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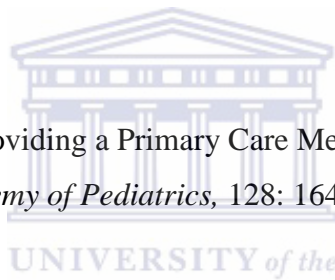
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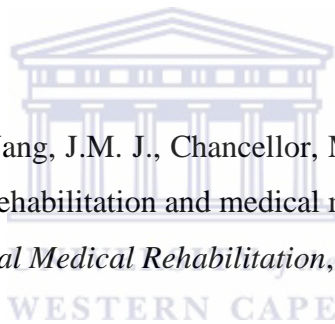
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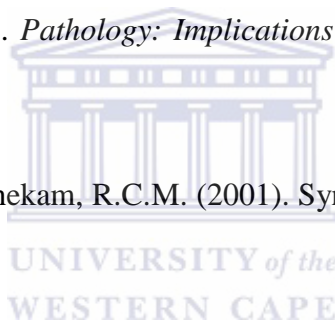
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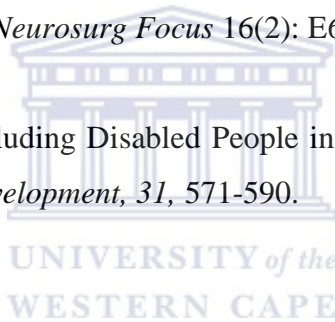
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APPENDICES

APPENDIX 1

DATA GATHERING INSTRUMENT

SECTION 1: DEMOGRAPHIC DATA

1.1 Code Number

1.2 Referral

Provincial (1)

District (2)

Direct contact to UTH /CURE (3)

Health centre (4)

1.3 Province of residence:

Northern (1)

Central (2)

Eastern (3)

North Western (4)

Luapula (5)

Southern (6)

Western (7)

Muchinga (8)

Lusaka (9)

Copperbelt (10)

1.4 Gender

Female (1)

Male (2)

1.5 Age on admission

Less than 1 month (1)



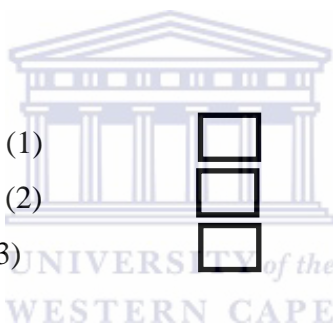
- 1 – 6 months (2)
- 7 – 12 months (3)
- 1 – 5 years (4)
- 6 – 10 years (5)

1.6 Birth history

- Normal delivery (1)
- Caesarean delivery (2)
- Fetal distress (3)
- Premature (4)
- Breech position (5)
- Unknown (6)

1.7 Mothers age at delivery

- Young mother (Less than 19 years) (1)
- Old mother (Over 40 years) (2)
- Unknown (3)



1.8 Mothers HIV status

- Positive (1)
- Negative (2)
- Unknown (3)

1.9 Folic Acid taken

- Yes (1)
- No (2)

1.10 Diagnosis

- Occulta (1)
- Meningocele (2)

- Myelomeningocele (3)
- Myelomeningocele & hydrocephalus(4)

1.11 Location of Spina Bifida

- Cervical (1)
- Thoracic (2)
- Thoraco- Lumbar (3)
- Lumbar (4)
- Lumbosacral (5)
- Sacral (6)

SECTION 2: MANAGEMENT

PART ONE: Overall management

2.1 What management did the patient undergo during their admission at UTH and BCIH?



PART TWO: Physiotherapy management

2.2 Referred for physiotherapy

A. Before surgery:

- Yes (1)
- No (2)

B. After surgery

- Yes (1)
- No (2)

2.3 Follow up:

- Yes (1)
- No (2)

2.4 Referral to other physiotherapy departments in areas closer to residence:

- Yes
- No

(1)

(2)



APPENDIX 2

INTERVIEW GUIDE: FOCUS GROUP DISCUSSION AND INTERVIEWS

Participant Number:

Qualification:

Gender:

Work experience:

1. What does physiotherapy management of Spina Bifida involve? What is your role as a physiotherapist in the rehabilitation process?
 - When do you see the patient pre-operatively or post operatively?
2. What interventions are used during the rehabilitation process?
3. How does the planning process at your hospital work? Do you feel included in the planning process?
 - Do you receive requests for physiotherapy?
 - The patient files did not show physiotherapy notes or even requests from doctors, is this information recorded in other files?
 - How are follow up programs conducted?
4. What has been your experience like managing children with Spina Bifida?
 - What factors have facilitated the rehabilitation process?
 - What factors have challenged the rehabilitation process?
5. Any recommendations you would like to make?
6. Anything else you would like to add?



UNIVERSITY of the
WESTERN CAPE

**OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT**

19 June 2015

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:
Ms F Banda (Physiotherapy)

Research Project: Physiotherapy management of Spina Bifida in Zambia

Registration no: 15/4/46

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

*Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape*



33 Joseph Mwilwa Road
Rhodes Park, Lusaka
Tel: +260 955 155 633
+260 955 155 634
Cell: +260 966 765 503
Email: eresconverge@yahoo.co.uk

I.R.B. No. 00005948
E.W.A. No. 00011697

14th August, 2015

Ref. No. 2015-June-025

The Principal Investigator
Ms. Faith Banda
Northern Technical College – H.E.R
Chela Road, Kansenshi
P.O. Box 250093,
NDOLA.

Dear Ms. Banda,

RE: PHYSIOTHERAPY MANAGEMENT OF SPINA BIFIDA IN ZAMBIA.

Reference is made to your resubmissions. The IRB resolved to approve this study and your participation as principal investigator for a period of one year.

Review Type	Ordinary	Approval No. 2015-June-025
Approval and Expiry Date	Approval Date: 14 th August, 2015	Expiry Date: 13 th August, 2016
Protocol Version and Date	Version-Nil	13 th August, 2016
Information Sheet, Consent Forms and Dates	• English.	13 th August, 2016
Consent form ID and Date	Version-Nil	13 th August, 2016
Recruitment Materials	Nil	13 th August, 2016
Other Study Documents	Data gathering Instrument, Questionnaire, Interview Guide	13 th August, 2016
Number of participants approved for study	10	13 th August, 2016

Specific conditions will apply to this approval. As Principal Investigator it is your responsibility to ensure that the contents of this letter are adhered to. If these are not adhered to, the approval may be suspended. Should the study be suspended, study sponsors and other regulatory authorities will be informed.


Conditions of Approval

- No participant may be involved in any study procedure prior to the study approval or after the expiration date.
- All unanticipated or Serious Adverse Events (SAEs) must be reported to the IRB within 5 days.
- All protocol modifications must be IRB approved prior to implementation unless they are intended to reduce risk (but must still be reported for approval). Modifications will include any change of investigator/s or site address.
- All protocol deviations must be reported to the IRB within 5 working days.
- All recruitment materials must be approved by the IRB prior to being used.
- Principal investigators are responsible for initiating Continuing Review proceedings. Documents must be received by the IRB at least 30 days before the expiry date. This is for the purpose of facilitating the review process. Any documents received less than 30 days before expiry will be labelled "late submissions" and will incur a penalty.
- Every 6 (six) months a progress report form supplied by ERES IRB must be filled in and submitted to us.
- ERES Converge IRB does not "stamp" approval letters, consent forms or study documents unless requested for in writing. This is because the approval letter clearly indicates the documents approved by the IRB as well as other elements and conditions of approval.

Should you have any questions regarding anything indicated in this letter, please do not hesitate to get in touch with us at the above indicated address.

On behalf of ERES Converge IRB, we would like to wish you all the success as you carry out your study.

Yours faithfully,
ERES CONVERGE IRB


Dr. E. Munalula-Nkandu
BSc (Hons), MSc, MA Bioethics, PgD R/Ethics, PhD
CHAIRPERSON

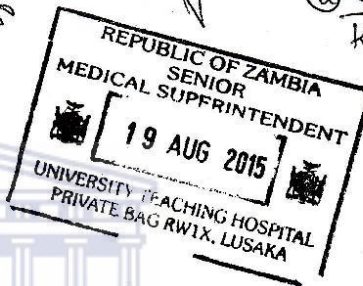
Ms .F. Banda
Clo Mr A.K. Banda
Northern Technical College – H.E.R
Chela Rd, Kansenshi
P.O BOX 250093
NDOLA

18th August, 2015

The Medical Superintendent,
University Teaching Hospital
P/Bag RWIX
Lusaka

① Head - Physio.
No objection
FJA
/h/v

② Supervisor D-Block
Kindly assist the
student to access
this information.
Maoma
25/08/15



Dear Sir/Madam,

RE: REQUEST FOR PERMISSION TO CARRY OUT STUDY AT YOUR INSTITUTION

Reference is made to the above stated subject. I am a student pursuing a Masters of Science in Physiotherapy at the University of Western Cape in Cape Town, South Africa.

PROPOSED TITLE: PHYSIOTHERAPY MANAGEMENT OF SPINA BIFIDA IN ZAMBIA

I therefore seek permission to enable me to carry out this proposed study at your institution. This will be carried out between August to October, 2015. The study will entail reviewing of Spina Bifida patient records and interviewing of Physiotherapists that manage these patients. All ethical issues will be addressed.

Find attached ethical clearance letters from University of Western Cape and ERES Converge. Your favourable response will be highly appreciated.

Yours Faithfully,

Banda

Faith Banda (Miss)

Contact: +260979878521



OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

19 June 2015

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:
Ms F Banda (Physiotherapy)

Research Project: Physiotherapy management of Spina Bifida in Zambia

Registration no: 15/4/46

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

P. Josias

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

Approved, 24 August 15

DR. G. LACROIX

[Handwritten signature]



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www.uwc.ac.za

A place of quality,
a place to grow, from hope
to action through knowledge



APPENDIX 7

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542 Fax: 27 21-959 1217

E-mail: bandafaithdoc@yahoo.com

INFORMATION SHEET

Project Title: PHYSIOTHERAPY MANAGEMENT OF SPINA BIFIDA IN ZAMBIA

What is this study about?

This is a research project being conducted by Faith Banda a student at the University of the Western Cape. We are inviting you to participate in this research project because you have important information that will benefit this research as it applies to the experiences of physiotherapists in the management of Spina Bifida in Zambia. The purpose of this research project is to explore the experiences of physiotherapists managing Spina Bifida in Zambia.

What will I be asked to do if I agree to participate?

You will be asked to attend a focus group discussion and interview for others that will last at least 20 to 50 minutes. A debriefing session will be held after the focus group discussion/interview to confirm what has been discussed in the first discussion at hospital premises in a secure venue. The discussions and interviews will be recorded using an audio tape recorder. All participants are encouraged to participate without reservations. The discussion and interviews will involve questions such as: What is the role of the physiotherapist in the management of Spina Bifida? What are the interventions given to patients with SB? Do you feel included in the rehabilitation process? What has been your experience in managing Spina Bifida?

Would my participation in this study be kept confidential?

The researcher undertakes to protect your identity and the nature of your contribution. To ensure your anonymity, your name will not be mentioned in this research. All participants will be given identification codes and tags that will be used to address participants during the discussions and also used on the consent forms and focus group confidentiality binding forms. The recordings will be stored in filing cabinets under lock which only the researcher will have access to. The identification codes will only be known by the researcher.

The researcher will write a report about the findings of the research and your identity will be protected.

This study will use focus group discussions and the extent to which your identity will remain confidential is dependent on participants' in the Focus Group maintaining confidentiality.

I agree to be audiotaped during my participation in this study.

I do not agree to be audiotaped during my participation in this study.

What are the risks of this research?

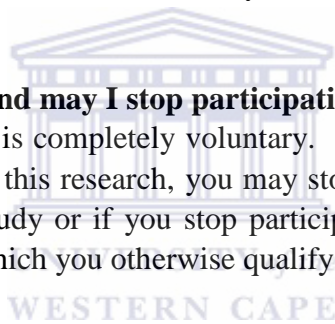
All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about your experiences as physiotherapists in managing Spina Bifida. We hope that, in the future, other people might benefit from this study through improved understanding of experiences of physiotherapists.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.



What if I have questions?

This research is being conducted by Faith Banda from the Physiotherapy Department at the University of the Western Cape. If you have any questions about the research study itself, please contact Faith Banda at:

Tel: +260979878521

+260955355237

Email: bandafaithdoc@yahoo.com

3416407@myuwc.ac.za.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department:

Dr. N. Mlenzana

Head of department Physiotherapy

University of the Western Cape

Private bag X17

Bellville 7535

nmlenzana@uwc.ac.za

Dean of the Faculty of Community and Health Sciences:

Prof José Frantz

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.



APPENDIX 8



UNIVERSITY OF THE WESTERN CAPE

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Tel: +27 21-959 2542, Fax: 27 21-959 1217

CONSENT FORM

Title of Research Project: PHYSIOTHERAPY MANAGEMENT OF SPINA BIFIDA AT UTH AND BEIT CURE INTERNATIONAL HOSPITAL.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name.....

Participant's signature.....

Date.....

CONTACTS:

Principal Investigator

Ms. F. Banda

Email: bandafaithdoc@yahoo.com

3416407@myuwc.ac.za

Tel: +260979878521

+260955355237

APPENDIX 9



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542, Fax: 27 21-959 1217

FOCUS GROUP CONFIDENTIALITY BINDING FORM

Title of Research Project: PHYSIOTHERAPY MANAGEMENT OF SPINA BIFIDA IN ZAMBIA

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I understand that confidentiality is dependent on participants' in the Focus Group maintaining confidentiality. I hereby agree to the following:

I agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

Participant's name.....

Participant's signature.....

Date.....

APPENDIX 10

MAP OF ZAMBIA





UNIVERSITY *of the*
WESTERN CAPE



LIENEKE BOESAK DEVELOPMENT PROJECTS

E-MAIL: lienekeboesak@webmail.co.za

Trading as:
Integrated Learning Systems
Reg No: 2012/172787/07

10 January 2016

This serves to confirm that the Masters of Science thesis of **FAITH BANDA** entitled:
"Physiotherapy management of Spina Bifida in Lusaka, Zambia" has been proof-read and
edited for submission to the University of the Western Cape.



LIENEKE BOESAK

