer to a DRS standardization sample and found no differences in resilience levels. Given the assumption that the Mains sample was not different than other populations, such as stroke survivors and dementia caregivers, it was expected that the resilience scores of the Ugandan caregivers would be similar to those already reported in stroke survivors and dementia caregivers in previous studies [10]; [11] have assessed resilience in bereaved older adults, caregivers of people with dementia, and adult cancer survivors, but have not compared these results to a sample of stroke survivors. This perceived similarity in resilience scores across different populations makes the resilience scores of stroke survivors a viable comparison for this study. Resilience Creator Theory has provided a broad platform for sustainability research, and this scale, developed from the theory, will advance a new ontology for measuring sustainability.

Many preliminary studies have great value in translating to sustainability promotion. This study identified general resilience-related factors and provided a preliminary 15-item dispositional resilience scale. The scale developers already consider the DRS to be a potentially useful tool, as it has shown good face and content validity. Further revision of the content validity and scale will be investigated. In the future, it is possible to remove cancer-related items and construct a general and specific resilience scale. To establish a preliminary idea for scale construction and item creation, global and specific forms of resilience were separated and examined. Items 1–11 reflect general resilience, and items 12–15 reflect cancer resilience. It was believed that these two factors could represent a simple continuum from adversity-independent to adversity-specific coping responses. The Dispositional Resilience Scale emerged from the development of the Creator Resilience Theory. It was designed as a brief scale to measure both conscious and unconscious behavioral responses. This scale is widely used by researchers who want to examine stable personality dimensions in populations seeking general assessment or when examining the lifestyle consequences of adversity. However, current research testing the Dispositional Resilience Scale focuses on a global form of resilience, attempting to measure personality traits that have a general impact on coping with and responding to adversity. This type of sustainability has been argued to be important and beneficial for health, well-being, and quality of life.

The purpose of this study was to test the scale in a sample of cancer caregivers in Uganda. There are various conceptual

understandings and dimensions of sustainability. For example, the stress and coping literature has proposed the ego-control model, the challenge model, or the general model. Recently, it has been proposed that resilience should be conceptualized and measured in a more comprehensive and specific form, based on the diversity of emotional, cognitive, and behavioral components of resilience. In this study, it is defined as a stable personality trait, a pattern of positive adaptation even in the face of severe adversity. Stability is like a rubber ball, capable of dynamic change with tension and relaxation simultaneously and returning to its original shape. A resilient person may experience sadness, anxiety, anger, or other negative emotions, but continue to function and recover from the underlying stress that triggers these emotions. The concept of temperamental resilience has received increasing attention in the general coping and stress literature. Resilience has been defined and measured in a variety of ways and has been associated with a variety of outcomes in the stress and coping literature.

According to [12]; approximately 60% of people diagnosed with cancer in Uganda do not seek medical help, but instead turn to family and friends for support. Informal caregivers face many cognitive, emotional, physical, social, and financial stressors while caring for a cancer patient. A study by [13] found that one-third of Ugandan women with breast cancer and the majority of their caregivers viewed the disease as a death sentence. Given the common belief that cancer is incurable, the burden of treatment is often prolonged.

3. Experimental Method/Procedure/Design

Specific objective

The study seeks to validate the adjusted dispositional resilience scale.

Study Area

The study was conducted at two tertiary care facilities in Uganda, namely Uganda Cancer Institute in Kampala City and Mbarara Regional Cancer Centre in Mbarara City (Western Uganda).

Study Design

This study employed a cross-sectional design.

Study Participants

The study participants were consenting adult caregivers of patients with cancer (Age 18 years and above). A caregiver was defined as a not formally trained person who spends substantial amounts of time caring for a cancer patient. Such a person should have played this role for at least one week.

Inclusion criteria

Caregivers of patients diagnosed with cancer at any stage, regardless of the type of cancer, who were accessing care at the Uganda Cancer Institute and Mbarara regional referral hospital were included in the study. The caregivers had to be 18years old and above and had to give both verbal and written consent. They had to have given care to the cancer patient for at least a week.

Exclusion criteria

Participants were excluded if they were less than 18 years of age and if for whatever reason, they could not answer the questionnaires. Those that were approached and declined to participate were excluded.

Sampling Method

The study used convenience sampling. This was because caregivers are a mobile population and a patient could have different caregivers at any given time making it impossible to have a sampling frame. A caregiver that was found giving care at the time the researcher walked in was included in the sample.

Data Analysis

The composite indices developed through the structural validation and internal consistency reliability testing was used to generate scores for each respondent. These scores were then used to carry out further analysis. The mean scores were determined together with their standard deviations. The relationship between coping and care giver satisfaction (as assessed by the different subscales) was assessed using multiple linear regression modelling and group differences between the means were compared using ANOVA.

4. Results and Discussion

Sample Characteristics

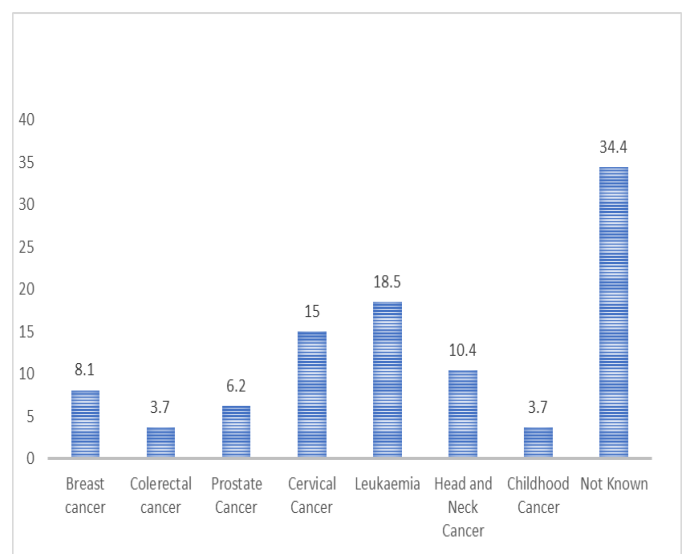


Figure 1: Type of cancer among patient

Results in Figure 1 above shows that most of the patients (34.4%) were suffering from unknown type of cancer, followed by 18.5% of the patients who were suffering from Leukemia, 10.4% of the patients who were suffering from head and neck cancer and 8.1% of the patients were suffering from breast cancer.

Table 1: Socio-demographic characteristic of respondents

Variable	Male	Female	Overall	Test statistics	p-value
Age of care giver (Mean, SD)	37.3 (12.2)	33.5 (11.4)	34.7(11.8)	3.181	0.002
Age of patient (Mean, SD)	38.0 (24.1)	32.0 (22.7)	35.4(23.6)	2.506	0.013
Occupation (% ,N)				19.114	.014
Farmer	59 (34.3)	113 (65.7)	173(39.9)		
Business	32 (28.6)	80 (71.4)	113(26.0)		
Others	49 (0.0)	98 (100)	1(0.23)		
Distance to nearest HC (% ,N)				7.298	.199
Less than 20 Km	12164 (37.2)	228108(62.7)	349172(40.1)		
More than 20 Km	18 (24)	57 (76)	75(17.6)		
Non-Response	1 (14.2)	6 (85.7)	7(1.62)		
Education level (% ,N)				20.730	.004
Primary level	47 (29.94)	118(70.0)	157(36.94)		
Secondary school level	50 (29.31)	97(70.69)	147(27.29)		
Completion of certificate Course	22 (37.92)	36 (62.07)	58(13.65)		
University Education	11 (40.74)	20 (59.26)	31(6.35)		
Non-Response	10	30 (16.7)	40(1.39)		
Disability (% ,N)				1.702	.427
No	136(32.5)	282(67.5)	420(97.7)		
Yes	4.0 (40)	6.0 (60)	10(2.3)		
Non-Response	0 (.0)	3.0 (100)	3(0.69)		
Level income (000) (Median, range)	309710.7 (402374.1)	276182.6 (555397.6)	150000(300-500000)	.588	0.557
Religion (% ,N)				16.417	.006
Anglican	62 (41.6)	87 (58.4)	152(36.1)		
Roman Catholic	49 (33.3)	98 (66.7)	147(34.9)		
Moslem	5 (11.4)	39 (88.6)	44(10.5)		
Born Again	19 (26)	54 (74)	73(17.3)		
Seventh Day Adventist	1 (20)	4 (80)	5(1.2)		
Non-Response	4 (30.7)	9 (69.3)	13(3.01)		
Type of CA (% ,N)					
Breast Cancer	11 (31.4)	24 (68.6)	35(8.1)		
Colorectal Cancer	6 (40)	9 (60)	16(3.7)		
Prostate Cancer	13 (48.1)	14 (51.8)	27(6.2)		
Cervical Cancer	18 (27.7)	47 (72.3)	65(15.0)		
Leukaemia	28 (35.4)	51 (64.5)	80(18.5)		
Head and Neck Cancer	14 (31.8)	30 (68.2)	45(10.4)		
Childhood Cancer	2 (12.5)	14 (87.5)	16(3.7)		
Not Known	48 (31.6)	102 (68.4)	150(34.4)		
Stage of CA (% ,N)				10.495	.033
Early Stage	37 (45.1)	45 (54.9)	82(19.3)		
Late Stage	35 (34.3)	67 (65.7)	104(24.4)		
Terminal Stage	11 (31.4)	24 (68.6)	36(8.5)		
Not Known	57 (26.1)	155(73.9)	213(47.9)		

A total of 436 caregivers participated. The male to female ratio was 32%:68%. The average age of the males was 37.3 SD= 12.2 compared to that of the females which was 33.5, Sd= 34.7. These age differences were significant (t= 3.181 & P- value= 0.002). The majority of the caregivers were from rural households (65%) followed by semi-urban (17% and urban (16%) households. Of the 436 respondents, 94% were Ugandan, 1.4 were South Sudanese, 1.52% were Rwandese, 0.9% each were Tanzanians and Kenyans. Congolese and Burundians were 05 and 07% respectively. The rest of the socio-demographics are summarized in Table 1 above.

Table 1 above shows that there were significant differences in the occupation of the caregivers (test statistic of 19.1, p=0.014) which implies that the occupation of the caregivers influences the caregiving experience. There were significant differences between the mean and SD of the male and female peasants/farmers who formed the majority 59(42.1) and 113(38.8) with the males most influenced and the females least influenced, followed by the business people with the females most influenced 80(27.5) and males least influenced 32(22.9).

The Level of income of the caregivers was found to have a test statistic of 0.588 and a p value = 0.557 which implies that there were no gender differences in the levels of income and that the level of income that a caregiver was at was not significant and did not matter whether it was for a male or a female.

The religious affiliation of the caregivers was found to have a test statistic of 16.417 and a p value=0.006 which implies that there were gender differences in the caregivers’ religious affiliations and these were significant between the male and female caregivers. There was a significant difference between the means and standard deviation of the male and female caregivers of the Anglican faith 62(44.30 and 87(29.9). This indicates that males of the Anglican faith were more influenced than the females whereas the reverse was true for the roman catholic faith with males with a mean and standard deviation of 49(35.0) and females with mean and standard deviation 98(33.7).

There were gender differences among the caregivers regarding the stage of cancer that the patient being taken care of was at (test statistic of 10.495 and a p value = 0.033). This implies that the stage of disease influences the caregiving differently when for males and for females. This significant difference was most pronounced in the means and standard deviation between males and females of those that did not know at which stage their patient was at 53(37.9) and 150(51.5) and least pronounced among those whose patients

were terminal 11(7.9) and 24(8.2). This indicates that caregivers who did not know the stage of disease at which their patients were at were most influenced as compared to those who knew that their patients were terminally ill. There were no gender differences regarding the type of care provided by the caregiver (test statistic of 10.882 p= 0.144) which implies that the type of care does not influence males and females differently.

There were gender differences regarding the relationship of the caregiver to the patient (test statistic was 19.796 p value= 0.019). This implies that there were significant differences between males and females in regards to their relationship to the patient. Results further showed that the categories of caregiver relationship most influenced were the female children of the patients with a mean of 130 and SD of 44.7 as compared to the males with a mean of 41 and SD 29.3, then followed by the siblings to the patient with female siblings most influenced with a mean of 47 and standard deviation of 16.2 as compared to the male siblings with a mean of 24 and standard deviation of 17.1 and lastly the spouses with the male spouses mostly influenced with a mean of 21,SD of 15 as compared to the female spouses with a mean of 19 and SD of 6.5.

There were no gender differences regarding the duration of care giving (test statistic of 3.183 p= 0.364) which implies that the duration of caregiving does not influence males and females differently.

Table 2: Cronbach Alpha results

Scale	Subscale and facets	Cronbach Alphas
Adjusted DRS	Subscale 1	0.9937
	1.I am proud to be a caregiver 2.I am an important stakeholder in my caregiving role 3.What I do in my caregiving is worthwhile 4.I feel responsible for my caregiving 5.I am committed to my caregiving role 6.How well I do in caregiving matters a great deal to me How I do in my caregiving influences how I feel.	
	Subscale 2	0.9734
	13.I have personal control over my caregiving performance 14.Once I am given Instructions, I am pretty much left alone to do my caregiving 15.I am allowed to do my caregiving without constant supervision from others 16.I feel caregiving is important for accomplishing my mission 17.I am making a real contribution as a caregiver to accomplishing my mission 18.What I do helps accomplish my mission	
	Subscale 3	
	My caregiving is very challenging 8.It takes all my resources to achieve my caregiving objectives 9.I work at full capacity in all of my caregiving duties 10.I strive as hard as I can to be successful in my caregiving 11.When I work, I really exert myself to the fullest.	0.7966

The research table above presents a comprehensive analysis of the hardiness assessment scale using factor analysis. It categorizes the identified subscales, each accompanied by their reliability coefficients, which reflect the internal consistency of the measures. The subscales include questions on Commitment, Control, and Challenge. The table succinctly illustrates the robust structure of the assessment tool, validating its utility in assessing hardiness effectively.

Discussion

The development and validation of a resilience scale for cancer caregivers in Uganda is an important step toward understanding resilience in an often-overlooked population. Our findings, showing a Cronbach’s alpha of 0.9937 for subscale 1 and 0.9734 for subscale 2 of the adjusted dispositional resilience scale, indicate excellent internal consistency and reliability of the scale. These results are

consistent with previous research that emphasizes the importance of sound psychometric properties in assessment tools designed for specific populations [14]. The high reliability coefficients observed in our study suggest that this scale is a reliable tool for measuring caregiver resilience in the Ugandan context. This is particularly relevant given the unique cultural and socioeconomic challenges faced by caregivers in resource-limited settings. Previous research has highlighted the need for culturally sensitive assessment tools that accurately reflect caregiver experiences and challenges across a variety of contexts [15].

Our results contribute to this body of literature by providing a validated scale that can be used in both clinical and research settings to assess caregiver resilience. Furthermore, the concept of hardiness, as defined in [16], encompasses commitment, control, and challenge that are important for caregivers coping with the stress associated with caring for a cancer patient. Validation of our scale supports the idea that hardiness is an important factor in mitigating the psychological distress experienced by caregivers. Research has shown that caregivers with higher levels of hardiness are better able to cope with stress and are less likely to experience burnout [17]. This highlights the importance of assessing resilience as a potential protective factor in the caregiver group. In the Ugandan context, where cancer is a growing public health problem, understanding caregiver resilience is important for developing targeted interventions. Research has shown that caregivers often experience significant emotional and psychological burdens, which can negatively impact their well-being and the quality of care they provide [18]. Health care providers can use resilience assessment scales to identify caregivers at risk for psychological distress and implement appropriate support mechanisms. Our results also echo the work of [19] which highlighted the need for resilience training programs for caregivers. Such programs could build on our scale of outcomes to allow for tailored interventions that enhance caregiver resilience and ultimately improve mental health and the care they provide to their patients. In conclusion, the development and validation of a robust assessment scale for cancer caregivers in Uganda represents an important advance in our understanding of caregiver resilience. The strong psychometric properties of this scale provide a reliable tool for future research and clinical practice. As we continue to explore the complexities of cancer-related caregiving, it is important to prioritize caregiver mental health and resilience to ensure they receive the support they need to successfully fulfill their role.

4. Conclusion and Future Scope

In conclusion, the Adapted Dispositional Resilience Scale (DRS) has been shown to be a reliable and valid tool for assessing resilience in a population of informal caregivers of cancer patients. Through rigorous testing and validation procedures, the scale has demonstrated strong psychometric properties, indicating its suitability for use in research and clinical settings. The successful application of the DRS to this specific population highlights its versatility and applicability

across contexts, providing a valuable tool for understanding and supporting the psychological well-being of caregivers facing challenges associated with caring for a loved one with cancer. The development of a resilience scale specifically designed for informal caregivers of cancer patients in Uganda represents a significant advance in understanding and supporting this important group.

Future research directions that could build on this framework include: Conducting longitudinal studies that examine changes in informal caregiver resilience over time could provide greater insight into the dynamics of caregiver experiences and resilience. This approach could help identify critical periods of stress and adaptation and inform targeted interventions to enhance caregiver support. Future research should focus on developing and evaluating interventions to increase informal caregiver resilience and coping strategies. Investigating the relationship between caregiver resilience and caregiver and patient health outcomes is important for understanding the broader implications of caregiver resilience. Future research could investigate whether higher levels of resilience are associated with better caregiver health outcomes and improved quality of patient care, which could lead to a more comprehensive approach to patient support. Future research should also focus on exploring cultural factors that influence the resilience of informal caregivers in Uganda. Qualitative approaches, including interviews and focus groups, may uncover culturally specific resilience strategies and beliefs that could be incorporated into support and intervention programs.

Policy Recommendations

Policy Recommendations Based on the findings of this study; we recommend that future research efforts examining resilience in cancer caregivers use an adapted Dispositional Resilience Scale. Additionally, health professionals and support organizations working with this population may consider incorporating the DRS into their assessment protocols to better identify caregivers who may benefit from targeted interventions to build resilience and mitigate the negative psychological impacts associated with stress management. Additional research and validation efforts are recommended to further establish the utility and effectiveness of the DRS in supporting the well-being of caregivers in this important and often overlooked population.

Data Availability

Data can be obtained by emailing the primary author.

Conflict of Interest

This study was conducted in the absence of any social or economic conflicts of interest.

Authors' Contributions

RK conceived, designed, and executed the study, including discussion of the results. SK supervised the data analysis and interpretation of the results. PB provided guidance on the conceptualization of the study, data analysis, and interpretation of the results.

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AUTHORS PROFILE

Rachel Kansime is a clinical psychologist and rehabilitation professional based in Uganda, renowned for her pioneering work in psycho-oncology. She holds a doctorate from Mbarara University of Science and Technology, where her research and clinical expertise have positioned her at the forefront of psychological care for patients with cancer and their families. Kansime has dedicated her career to addressing the unique psychological challenges faced by individuals affected by cancer. She is particularly passionate about the mental health and wellbeing of informal caregivers—those who provide support to patients navigating their cancer journey. Her innovative approaches incorporate hardiness therapy, a technique she is certified in, emphasizing resilience and coping strategies to enhance caregivers' emotional strength. Kansime's work includes research in cancer caregiving, conducting workshops, providing therapy, and advocating for more robust psychological support systems within Uganda's healthcare framework. Through her efforts, she aims to improve the overall quality of life for both patients and caregivers, fostering a more supportive environment for those impacted by cancer. Her commitment to research and community engagement continues to inspire many in the field of psychology and beyond.



Simon Kizito is a clinical psychologist and lecturer at the school of psychology Makerere university. He holds a PhD in clinical psychology and public mental health from Stellenbosch University. He has supervised a number of Masters and PhD students. His research interests are in mental health and psycho-social support among others.



Paul Bartone is an Adjunct Faculty member in Psychiatry at the Uniformed Services University of the Health Sciences, and past Professor and Senior Research Fellow at the National Defense University in Washington, DC. He holds a Masters and Ph.D. in Human Development from the University of Chicago. A Fulbright Scholar (Norway, 2006–07), Bartone is past-President of the American Psychological Association Society for Military Psychology. Bartone has published multiple studies on hardiness, health and adaptation.

