

## APPENDIX A: PARTICIPANT INFORMATION SHEET



School of Human and Community Development

*Private Bag 3, Wits 2050, Johannesburg,  
South Africa  
SUPERVISOR: Dr. Vinitha Jithoo  
Tel: (011) 717-4523 Fax: (011) 717-4559*

Dear Sir/Madam,

Hello. My name is Shani Zuk. I am currently enrolled for a Masters degree in Clinical Psychology at the University of the Witwatersrand. One of the requirements of the degree is the completion of a research report. I would like to do research focusing on the impact of nursing in paediatric palliative care. I invite you to participate in this study.

I would like to examine the scope and practice of paediatric palliative nursing as practiced in the context of HIV and Aids. Research in this area is very new and limited and hence I would like to examine what this form of work entails, the type training and education you go through and how well this prepares you for your line of work. Research has also found that professionals working in palliative care may also experience a range of emotions. I am curious about these feelings and how you cope with them.

Participation in this research will entail being interviewed by myself, at the Hospice/Cotlands premises, at a time that is convenient for you. Participation is voluntary, and no person will be advantaged or disadvantaged in any way for choosing to participate or not participate in the study. The interview will last approximately one to one and half hours. With your permission this interview will be audio recorded, in order to ensure accuracy. Additionally, direct quotes from the interviews may be used in the research report. However all of your responses will be kept confidential. Thus, no information that could identify you would be included in the research report, such as names or contact details. The interview material (tapes and transcripts) will not be seen or heard by any person in this organisation at any time, and will only be accessed by myself and my supervisor. My supervisor is Dr. Vinitha Jithoo and her email details are [Vinitha.Jithoo@wits.ac.za](mailto:Vinitha.Jithoo@wits.ac.za) and her telephone number is (011) 717-4523. You may choose to withdraw from the study at any point. There are no anticipated risks to this study, however if participation in this study arouses any emotional distress, free counselling may be obtained through Lifeline (011-728 3497), as well as at the Emthomjeni Centre (011-717 4513). Upon completion of the study, the audio tapes, as well as the transcribed material, will be kept in a secure place at the university for a period of six years. The results of the study will be reported in the research report and a summary will be given to the Soweto Hospice and Cotlands Baby Sanctuary.

If you choose to participate in the study please fill in your details on the form below and place it in the sealed box provided. I will empty the box at regular intervals, and will contact you within two weeks in order to discuss your participation. Alternatively, I can be contacted telephonically at 084 242 2004 or via e-mail at [zukshani@gmail.com](mailto:zukshani@gmail.com).

Your participation in this study would be greatly appreciated. This research will contribute both to a larger body of knowledge regarding the experiences of paediatric palliative care, as well as to your organisation's understanding of how to assist you to cope with the distressing elements of paediatric palliative care.

Kind Regards  
Shani Zuk  
Contact details:  
084 242 2004  
[zukshani@gmail.com](mailto:zukshani@gmail.com)

**APPENDIX B: CONSENT FORM 1**

This consent form confirms that I have read and understood the scope of this study. Additionally, it confirms that I have understood the terms of this study.

I \_\_\_\_\_ (respondent's name) consent to:

Participation in this study, entitled, "*A study of Paediatric Palliative Care Nursing*".

I understand that:

Participation in this interview is voluntary.

That I can withdraw from the study at any time.

That I may refrain from answering any questions I do not wish to answer.

That no risks or benefits are anticipated

Signature of Respondent \_\_\_\_\_

Signature of Researcher \_\_\_\_\_

**APPENDIX C: CONSENT FORM 2**

This consent form confirms that I have read and understood the scope of this study. Additionally, it confirms that I have understood the terms of this study.

I \_\_\_\_\_ (respondent's name) consent to:

Participation in this study, entitled, "*A study of Paediatric Palliative Care Nursing*".

I understand that:

The audiotapes will be kept in a locked draw that can only be accessed by the researcher and the supervisor.

Upon completion of this study, all data will be destroyed.

Signature of Respondent \_\_\_\_\_

Signature of Researcher \_\_\_\_\_

## **APPENDIX D: POSSIBLE INTERVIEW QUESTIONS:**

### **1. Establishment of rapport**

What is your level of training?

What position do you currently occupy?

How long have you been working in the nursing field?

How long have you been working in the paediatric palliative care nursing field?

### **2. CORE THEME 1: Nature and scope of practice**

Question: What does your work entail?

**Probes:** types of support do you offer to your patients and their families,  
challenges and obstacles, training and education, organisational support.

### **3. CORE THEME 2: Impact of PPC work**

Question: What is the impact of this type of work?

**Probes:** feelings: grief and loss, personal relationships, attitudes about HIV and aids,  
support needs, coping mechanisms.

**APPENDIX E: INSTITUTION CONSENT FORM**



**SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT  
UNIVERSITY OF THE WITWATERSRAND**

Private Bag 3, WITS, 2050  
Tel: (011) 717 4500 Fax: (011) 717 4559

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**Consent to conduct research**

I JOAN BUCHANAN grant Ms. Shani Zuk permission on to conduct research at SOWETO HOSPICE (name of institution) subject to her following the ethical and moral guidelines which guide the research process.

Date 30.3.09.

Signature: J Buchanan

**APPENDIX F: INSTITUTION CONSENT FORM**

T01R, P.01



**SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT  
UNIVERSITY OF THE WITWATERSRAND**  
Private Bag 3, WITS, 2050

Tel: (011) 717 4500 Fax: (011) 717 4559

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**Consent to conduct research**

I, Stella Dubazana grant Ms. Shari Zuk permission on to conduct research at Cottarod (name of institution) subject to her following the ethical and moral guidelines which guide the research process.

Date 21.03.09

Signature

A handwritten signature in black ink, appearing to be 'Stella Dubazana', written over a horizontal line.

P.01/01

T0 0866857688

FROM 9661-884-08 03:35

## **APPENDIX G: LETTER REQUESTING INSTITUTIONAL PERMISSION TO CONDUCT RESEARCH**



School of Human & Community Development  
**University of the Witwatersrand**  
Private Bag 3, WITS, 2050  
Tel: (011) 717 4500 Fax: (011) 717 4559

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Sir/Madam

### **RE: Permission to conduct research**

My name is Shani Zuk. I am currently enrolled for a Masters degree in Clinical Psychology at the University of the Witwatersrand. I am seeking permission to conduct research in partial fulfilment of my degree at your institution. My interest lies in examining work, personal, and interpersonal issues as experienced by paediatric palliative care nurses.

Last year I conducted a research project as part of my Honours degree in Psychology entitled, "A study of Compassion Fatigue among Palliative Care nurses working at Hospice". This study aimed to discover the experience of compassion fatigue, as well as the coping strategies, that are employed among hospice nurses in Gauteng. The focus was on the psychosocial impact of palliation on the nurses' personal views, health, and relationships, as well as the personal and work factors that either predisposed to or protected from developing CF. Ten nurses were interviewed, using a semi-structured interview schedule. The data was analysed using thematic content analysis. Results showed that there are various dimensions of empathy, which may serve as both a risk and protective factors. This depended on whether an individual could disengage from ones work, as well as whether they were able to not become over involved, or over identify with one's patient. Furthermore, different coping mechanisms and resources were found, including various creative outlets, social support, colleague support, exercise, and relaxation. In conclusion, it was found that despite the job of a hospice nurse being very demanding, this sample of hospice nurses appeared to remain relatively positive about their jobs, as well as utilize quite effective coping strategies.

This year, my aim is to focus on the experiences of paediatric palliative care nurses. I would like to study how the nurses are affected by their job; as well as what coping methods they employ in order to cope with the unique stressors of their work. I would like to conduct one-on-one interviews with eight to ten paediatric palliative care nurses. The duration of these interviews will be approximately one hour. If permission is granted I will contact the nurses and set up appointments and ensure that the interviews do not interfere with their work schedule. These interviews will be kept separate from the nurses' work, and will not interfere with their work performance. Participation would also be voluntary and staff anonymity will be guaranteed. I will come to Hospice/Cotlands Baby Sanctuary, in order to explain the focus of my research, and what it entails.

I look forward to a positive response. If you have any further queries please do not hesitate to contact either myself or my supervisor. Should you decide to permit this indulgence please sign the consent slip below. This slip is for the purposes of the ethics and consent process which is a standard requirement at the University of Witwatersrand.

Yours faithfully

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**Ms. Shani Zuk**  
(Honours Student)  
Tel: 0842422004  
Email: [zukshani@gmail.com](mailto:zukshani@gmail.com)

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**Dr. V. Jithoo**  
(Research Supervisor)  
Tel: 011 7174523  
Email: [Vinitha.jithoo@wits.ac.za](mailto:Vinitha.jithoo@wits.ac.za)

**APPENDIX H: MEDICAL ETHICS CLEARANCE CERTIFICATE**

**UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG**

Division of the Deputy Registrar (Research)

**HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)**

R14/49 Ms Shani E Zuk

**CLEARANCE CERTIFICATE**

**M090667**

**PROJECT**

A Study of Paediatric Palliative Care Nurse

**INVESTIGATORS**

Ms Shani E Zuk.

**DEPARTMENT**

School of Human & Community Development

**DATE CONSIDERED**

09.06.26

**DECISION OF THE COMMITTEE\***

Approved unconditionally

**Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.**

**DATE** 09.07.03

**CHAIRPERSON**.....



(Professor P E Cleaton Jones)

\*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr V Jithoo

**DECLARATION OF INVESTIGATOR(S)**

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

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