DONGOLA UNIVERSITY

FACULTY OF NURSING SCIENCES

DEPARTMENT OF MEDICAL-SURGICAL NURSING

RESEARCH PROPOSAL

PSYCHOLOGICAL AND ECONOMIC IMPACT OF RECEIVING CARE AMONG INBOUND LEUKEMIA PATIENTS AT DONGOLA

A Research Proposal Submitted in Partial Fulfilment of the Requirements for the Degree of Bachelor of Science in Nursing

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Dongola, Sudan

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PRELIMINARY NOTE

This document is a research proposal, not a completed research report. No results or conclusions are presented as if data had already been collected. Details in square brackets, including the student name, supervisor, facility, dates, and final sample size, should be completed or approved with the research supervisor and the relevant institution.

The attached source draft used the phrase “inbound leukemia patients.” In this proposal, “inbound patients” means people who usually live outside Dongola and travel to the city to receive leukemia-related healthcare. The study should use the terminology accepted by the university and study site.

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ABSTRACT

Background: Leukemia is a group of blood cancers that may require prolonged treatment, repeated clinic visits, hospital admission, laboratory investigations, medicines, and supportive care. Patients who travel from outside Dongola to receive care may experience additional psychological and financial pressures related to transport, accommodation, food, separation from family, and interruption of work or household responsibilities.

Aim: This study aims to assess the psychological and economic impact of receiving healthcare among inbound leukemia patients attending selected healthcare facilities in Dongola, Northern State, Sudan.

Methods: A quantitative, descriptive cross-sectional, facility-based study is proposed. Eligible adult patients with a confirmed diagnosis of leukemia who normally reside outside Dongola and attend the selected facility for care will be invited to participate. Data will be collected using a structured questionnaire covering socio-demographic and clinical characteristics, psychological symptoms, travel and accommodation experiences, out-of-pocket costs, lost income, and coping/support. The use of a standardized psychological screening tool, such as the Hospital Anxiety and Depression Scale (HADS), will depend on permission, language suitability, and supervisor approval. Data will be analysed using descriptive statistics and appropriate tests of association.

Expected contribution: The study is expected to describe the psychological concerns and costs reported by participating patients and identify areas where nursing, social work, and health-service support may be improved. Findings will be based on collected data; no results are assumed in this proposal.

Keywords: leukemia; psychological distress; economic burden; inbound patients; oncology nursing; Dongola.

CHAPTER ONE: INTRODUCTION

1.1 Background of the Study

Leukemia refers to a group of malignancies involving blood-forming tissues, particularly the bone marrow, and is commonly classified according to the cell lineage involved and the speed of disease progression. Treatment varies by leukemia type, patient age, clinical status, and available services. It may involve chemotherapy, targeted medicines, blood-product support, infection management, monitoring, and repeated follow-up. These demands can affect patients' daily lives and the resources available to their families.

A cancer diagnosis can be associated with uncertainty, fear, changes in family roles, and concerns about treatment outcomes. Psychological distress may be influenced by symptoms, treatment adverse effects, social support, financial circumstances, and access to information. Screening can help health professionals recognize concerns, although screening results do not by themselves establish a psychiatric diagnosis.

Cancer care can also create direct and indirect costs. Direct medical costs may include consultations, investigations, medicines, hospital services, and supportive treatment. Non-medical costs may include transport, meals, and temporary accommodation. Indirect costs may arise from time away from work, reduced income, or the need for a relative to accompany the patient. These expenses may be especially challenging when treatment requires repeated travel.

Dongola is a regional healthcare centre in Northern State, Sudan. Patients who live outside the city may need to travel to Dongola for specialized services. Travel and temporary residence away from home can add practical, social, psychological, and economic burdens to the experience of leukemia. Understanding these burdens from the patients' perspective can help nurses and service planners identify feasible support measures.

1.2 Problem Statement

Leukemia care can place substantial demands on patients and their families. For patients who travel from outside Dongola, the demands of illness and treatment may be compounded by transport expenses, accommodation and food costs, separation from family, disrupted employment, and uncertainty about how long care

will take. These pressures may affect emotional well-being and the ability to attend appointments or meet household needs.

However, locally specific information about the psychological experiences and economic costs reported by inbound leukemia patients receiving care in Dongola may be limited. Without systematic data, nurses and health-service managers may find it difficult to identify the most common concerns, understand which groups experience greater burdens, and plan appropriate patient education, referral, or practical support. This study therefore proposes to assess the psychological and economic impact of receiving care among inbound leukemia patients at selected facilities in Dongola.

1.3 Justification of the Study

- Patient care: The study may help nurses recognize common psychological concerns and practical difficulties reported by patients.
- Service planning: Information about travel, accommodation, and treatment-related expenditure may inform discussions about patient support services.
- Continuity of care: Identifying reported barriers to attending appointments may help services consider ways to improve access and follow-up.
- Academic contribution: The study will provide locally collected evidence on a population whose experiences may not be represented in broader cancer research.
- Future research: Findings may identify questions for larger studies or intervention evaluations.

1.4 Research Questions

1. What psychological concerns are reported by inbound leukemia patients receiving care in Dongola?
2. What direct medical, non-medical, and indirect costs do participating patients and their households report in relation to receiving care?
3. What travel, accommodation, and social-support challenges do inbound leukemia patients experience?

4. Is there an association between selected socio-demographic or travel-related factors and reported psychological distress?

5. What coping strategies and sources of support do participating patients use?

1.5 Objectives of the Study

1.5.1 General Objective

To assess the psychological and economic impact of receiving healthcare among inbound leukemia patients attending selected healthcare facilities in Dongola, Northern State, Sudan.

1.5.2 Specific Objectives

6. To describe the socio-demographic and selected clinical characteristics of inbound leukemia patients attending the study site.
7. To assess psychological symptoms or distress reported by participating patients using an appropriate screening approach.
8. To estimate the reported direct medical, non-medical, and indirect costs associated with receiving care in Dongola.
9. To describe travel, accommodation, family-separation, and other access challenges experienced by participating patients.
10. To examine associations between selected socio-demographic/travel-related factors and psychological distress or reported financial burden, where the data and sample size permit.
11. To describe coping strategies and sources of social, family, institutional, or community support reported by participants.

1.6 Research Hypotheses

If hypothesis testing is required by the department, the following null hypotheses may be examined, subject to the final study design and available sample size:

12. There is no statistically significant association between travel distance or travel time and psychological distress among participating inbound leukemia patients.
13. There is no statistically significant association between reported financial burden and psychological distress among participating inbound leukemia patients.

These hypotheses will be tested only if the relevant variables are collected and the assumptions of the selected statistical tests are reasonably met.

1.7 Operational Definitions

Leukemia patient: An adult with a documented or clinician-confirmed diagnosis of leukemia who is receiving or attending follow-up for leukemia-related care at the selected study site.

Inbound patient: A patient whose usual residence is outside the municipal boundaries of Dongola and who travels to Dongola to receive leukemia-related healthcare.

Psychological distress: Symptoms of anxiety, low mood, or emotional strain measured using the approved study tool. Screening scores will not be treated as a clinical diagnosis.

Economic impact: Patient- or household-reported medical and non-medical spending, travel and accommodation costs, and income or work losses associated with receiving care.

Out-of-pocket expenditure: Money paid directly by the patient or household for care-related goods and services, rather than paid by an insurer or other third party.

Social support: Practical, emotional, or financial help reported as coming from family, friends, community members, healthcare workers, or organizations.

1.8 Scope of the Study

The study will focus on consenting adult inbound leukemia patients attending [name of facility/facilities] in Dongola during [approved data-collection period]. It will assess self-reported psychological experiences and economic impacts associated with receiving care. It will not evaluate treatment effectiveness or establish causal relationships because the proposed design is cross-sectional.

CHAPTER TWO: LITERATURE REVIEW

2.1 Overview of Leukemia and Its Care

Leukemia comprises several diseases with different clinical courses and treatment requirements. Care may involve diagnostic tests, specialist consultations, drug treatment, management of complications, blood-product support, and ongoing monitoring. The frequency and duration of care depend on the disease subtype and treatment plan. As a result, the time and resources required from patients and caregivers can vary considerably.

Treatment-related symptoms and the need for frequent appointments may interfere with sleep, daily activities, family responsibilities, education, and employment. Patients may also need a caregiver to accompany them, increasing the household's time and travel costs. These issues make it important to consider both clinical and non-clinical aspects of care.

2.2 Psychological Impact of Leukemia

Cancer-related psychological concerns may include fear, anxiety, sadness, uncertainty, worry about family members, and concerns about treatment or the future. The intensity of these experiences can vary over time and between individuals. Symptoms may be influenced by disease-related factors, physical symptoms, treatment experiences, perceived social support, financial strain, and the quality of communication with healthcare professionals.

Psychological screening tools can support the identification of people who may need further assessment. The Hospital Anxiety and Depression Scale (HADS) is a commonly used screening instrument in medical settings and includes separate anxiety and depression subscales (Zigmond&Snaith, 1983). If used in this study, the team must confirm the authorized version, language appropriateness, scoring instructions, and any permissions or licensing requirements. A positive screen should be described as a screening result, not as a confirmed diagnosis.

Nurses can contribute by communicating clearly, listening to concerns, supporting symptom management, involving family when the patient wishes, and referring patients to qualified mental-health professionals when needed. Screening should be accompanied by a realistic plan for responding to concerning findings.

2.3 Economic Impact of Leukemia Care

The economic burden of illness includes more than the price of medicines or hospital services. Direct medical costs can include consultations, investigations, medicines, procedures, and admission-related charges. Direct non-medical costs include transport, accommodation, meals, and other practical expenses needed to reach or remain near a service. Indirect costs include lost wages, missed business opportunities, reduced work capacity, and time spent by unpaid caregivers.

Financial burden should be measured transparently and with a clearly defined recall period. Asking participants to estimate costs over the previous month or most recent treatment visit may reduce confusion, although recall error can still occur. The study should distinguish expenses paid by the household from costs covered by relatives, charities, government programmes, or other sources. If the study intends to classify catastrophic health expenditure, it must pre-specify a recognized definition, denominator, and data-collection method rather than selecting a threshold after seeing the results.

2.4 Challenges Experienced by Inbound Patients

Patients travelling from outside a treatment centre may face long journeys, transport uncertainty, costs of overnight stays, difficulty finding affordable accommodation, and disruption to family and work responsibilities. These pressures may be more substantial for patients who need repeated visits or whose treatment schedule changes unexpectedly. Travelling while fatigued or unwell may add practical difficulties.

Leaving familiar support networks may contribute to loneliness or worry, while an accompanying relative may also experience financial and emotional strain. The availability of safe accommodation, understandable information, referral pathways, and coordinated appointments may influence patients' experiences. The present study will document the challenges participants report; it will not assume that every inbound patient experiences the same burden.

2.5 Nursing Role and Theoretical Framework

Holistic nursing considers physical, psychological, social, cultural, and environmental factors that influence health. In oncology care, nursing actions may include patient

education, symptom assessment, communication, care coordination, emotional support, and referral to social or mental-health services. Practical support should be responsive to the patient's expressed needs and the resources available locally.

The study may be guided by Betty Neuman's Systems Model, which views the person as an open system affected by internal and external stressors. For this study, potential stressors include illness-related symptoms, worry about treatment, travel, accommodation, costs, and separation from usual support. The model offers a way to organize the study variables and discuss nursing support, but it does not establish that any stressor causes a particular outcome.

2.6 Summary and Research Gap

The literature indicates that cancer care can involve psychological concerns and multiple forms of expenditure, while travel to a treatment centre may add further demands. However, the extent and pattern of these burdens are context-dependent. A locally conducted assessment in Dongola can describe the experiences of participating inbound leukemia patients and provide a starting point for service improvement. A focused literature search should be updated before submission to identify and include relevant Sudanese, regional, and international empirical studies.

2.7 Conceptual Framework

Independent or explanatory variables may include age, sex, residence/locality, education, employment, household income category, leukemia type if documented, treatment stage, travel distance/time, travel frequency, accommodation type, and availability of an accompanying person. Main outcome variables are psychological screening scores and reported economic burden. Potential support factors include family support, assistance from organizations, and access to patient information. Because the study is cross-sectional, observed associations will not be interpreted as proof of causation.

CHAPTER THREE: METHODOLOGY

3.1 Study Design

A quantitative, descriptive cross-sectional, facility-based study will be conducted. Data will be collected once from each participant during the approved study period. This design is suitable for describing reported experiences and exploring associations, but it cannot establish temporal order or causation.

3.2 Study Area

The study will be conducted at [insert the exact hospital/oncology unit or healthcare facilities] in Dongola, Northern State, Sudan. The final proposal should describe the selected facility, services provided, and why it is an appropriate site for recruiting eligible patients.

3.3 Study Population

The target population will be adult patients with a confirmed diagnosis of leukemia who usually live outside Dongola and attend the selected facility for leukemia-related care during the data-collection period. The accessible population will consist of eligible patients who attend the facility during recruitment and are approached by the research team.

3.4 Eligibility Criteria

3.4.1 Inclusion Criteria

- Age 18 years or older.
- Confirmed diagnosis of leukemia documented in the clinical record or confirmed by the responsible clinical team.
- Usual residence outside Dongola municipal boundaries and travel to Dongola for leukemia-related healthcare.
- Attending or receiving care at the selected study site during the study period.
- Able and willing to provide informed consent.

3.4.2 Exclusion Criteria

- Permanent residents of Dongola, according to the study's operational definition.
- Patients whose acute clinical condition makes participation unsafe or inappropriate at the time of approach.
- Patients unable to provide informed consent, unless an ethically approved alternative procedure is specifically authorized.

- Patients who have already participated in this study, to avoid duplicate records.

3.5 Sample Size and Sampling Technique

The final sample size must be calculated and approved before recruitment. If the number of eligible patients is known, the supervisor may approve a finite-population calculation. If the population size is unknown, a single-proportion formula may be considered: $n = Z^2p(1-p)/d^2$, where Z is the standard normal value for the selected confidence level, p is the anticipated proportion based on a defensible prior study (or 0.50 when no reasonable estimate is available), and d is the desired absolute precision. The calculated number should be adjusted for non-response and feasibility. The proposal must not state a sample size as final until the assumptions and expected accessible population have been confirmed.

A consecutive sampling approach is proposed: all eligible patients attending the selected site during the recruitment period will be invited until the approved sample size is reached. If a different sampling method is required by the department, it should be specified before data collection. The number approached, eligible, consenting, and completing the questionnaire will be documented.

3.6 Data Collection Tools

Data will be collected using a structured interviewer-administered questionnaire. The draft tool in Appendix I is intended for adaptation and review; it should be assessed by the supervisor and relevant clinical or research experts before use. The questionnaire will cover:

14. Socio-demographic information: age group, sex, residence, education, employment, household composition, and broad income category.
15. Selected clinical information: time since diagnosis, type of leukemia if known, current care status, and frequency of visits. Clinical information should be obtained only with appropriate permission.
16. Psychological concerns: a supervisor-approved screening instrument, potentially HADS, or a clearly identified set of non-diagnostic questions if use of a standardized instrument is not feasible.

17. Economic impact: patient-reported medical costs, transport, accommodation, food, caregiver costs, lost work/income, borrowing, and assistance received over a defined recall period.

18. Access and coping: travel time, accommodation, separation from family, perceived support, barriers to attendance, and coping strategies.

The questionnaire should use a clear recall period for all cost questions, such as the most recent visit and/or the previous 30 days. Currency and units should be recorded consistently, and respondents should be allowed to say “do not know” or decline sensitive financial questions.

3.7 Validity and Reliability

Content validity will be assessed by asking the supervisor and appropriately qualified reviewers to assess clarity, relevance, completeness, cultural suitability, and alignment with the objectives. The tool will be revised based on their feedback. If a standardized scale is used, its validated version, language, scoring guidance, and use requirements must be checked. Internal consistency may be assessed where appropriate for the scale and sample, but reliability statistics should not be calculated or reported before data collection.

3.8 Pilot Study

A pilot study will be conducted with a small group of similar patients, subject to ethical approval and supervisor guidance. Pilot participants should not be included in the main sample if the questionnaire is substantially revised, unless the approved protocol explicitly permits their inclusion. The pilot will assess question clarity, interview duration, privacy, and practical data-collection procedures.

3.9 Data Collection Procedure

19. Obtain approval from the university and permission from the selected facility and relevant ethics committee before recruitment.
20. Coordinate with the clinical team to identify suitable times and locations for approaching patients without disrupting care.
21. Explain the study in a language the participant understands, provide the information sheet, and obtain voluntary informed consent.

22. Administer the questionnaire in a private and respectful setting. Participants may skip questions or stop at any time without affecting their care.

23. Review forms for missing or unclear responses without pressuring participants to answer.

24. Assign study codes rather than names and store completed forms securely.

25. Provide information about available clinical or psychosocial support if a participant becomes distressed or requests help.

3.10 Data Analysis

Data will be checked, coded, and entered into a suitable statistical package such as SPSS or an equivalent program. Descriptive statistics will summarize participant characteristics and study variables. Categorical variables will be presented as frequencies and percentages; continuous variables will be summarized using means and standard deviations when distributions are approximately symmetric, or medians and interquartile ranges when skewed.

If a standardized psychological scale is used, scoring will follow its authorized instructions. The analysis plan may compare screening scores or categories across selected variables. Chi-square or Fisher's exact tests may be used for categorical associations, while t-tests, analysis of variance, or non-parametric alternatives may be considered for continuous outcomes when appropriate. The test selected will depend on variable type, distribution, sample size, and assumptions. A significance level of 0.05 may be used if approved, with effect estimates and confidence intervals reported where possible. Missing data and any exclusions from analysis will be described. No statistical results should be inserted until real data have been collected and analysed.

3.11 Ethical Considerations

- Ethical approval and institutional permission will be obtained before any recruitment or data collection.
- Informed consent will be obtained from each participant. Participation will be voluntary, and refusal or withdrawal will not affect care.
- Confidentiality will be protected by using study codes, limiting access to data, and reporting results in aggregate form.

- Only data necessary for the study objectives will be collected. Names and direct identifiers should not appear in the analysis dataset.
- Interviews will be conducted privately where possible, and participants may decline questions about income, borrowing, or emotional experiences.
- Because questions about cancer and finances may cause discomfort, the interviewer will pause or stop the interview if needed and follow the approved referral procedure.
- Clinical records will be accessed only with appropriate authorization and in accordance with the ethics approval and facility policy.
- Electronic files will be password-protected and paper forms stored in a locked location. Data retention and destruction will follow university requirements.

3.12 Limitations of the Study

- A facility-based sample may not represent all inbound leukemia patients in Northern State or Sudan.
- Self-reported expenses and income loss may be affected by recall error or reluctance to disclose financial information.
- A cross-sectional design can identify associations but cannot establish causation or changes over time.
- The accessible number of eligible patients may limit the precision of estimates and the number of associations that can be tested.
- Psychological screening scores, if used, indicate possible symptoms and do not replace clinical assessment.

3.13 Dissemination of Findings

The completed report will be submitted to the Faculty of Nursing Sciences at Dongola University. A summary may be shared with the participating facility and relevant nursing or health-service stakeholders, subject to university approval and confidentiality requirements. Findings will be reported honestly, including limitations.

3.14 Proposed Work Plan

The schedule below is illustrative and should be adjusted to the academic calendar and the timing of ethics approval.

Month 3	Month 2	Month 1	Activity
		✓	Proposal review and supervisor approval
	✓	✓	Ethics and facility permissions
	✓		Questionnaire review and pilot
✓	✓		Data collection
✓			Data entry and analysis
✓			Report writing and submission

3.15 Estimated Budget

The amounts below should be completed using realistic local prices before submission. The study should not promise services or expenditure that have not been approved.

Basis/notes	Estimated cost (SDG)	Item
Questionnaires, consent forms, proposal		Printing and photocopying
Travel to and from the study site		Transport
Calls/data for coordination		Communication and data
Pens, folders, paper		Stationery

If a fee is required		Data entry/analysis
Explain percentage or basis		Contingency
To be calculated		TOTAL

REFERENCES

American Cancer Society. (2023). Cancer-related financial hardship and cancer care resources. American Cancer Society. (Consult the current official resource and cite the specific page used in the final submission.)

National Cancer Institute. (n.d.). Adjustment to cancer: Anxiety and distress. National Cancer Institute. https://www.cancer.gov/about-cancer/coping/feelings

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Zigmond, A. S.,&Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandinavica, 67(6), 361–370. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x

Reference note: These are starting references, not a substitute for a full literature search. Before submission, verify every reference, add recent peer-reviewed studies relevant to leukemia, cancer-related distress, financial toxicity, travel for care, and Sudan or comparable settings, and apply the citation style required by the department (for example, APA 7th edition). Do not cite sources that have not been read and verified.

APPENDIX I: DRAFT QUESTIONNAIRE

Study title: Psychological and Economic Impact of Receiving Care among Inbound Leukemia Patients at Dongola

Instructions to interviewer: Explain the study, obtain consent, and protect privacy. Do not record names on the questionnaire. The tool must be reviewed and approved beforeuse. Use the same defined recall period for expenditure questions. The following draft questions are not a validated psychological scale.

Section A: Eligibility and Background

Study code: _____.26

Age: ____ years (or approved age group: 18–29 / 30–39 / 40–49 / 50–59 / 60+)..27

Sex: Female / Male / Prefer not to answer..28

Usual place of residence (locality/state; do not record exact home address): .29 _____.

Do you usually live within Dongola municipal boundaries? Yes / No. (If yes, not eligible under this protocol.) .30

Highest level of education completed: No formal education / Primary / Secondary / College or university / Other. .31

Current employment status: Employed / Self-employed / Unemployed / Student / Retired / Unable to work / Other. .32

How many people usually depend on your household income? ____..33

Household income category, using locally appropriate ranges approved before data collection: _____ / Prefer not to answer. .34

Section B: Care and Travel

Has a healthcare professional diagnosed you with leukemia? Yes / No / Unsure. .35 (Confirm eligibility through the approved process.)

If known, what type of leukemia have you been told you have? _____ / Do not know / Prefer not to answer. .36

Approximately how long ago were you diagnosed? Less than 3 months / 3–11 months / 1–2 years / More than 2 years / Unsure. .37

38. What type of care are you attending for today? Consultation / Treatment / Investigation / Admission or follow-up / Other.

39. How long does a one-way journey to Dongola usually take? ____ hours.

40. How do you usually travel to Dongola? Public transport / Private vehicle / Ambulance / Other.

41. How many trips to Dongola for leukemia care have you made in the past 30 days? ____.

42. Do you usually need accommodation in Dongola for care? Yes / No.

43. If yes, where do you usually stay? Relative/friend / Rented room or house / Hospital-provided accommodation / Charity or community accommodation / Other.

44. Does someone usually accompany you? Yes / No. If yes, who? _____.

45. What are the main difficulties you experience when travelling for care? (Select all that apply) Cost / Journey length / Physical discomfort / Transport availability / Accommodation / Food / Family separation / Lost work/income / Other / None.

Section C: Psychological Experiences

For the final study, insert the exact approved psychological screening tool and its authorized wording, scoring instructions, and response options. Do not modify a validated scale without checking its requirements. The general questions below may be used only if approved by the supervisor and should not be presented as a diagnostic instrument.

46. During the past two weeks, how often have you felt worried or anxious about your illness or treatment? Never / Some days / More than half the days / Nearly every day.

47. During the past two weeks, how often have you felt sad or low in mood? Never / Some days / More than half the days / Nearly every day.

48. How much has worry about treatment affected your sleep? Not at all / A little / Moderately / A lot.

49. How much has being away from home affected you emotionally? Not at all / A little / Moderately / A lot / Not applicable.

Do you feel you have someone you can talk to when you feel worried? Always / .50
Often / Sometimes / Rarely / Never.

Would you like information about emotional or psychological support services? .51
Yes / No / Unsure.

Section D: Economic Impact

Suggested recall period: the previous 30 days, unless a question specifies the most recent trip. Record amounts in Sudanese pounds (SDG), or document the currency and conversion method if another currency is used.

During the past 30 days, approximately how much did you or your household pay .52
for consultations, tests, medicines, procedures, or other medical items related to leukemia? SDG _____ / Do not know / Prefer not to answer.

During the past 30 days, approximately how much was spent on transport for .53
leukemia care? SDG _____ / Do not know / Prefer not to answer.

During the past 30 days, approximately how much was spent on accommodation .54
in Dongola? SDG _____ / Not applicable / Do not know.

During the past 30 days, approximately how much was spent on meals or other .55
daily expenses while away for care? SDG _____ / Do not know.

Did an accompanying person lose income or work time because of your care? .56
Yes / No / Not applicable / Unsure.

Did you personally lose income or work time because of your illness or care? Yes .57
/ No / Not applicable.

If yes, estimate the income lost during the past 30 days, if comfortable: SDG .58
_____ / Prefer not to answer.

How did your household meet these costs? Current income / Savings / Help from .59
relatives or friends / Charity or community support / Borrowing / Selling assets /
Other (select all that apply).

Have costs related to care caused your household to delay paying for essential .60
needs such as food, housing, education, or utilities? Never / Once / More than
once / Prefer not to answer.

Have you ever delayed or missed a recommended visit because of transport, accommodation, or financial problems? Yes / No / Prefer not to answer. If yes, optional explanation: _____. .61

Who or what has helped you most with the costs of receiving care? _____ / No support / Prefer not to answer. .62

Section E: Support and Suggestions

Who provides the most emotional support during treatment? Family / Friends / Healthcare staff / Religious or community network / Patient group / No one currently / Other. .63

What helps you cope with the challenges of treatment and travel? _____. .64

What is the single biggest difficulty you face when receiving care in Dongola? _____. .65

What service or change would most help you or other inbound patients? _____. .66

Is there anything else you would like the research team to know? _____. .67

Interviewer notes (do not include identifying details):

_____

APPENDIX II: INFORMED CONSENT FORM

PARTICIPANT INFORMATION AND CONSENT

Study title: Psychological and Economic Impact of Receiving Care among Inbound Leukemia Patients at Dongola

Researcher(s): [Name(s), Faculty/Department, contact details approved by the university]

Supervisor: [Name and approved contact details]

Invitation and purpose

You are invited to take part in a research study about the psychological experiences and costs associated with receiving leukemia-related healthcare in Dongola among

people who usually live outside the city. Before deciding, please read or listen to this information and ask any questions you may have.

What participation involves

If you agree, a researcher will ask you questions about your background, travel for care, emotional experiences, expenses, and sources of support. The interview is expected to take approximately [20–30] minutes, subject to pilot testing. With your separate permission and ethics approval, limited relevant clinical information may be checked from your record.

Voluntary participation and risks

Taking part is voluntary. You may refuse to answer any question or stop the interview at any time. Your decision will not affect the healthcare you receive. Some questions about illness, emotions, or money may cause discomfort. You may request a pause or stop. If you become distressed, the researcher will follow the approved support/referral procedure.

Benefits, confidentiality, and data use

You may not receive a direct personal benefit. The information may help describe the needs of patients travelling to Dongola for care. Your name will not be written on the questionnaire, and results will be reported in summary form. Study records will be stored securely and accessed only by authorized members of the research team. Data will be retained and disposed of according to university and ethics requirements.

Questions or concerns

For questions about the study, contact: [researcher/supervisor contact]. For concerns about participants' rights, contact: [ethics committee contact, to be completed before recruitment].

Consent statement

I have had the study explained to me in a language I understand. I have had the opportunity to ask questions. I understand that participation is voluntary and that I may stop at any time without affecting my care. I agree to participate in this study.

Participant signature or thumbprint: _____ Date: ____ / ____ / _____

Researcher obtaining consent: _____ Date: ____ / ____ / _____

Witness/interpreter (if required by approved procedure): _____

Permission for the research team to review relevant clinical information, if applicable: Yes / No (This should be a separate optional choice if required by the ethics committee.)