Scrutinizing care in nursing practice

An ethnographic study of nurse-mother interaction in programmes to prevent HIV transmission from mother to child in Tanzania

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Dissertation for the degree of philosophiae doctor (PhD)
at the University of Bergen

2015

Dissertation date: 02.10.2015

LIST OF ABBREVIATIONS

AIDS:	Acquired Immune Deficiency Syndrome
AFASS:	Available, feasible, affordable, sustainable and safe
ART:	Anti-retroviral treatment
ARV:	Anti-retroviral
CTC:	Care and treatment centre
EMTCT:	Elimination of mother-to-child transmission of HIV
HAART:	Highly active anti-retroviral
HBC:	Home based care provider
HIV:	Human Immunodeficiency Virus
LMIC:	Low- and middle-income countries
MOHSW:	Ministry of Health and Social Welfare
MTCT:	Mother-to-child transmission
NGO:	Non-governmental organisation
PhD:	Philosophiae doctor
PMTCT:	Prevention of mother-to-child transmission of HIV
RCHS:	Reproductive and child health services
TACAIDS:	Tanzania Commission for AIDS
UNAIDS:	Joint United Nations Programme on HIV and AIDS
UNFPA:	The United Nations Population Fund
UNICEF:	United Nations International Children's Emergency Fund
URT:	The United Republic of Tanzania
WHO:	World Health Organization

SCIENTIFIC ENVIRONMENT

This PhD project was funded by the Department of Health Studies at the University of Stavanger through a three-year full-time scholarship. Research training and supervision has been carried out at the Department of Global Public Health and Primary Care at the University of Bergen. I had daily affiliation at the University of Stavanger with regular trips to Bergen for supervisory sessions and attendance at the Research group meetings in ‘Global Health Anthropology’. Professor Astrid Blystad (University of Bergen) has been my main supervisor, with co-supervisors Professor Karen Marie Moland (University of Bergen), Associate Professor Bjørg Evjen-Olsen (University of Bergen and Sørlandet Hospital, Avd. Flekkefjord) and Dean Sebalda Charles Leshabari (Muhimbili University of Health and Allied Science, Tanzania).

ACKNOWLEDGEMENTS

There are many people who deserve warm thanks for their willingness, contributions and support during the work of this PhD project. First and foremost a debt of gratitude goes to the nurses and women enrolled in the present ‘Prevention of mother-to-child transmission of HIV’ (PMTCT) programmes for their willingness to participate in the study, their sincerity in sharing their experiences and their openness in including me in their daily interactions and work. Without their participation and co-operation the project would not have been possible.

There are few words that can express my deep thankfulness to my supervisors who have followed me closely through all these years. Professor Astrid Blystad has been my main supervisor and has followed me from my master studies in 2001 and has, through her invaluable guidance, knowledgeable and skilled supervision, enthusiasm, kindness and friendship, been a decisive part of the project and I cannot thank her enough. Together with her academic excellence, her capacity and generosity seem to be endless and you have pushed me up the steepest peaks and guided me gently down the hillsides time and again. Thank you so much! Professor Karen Marie Moland deserves my warmest gratitude for her contributions through her sharp and well-informed eye, her motivating response and continuous support. Her warm presence and constant awareness for others wellbeing has been immensely appreciated – thank you so much! A deep gratitude goes to associate professor Bjørg Evjen-Olsen for her vital contributions to the project as well as her deep knowledge in the field area, her kindness and continuous support – thank you! Dean Sebalda Leshabari has particularly been an important contributor, inspiration and helpful co-ordinator in the planning of the project and through its first phases – thank you!

Many thanks also go to the regional and district administrative and medical authorities as well as to the hospital management at both hospitals for their interest and trust in the research, and for allowing access to the hospital clinics. The research assistants, Astelina Mussa, Julietha Sinyaw, Jovita Daniel and Captolina Kassy, who provided invaluable assistance and dedicated work, deserve warm thankfulness.

The project has been funded by the Department of Health at the University of Stavanger. Venche Hvidsten, former Head of Department, gave me the opportunity to initiate the project with her positive support which has continued throughout the project as we have worked closely together in recent years – thank you. Kari Vevatne, Head of Department, has followed and supported the project and provided financial as well as kind-hearted support and generosity.

Among my colleagues, many deserve to be thanked. Bjørg Oftedal in particular has been an inspiration with her continuous support, excellent expertise and friendship, and together with Margareth Kristoffersen, my wise and much-appreciated colleague, they constitute role models in academic writing. Colleagues and fellow PhD-students with whom I have worked particularly closely and who have also contributed with endless encouragement are Kristin Hjorthaug Urstad, Brynjar Foss, Kristin Bodsberg, Torunn Strømme, Maria Handeland, Ingrid Ølfarnes Røysland, Kristin Kavli Adriansen and Anne Marie Lunde Husebø – thank you all so much. Thanks also go to Kjellaug Kaldestad Johannessen, Anne Bakke-Erichsen, Tone Knutsen Brandeggen and Bente Rossavik for excellent co-operation and friendship during the last years. Those PhD-students and colleagues at the University of Bergen who have followed me throughout the process, I would like in particular to thank are Anne Siri Fismen, Anne Marie Sandvoll, Marit Tolo Østebø, Elin Vestbøstad and Nils Gunnar Songstad – thank you for your friendship and supportive talks through the ups and dows of the project. I would also like to thank Ingvild Fossgard Sandøy, associate professor at the Department of Global Public Health and Primary Care, for always being positive, helpful and giving constructive and insightful comments to drafts and presentations held at the research group meetings. Heather Owen is given a special thank you for excellent language editing and co-operation through short deadlines.

Without dear friends and family life, in spite of the ever-present thesis, would not be the same. Thanks go to my dearest friends Martha Vadset, Liv Åse Flotve and Kristin Lundblad for making an extra bed for all my overnight stays in Bergen – these visits have been a major bonus throughout the project period which I will miss for sure. A special thank you goes to my wonderful friends in Stavanger, Astrid Aadland and Turid Marie Espeseth, for true friendship through life's ups and downs. My parents, Aase and Ole Arild Bø, and my parents in law, Solveig and Leiv Våga, all visited us during our stay in Tanzania, which was greatly appreciated. I hope, and believe, it provided an understanding of my commitment to Tanzania. My deepest thanks go to my beloved sister, Marit Bø Reitan, who is always there for me! In addition to practical support, like watching the children, telling my husband to clean the house and feeding us, your continuous support and encouragement has been invaluable – thank you!

During the PhD-period I have been blessed with three children – Ole, Laurits and Lise – each of you enrich my life endlessly and remind me of the most important part of life – love! My dear husband and best friend, Hans Marius, our shared dedication for Tanzania, its people, language and culture made *my* fieldwork *our* fairytale, which has inspired and maintained our

common affiliation with this project during the years of writing. You have been exceptionally patient and your support and wisdom fill me every day. I am immensely grateful for your presence in life!

ABSTRACT

Background: Care lies at the core of professional nursing practice worldwide, however, the content of the concept and what care implies in actual practice have been debated for decades. The constructions and essence of care as particularly connected to nursing practice have attracted limited attention in research from sub-Saharan Africa. The major aim of the present study has been to scrutinize nursing care in nurses' every day practice in low-income settings. The study seeks to explore the caring behaviours found in nurses' interaction through the examination of nursing practice in a context of HIV-positive women enrolled in Prevention of mother-to-child transmission of HIV (PMTCT) programmes in rural and semi-urban areas of Tanzania.

Methods: The study is based in ethnographic tradition. Fieldwork took place from November 2008 to August 2009 in a rural and a semi-urban area in Tanzania. The study settings were PMTCT programmes in two hospitals, one church-run and one government-run, and their outreach areas. Participant observation in clinical settings and during home visits combined with in-depth interviews, informal conversations and group discussions produced the bulk of the data material. The main categories of informants were nurses employed in the two PMTCT programmes and HIV-positive women enrolled in these programmes. Two female research assistants were trained to help with translation during the interviews, and worked closely with the researcher throughout the fieldwork period. Two additional research assistants transcribed and translated the interviews and counselling sessions that were audio recorded. The observations and transcriptions were discussed and clarified with the research assistants, the nurses and the HIV-positive women on a daily basis in efforts to enhance the understanding and the emerging meaning of the findings. After leaving the field, a thorough reading of the material was followed by manual coding of the data set, a process that identified key categories and themes. All supervisors and co-authors have extensive research experience from Tanzania, have proficiency in Swahili and took part in discussions of the emerging themes and their meanings during the diverse stages of the analysis.

Findings: The three papers present the major findings. Paper I focuses on care, Paper II on counselling and choice, and Paper III on confidentiality. The findings provide a scenario characterized by stark diversity between the two programmes in terms of how the nurses perceive and practically handle and relate to the national guidelines on PMTCT and infant feeding while the nurse-mother interaction did not, overall, vary to the same degree. All nurses enrolled in the study were found to ‘care about’ their patients, while their opportunities to ‘care for’ their patients varied due to the differing terms and conditions of the two programmes. How the nurses in the two programmes were observed to ‘care about’ was expressed through examples of a genuine concern for the HIV-positive women enrolled in the programmes. HIV-positive women were seen to adhere to, and trust, the nurses in situations where the mothers’ experiences of care were expressed and observed to be appreciated and to coincide with their expectations of the nurses, who were impacted by authoritative knowledge and a combination of instructive communication and personal involvement in the women’s lives. Such behaviours were observed to make the HIV-positive women feel safe and secure, which led them to trust the nurses and follow their advice in infant feeding practice. In situations where the expectations of the HIV-positive women were not met by the nurses, the mothers felt that they had provided unclear and diverging advice as well as not being able to ‘care for’ them. In such situations the HIV-positive women expressed being frustrated and lacking confidence in how to relate to the PMTCT programme and were often found not to follow the advice on infant feeding practices given to them by the hospital nurses. The key findings are the manner in which caring conduct emerges through a communication characterized by the clear and direct education (‘giving instructions’) and by broader and less strictly defined borders between private and professional lives (Paper I). Nursing care is scrutinized as it emerges at the intersection between health-related ethics and nurse-patient interaction, and is exemplified through a concrete focus of contexts calling for ‘informed choice and patient participation’ (Paper II) and ‘confidentiality’ (Paper III).

Conclusion: The study has added to the understanding of nursing care as culturally- and socially constructed and as produced, re-enforced and changed not only through policy, socio-economic structures and training but also in the interaction between the nurse and the client. The way nursing care is constructed in the example provided in this work is an important comment to the dominant discourse on nursing care which emanates from nursing in Europe and North-America where the socio-cultural, professional and health system context is very different. As illustrated here, this does not imply that patients in the PMTCT programme in Tanzania feel less cared for. On the contrary, the care given to them resonates with their desires and strengthens their trust in the nurses. The implications drawn from the study are that although nurses globally aim to relieve pain and suffering, their approach should be allowed to evolve in local contexts of authority, knowledge and legitimacy.

LIST OF PUBLICATIONS

Paper I:	Våga, B. B., Moland, K. M., Evjen-Olsen, B., Leshabari, S. C. & Blystad, A. (2013) Rethinking nursing care: An ethnographic approach to nurse-patient interaction in the context of a HIV prevention programme in rural Tanzania. *International Journal of Nursing Studies* Aug;50(8):1045-53.
Paper II:	Våga, B.B., Moland, K.M., Evjen-Olsen, B. & Blystad, A. (2014) Reflections on informed choice in resource-poor settings: The case of infant feeding counselling in PMTCT programmes in Tanzania. *Social Science & Medicine.* Mar;105:22-9.
Paper III:	Våga, B.B., Moland, K.M. & Blystad, A. (2015) Boundaries of confidentiality in nursing care for mother and child in HIV programmes. *Nursing Ethics.* May 8. [Epub ahead of print].

CONTENTS

RESEARCH PAPERS

APPENDICES

1.0. INTRODUCTION

This dissertation focuses on how care is expressed and experienced in encounters between nurses and HIV-positive women in Tanzania. The study explores care and care interactions through the WHO initiated programme *Prevention of mother-to-child transmission of HIV* (PMTCT) which aims to assist HIV-positive women protect their infants from HIV-transmission through safer infant feeding, medication and support.

Providing care to patients has been located at the core of nurses' work since the inception of professional nursing practice. What nursing care is and what it is supposed to involve has however been hotly debated, particularly in discourses in dominant academic nursing milieus, where care as a concept as well as care in nursing practice have been scrutinized substantially. A key assumption underlying this research is that nursing care cannot be understood independently of the social and cultural contexts that surround care, and that what good care implies will vary between social settings. A study seeking to make sense of how nursing care is expressed and experienced hence has to take into account the context in which care is being practised and made sense of.

The severity of the health care- and health system challenges in low-income countries was brought to the forefront of attention with the growing scale of the HIV epidemic through the 1980s and 1990s. In sub-Saharan Africa, the HIV epidemic placed a huge burden on the health care sector both in terms of the escalating number of patients with demanding care needs, and in terms of the loss of health workers. Nurses' workload thus expanded tremendously while their working conditions often deteriorated (Delobelle et al., 2009, p. 1068; Harrowing & Mill, 2010, pp. 724-5). After HIV was detected in breast milk in the mid-1980s (UNAIDS et al., 1997, p. 3; Ziegler et al., 1985, p. 897), mother-to-child transmission (MTCT) of HIV attracted particular attention as a major global public health dilemma because, while breastfeeding is critical to infant survival in low-income settings, HIV-positive women risked infecting their infants through their breast milk.

Nurses, constituting the core of the health work force in sub-Saharan Africa (Dovlo, 2007, p. 1375; Harrowing & Mill, 2010, p. 724), were, in early phases positioned as the backbone to provide care and counselling for HIV-positive women within the PMTCT programmes (Raisler & Cohn, 2005, p. 279). In an HIV context, women as mothers of HIV-exposed infants are in particular need of care and guidance on how to feed their infants safely to avoid the transmission of HIV to their children, and counselling on safer infant feeding was designated as a significant part of nurses' practice within these programmes (Raisler & Cohn, 2005, p. 276; WHO et al., 2003a, p. 15). With the central location of the nurses as counsellors, the PMTCT programme seems to provide an interesting vantage point from which to explore how nursing care is constituted and given meaning in a particular context in a resource-poor setting.

Smit (2005, p. 23) points to the limited research pertaining to nurses' experience of providing care for people with HIV/AIDS, while Fassin (2008, p. 269) writes that qualitative research knowledge pertaining to nurses' everyday practice in low-income contexts is scarce. The present study aims to scrutinize nursing care as it emerges in nurses' everyday practice with an empirical focus on nurse-mother interaction in HIV prevention programmes in Tanzania. The study seeks to generate knowledge that contributes to the debates that highlight the social and cultural embeddedness of nursing practice in global nursing care discussions.

DEBATES ON CARE AND CARING IN NURSING

There have been, and continue to be, wide-ranging discussions on the content of 'care' and its implications for nurses' and patients' everyday practice in varying health care contexts. These debates have been located at the heart of nursing theory and nursing science research with implications for professional nursing practice. It seems fruitful to bring up some central perspectives from the theoretical debates on 'care' which emanates from dominant academic nursing environments. These perspectives have provided guidance on how nursing care has been developed worldwide in nursing education and nursing practice, and provide an important backdrop for the later review of the literature that has addressed studies of care in nursing practice in diverse settings in Africa, as well as for making sense of the present study findings.

The essence of care

This section gives a brief introduction of 'the essence of care' as it has been discussed in the literature. Clarke (2007, p. 364), referring to *The Shorter Oxford Dictionary on Historical Principles*, writes that: 'Originally, caring was a feeling state stemming from the word Kara or Chara to grieve or lament and relates to Karar, bed of sickness.'. With reference to the Oxford English Dictionary, Dunlop (1986, p. 662), however, writes that the origin of care is linked to the Old English word 'carian', 'denoting in the verbal form from "to trouble oneself"', and concludes, from an etymologic perspective, that the old version of care brings with it a negative and lower-order association relegated to women. Caring is described to have emerged from the private sphere of the home, taking place 'within the context of love – of personalized affection' (Dunlop, 1986, p. 662). As a part of professional nurses' duties, care or caring can be traced back to the 14th century when caring was religiously based and located within the three-dimensional relationship between the nurse, the patient and God. However, as care was increasingly secularized and professionalized, the religious aspect diminished, and caring was gradually transformed into a two-dimensional relationship comprising the nurse and the patient (Clarke, 2007, p. 364).

Whatever perspective and historic horizon chosen, there seems to have been a general agreement that care and caring make up vital parts and is located at the core of nursing, so also of the professional discipline of nursing.[1] Throughout the past four decades this has been manifested through a tremendous focus on care in the nursing literature and in nursing practice, and substantive theories, research and practice models have been developed (Smith, 2013, p. 1). Smith (2013, p. 1) writes that there are roughly 60 books and literally thousands of journal articles published on care and caring as nurse theorists and researchers have debated its content and attempted to deconstruct and clarify the concept. In the section below, this body of literature will be briefly addressed through three different approaches to care and caring launched by central nurse theorists; (1) the discussion of the uniqueness of care within nursing, (2) the distinction made between instrumental and expressive elements of care and (3) the complexity of the content of care.

The most contentious debates bring us back to the early 1980s when a theoretical debate emerged centred on the position of care and caring as embodied in nursing (Paley, 2002, p. 25) – and more specifically explored whether care was a defining attribute of nursing. While known nursing theorists like Leininger (1978, p. 13; 1988a, pp. 3-4) and Watson (1979, pp. 8-9; 1990, p. 21) argued that caring was the central aspect of nursing science and unique to nursing, others argued that 'caring is ubiquitous among all professions and does not reflect the uniqueness of the knowledge and practice of nursing' (Smith, 1999, p. 14). Rogers, Parse, Peplau and Smith were among those opposing the idea that caring was a defining attribute of nursing, arguing that nurses could not claim care and caring to be particular to their profession (Huch, 1995, pp. 38-9; Smith, 1999, pp. 15-6; Smith, 2013, p. 3). To sum up the main argument from this point of view, Dunlop (1986, p. 665), some 30 years ago, wrote: 'While it seems possible to claim that nursing is *a* form of caring, it seems much less reasonable to claim it as *the* form of caring.'

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[1] See e.g. Morse et al., 1990, p. 1; Newman et al., 1991, p. 5; Smith, 1999, p. 14; Watson & Smith, 2002, p. 453

Moving into the last decade, the debate on the essence of care within nursing has calmed, and there seems to be a settlement that there is no universal agreement on this particular part of the discussion. It will nonetheless be of interest to bring with us the above arguments in our encounter with care as an inherent part of nurses' practice, and as expressed and experienced within a Tanzanian health care setting.

A focus on the *content* of care has, however, until recently remained vivid, and the multiple meanings and complexity in the understanding of what care embraces or implies has continued to pose a challenge for both theorists and researchers within the nursing field. There have been multiple ways of categorizing diverging dimensions of care. At this point I will attempt to review central debates pertaining to the concept of care as it has been focused in the dominant discourses in nursing science during the past couple of decades, partly to indicate the substantial importance attached to the care concept in nursing, and partly as a backdrop for the coming study.

Looking first at research on care from clinical contexts, nurses and patients within this body of research are typically observed or asked to express their perceptions or experiences of care in general or of particular caring behaviours. One classic way to differentiate various dimensions of care within nursing practice has, for decades, been to divide care into two overarching categories, namely: (1) instrumental elements and (2) expressive elements. Griffin (1980), with reference to McFarlane (1976), wrote: 'Thus, there are two aspects of caring – the activities aspect, and those attitudes and feelings underpinning them' (Griffin, 1980, pp. 263-4). In their article focusing on the concepts 'care' and 'cure', Jecker and Self (1991, p. 294) made the same distinction of two main elements of caring, labelling them 'caring about' linked to the expressive element and 'caring for' related to the exercise of skills and the 'instrumental' elements of caring.

To be able to provide quality care for their patients, nurses need to understand their patients' caring needs, which has directed attention to the caring elements that patients and nurses seem to emphasize most strongly (Patistea & Siamanta, 1999, p. 302). A key finding repeatedly referred to in this context has been that nurses and patients often disagree about what they perceive to be the most central caring elements. Nurses generally report seeing the expressive element as the most essential while, from the patients' perspective, the instrumental and technical skills are perceived to be the most essential; i.e. to meet basic physical needs as a prerequisite for receptiveness to expressive nursing care.[2] These research findings were already reported some 40 years ago (White, 1972, pp. 11-2), and have been repeated in research until today (Papastavrou et al., 2011, p. 1199) primarily from European and North-American contexts. Patients do also report valuing the affective and 'humanistic' aspects of care, but seemingly not to the same levels as the nurses (Bassett, 2002, p. 14). A critical response to the above research findings has been that most of it is based on the informants' response to questions about what care is and how it is perceived. Paley (2001, p. 192; 2008, p. 1668), being among the critical voices in these debates, holds that knowledge on care in health care practice has largely been based on 'things said', and calls for attempts to describe how care emerges in actual health care settings through observational research.

Paley (2001, p. 189) states that care has a complex, nebulous, vague and ambiguous nature[3], and argues that the complexity surrounding care exists because the '[a]uthors do not generally distinguish between "perceptions" of care, the "concept" of caring, the "experience" of caring, and caring itself' (Paley, 2001, p. 190). Looking at the nursing-theory literature, care is approached as a 'phenomenon', as 'science', 'practice', 'behaviour', 'attitude' and 'philosophy' (Como, 2007, p. 38; Sherwood, 1997, p. 32). As care has repeatedly been described as lacking consensus and criticism of the theorisation of care has increased, several nurse scientists have aimed to clarify the concept through reviews that have included both theoretical debates on the concept of care as well as research on care as it emerges in clinical contexts. These reviews have included dimensions of care beyond the 'instrumental' and 'expressive' dichotomy of care referred to above. One example is Morse et al.'s (1990) acclaimed review. Table 1 makes an attempt to sum up key findings in the central reviews of nursing care published during the past two decades. Three central focuses within these reviews on care and caring are found to be of particular interest to the present study, and will be drawn upon in the discussion of the core findings.

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[2] See e.g. Baldursdottir & Jonsdottir, 2002, p. 73; Bassett, 2002, p. 14; Gardner et al., 2001, p. 37; Gooding et al., 1993, p. 73; Komorita et al., 1991, p. 27; Kvale, 2007, p. 323; Kvale & Bondevik, 2010, p. 438; Larson, 1984, p. 50; 1986, p. 90; 1987, p. 191; Papastavrou et al., 2011, p. 1202; Scharf & Caley, 1993, p. 8; von Essen & Sjoden, 1991, p. 1371; Webb, 1996, p. 964; Widmark-Petersson et al., 2000, p. 37; Wilkin & Slevin, 2004, p. 57; Yam & Rossiter, 2000, p. 299

[3] Paley refers to: Greenhalgh et al., 1998; Komorita et al., 1991; Kyle, 1995; Lea & Watson, 1996; Leininger, 1988b; Mackintosh, 2000; McCance et al., 2001; McCance et al., 1997; Smith, 1992; Staden, 1998; Stockdale & Warelow, 2000; Valentine, 1991; Webb, 1996; Wilkes & Wallis, 1998; Yam & Rossiter, 2000

Table 1.

Morse et al. (1990)	Five ‘categories’ of caring	1) Caring as a human trait 2) Caring as a moral imperative or ideal 3) Caring as an affect 4) Caring as an interpersonal relationship 5) Caring as a therapeutic intervention
Sourial (1997)	Eight ‘uses’ of caring in nursing literature	1) Ethics 2) Instrumental and affective 3) Traits 4) Patients’ and nurses’ perceptions of caring 5) Holism 6) Humanism 7) Organizational 8) Quality
Sherwood (1997)	Four ‘patterns’ of care	1) Healing interaction pattern 2) Nurses’ knowledge pattern 3) Intentional response pattern 4) Therapeutic outcomes/healing patterns
Swanson (1999)	Five ‘levels’ of caring	1) The capacity for caring 2) Concerns/commitments 3) Conditions 4) Caring actions 5) Caring consequences
Brilowski and Wendler (2005)	Five ‘attributes’ of care	1) Relationship 2) Action 3) Attitude 4) Acceptance 5) Variability
Finfgeld-Connett (2008)	Three ‘attributes’ of caring process	1) Expert nursing 2) Interpersonal sensitivity 3) Intimate relationship

First, the *relationship* between the nurse and the patient is naturally found to be a vital part of care and caring in all these studies. Morse et al. (1990, p. 6) label one category of caring ‘the interpersonal relationship’, which both expresses and defines caring, and they refer to authors who suggest ‘that the nurse-patient relationship *is* the essence of caring’. Brilowski and Wendler (2005, p. 643) and Finfgeld-Connett (2008, p. 199) also point to the *relationship* between the nurse and the patient as being among the most central attributes of nursing care in their concept analysis. Also, among Sherwood's (1997, p. 38) four patterns of caring, the *healing interaction pattern* includes a trusting relationship between a nurse and a patient. Within this pattern of care '[t]he establishment of a supportive or protective environment developed and sustained the trusting relationship from the nurses' reassuring presence, availability, and accessibility'(Sherwood, 1997, p. 38). [4]

Second, several of the reviews highlight what Swanson (1999, p. 41) names *caring actions*. These actions include competence in physical, technical care as well as in affective care. Among Brilowski and Wendler's (2005, pp. 643-4) caring attributes, the attribute of 'action' includes physical care, touch, presence and competence in skills and technology. Finfgeld-Connett (2008, p. 199) labels one of her caring attributes 'expert nursing', which she describes as 'the execution of expert physical, psychosocial and spiritually oriented nursing interventions'. Moreover, Morse et al.'s (1990, p. 6) category 'Caring as a therapeutic intervention', described as 'attentive listening, patient teaching, patient advocacy, touch, "being there", and technical competence', can be linked to caring actions. Sherwood's (1997, p. 38) expression 'Nurses' knowledge pattern' moreover involves helping the patient with physical and affective needs and concludes that task and affective dimensions of care are not separable. These *caring actions* are hence found to include both 'instrumental' and 'expressive' elements of caring.

A third central focus that we wish to point out for the purpose of the present study is how care is referred to as a *human trait*. Morse et al.'s (1990, p. 4) category of 'care as a human trait' refers to the assumption that care is essential to human existence and is part of human nature. Morse et al. (1990, p. 4) among others refer to Roach's (1987) view of care, which describes how a person's own experience in being cared for influences his/her ability to care. Furthermore, they include Benner and Wrubel's (1989, p. 389) view on care as they state that caring is 'the "basic way of being in the world" from which all nursing practice evolves' (Morse et al., 1990, p. 4). Sourial (1997, p. 1190) also includes 'trait' in her analysis of how 'caring' is found in the nursing literature while Brilowski and Wendler (2005, pp. 644-45), in their concept analysis, include the attributes of 'attitude' and 'acceptance'. 'Attitude' is referred to as 'not simply a series of actions, but is also a way of acting' which also includes 'a positive approach to people and to life',[5] while 'acceptance' involves that a nurse cares for a patient based on the

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[4] Even if it is not among her five levels of caring, Swanson (1999:55) also highlights the *'Caring Relationship'*, heading the last section of her chapter 'What is known about caring in nursing science'

[5] Brilowski and Wendler here refer to: Fealy, 1995; Halldorsdottir & Hamrin, 1997; Kearns, 1999

compelling reason that 'the other is a fellow human being worthy of dignity and respect' (Brilowski & Wendler, 2005, p. 645).[6]

Within approaches to care as a human trait, Roach's (1990) writings emerge as central. In 1990, Roach published the book *Caring – the human mode of being,* where she said that caring behaviour in nursing is manifested through five 'attributes' of professional nursing care, known as the five C's (table 2); *Compassion, Competence, Confidence, Conscience and Commitment,* which evolved in response to the question: 'What is a nurse doing when he or she is caring?' (Roach, 1990, p. 19).[7] 'Compassion' is said to be a way of living 'born out of an awareness of one's relationship to all living creatures' (Roach, 1990, p. 19). Compassion is a relationship where solidarity with one's fellow human being as well as a humble presence to each other emerges (Roach, 1990, p. 20). 'Competence' implies having 'the knowledge, judgement, skills, energy, experience and motivation required to respond adequately to the demands of one's professional responsibilities' (Roach, 1990, p. 22), while the third 'C' 'Confidence' is defined as 'the quality which fosters trusting relationships' (Roach, 1990, p. 23). Roach states that it is impossible to reach the goals of nursing without a condition of mutual trust and respect between the patient and the nurse, trust lying at the core of confidence between the two parts. 'Conscience' is said by Roach to be a 'compass directing one's behaviour according to the moral fitness of things' (Roach, 1990, p. 24), while 'commitment' as an attribute of care is defined to be a complex affective response where a person merges his or her desires and obligations and acts in accordance with them. Commitment is described as a call which draws a person to a conscious, willing and positive course of action (Roach, 1990, p. 25). Of the five C's, 'compassion', 'competence', 'confidence' and 'commitment' will in particular be returned to in the discussion of the study findings.

Table 2

Roach (1990)	Five attributes of professional caring	1) Compassion 2) Competence 3) Confidence 4) Conscience 5) Commitment

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[6] Brilowski and Wendler here refer to: Fealy, 1995

[7] In 2002, Roach attached a 6th C, Comportment

This section has attempted to give a brief introduction to and overview of the complex, and highly intricate and ambiguous explorations of care and caring found within the dominant discourses in nursing theory – central perspectives which will inform the discussion of the core findings of the present study. I have tried to indicate how the understanding of the essence of care has been attributed enormous importance within central theoretical nursing milieus, and form debates with substantial impact on the nursing profession. The preoccupation with and significance placed on the content of nursing care in academic nursing makes an interesting vantage point for a study of care in a low-income, African setting, where care may potentially be surrounded by different connotations and meanings, expectations, expressions and experiences. From a vantage of care within nursing science, the next section makes a modest attempt to outline some lines of thinking within medical anthropology that have inspired the present research endeavour and its intersections with nursing theory.

The social and cultural construction of care

Within nursing it is well established that caring in nursing practice is both value bound and contextually dependent.[8] Connected to patients' and nurses' perceptions of caring, Patistea and Siamanta's (1999, p. 310) literature review conclude that 'caring meanings and behaviours are context specific and suggest that nurse clinicians should determine caring needs and actions in the context they practice.'

As the founder of what was named 'transcultural nursing', and the first nurse to hold a PhD in cultural and social anthropology (McFarland, 2014, p. 417), Madeleine Leininger should be mentioned in this context. Her interest in 'transcultural nursing' emerged in the mid-1950s when she worked with children with diverse cultural backgrounds in the United States, and became confused as she found herself unable to respond to the children's needs (Leininger, 1995, p. 41). In the early 1960s she lived for nearly two years in New Guinea, which further spurred her interest in what she termed 'culturally appropriate nursing' (Leininger, 1995, p. 42). The main concern of her work was to understand how people perceived, understood and experienced caring behaviours within different cultures. Her contention was that such knowledge could help nurses provide both 'cultural-specific' as well as 'cultural-universal' nursing care practices (Leininger, 1988a, p. 12). Leininger refers to the 'diversities' and 'universalities' in her cultural care theory, and defines 'culture care diversity' as 'cultural

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[8] See e.g. Andrews & Boyle, 1995, pp. 40-1; Benner, 1984, p. 171; Dunlop, 1986, p. 666; Fealy, 1995, p. 1136; Leininger, 1988a, p. 9

variability or differences in care beliefs, meanings, patterns, values, symbols, and lifeways within and between cultures and human beings' (in McFarland, 2014, p. 421). 'Culture care universality' is defined as the 'commonalities or similar culturally based care meanings, patterns, values, symbols, and lifeways reflecting care as a universal humanity' (McFarland, 2014, p. 422). Centred in these definitions, Leininger's work implied that people with a different cultural background from the nurse had different expectations of care (Williamson & Harrison, 2010, pp. 762-63).

Leininger's work has been applied by nurses worldwide as they have pursued research using Leininger's ethnonursing method to derive new knowledge on transcultural nursing (McFarland, 2014, p. 429), but her theory has also been subjected to critique. One concern has been Leininger's and transcultural theory's static approach to 'culture' (Price & Cortis, 2000, p. 235) which implies a 'lack of variability and change in cultural traits, a notion reflected in the conception of ethnic groups as "units" in which members articulate a uniform set of beliefs' over time (Bruni, 1988, p. 29). Leininger's transcultural theory is moreover criticised for having a focus on assumed universal values in health-care within a culture and, as such, hides disparities within cultures, leading to cultural essentialism and stereotyped information. Yet another criticism is that transcultural nursing is said to have a too-narrow focus 'on the attitude of the individual practitioners to clients' cultural needs, to the exclusion of wider socio-political factors' which obscures the effect of social class on health care (Mitchell et al., 2002, p. 27).

Andrews and Boyle (1995, 2012) and Giger and Davidhizar (2008) have also been central in bringing attention to the concepts of culture and care within nursing, and have published several editions of their books about transcultural concepts in nursing. While Leininger has been criticised for a static culture concept, Andrews and Boyle (1995, p. 16) state that '[c]ultures have both stabilizing and dynamic qualities'. While the stabilizing qualities are subtle and relatively-constant, forces that work in ways that generate patterns or norms and predictable social interactions, the dynamic qualities 'incorporate change as a matter of course' (Andrews & Boyle, 1995, p. 16). In their focus on cultural care in nurses' practice they write that nurses have to understand both themselves and their patients in order to find the caring behaviour that matches the clients' perceptions and expectations (Andrews & Boyle, 1995, p. 41). In their focus on transcultural nursing care, Boyle and Andrews (2012) as well as Giger and Davidhizar (2008) ground their theories on the complexity of cultural diversity encountered within nurses' practice in the context of Northern America.

It is impossible to produce generalized assumptions about what is good nursing care in a particular time and space. Dunlop (1986, p. 665), in her reflections on caring within nursing, says that in following Heidegger (1962) it is not possible to state exactly what good nursing is because these judgements are typically 'part of the deep background of the nursing world. They are, moreover, contextual judgements rather than ones made on the basis of some explicit, decontextualized nursing theory' (Dunlop, 1986, p. 665). What people perceive as caring activities and caring behaviour at any particular moment is thus highly dependent upon context (Bassett, 2002, p. 14; Dunlop, 1986, p. 666). Reverby (1987, p. 5) writes about the complex components that influence care and caring:

> Caring is not just a subjective and material experience; it is a historically created one. Particular circumstances, ideologies, and power relations thus create the conditions under which caring can occur, the forms it will take, the consequences it will have for those who do it.

In the same manner, Benner (1984), a central nurse theorist, holds that it is not possible to control or coerce caring – it needs to be understood and facilitated, and she writes: 'Caring is embedded in personal and cultural meanings and commitments. Therefore, the strategies for studying it must take into account meanings and commitments' (Benner, 1984, p. 171).

The bulk of the literature on culturally competent nursing care, as well as the theories and research on care and caring that underlie it, are based in contexts of cultural diversity found within European and North-American health-care settings – i.e. spring out of experiences with patients with varying cultural backgrounds encountered in health care contexts within these coutries. There is however an important distinction between exploring nurses' work and the provision of culturally congruent care to patients from cultural backgrounds that differ from the one the nurse belongs to – i.e. of the majority population – to the exploration of nursing care in low-income settings where patients and nurses reside within a cultural and social context where nurses and patients by and large share culturally-constituted meanings, experiences and expectations. Rather than exploring the basis for culturally competent care, this study asks: What is considered to be socially and culturally competent care by nurses and patients in the study context?

In theoretically-diverse and empirically-intriguing studies, medical anthropologists have demonstrated the processes of culturally-embedded meaning-making taking place in contexts of illness and suffering (Good, 2010; Kleinman, 1980,1988). When we seek to enhance our understanding of how nursing care is expressed and experienced in specific cultural contexts, Kleinman's (1980, 1988) and Mol's (2008) theoretical viewpoints on how patients' symptoms, disorders and illness are given meaning and handled within particular health care context are found central to the present study. Kleinman (1980,1988), a renowned medical anthropologist, has written central texts on how medicine as a cultural system is a ‘system of symbolic meanings and patterns of interpersonal interactions’ (Kleinman, 1980, p. 24). He states that in every culture, illness is systematically interconnected with how people responded to it, experienced it, treat it as well as how social institutions relate to it (Kleinman, 1980, p. 24). Furthermore, Kleinman (1988, p. 8) emphasises the personal and social meanings that are given to symptoms and disorders by patients and their families, and says that the illness meanings are bound to a relationship and as such belongs to the patient’s wider family – the spouse, child, friend, care giver etc. In the same manner, Mol (2008), from a political philosophical point of view, reflects on the meanings of illess in patients’ lives as related to good care. She argues that patients’ collective surroundings are a part of how they make meaning out of their symptoms and that good care is highly dependent upon how the health worker is able to look beyond the patients’ apparent symptoms and find out how the patients understand and give meaning to those symptoms (Mol, 2008, p. 57). Mol (2008, p.11) writes that good care is an ongoing process and not a limited product and exemplifies this through how the practitioner has to interact with the patient, ‘shifting the action around so as to best accommodate the exigencies of the disease with the habits, requirements and possibilities of daily life.’ Mol (2008, p. xi) further includes reflections on the highly valued aspect of individual patient choice within medical contexts and reflects upon how ‘the logic of choice’ might lead to poor care. She writes:

> In health care […] “patient choice” and “good care” may sometimes complement each other, but more often they clash. Practices designed to foster “patient choice” erode existing practices that were established to ensure “good care”. (Mol, 2008, p. 1)

Although not dwelled at in depth in the papers, medical anthropological thinking emphasizing cultural and structural conditions of health and illness has underpinned and framed the project from the planning phase, throughout the data collection, analysis and writing phase. Kleinman’s (1980, 1988) and Mol’s (2008) reflections make an interesting vantage point for the discussion of the findings of this study, both in term of what good nursing care is within the nurse-patient interaction and reflections upon the concept of individual patient choice, a concept highly present in HIV prevention programmes.

NURSING CARE, HIV AND PMTCT PROGRAMMES IN SUB-SAHARAN AFRICA

The present study is placed within the context of HIV prevention programmes in sub-Saharan Africa. Before we move to the Tanzanian study context, a brief introduction will be provided about how nursing care has been reported in the literature from sub-Saharan Africa. This introduction is followed by a focus on HIV, on how the virus transmits from mother to child, on the programmes that have a particular focus on preventing such transmission – the PMTCT programmes – and on how they have been designed and rolled out in low-income contexts in order to ease the comprehension of nursing care within the contexts of such programs. This part of the chapter closes with a review of the infant-feeding guidelines employed within the PMTCT programmes, the severe challenges reported as linked to these in everyday nursing practice as well as the range of nurses' responsibilities implied in the care for HIV-positive women within these programmes.

Nursing care in an African context

Nurses constitute the core of the health work force with higher education in sub-Saharan Africa and have responsibility for a broad range of services (Dovlo, 2007, p. 1375; Fournier et al., 2007, p. 257, Kyakuwa, 2011, p. 256-7) in a context where the health sector suffers from a major human resource crisis[9]. Meena (2010, p. 533) writes that Tanzanian nurses are known to be skilled, but are located at the lowest position in the hierarchy of skilled health staff. Nurses in these areas are increasingly found to carry out tasks they are not trained to do, primarily because of the health worker shortage (Meena, 2010, p. 533). Nurses have, moreover, at large scale moved to work in other countries (WHO, 2014, p. 107) and have long been pulled into international Non-Governmental Organisations (NGOs), leaving the remaining nurses with even heavier workloads (Chikanda, 2005, p. 169; Kingma, 2007, p. 1286).

The deteriorating quality of care of nursing in African contexts is frequently described in research and reports from nursing care settings in sub-Saharan Africa. A literature review, however, shows that there is not a large number of thorough studies on the topic, particularly not those based on qualitative research and, in most of the studies mentioned below, nursing care is referred to on a very general basis, and does not define what care comprises in the particular study context. A few examples explored from the patients' point of view indicate

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[9] See e.g. Dovlo, 2005, p. 1; Narasimhan et al., 2004, p. 1469; Scheffler et al., 2009, p. 852; WHO, 2014, p. 107

much the same response to nurses' caring behaviour in recent studies as in studies carried out twenty years ago.

In studies from countries in sub-Saharan Africa, low quality care has generally been linked to how patients have expressed dissatisfaction with the service they receive (Uys & Naidoo, 2004, p. 6), and to challenges in nurses' caring behaviours based on the patients' experience. Jewkes et al. (1998, p. 1785), in a study from South Africa, report that the patients experienced the nurses to be 'inhuman', 'not caring' and not showing any kindness. Another study from a South African context reported how the patients experienced the nurses' approach as rude in manner and that they were scolded by the nurses (Abrahams et al., 2001, p. 244). Complaints of 'bad language' were also among the findings from an out-patient clinic in Tanzania where informants, for example referred to harsh wording and nurses shouting at patients (Juma & Manongi, 2009, p. 199). Yeap et al. (2010, p. 1103) similarly report from a South African health facility that patients experienced unapproachability, rudeness and nurses who were blaming them. Mwangi et al. (2008, p. 808), in their study from Tanzania, found that the patients – who referred to the nurses as rude, strickt and uncaring – were more likely to criticise the nurses than other health workers because the nurses were most accessible.

From the nurses' point of view, studies report that they experience overwhelming challenges (Harrowing & Mill, 2010, p. 728). Health care facilities are frequently referred to as being overcrowded, understaffed and lacking the most basic equipment (Bassett et al., 1997, p. 1847; Fournier et al., 2007, p. 262; Haggstrom et al., 2008, pp. 482-84) – key barriers to nurses' opportunity to properly care for their patients. In Fournier et al.'s (2007, pp. 260-61) study, nurses in Uganda explained that the practical challenges they met in their clinical practice, such as congested wards, lack of electricity and inadequate resources, even very basic resources such as bandages, forceps and gloves, prevented them from providing quality nursing care. Moreover, in a context where a nurse-patient ration of 1 to 50 during the day was not unusual, the nurses reported that the massive nursing shortage interfered with their care for the patients (Fournier et al., 2007, p. 261). Similar frustrations were expressed by Tanzanian nurses, who found their work to be filled with challenges, referring to heavy workloads, shortage of staff and lack of equipment (Haggstrom et al., 2008, p. 480). A young nurse commented upon how she was 'struck by the fact that "the place was filthy and nurses were rude"' when she was asked about her experienced when she first started to work at a hospital (Fassin, 2008, p. 266).

This bundle of challenges, often combined with low salaries, has been documented to lead to absenteeism, lack of motivation and low work-morale among nurses[10].

These reported challenges clearly influence the nurses-patient interaction. Tanzanian nurses working in a regional hospital expressed that the lack of governmental supply of basic equipment often resulted in conflicts with patients, who expected to be better cared for (Manongi et al., 2009, p. 5). A nurse in Bassett et al.'s (1997) study from Zimbabwe argued that low quality care was related to overworked nurses because of the absence of qualified staff; 'The nurse is the doctor, the nurse, everything. No wonder she becomes irritable' (Bassett et al., 1997, p. 1848). In their study from Nigeria, Reis et al. (2005, p. 0748) found that a significant number of health workers, most of them nurses, had engaged in 'discriminatory and/or unethical behaviour'. Another related feature, and surely of relevance to the nurse-patient relationship, is how research demonstrates that nurses in sub-Saharan countries commonly fall back on medicalised- and task-oriented care rather than on patient-oriented care (Fassin, 2008, p. 268). In a qualitative study from Tanzania, Juntunen and Nikkonen (1996, pp. 541-42) refer, for example, to 'non-caring aspects of professional nursing care' where they describe how nurses were observed to neglect patients' basic care while focusing on medical tasks. They observed that relatives rather than the nurses were found to take care of basic caring activities like hygiene and feeding (Juntunen & Nikkonen, 1996, p. 541). Torsvik and Hedlund (2008, p. 394) importantly emphasize that the health facilities in Tanzania are very dependent upon the strong involvement from family and relatives; most hospitals, for example, do not provide food, and relatives are expected to take responsibility for the patients' basic care. They explain this with reference to the norms related to 'familism', which refers to a strong obligation for relatives to care for their family members whatever their needs are (Torsvik & Hedlund, 2008, p. 394). Focusing on the nurse-patient interaction, nurses have on their part expressed experiencing lack of respect from their patients, and one nurse explained that 'this situation contributes to the use of harsh language, hating our job and not working hard' (Manongi et al., 2009, p. 5). Nurses from a study in Zimbabwe similarly described how a stressful work environment had a negative impact on the nurse-patient interaction, and that people's respect for nurses was declining. One nurse explained: 'Sometimes the queue is too long and you end up answering a patient in the wrong way. They don't respect us as they used to' (Bassett et al., 1997, p. 1848). Nurses in South Africa have moreover reported to be disrespectfully treated by

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[10] See e.g. Chikanda, 2005, pp. 170-71; Delobelle et al., 2009, p. 1068; Manongi et al., 2009, p. 6; Manzi et al., 2012, p. 7

patients who were not appreciative of the care they received, and nurses had experienced being 'spat at, cursed and verbally abused by patients' (Smit, 2005, p. 26). Munyewende et al. (2014, p. 8) similarly report the combination of a heavy workload and nurses' experience of disrespect from the patients in their study from two South African provinces. This brief literature review show that recent studies provide much the same picture of nurses' experiences of high workloads that affect communication and relations with the patients, and circles of disrespect from both parties in the nurse-patient relation that were reported from studies nearly twenty years earlier (Bassett et al., 1997; Munyewende et al., 2014).

Another obstacle reported has been that patients may demand health services promised by politicians but which are not possible to fulfil (Munyewende et al., 2014, p. 8). In many studies, nurses report being frustrated and feeling unfairly blamed for giving poor quality care because of limited material supplies, deprived support systems and shortage of health personnel – all factors beyond their control. The research by van der Doef et al. (2012, p. 1770) shows that, compared to a European hospital setting, 'East African nurses experience more understaffing, heavier workloads, less favourable physical working conditions and less availability and poorer quality of equipment and materials.' In Uganda, nurses experienced that patients failed to acknowledge the major constraints under which they worked in the interpretation of nurses' behaviours (Harrowing & Mill, 2010, p. 727). The same nurses experienced being the ones to receive the blame for unfortunate outcomes because of their position as the front line health care workers in continuous contact with the patients. They talked of 'suffering' to describe their experience when they were not able to provide the nursing care they felt their patients needed and deserved (Harrowing & Mill, 2010, pp. 726-27). Nurses in a study from Tanzania expressed that they tried to make the best of the situation to protect their patients and to provide good nursing care, a care which they themselves described as 'not bad' or 'acceptable' (Haggstrom et al., 2008, p. 484). A study based on observation, however, challenged the finding that the workload prevented health workers from carrying out high quality care, stating that the number of health workers in rural Tanzania is not seen to be a decisive factor in explaining the low quality of health care and concluded that the health workers were not overworked and had 'ample amounts of idle time' (Maestad et al., 2010, p. 686, 695). Mæstad et al. (2010) held that low health worker motivation is key to understanding the challenge of poor care.

As stated above, a challenge related to the above studies is that the majority of them do not define what care comprises in the particular study context and 'nursing care' is frequently referred to on a very general basis. A few studies rely on observations while most rely on patients’ and nurses’ verbal descriptions of the work situations, which makes it difficult to assess the extent to which nurses do not manage to fulfil expected roles.

Nurses and nursing in the context of HIV/AIDS

The HIV/AIDS epidemic brought with it a dramatic increase in patients, and thus in the work load for nurses, as it struck sub-Saharan Africa from the mid-1980s. The epidemic evolved rapidly throughout the 1990s and by June 2000 the UNAIDS (2000, p. 6) reported that more than two-thirds of the 34.3 million people living with HIV/AIDS worldwide resided in sub-Saharan Africa.

The increase in workloads and demands on nurses is exemplified by nurses from Uganda who remembered the days before the HIV epidemic, with less overwhelming demands on the health care system and relatively more available resources (Harrowing & Mill, 2010, p. 728). Alongside the increase in patients who needed care, nurses’ knowledge and attitudes were also challenged and put to the test with the coming of this new and deadly disease. The vast number of ‘Knowledge, Attitude and Practice’ studies reported challenges among nurses in the majority of sub-Saharan African areas from the very onset of the epidemic and throughout the following decades.[11] The nurses’ lack of access to training and sufficient support in the care for the category of patients implied enormous challenges (Raisler & Cohn, 2005, p. 279) and the complex care demands of the patients with HIV/AIDS during the phase with no ART also induced role shifts for nurses, implying new tasks and new work-related settings (Dohrn et al., 2009, p. S28). One important example was the introduction of time-consuming individual patient counselling linked to HIV testing, and the individual consultations on disclosure and infant feeding practices among HIV-positive pregnant women, which turned out to be one of the most complex and time-consuming new tasks introduced to nurses in the wake of HIV (Raisler & Cohn, 2005, p. 276). Nurses working in HIV programmes have themselves expressed that the demand for lengthy counselling procedures in contexts of limited or lacking training opportunities affected their ability to care for their patients in a satisfactory way, leading them to feel demoralized (Delobelle et al., 2009, p. 1068). The introduction of counselling linked to the infant feeding practice of HIV-positive women will be explored further in the section below.

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[11] See e.g. Adelekan et al., 1995, p. 65; Kohi & Horrocks, 1994; Mbanya et al., 2001, p. 247; Oyeyemi et al., 2006, p. 201; Uwakwe, 2000, p. 423; Walusimbi & Okonsky, 2004, p. 97

The challenges of nurses' caring conduct as presented in the section above is reiterated in the literature on nurses' care for HIV/AIDS patients: nurses have generally been accused of low quality care. Reports of slow service and rough treatment of HIV-positive patients is, for example, reported from Tanzania (Manongi et al., 2009, p. 8), while nurses' negative attitudes to patients with AIDS are reported from a quantitative survey from Nigeria (Oyeyemi et al., 2006, p. 201). Greeff et al. (2008, p. 321) found that the HIV-positive patients expressed a distrustful relationship towards the nurses in their study in five African countries while in Deressa et al.'s (2014, pp. 7, 9) study from Ethiopia, pregnant women reported that barriers to seeking PMTCT services were that the nurses insulted and mistreated their patients. In a qualitative study from South Africa nurses were reported to blame HIV-positive patients for contracting the disease, and that the patients therefore were not worthy of sympathy, love and care (Manganye et al., 2013, p. 38). The studies by Yeap et al. (2010) from South Africa and Reis et al. (2005) from Nigeria – referred to in the above section on nursing care in African contexts – also reports from a HIV/AIDS context where challenges in the nurse-patient interactions are highlighted.

However, some studies of nurses and HIV/AIDS patients, particularly from the last decade, reveal empathic and positive attitudes from the nurses. Positive attitudes on the part of the nurses have in several studies been reported to correlate with high levels of HIV/AIDS knowledge (Walusimbi & Okonsky, 2004, p. 98).[12] Even though Delobelle et al. (2009, p. 1068) note how nurses may feel demoralized due to increased workloads, they sum up the findings from their focus group discussions by saying: 'Overall nursing attitudes were characterized by empathy, compassion, respect and dignity.' In a similar vein, Smit's (2005, pp. 26-7) study, based on in-depth interviews with nurses in South Africa, described positive experiences and perceptions including feelings of empathy and compassion towards the HIV-positive patients. From a mixed-methods study among HIV-positive women in four African countries, Hardon et al. (2012, p. 6) found that nearly all women reported being treated well in the HIV prevention programme they were enrolled in. Kyakuwa (2011) says about the nurses in her study in Uganda that they 'often went beyond the call to duty – they went the extra mile – to give care to their patients' (Kyakuwa, 2011, p. 257). Important in this context are the radical changes implied by the availability of ART, which affected the situation for both patients and nurses. In 2005,

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[12] Walusimbi and Okonsky (2004) here also refer to: Lohrmann et al., 2000; McCann & Sharkey, 1998; Uwakwe, 2000

Marchal (2005, p. 301) predicted that the roll-out of ART on a large scale would improve the effectiveness of care and reduce the levels of professional frustration. Since then a few articles have demonstrated positive changes in the nurse-patient relationship, perceived as a direct consequence of a renewed sense of hope among nurses engaged in HIV/AIDS-care (Campbell et al., 2011, p. 182; Stein et al., 2007, pp. 961-2).

Reports indicate that, despite the nurses' central role in sub-Saharan Africa's health care, detailed explorative research on the content and quality of the work nurses carry out in low-income contexts remains scarce. Fassin (2008, p. 269) for example writes that there is a lack of scientific documentation on nurses' work and that qualitative studies of everyday practices of what nurses do in hospitals should be given scientific priority. While Bland et al. (2007, p. 289) in 2007 called for more knowledge about the process of infant feeding, Evans and Ndirangu (2009, p. 729) point to the immediate need for observational research related to 'real time' counselling practice in HIV programmes in low-income contexts, particularly exploring patients' experiences. The present ethnographic study aims to contribute to enhanced knowledge on nurses' everyday practice in Tanzania with a particular scrutiny on caring behaviours in the nurse-patient interactions in PMTCT programmes. In the next section the content of the PMTCT programmes emphasizing the position of the nurses within these programmes will be presented.

Prevention of mother-to-child transmission of HIV (PMTCT) programmes

Transmission of HIV from mother-to-child (MTCT), or vertical transmission, has become one of the greatest challenges in HIV prevention in low-income settings, and has been coined the most ethically taxing public health issue of our time (De Cock & Grubb, 2006; De Cock et al., 2000; Kuhn et al., 2004). The news that transmission of HIV could take place during pregnancy and delivery as well as through breast milk[13] was met with shock. The study of De Cock et al. (2000) on the transmission rate in absence of any interventions is still referred to in global reports, the results presented in Table 3.

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[13] See e.g. Blanche et al., 1989, p. 1647; Colebunders et al., 1988, p. 1487; Dunn et al., 1992, p. 587; Ehrnst et al., 1991, p. 205; Guay et al., 1996, p. 442; Hira et al., 1990, p. 423; Jovaisas et al., 1985, p. 1129; Lapointe et al., 1985, p. 1325; Lepage et al., 1987, p. 400; Leroy et al., 1998, p. 599; Oxtoby, 1988, p. 825; Sprecher et al., 1986, p. 288; Thiry et al., 1985, p. 892; Van de Perre et al., 1993, p. 917; Van de Perre et al., 1991, p. 597; Weinbreck et al., 1988, p. 482; Ziegler et al., 1985, p. 897

Table 3.

Overview of transmission rate without intervention:	
During pregnancy	5 – 10%
During labour and delivery	10 – 20%
Overall without breastfeeding	15 – 30%
Overall with breastfeeding till 6 months	25 – 35%
Overall with breastfeeding till 18 to 24 months	30 – 45%

(De Cock et al., 2000, p. 1176)

Today the WHO states that it is possible to reduce the total MTCT rate to less than five per cent in breastfeeding populations, depending on the duration of breastfeeding and if the mother receives effective anti-retroviral treatment (ART). In the absence of breastfeeding, the transmission rate can be less than two percent (WHO, 2014, p. 28) – in line with the elimination of mother-to-child transmission of HIV (EMTCT) impact targets (WHO, 2014, p. 30).

To prevent transmission from mother-to-child, global authorities have developed particular HIV prevention programmes aimed to implement preventive interventions to ensure the best possible follow up of HIV-positive women through the perinatal and postnatal period to make the HIV-transmission risk to the baby as low as possible (Desclaux et al., 2009, p. 804). They were labelled 'Prevention of mother-to-child transmission of HIV' (PMTCT) programmes, and have been at the forefront of global HIV prevention activity since 1998 (WHO, 2010, p. 5). PMTCT programmes typically offer routine HIV testing during antenatal care and enrolment into the programme of those found to be HIV-positive. After enrolment, vital parts of the programme consist of counselling on infant feeding methods based on the national infant feeding guidelines, follow-up and ART-prophylaxis for the woman and child and early diagnosis of the child (Moland et al., 2010, p. 2; WHO et al., 2012).

WHO (2014) reports that the number of HIV-positive pregnant women in low- and middle-income countries (LMIC) is estimated to be 1.4 million – a number that has been relatively stable since 2009. The rate of MTCT was in the last update 17 per cent, and the vast majority of the 240,000 children who were reported acquiring HIV infection in LMIC in 2013 were infected through MTCT. Eighty nine per cent of these children are found in the African region (WHO, 2014, pp. 25, 28). The introduction of ART has prevented HIV-transmission during pregnancy, delivery and breastfeeding, and the proportion of HIV-positive women 'receiving at least some effective anti-retroviral (ARV) drugs in 2013' to prevent MTCT has increased from 47 per cent in 2009 to the reported 67 per cent in LMIC in 2013 (WHO, 2014, p. 31).

However, in their evaluation of the scaling up of PMTCT programmes in LMIC, Govender and Coovadia (2014, p. S58) write:

> Effective programmes to prevent new HIV infections in children have increased in developing countries, but the percentage of pregnant women who receive ARV regimens is still suboptimal and PMTCT programmes reveal too many gaps still to be covered.

Among the gaps to be filled, studies have reported poor adherence to ART among pregnant women (Delvaux et al., 2009, p. 227; Ngarina et al., 2013, p. 3), and a review study showed that although 76 per cent of pregnant women received ART during pregnancy, only 53 per cent continued to adhere postpartum (Nachega et al., 2012, p. 2039). Evaluation studies following the implementation and roll out of PMTCT programmes reported several additional challenges such as limited access to health care facilities, insufficient staff to provide quality care and follow up, stigmatization of patients and low uptake of HIV counselling and testing (Doherty et al., 2005, p. 218; Perez et al., 2004, p. 781; Temmerman et al., 2003, p. 1241). The more recent review by Gourlay et al. (2013, p. 19) on barriers to the uptake of ART in PMTCT programmes showed that some of the causes for low uptake were linked to stigma, fear of disclosure and lack of partner support.

As in the health sector in general, nurses have, since the inception of the PMTCT programmes, also been the front line care providers at all levels of the implementation of these programmes. Given the small number of medical doctors, nurses usually run most of the activity in the PMTCT programmes and typically play central roles at the prenatal clinics. During the antenatal clinics, nurses are in charge of pre- and post-test HIV-counselling where pregnant women may first get to know their HIV-positive status – emotionally challenging interactions which require time, knowledge and privacy (Raisler & Cohn, 2005, p. 276). Many countries have scaled up health worker training courses on HIV and PMTCT; however, most low-income countries are far from reaching a fully-trained nurse workforce, and it is a recognised challenge for nurses to provide HIV-infected women with care, counselling and support in overcrowded clinics with limited staff and resources (Doherty, 2011, pp. 187-8). The lack of nurses and health personnel ultimately affects the quality of the PMTCT programme, and the review of Colombini et al. (2013, p. 10)[14] refers to how health care providers' attitudes are barriers to HIV-positive women

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[14] Colombini (2013:10) here refer to: Chinkonde et al., 2009; Kebaabetswe, 2007; Nguyen et al., 2008; O'Gorman et al., 2010; Painter et al., 2004

in adhering to PMTCT programmes in contexts where patients lack confidence in the health facilities.

Infant feeding, global guidelines and nurse counselling

Some of the most vital, challenging and controversial parts of the PMTCT programme's actions have been connected to infant feeding (Chopra et al., 2005, p. 357; Raisler & Cohn, 2005, p. 278). Three central infant feeding methods have been highlighted in this context: 'exclusive breastfeeding', 'mixed feeding' and 'replacement feeding'. 'Exclusive breastfeeding' is defined as giving breast-milk only, with no addition of other solids or liquids, while 'mixed feeding' is defined to be feeding both breast milk and other foods or liquids (WHO et al., 2004, p. v). 'Replacement feeding' is defined as giving the infant commercial infant formula or home-modified animal milk (WHO et al., 2004, p. 1). Before we take a look at the PMTCT infant feeding guidelines, a brief introduction to infant feeding practices in sub-Saharan Africa is needed to provide an understanding of the challenges nurses and HIV-positive women have met in these programmes.

Sub-Saharan Africa consists of countries and areas that have highly different HIV rates and cultural and social norms bound to breastfeeding. Generally, exclusive breastfeeding has long since been established as the most effective way to save children in low-income countries from early child mortality due to breast milk's ability to protect against diarrhoea, pneumonia and neonatal sepsis (Black et al., 2003, p. 2227; Brown et al., 1989, p. 40; Popkin et al., 1990, p. 878). However, infant feeding practices in sub-Saharan Africa are commonly characterised by prolonged mixed feeding patterns as a strong norm (Doherty, 2011, p. 184). Exclusive breastfeeding is rare, as breastfeeding customarily is already supplemented by other fluids and soft solids during the very first months of an infants' life[15] while breastfeeding is habitually practised for about two years. Infant feeding is said to involve transmission of social and cultural traditions between the mother and her extended family (Desclaux & Alfieri, 2011, p. 199) which among others indicates that breastfeeding involves more than infant nutrition, and engages women in 'social obligations and customary ideas and values surrounding motherhood' (Doherty, 2011, p. 184). That breastfeeding in sub-Saharan Africa is highly valued and has been located at the heart of socio-cultural expectations is revealed by, among others, Hofmann et al. (2009, p. 324) in South Africa, where women referred to breast milk as 'water that supports and

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[15] See e.g. Buskens et al., 2007, p. 1103; Doherty, 2011, p. 184; Engebretsen et al., 2007, p. 6; Nwankwo & Brieger, 2002, pp. 110-1; Ssenyonga et al., 2004, p. 352

preserves life.' Hofmann et al. (2009, p. 324) describe how breastfeeding is viewed to be a main channel for the mother to show attention and affection towards the child. Breastfeeding is an inherent part of motherhood, as expressed by the HIV-positive women interviewed in Leshabari et al.'s (2007b, p. 549) study from Tanzania, where one mother said: 'All good mothers breastfeed their children'. A woman in Hofmann et al.'s (2009, p. 324) study said: 'A breastfeeding woman passes her character onto the child' – a comment that highlights how the mother and child are seen to be attached to each other through the highly valued practice of breastfeeding. Alternatives to breast milk, like formula milk, may pose social challenges for the women (Doherty, 2011, p. 184) in addition to being commonly 'unavailable, unaffordable, or culturally unacceptable' (Raisler & Cohn, 2005, p. 278). In the light of HIV, Desclaux and Alfieri (2011, p. 197) write that HIV-positive women were found to be located at the intersection between two 'sub-cultures' related to infant feeding practices – one within the local culture related to the provision of care for the infant and the perceptions of motherhood; the second sub-culture within a medical culture of the health services which included biomedical norms, techniques and knowledge directly linked to infant feeding and the PMTCT programmes (Desclaux & Alfieri, 2011, p. 197).

WHO and affiliates UNAIDS, UNFPA and UNICEF have developed, and continuously revised, specific PMTCT guidelines on HIV and infant feeding during the last decades[16] in attempts to cater for a rapidly evolving knowledge base. The guidelines are meant to guide health workers worldwide on how to approach and counsel HIV-positive pregnant or lactating women about 'best practice' in infant feeding – but it has proved challenging to operate with global recommendations in a situation of highly different resources and opportunities. A main challenge for local authorities has been to translate global guidelines into national and operational settings, based on which infant feeding is proved best for the individual context and HIV-positive woman, and the gap between the two outer points of infant feeding, replacement formula feeding and exclusive breastfeeding, has been difficult to bridge (Doherty, 2011, p. 185). In this situation, health care workers, nurses not the least, in low-income contexts have had to make sense of and implement these rapidly revised guidelines into local PMTCT programmes. We will briefly look at the main challenges linked to HIV, PMTCT and global

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[16] Infant feeding guidelines produced by the WHO and affiliates: UNAIDS et al., 1997; WHO et al., 1998a,b; WHO et al., 2003a,b; WHO et al., 2007; WHO et al., 2010; WHO et al., 2012

infant feeding guidelines to get a sense of nurses' vantage point for caring interactions with the HIV-positive women enrolled in the PMTCT programmes.

Throughout the 1990s reports on mother-to-child transmission (MTCT) of HIV through breastfeeding became progressively complex and uncertain (Thairu, 2011, p. 166), and the discussion about safer infant feeding among HIV-positive women was surrounded by substantial confusion (De Cock et al., 2000, p. 1176). One of the core messages brought forth was the introduction of 'informed choice' into the infant feeding strategy of HIV-positive women in the late 1990s (UNAIDS et al., 1997, pp. 4-5). Nurses were now given the responsibility to provide HIV-positive women with information on the risks and benefits of all the available infant feeding methods, and then leave it to the women to make an individual informed choice on the optimal feeding practice for her particular situation. Multiple options were to be presented during individual counselling sessions (WHO et al., 1998a, pp. 8-10) but the infant feeding forms that gained prominence were, at this point 1) exclusive breastfeeding with early cessation, and 2) commercial infant formula.

A benchmark linked to safer infant feeding practices for HIV-positive women was at the point where research indicated that exclusive breastfeeding for the first six months of life led to less HIV-transmission than so-called mixed feeding (Coutsoudis et al., 1999, p. 474). Exclusive breastfeeding was found to result in a significantly lower risk of HIV-transmission compared to mixed feeding in a series of large prospective studies in South Africa (Coovadia et al., 2007, p. 1113; Coutsoudis et al., 1999, p. 474), Zimbabwe (Iliff et al., 2005, p. 703), Zambia (Kuhn et al., 2007, p. 8), and Ivory Coast (Becquet et al., 2008, p. 31). Mixed feeding is found to likely increase gut permeability, induce local inflammation and thus facilitate the passage of HIV (Coovadia et al., 2007, p. 1114; Coutsoudis et al., 2001, p. 386; Coutsoudis et al., 1999, p. 474). As research provided findings on the dangers of mixed feeding patterns (WHO et al., 2004), the customary infant feeding pattern in the parts of the world with highest HIV prevalence, the global infant feeding guidelines were revised in 2003. Nurses in low-income settings thus had to change the message presented to HIV-positive women during counselling.

The infant feeding guidelines were once again updated in 2007 (WHO et al., 2007) when research documented that early cessation of breastfeeding for babies born to HIV-positive women (before or at six months) led to worse overall outcomes, leading to increased mortality and decreased rates of HIV-free survival compared to babies provided with longer periods of breastfeeding (Homsy et al., 2006; Kafulafula et al., 2007; Onyango-Makumbi et al., 2007).[17] Hence, again, nurses had to provide HIV-positive women in their clinics with new messages on safer infant feeding options and justify why the previous message of the dangers of mixed feeding, particularly linked to the abrupt cessation criterion, was no longer applicable. Early cessation of breastfeeding, at around six months of age, was at this point only to be recommended if avoiding all breastfeeding and transition to replacement feeding was available, feasible, affordable, sustainable and safe (AFASS) (WHO et al., 2007, p. 4). Otherwise, the mother should continue breastfeeding and introduce complementary foods at six months, and stop breastfeeding 'once a nutritionally adequate and safe diet without breast milk can be provided' (WHO et al., 2007, p. 9). Abrupt or rapid cessation was no longer recommended due to 'possible negative effects on the mother and infant'; weaning should thus be carried out gradually (WHO et al., 2007, p. 4).

Research closely followed the progress and effect of these rapidly shifting infant feeding policies. The strategy of 'informed choice' in infant feeding counselling was early highlighted as greatly problematic. In a summary of this part of the debate, Doherty (2011, p. 185) writes: 'In the context in which most HIV-positive women in Africa find themselves truly informed, choice is seldom a reality either due to social or economic constraints', which has also been reported elsewhere (Desclaux & Alfieri, 2009, p. 827; Leshabari et al., 2007b, p. 552; Moland & Blystad, 2009, p. 469). The challenges eventually resulted in a toning down of the 'choice-approach' in the 2010 revision of the global infant feeding guidelines, locating the responsibility of the 'choice' on the national authorities (WHO et al., 2010, p. 3).

In the PMTCT programmes infant feeding counselling has been a major activity. In the 'infant feeding counselling process', the nurse and the HIV-positive woman should meet and discuss the infant feeding options and agree upon the safest possible infant feeding strategy for the particular mother. However, the speedy revisions of the infant feeding guidelines from global authorities throughout the last decade have led to substantial difficulties and uncertainty among nurse counsellors and HIV-positive women about what to recommend and how to approach the infant feeding issue.[18] Courses and training manuals have been developed alongside the infant feeding guidelines to ensure nurses' qualifications in counselling.[19] However, among the many

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[17] Later publised in scientific articles: Homsy et al., 2010, p. 33; Kafulafula et al., 2010, p. 12; Onyango-Makumbi et al., 2010, p. 8

[18] See e.g. Chopra et al., 2005, p. 361; Chopra & Rollins, 2008, p. 290; Coutsoudis et al., 2008, p. 211; de Paoli et al., 2008, p. 1667; Shah et al., 2005, p. 35

[19] See e.g. WHO & UNICEF, 2006; WHO et al., 1998a, 2000; WHO et al., 2003a; WHO et al., 2005

challenges reported are limited access to the continuously revised guidelines and training manuals, inadequate training of infant feeding counsellors, and the limited possibility of implementing the proposed changes because of insufficient resources and cultural concerns,[20] which 'all make appropriate and effective infant feeding counselling difficult' (Doherty, 2011, p. 187). It has been acknowledged that poor counselling and the nurses' strong impact on women's infant feeding choice could have adverse effects on child survival, as women have been reported to make inappropriate choices which compromised the possibility of the survival or HIV-free survival of their children.[21]

The HIV/AIDS-related stigma has continuously been recorded as a major contributing factor to the challenges HIV-positive women face related to infant feeding practices. In studies from sub-Saharan Africa, HIV-positive women have reported experiencing stigmatisation connected to infant feeding if they chose to formula feed because they stood out from the cultural expectation of breastfeeding and motherhood (Leshabari et al., 2007b, p. 551; Mill et al., 2013, p. 1072). Cames et al. (2010, p. 256) write that HIV-positive breastfeeding women in Burkina Faso were indeed worried about the risk of HIV transmission 'but were even more concerned about confronting social risks inherent in not conforming to the tradition of breastfeeding.' Also the infant feeding practice of exclusive breastfeeding for six months and abrupt cessation of breastfeeding proved difficult as, referred to above, solely breastfeeding for months and the sudden discontinuation of breastfeeding are highly uncommon scenarios (Desclaux & Alfieri, 2011, p. 202; Doherty, 2011, p. 184; Engebretsen et al., 2007, p. 6).

Let us now move into the study country of Tanzania, with a particular focus on the roles nurses have played and play in the Tanzanian health sector in general and in PMTCT programmes in particular.

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[20] See e.g. de Paoli et al., 2002, p. 151; Leshabari et al., 2007a, p. 7; Moland & Blystad, 2009, p. 471; Moland et al., 2010, p. 4; Piwoz et al., 2006, p. 4

[21] See e.g. Desclaux & Alfieri, 2009, p. 824; Doherty, 2011, p. 188; Rollins et al., 2008, p. 2355; Sprague et al., 2011, p. 3

NURSING AND PMTCT IN TANZANIA

This study was carried out in rural and semi-urban areas of the United Republic of Tanzania. The following section aims to provide brief background information on Tanzania's health care system with a particular emphasis on nurses' working conditions and their position within the health system. Background information on the case of HIV/AIDS and the introduction and roll out of the PMTCT programme within the Tanzanian health care system will also be provided. Demographic background information will follow in Chapter 3.0. in the section 'Field sites'.

Health care in Tanzania

After colonisation by Germany (1880-1919) and Britain (1919-1962) Tanzania became independent in 1962. The nation's first president, President Nyerere, immediately declared war against what he termed the main enemies of the country: poverty, ignorance and disease (Jonsson, 1986, p. 745). Within health care the prime goal was to provide the rural population with access to health services (Kwesigabo et al., 2012, p. S36), which in the 1970s led to an emphasis on the training of health cadres and on preventive health services in the rural areas where the majority of the population lived (Bech et al., 2013, pp. 68-9; Chagula & Tarimo, 1975, pp. 154-5). The difficult economic situation in the1970s and 1980s had severe impact on the public health services throughout the 1980s (Songstad et al., 2012, p. 2), which led to a freeze in public health employment, 'The Retrenchment Policy', in the 1990s (Ministry of Health and Social Welfare[22], 2008, p. 2). This hiring freeze led to a marked move from the public health sector to the private health sector among health workers in the 1990s, as they were 'attracted by higher salaries, better benefit packages, working environments and training opportunities' (COWI et al., 2007, p. 80). However, as the public health sector started to offer better employment conditions from early 2000, the movement of health workers reversed, largely due to the same factors (COWI et al., 2007, pp. 80-1). A result is that the health worker shortage is reported to be higher in private- and church-run health facilities than government-run health facilities, and in 2009 Pamba and Kahabi (2009, p. 66) reported:

> Since 2006 the average salary for nurses working in CSSC[23] is Tshs 172.000, while the public sector pays an average salary of Tshs 402.000. Moreover, public sector workers have also a higher housing allowance and higher pension.

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[22] 'Ministry of Health and Social Welfare' will hereafter be referred to as 'MOHSW'

[23] The Christian Social Services Commission (CSSC) is an ecumenical body representing the interests of about 15 churches and 10 church-related organisations. Most Faith Based Organisations (FBOs) are represented by the CSSC

Songstad et al. (2012, p. 8) also found a marked preference for public sector employment in their study which was associated with the pension scheme, which in turn challenges the resource-constrained health systems in rural areas where church-run health facilities make up a vital part of the health infrastructure.

In 2013, the health care system in Tanzania had a total of 6,876 health facilities, which in addition to governmental facilities includes facilities owned by private, faith-based organizations and parastatal institutions such as NGOs (MOHSW, 2014, p. 12). The term ‘health facilities’ covers hospitals, health centres and dispensaries that provide health care at different levels. The division of labour between the various facilities varies connected to (1) the number of staff with varying level of education, which in turn is linked to (2) access to equipment and available procedures carried out (Kwesigabo et al., 2012, pp. S36-7). Health centres and dispensaries are ranked below the hospitals within the health care system. Dispensaries are ideally headed by a nurse who should be assisted by clinical assistants, however, it is not unusual to find dispensaries in remote areas staffed only by medical attendants – health workers without any professional training. The health centres are ranked above the dispensaries and provide minor surgeries and reproductive health services. They should be run by clinical officers assisted by nurses (Kwesigabo et al., 2012, p. S37). Statistics from 2013 show that 70 per cent of the rural population in mainland Tanzania lives within five kilometres of a health facility (Tanzania Commission for AIDS[24] et al., 2013, p. 18).

As in the other countries of sub-Saharan Africa, and referred to above, Tanzania has a substantial health-worker shortage. The Tanzanian government reports a health-worker shortage of 82,007 in 2013, which is about 56 per cent (MOHSW, 2014, p. 12). Importantly, 43 per cent of the available health workforce is reported to be occupied by non-professionals (MOHSW, 2008, p. 19), so-called ‘auxiliaries’, which demonstrates the serious shortage of staff with higher education, including nurses. The already-mentioned ‘Retrenchment Policy’ resulted in a workforce which declined by 35.4 percent between 1994 and 2005 (The United Republic of Tanzania[25], 2009, p. 5) – at a time when the disease burden rapidly increased with HIV/AIDS (MOHSW, 2008, p. 2). Globalization and the related brain drain inside and outside the country further contributed to the human resource crisis in Tanzania (MOHSW, 2008, p. 2). Olsen et al. (2005, p. 10), moreover, report that the number of health worker staff available in Tanzania is

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[24] ‘Tanzania Commission for AIDS’ will hereafter be referred to as ‘TACAIDS’

[25] ‘The United Republic of Tanzania’ will hereafter be referred to as ‘URT’

very low compared to comparable African countries. Even though the number of health care workers in recent years is reported to have increased from 47,000 in 2006 to 56,000 in 2011 (URT, 2013b, p. 12), rural areas continue to be disadvantaged (Manzi et al., 2012, p. 6; Munga & Maestad, 2009, p. 5; Olsen et al., 2005, p. 10). Fifty-five per cent of the country's health workers serve the rural population – where 75 per cent of the total population live – and the figures for specialists in rural areas are, respectively, lower (URT, 2013b, p. 12).

Nurses and nursing in Tanzania

In pre-colonial times, i.e. prior to the 1880s, care for patients and women in labour was largely provided by elderly married women within the community. Biomedical health care was introduced in this era through diverse missionary organizations (Barry & Bia, 1986, p. 438; Benson, 2001, p. 1904), and during the colonial period missionaries brought ideas of nursing at the same time as medical services arrived and expanded within the country. The first organised training of nurses started in 1939 (Moyo & Mhamela, 2011, pp. 161-3), and in 1943 the first African woman obtained her nursing certificate in Tanzania (Barry & Bia, 1986, p. 438). In independent Tanzania, the Ministry of Health was until the late 1980s responsible for all nursing education in Tanzania (Mkony, 2012, p. 55). Figures from 2014 show there are 31 public nursing colleges and 42 private or faith-based nursing colleges in Tanzania (MOHSW, 2014, p. 14).

Education was, from the first day of independence, given substantial emphasis in Tanzania, and is by and large highly valued in Tanzania. Nursing has been and continues to be an attractive education, particularly for women, and the knowledge achieved through the nursing education has, since independence, lent an authoritative status associated with modern life (Moland, 2002a, p. 54; Moland, 2002b, pp. 8, 15). Moland (2002b, p. 8) writes: 'At the same time as nursing represented access to education and modern life, it was a kind of work that did not compromise young women's respectability.' The nursing occupation in a Tanzanian context has been referred to as a calling, a work for God (*kazi ya Mungu*), and is connected to 'goodness rather than as a meaning of earning a living' (Moland, 2002a, pp. 54-5).

The shortage of trained nurses is estimated to be 38.3 per cent (URT, 2009, p. 5). The Tanzanian education system has three categories of nurses: (1) nurse/nurse midwife, (2) assistant nursing officer and (3) nursing officer. Statistics report that the total number of nurses/midwifes in Tanzania in 2012 was 21,726 which led to a nurse/midwife[26]-to-population ratio of 0.5 per 1000 (MOHSW et al., 2013, p. 85), while Manzi et al. (2012, p. 4) a year earlier reported a nurse-to-population rate of only 0.14 per 1000 population in the 134 health facilities they surveyed. The WHO (2015) reports that Tanzania[27] is the country with the lowest nurse/midwife-to-population ratio (0.2 per 1000 population) among the countries in east Africa; Kenya has a ratio of 0.8[28], Mozambique 0.4[29], Zambia 0.8[30] and Uganda 1.3[31], while, in Europe, Germany has a ratio of 11.4[32] and the United Kingdom 8.8.[33]

HIV/AIDS and PMTCT in Tanzania

Tanzania's first case of AIDS was serologically confirmed in August 1985, but cases of AIDS can be traced back to November 1983 in the Kagera region (Killewo et al., 1990, p. 1081; Mhalu et al., 1987, p. 217). As in most other east- and southern African countries, HIV spread quickly, and reached its peak at 8.4 per cent in 1996 in Tanzania (URT, 2013b, p. 16). In December 1999 the government declared HIV/AIDS to be a national disaster. It was estimated that a total of 1.4 million people lived with HIV in Tanzania in 2013 (URT, 2014, p. 11), and the most recent estimate among adults aged 15-49 is 5.1 per cent (TACAIDS et al., 2013, p. 109) while the UNAIDS estimate an HIV/AIDS prevalence of 5.0 per cent for the same age group (UNAIDS, 2013). The overall picture in the Tanzania mainland shows a decrease in adults living with HIV, from seven per cent in 2004 to five per cent in 2012, which also reflects the decreasing prevalence among women from eight to six per cent during the same period (TACAIDS et al., 2013, p. 111). 250,000 children (aged 0-14) were estimated to be HIV-positive in 2013 (UNAIDS, 2013). Despite the enormous efforts in implementing the PMTCT programme, more than 23,000 new infants tested positive for HIV infection in Tanzania in 2013 (URT, 2014, p. 22). Of all pregnant women in Tanzania, six per cent were estimated to be HIV-positive in 2013 (WHO, 2014, p. 32). Mother-to-child transmission accounts for about 18 per cent of the total HIV infections in the population (URT, 2013b, p. 14).

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[26] 'In 2012, the classification of nurses and midwives differed from previous years, making it hard to assess the trend. The three main categories are nurse & nurse-midwife (not separated, 14,096), assistant nursing officer and nursing officer. These combined figures correspond with 21,736 or 5.0 nurse-midwives per 10,000 population' (MOHSW et al., 2013, p. 85)

[27] Reported on statistics from 2006

[28] Reported on statistics from 2011

[29] Reported on statistics from 2012

[30] Reported on statistics from 2010

[31] Reported on statistics from 2005

[32] Reported on statistics from 2011

[33] Reported on statistics from 2012

In Tanzania, like many countries in sub-Saharan Africa, there is a noticeable variation in HIV prevalence within the country, with a higher prevalence in urban (seven per cent) than in rural (four per cent) areas. There are also marked differences between the country's regions, the highest prevalence being near 15 per cent in Njombe Region, while the Zanzibar Regions are all below 1.5 per cent (TACAIDS et al., 2013, p. 110). Women aged 23-24 are almost three times more likely to be HIV positive compared to men of the same age (URT, 2014, p. 13).

In 1998, the Ministry of Health and Social Welfare initiated the planning of PMTCT programmes in Tanzania, and in April-September, 2000, five UNICEF-sponsored pilot projects were implemented (Centers for Disease Control and Prevention, 2002, p. IV). Two years later the evaluation report concluded that 'it is feasible to implement and scale-up PMTCT services in Tanzania' (Centers for Disease Control and Prevention, 2002, p. V) and, from 2003, a scale-up and roll-out was carried out, guided by the first developed National PMTCT Guidelines in 2004 (URT, 2004). The national PMTCT programme has largely followed the global guidelines on PMTCT and infant feeding and revised their national guidelines accordingly in 2007 (URT, 2007), 2012 (URT, 2012a) and 2013 (URT, 2013a). The PMTCT services across the country have progressively been scaled up, and the Tanzanian authorities report that, by December 2012, 4,914 out of 6,342 health facilities had integrated PMTCT services. Even though coverage of PMTCT services is by and large good, only 1,404 of these clinics provided full ART services in 2013 (URT, 2013b, p. 13). More than 18 per cent of infants of HIV positive mothers were born HIV-positive because their mothers had 'inefficient regimens (single dose nevirapine in some facilities), drug stock outs or poor adherence to treatment, or simply lack of access to PMTCT services during pregnancy' (URT, 2014, p. 16).

Infant feeding and counselling in PMTCT programmes

The customary infant feeding practices of women in Tanzania largely follow the practice found elsewhere in sub-Saharan Africa, with prolonged breastfeeding and early introduction of complementary foods and liquids. Exclusively breastfeeding is not commonly practiced and a study from rural areas in Rukwa and Manyara Regions found that more than 40 per cent of the women agreed that infants aged one month should receive water and other liquids in addition to breast milk (Hadley et al., 2010, p. 555). Poggensee et al.'s (2004, p. 484) study from Western Tanzania reported the mean duration of breastfeeding to be 24 months. Women in the study area are reported to nurse their children for at least a year, and commonly up to two years, and '[m]other's milk and the flows that exist between the mother and her child during the period of nursing are considered to be inherently good, intimate and nourishing' (Blystad & Rekdal, 2004, p. 635). The social and cultural meaning of breastfeeding is further pictured through how the mother and her child is perceived to be 'one body' as long as the mother is nursing (Blystad & Rekdal, 2004, p. 635).

Tanzania's PMTCT and infant feeding guidelines have, as mentioned above, largely followed the development of the global WHO guideline, and the 2007 national guidelines, which were applicable at the time of the fieldwork, state:

> The national recommendation for HIV infected women is to breastfeed their infants exclusively for the first 6 months of life, followed by the addition of complementary foods after 6 months. Mothers should continue to give their infants breast milk until they can wean them safely.
>
> Mothers who wish to reduce the risk of transmitting HIV to their infants may choose to replacement feed their infants exclusively for the first 6 months of life. However, exclusive replacement feeding is recommended only when it is acceptable, feasible, affordable and safe (AFASS). (URT, 2007, p. 48)

The Tanzanian 2007 PMTCT infant feeding guidelines stated that HIV-positive women had the 'right to choose how and what to feed their infants after being given information on different recommended infant feeding options' (URT, 2007, p. 49). With reference to the above described challenges, found in many low-income context connected to the 'informed choice' approach, the Tanzanian PMTCT guidelines were revised in 2012 and 2013 according to the WHO 2010 guidelines, where the national decision to opt for exclusive breastfeeding as the first choice for HIV-positive women in Tanzania was recommended:

> Women living with HIV should be encouraged to breastfeed exclusively for the first six months of life and then introduce complementary foods while continuing to breastfeed to 12 months of age. (URT, 2013a, p. 67)

The 2013 Tanzanian guidelines, however, also state: 'Quality infant feeding counselling should include information that assists women and their families in making informed decisions about what to feed their children' (URT, 2013a, p. 66) and, as such, changed 'choice' to 'informed decision' where the meaning is difficult to capture.

Today, the world's focus lies on the plan of eliminating mother-to-child transmission of HIV and, in December 2012, the Tanzanian Ministry of Health and Social Welfare launched their 'Elimination of mother-to-child transmission of HIV' plan, aimed 'to eliminate new HIV paediatric infections and keep mothers alive through improved maternal, new born and child health and survival programmes by 2015 in Tanzania' (URT, 2012b, p. 22). Among others, the plan has a goal to reduce the transmission of HIV from mother to child from 26 per cent in 2011 to four per cent in 2015, and to increase the percentage of HIV positive pregnant women who receive ART from 55 per cent in 2010 to 98 per cent in 2015 (URT, 2012b, p. 22). The more recent ‘Multi sectoral strategic framework for HIV/AIDS 2013/2014-2017/2018’ state that by 2018, 100 per cent of pregnant HIV-positive women shall receive ARVs to prevent HIV transmission (URT, 2013b, p. 44). The latest statistics from Tanzania from 2014 indicate that these goals for 2015 are far from met (URT, 2014, p. 16).

2.0. AIM AND OBJECTIVES OF THE STUDY

The major aim of the study is to generate knowledge on nursing care in nurses' every day practice in low-income settings. It aims to enhance the understanding of the manner in which caring conduct emerges in nurses' interaction with their patients, with a particular scrutiny on nurse encounters with HIV-positive women enrolled in prevention of mother-to-child transmission of HIV (PMTCT) programmes in rural and semi-urban settings in Tanzania.

The sub-objectives of the study:

1) To explore how nursing care is experienced and expressed in nurses' everyday work among HIV positive women enrolled in a PMTCT programme in rural Tanzania (Paper I).
2) To scrutinise how nurses and HIV-positive women enrolled in PMTCT programmes in rural and semi-urban Tanzania experience approaches of patient participation and informed choice in counselling sessions (Paper II).
3) To study how dilemmas of confidentiality are approached in nurses' work among HIV-positive women and their infants in PMTCT programmes in Tanzania (Paper III).

3.0. METHODS

The present study was grounded in an enthographic tradition based on fieldwork within two hosptials in Tanzania. Observations, participant observation, interviews and informal conversations make up the bulk of the material. This chapter provides a relatively detailed description of the research process from the initial phase of the study, throughout the fieldwork and analysis to the writing up of the articles and the thesis. The chapter's last section includes reflections and discussions of methodological strengths and challenges of the project. I shall start with a brief overview of the study context.

FIELD SITES

The study was carried out in two districts located within the same region in the northern/central parts of Tanzania. The area is characterized by complex linguistic and ethnic composition; all the four major African language groups of sub-Saharan Africa are represented (Bantu, Cushitic, Nilotic and Khoisan), but the Iraqw and Datoga ethnic groups make up the majority of the population, although the pastoral Datoga have dwindled, moving southwards and eastwards in large numbers during the past two decades in search of pasture. Agro-pastoral adaptations based on the keeping of goats, sheep, chickens and cattle combined with the cultivation of maize, beans, sorghum and sunflowers dominate in the region. In the two areas, one highland and highly rural and one semi-urban, poverty is rampant and, as in Tanzania overall, the formal educational level is generally low (Wedgwood, 2007, p. 386).

Compared to the national HIV/AIDS prevalence of 5.1 per cent, the study region's HIV prevalence was 1.5 per cent in 2012 (TACAIDS et al., 2013, pp. 109-10), a reduction from 2 per cent in 2003/2004 (TACAIDS et al., 2005, p. 75; Yahya-Malima et al., 2006, p. 5). Notably, the prevalence in the study region varies between women and men – 2.7 per cent among women and 0.3 per cent among men (TACAIDS et al., 2013, p. 110). As mentione above, six per cent of pregnant women aged 15-49 years in Tanzania were estimated to be HIV-positive in 2013 (WHO, 2014, p. 32). Numbers from 2007 report, however, variations between pregnant women in urban areas (10.4 per cent) and in rural areas (4.6 per cent) (WHO, 2007, p. 14). Even though district-specific data on HIV prevalence is not available, it is nevertheless assumed that the HIV prevalence in the semi-urban study area is substantially higher than in the rural area.

Data was collected from the PMTCT programmes at two hospitals located, one in each district. The hospitals were chosen according to the following criteria: (1) location: rural district compared to semi-urban district, (2) administrative structure: church-run compared to government-run and (3) five months previous fieldwork experience from the rural/highland area, and hence some important prior knowledge of people and places. A brief introduction to the settings of the two hospitals follows. Due to the research participants' confidentiality, operating in small and vulnerable working communities, the districts and hospital names are not specified, and the hospitals will be referred to as 'hospital A' (the rural/highland) and 'hospital B' (semi-urban/low lands), respectively.

Hospital A is church-run and located in a highly rural area situated about 1700 meters above sea level in a district with a population of 320,000 (URT et al., 2013, p. 191). The hospital is divided into nine divisions, has 400 inpatient beds and is the first referral hospital for a population of about 500,000 – however, it is estimated to cover a greater reference area of roughly 2,000,000 people (Evjen-Olsen et al., 2009, p. 2). In addition to hospital A, there is one hospital, one health centre and 21 dispensaries which are government-run in the district. In addition, various church organizations run two health centres and four dispensaries, while three dispensaries are privately-run (MOHSW, 2015). The hospital's HIV/AIDS work was located in the Care and Treatment Centre (CTC), which at the time of the fieldwork was staffed five days a week by one clinical officers, three nurses, two secretaries and one ward attendant. One lab-technician and one pharmacist were also involved on the ward, but were not present on a daily basis. The clinic was also staffed by one nurse every Saturday for the distribution of medicine. In addition, the staff covered an outreach clinic at a health centre located 50 km from the hospital once every second week. One of the many components of the CTC clinic was the PMTCT programme. A comprehensive HIV-prevention and intervention programme, defined as a PMTCT Plus alternative, was launched in 2003 (Robberstad & Evjen-Olsen, 2010, p. 397) through foreign support. This programme consisted from the very start of (1) free, highly active ART (HAART) for HIV-positive pregnant women from 20 weeks of pregnancy, and (2) a follow-up component comprising home visits to vulnerable mothers and limited food- and milk support for babies at weaning to ensure a safe transition to replacement feeds (Evjen-Olsen et al., 2009, p. 8). HIV-positive women received regular consultations and counselling at the clinic from the time they tested HIV-positive and were enrolled in the programme. A close co-operation with hospital-funded, home-based care providers (HBC), facilitated a system where the enrolled HIV-positive mothers would receive basic care at home in large parts of the hospital's catchment area. The CTC clinic and PMTCT programme collaborated closely with the other divisions at the hospital, particularly the Reproductive and Child Health Service (RCHS) and the Maternity ward.

Hospital B is located in a semi-urban district in the centre of the region and has a population of 312,000 (URT et al., 2013, p. 191). The hospital has a total of 120 beds spread over the hospital's four main wards.[34] In addition to hospital B, there are eight health centres and 24 dispensaries which are government-run in the district. In addition, various church organizations run two hospitals, two health centres and four dispensaries, while five dispensaries are privately-run (MOHSW, 2015). The PMTCT programme at hospital B was launched in 2007[35] and consisted of two categories: pre- and post-natal. (1) HIV-positive pregnant women were referred to the HIV/AIDS clinic from the RCHS clinic at 28 weeks of pregnancy. At this point they were supposed to initiate the officially recommended regimen of ART (AZT + sdNVP) (URT, 2007, p. 119). However, many mothers reported during interviews being supplied with the minimum ART prophylaxis regimen, single-dose Nevirapine (URT, 2007, p. 120) as the only medication to prevent MTCT. (2) After birth, the women received medication and consultations at the CTC clinic while the RCHS carried out the follow-up on the child. The CTC clinic was staffed three days a week, and two outreach HIV/AIDS clinics were staffed once every month. On an ordinary day at the CTC the staff consisted of two or three nurses, one pharmacist, one lab-technician and one clinical officer or medical doctor. As the CTC was only operational three days a week, the staff worked on other hospital wards the remaining days. While many of the nurses and the pharmacist worked in CTC quite regularly, the nurses reported that there was little continuity with regard to the work of the medical doctor or clinical officer at the clinic.

This brief introduction of the two PMTCT programmes indicates how the PMTCT programme at hospital A was more economically funded and hence more extensive than the programme at hospital B with regard to days of open clinic and access to health care workers, in addition to the types of services they provided.

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[34] Personal communication

[35] Personal communication

SITUATING THE RESEARCHER

Hammersley and Atkinson (2007, p. 73) refer to how there are so-called ‘ascribed’ characteristics of the researcher that ‘may limit the negotiation of identities in the field’. Ascribed characteristics may be gender, age, race, ethnicity and religious affiliation which can interfere and pose challenges or benefits for the relationship between the researcher and the informants, and may thus affect the process of data collection and analysis. Ascribed characteristics may also affect or guide the role the researcher takes or is given during the fieldwork. Before we look at how the two hospitals in particular were accessed, I will provide some information on myself as a researcher within the present context.

I entered the field as a Norwegian, a Christian (Lutheran), a nurse, a married woman and a mother of two children. My origin as a Norwegian and Christian may be linked to hospital A as a missionary hospital with roots to the Norwegian mission. At the time of my fieldwork the hospital was, however, owned and run by the Tanzanian Evangelical Lutheran Church. Hospital A also had a continuous presence of European and North-American health workers, students and researchers in past decades, which implied that both staff and patients were accustomed to European and American presence in research and in health-related positions. My presence was thus not particularly commented upon by the health workers, and my origin as Norwegian was commented upon several times in positive terms, most likely connected to the fact that the founder of the hospital was Norwegian. Hospital B was government-run and the health workers and patients were not as familiar with European visitors – health workers or researchers – and my presence and research activities were therefore noticed and commented upon to a much greater extent than at hospital A.

Since during my MA studies, I had carried out five months of fieldwork in the same area in Tanzania, I entered the field with some knowledge of the facilities and structures surrounding hospital A, and I already knew a few of the key health workers. Due to the earlier and renewed Swahili language training, I was also able to conduct short conversations in basic Swahili. I worked hard to gradually expand my Swahili during the fieldwork period, and midway through the fieldwork I felt relatively confident in understanding most of what the HIV-positive women communicated during observations and interviews. However, my oral Swahili was not satisfactory, and I hence kept research assistants close throughout the fieldwork for translations and verifications in situations and communications I was not able to handle alone.

ACCESS TO THE FIELD SITES

The literature refers to how the researcher, during the initial phase of ethnographic fieldwork, has to find his or her role in the field in order to gain access to information (Hammersley & Atkinson, 2007, p. 41). The entry to the two hospitals took different forms. In hospital A – the field I accessed first – I approached the CTC progressively over the course of several weeks. The first day of my fieldwork started with a presentation of myself and my study at the hospital's daily morning 'prayer meeting' (sala ya asubuhi = morning prayer) where the majority of the hospital staff on duty was present. I was then introduced to the nurse in charge of the CTC clinic, informed her carefully about the study, asking for input, and subsequently followed her work for a couple of days to get to know her and to get a brief impression of how the clinic was organized. Early on I found her to be a 'gatekeeper', which, according to Hammersley and Atkinson (2007, p. 49), is a person who '[h]as the power to open up or block off access, and who consider[s] themselves and are considered by others to have the authority to grant or refuse access' (Hammersley & Atkinson, 2007, p. 50). To get an understanding of how the clinic was organized according to the patient flow, I spent several days during the second week in the patients' area of the clinic, which was labelled the 'reception'. These initial observations gave me insight into the manner in which the patients organized themselves on different benches and in lines pertaining to the diverse consultations and tests they were awaiting. Further, it also gave me an early opportunity to greet patients and practise my basic Swahili through the introduction of myself and my role in the clinic. This was found to be a productive ice-breaker, as many of the patients were curious about my presence. As I gradually learnt the 'rules' of the reception area and the faces and names of some of the patients, I slowly started to approach the nurses and their everyday chores at the clinic, which would be where I was to spend most of my time, and where I gained access to informants and information throughout the fieldwork period.

In the early parts of the fieldwork I tried to gain an overview of the diverse administrative and clinical roles and tasks of each health worker group at the clinic; from the secretaries, the clinical officers and the pharmacists to the nurses' responsibilities. Verbal and written information about the study was provided to all health workers in the clinic (appendix IX). I explained my role as a researcher and observer at the clinic, and received acceptance and the consent to follow everyone's work. During the first month my main focus was to learn how the clinic worked, get to know the health workers, and gradually gain the trust of both the employees and patients of the clinic at hospital A. At this point I felt relatively confident about my role in the clinic. Access to the field is, however, a continuous part of fieldwork and throughout the fieldwork period I constantly negotiated my role within and outside the clinic, as I wished to gradually gain more room and time for informal and formal talks, particularly with the HIV-positive women, outside the domain of the clinic.

The study in hospital B was initiated four months after hospital A. The initial plan – to move to the town where hospital B was located for the rest of the fieldwork period – had by this time changed, primarily due to the perceived value of the follow-up of key informants in hospital A. The introduction and implementation of the collection of data in hospital B was instead carried out during nine trips lasting from one to three days. The first day, I introduced the study to the Medical Officer in Charge, the Nursing Officer in charge and the nurse in charge of CTC. I received approval to carry out the study and was welcomed to initiate interviews with HIV-positive women from the very first day.

Even though these short trips obviously made the access to the field site in hospital B quite different from hospital A, I soon experienced that much of what I had learnt from the access process in hospital A, particularly in connection with the organisation of the daily tasks at the CTC, were similar in the two hospitals. The first visits were characterized by a number of informal talks in the reception are, the corridor and in the lab-room which we were welcomed to use for the more formal interviews with the HIV-positive women. The nurses were, however, reluctant to let me observe their work inside the clinic offices. During the last four visits, the nurses acted more freely and I was at this point also able to follow some of their work at the clinic offices. The HIV-positive women enrolled in the PMTCT programme at hospital B appeared to be open, and willingly participated in interviews. I was however not able to follow the women at hospital B through later clinical consultations or home visits.

My earlier experiences from the fieldwork area directed the way I chose to enter the field, and thereby clearly influenced the role I was given during the early parts of my fieldwork. I chose to enter the field through the HIV/AIDS clinic, and secured contact with the clinic's health workers, through whom I gained access to the HIV-positive women as informants. It was thus through the CTC clinic – and not from outside the hospital – that I encountered the women.

The way a researcher dresses naturally has implications for the study and the access to the field. My approach to the way I dressed changed during the fieldwork period. During the early parts of the fieldwork, while observing in the clinic, I chose to wear a white health worker coat. This choice seemed natural, based on my background as a nurse, and was an attempt to gain position as an acceptable member in the clinical context, as Hammersley and Atkinson (2007, p. 69) highlight in their writing. During the early phase of the fieldwork, the white hospital coat seemed like a door opener in the sense that it facilitated access to new arenas of observation. When entering the office where the interviews with the HIV-positive women were carried out, I took off the white coat as a signal of the change of context and milieu in an attempt to detach the interview from the clinic, although I had no illusion about fully separating the two contexts. At the time when I initiated the study in hospital B I had started to wear ordinary clothes at hospital A, as at this point I believed it was important to distance myself somewhat from the 'health worker role'. Therefore I also chose to enter hospital B without a white coat, and always wore ordinary clothes in the clinic. During the home visits, the nurse, the driver and I wore ordinary clothes to draw as little attention as possible. Reflections on how this might have affected my position as a researcher on part of the informant will follow in the section 'Ethnigraphy in the present study'.

Throughout the fieldwork period, my access to the field was a continuous process of negotiation of my position within the field, which included the necessity to keep 'gatekeepers', informants and the clinics comfortable with my presence while the data collection and my learning process developed. The latter meant that the focus of the study became clearer and the data collection could become more structured and focused.

RESEARCH ASSISTANCE AND LANGUAGE

The fieldwork required the help of research assistants. To be able to communicate adequately with the HIV-positive women during the interviews and follow-up conversations, I was dependent upon language assistance through an interpreter to chair the interview and provide me with translations, particularly through the first months of the fieldwork. Through previous fieldwork I had gained experience in collecting data with the assistance of an interpreter and, hence, I was familiar with quite a few of the advantages and disadvantages of such co-operation. The selection of research assistants was based on a thorough discussion with an experienced nurse who had assisted several large research projects. Two female research assistants were hired during the early part of the fieldwork. The first was a relatively young girl, a 'form-four' leaver, meaning she had completed four years of secondary school – her English was good and she had previously assisted in minor research projects. However, her young age and her life situation as an unmarried woman with no children or experience with infant feeding made it important to include another assistant. The second woman had previously assisted several large qualitative studies; she was a mother of five and a well-known and respected woman in the area. As such, she was a highly-qualified candidate to assist during interviews, and also as a discussion partner during the continuous analysis and interpretation process of the emerging material. Her competence in oral English was limited, however. Both of the research assistants were fluent in the two major local languages in the area in addition to Swahili, the official national language of Tanzania. During the course of the fieldwork, the young research assistant was trained by the elder in how to approach the informants in a correct manner in the interview setting, the elder research assistant gradually improved her oral English while I gradually improved my Sawhili. The two research assistants worked closely together with me on a daily basis at hospital A and also accompanied me during the trips to hospital B.

To make the interview contexts as relaxed as possible, it became natural from the early stages of the fieldwork that the eldest and most experienced research assistant chaired the interview while the younger assistant kept me updated on wording or communications that I struggled to understand. The eldest assistant's position in the fieldwork area made her the most suitable chair of the interviews and she proved to be particularly skilled at the small talk that took place in the minutes before starting the interview. Such small talk seemed to be vital in establishing the 'nature and tone' (Hammersley & Atkinson, 2007, p. 110) of the interview context. She almost always made the mothers smile and laugh during the interviews, which seemed to make them relaxed, and this might have influenced the informants' willingness to return for follow-up conversations. With time, the younger assistant learnt from the elder assistant, and they both became skilled interviewers who were also able to carry out interviews on their own in cases where I observed in the clinic.

As the fieldwork progressed and the number of recordings increased, the need for more assistance arose, and two more research assistant were hired. A male assistant – a 'form-six' leaver – was already trained in transcribing and translating recordings, and transcription became his full-time work. The fourth assistant – a young woman and 'form-four' leaver – also assisted in translating the transcribed recordings. Because of the research assistants' restricted typing skills most recordings were transcribed and translated in hand-written files. It was not until I returned to Norway that I entered the files into the computer and made them electronically available. A few of them are indeed still just handwritten, and were analysed directly on paper.

Nurses and educated health personnel at the two hospitals were all well trained in English, and the field observation and informal conversations inside the clinic were hence carried out without an interpreter. Many counselling sessions (13) were audio recorded, transcribed and translated to confirm whether I had grasped the content of the conversation. Occasionally I asked the nurses for a translation if there were words I did not understand; however, for the short follow-up conversations and consultations in the clinic I was quite soon able to grasp the main content of what was communicated between the parties involved. Being unable to follow all details in the communication during such clinical observations eventually made me more attentive towards the non-verbal communication, and how the nurses and HIV-positive women interacted and related to each other. These observations were written down and made a vital contribution to the analysis of these particular conversations.

THE STUDY INFORMANTS

The main informants of the present study were nurses working in two hospitals' CTC and HIV-positive women enrolled in the PMTCT programmes at the same clinics. In addition, reflecting the data-collection process, a number of other informants contributed with information such as clinical officers, ward attendants, non-governmental organisations (NGO)-volunteers, home-based care providers (HBCs), pregnant women attending the Reproductive Child and Health Service (RCHS) and relatives of the HIV-positive women.

The nurses at the two hospitals who were included were all educated nurse midwives, but only half of them were registered PMTCT counsellors. In hospital A, three nurses were employed on a regular basis at CTC, which meant they were present at the clinic every day during working hours. On Saturdays, one nurse was present for the distribution of medication. Two of the nurses were registered PMTCT counsellors. In hospital B, the nurses were not regularly employed at the CTC and, hence, the nursing staff at the clinic could vary from one week to the next. Three of the nurses included in the study in hospital B were however observed to work at the CTC quite regularly during the nine fieldwork trips. The nurse in charge of the clinic was present during all the field trips and explained that she was generally present during opening hours – daytime, three days a week. All these nurses were nurse midwives but none of them were registered PMTCT counsellors. Two more nurses who were registered PMTCT counsellors were regularly employed at hospital B's RCHS but addressed the HIV positive pregnant women and HIV-positive mothers at both RCHS and CTC when necessary.

The HIV-positive women who were recruited as informants can be categorised into four main groups: (1) pregnant women, (2) women with infants 0-6 months old, (3) women with children 6-18 months old and (4) women with children > 18 months old who had previously been enrolled in the PMTCT programme (table 4). The categorisation was made in the early fieldwork periods following the stages of the PMTCT programme with regard to what kind of follow up and counselling the HIV-positive women got at the different stages. A total of 76 HIV-positive women were recruited as informants at the two clinics, 54[36] at hospital A and 22 at hospital B (table 4).

Table 4.

HIV-positive women	**Hospital A (54)**	**Hospital B (22)**
Pregnant	3	1
Infant < 6 months	26	9
Child 6-18 months	22	10
Child > 18 months	3	2

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[36] Paper I refers to a total of 53 HIV-positive women interviewed in hospital A. The one missing from this number is one informant who only conducted limited parts of the interview and was expected to return, but did not.

The age of the informants was documented from the informants' files in hospital A (table 5).

Table 5.

Age of informants	Hospital A (54)
15-19	1
20-24	12
25-29	12
30-34	9
35-39	18
40-44	2

All the HIV-positive women were recruited as informants through the CTC by the research assistants or the nurses employed in the clinics. Several of the eldest women had experience from the PMTCT programme through the enrolment in the programme with more than one child (12).[37]

While I gained access to the field sites at the two CTCs, the research assistants collected information through qualitative (semi-structured) interviews with HIV-negative pregnant women at the RCHS in both hospitals in order to learn about the common infant feeding patterns among women in the areas. Thirty-six interviews lasting for about 30 minutes were carried out in hospital A – five interviews in hospital B.

Several additional categories of individual informants provided valuable information for the project. The HBCs) at hospital A were employed by the hospital, and were closely connected to the CTC as they followed up on various patients with chronic diseases living in the vicinity of their homes, among them HIV-positive women with infants enrolled in the PMTCT programme. The follow up of the HIV-positive mothers was particularly close during the first

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[37] A total of 12 informants hade more than one enrollment in the PMTCT programme at hospital A: Inf. nr. 1, 3, 4, 9, 10, 19, 28, 41, 48, 51, 57, 58

six months when the women were intended to exclusively breastfeed, and their work was observed to be two-fold: (1) to assure that the women were doing fine and to check on their living conditions in order to help and support, and (2) to check whether the mothers were able to follow their intended infant feeding practice. On the first Monday every month the CTC arranged a meeting where the HBCs reported their activity and received their small salary. At these monthly meetings the HBCs were recruited as informants for group discussions in the study; three group discussions were carried out in hospital A with a total of 14 informants. In hospital B, an NGO facilitated the services of HBCs for HIV-positive patients through outreach clinics from hospital B. During one of these outreach clinics I was invited to participate in the HBCs' meeting. Four of the HBCs attended a short, informal, group conversation after the meeting. The focus of these HBC group discussions was to learn about the HBCs work among the patients in their community and their co-operation with the nurses at CTC to inform the broader picture of the nurse-patient relationship. From this elaboration of the study's main groups of informants we will now move on to look at how the material was collected through diverse data collection methods.

ETHNOGRAPHY IN THE PRESENT STUDY

The chosen study focus was complex and multifaceted; the project was thus found to require a broad qualitative methodological approach. An ethnographic approach was deemed fruitful due to the wish to observe nurse-patient interaction over an extended period of time. It was hoped that, being a trained nurse, I could take part in some of the daily nursing activities at the hospital during the fieldwork, thus being able to engage in the field through participant observation.

The literature suggests that the label 'ethnography' might to some degree vary in its meaning and, not least, overlap with other labels (Hammersley & Atkinson, 2007, p. 1). The book 'Ethnography – principles in practice' by Hammersley and Atkinson (2007) has guided the work of this study, and the introductory chapter, entitled 'What is ethnography', puts forward five central features of ethnographic work. First, people's actions are studied in everyday contexts, which refers to the research taking place 'in the field'; second, data may be gathered from a range of sources and by diverse methods; the third feature is that this kind of research is typically relatively open-ended in its approach, the data collection might be fairly 'unstructured' while the design is flexible in nature; the fourth feature is that the research usually focuses in depth on a few cases; while the fifth is that the analysis of data 'involves interpretation of the meanings, functions, and consequences of human actions and institutional practices, and how these are implicated in local, and perhaps also wider, contexts' (Hammersley & Atkinson, 2007, p. 3).

The ethnographic research design is exploratory and inductive in nature, however, and according to Malinowski (1922, pp. 8-9), the recognized founder of ethnography, the researcher commonly has a 'foreshadowed problem' that is explored (Hammersley & Atkinson, 2007, p. 21). In the present study the 'foreshadowed' problem was 'How do nurses and HIV-positive mothers relate to the national infant feeding guidelines and infant feeding practices in a rural, low-income context?' This initial focus was refined and partly transformed through the course of the fieldwork – in line with literature that states that through the research process the initial inquiry will become more focused on particular research questions – which again allows for more strategic data collection to answer the progressively-specific queries (Hammersley & Atkinson, 2007, pp. 3-4).

Methods triangulation is an integral and inherent part of ethnography through its use of numerous modes to collect data (Hammersley & Atkinson, 2007, p. 3). In ethnographic research, communication ranges from spontaneous, informal conversations to more formal interviews in settings out of range of other people – data collection methods that were all drawn upon in the present study in combination with observation and participant observation which allowed me to approach the study topic from diverse angles. The initial plan as I arrived in the field was to collect data primarily through in-depth interviews with nurses working within the PMTCT programmes, as well as HIV-positive women enrolled in the same programmes. However, I found early on in the fieldwork that I was able to be present on the ward far more than I had envisaged, and that participant observation provided a vital approach for the present study. To make use of ethnography and collect data through a varity of methods was hence found an appropriate way to approach the data collection in the two hospitals. The material from hospital A is based on both participant observation, observation, in-depth interviews, informal conversations and group discussions, while the material from hospital B is largely based on informal conversation in diverse settings, interviews and to a lesser extent on observation.

The flexible nature of ethnography was a vital and valued necessity in the present study. Allowing time and a close follow up in order to gain an understanding of the nuances of the everyday nurse-patient-interactions as it is emerged in practice was central in the attempt to enhance the understanding of nurses' practice and nurse-mother interaction in the present context. The literature on ethnography emphasises the dimension of time, and describes the immense importance for qualitative researchers to remain in the field for lengthy periods (Hammersley & Atkinson, 2007, p. 3). The data of the present study were collected through a continuous fieldwork period of nine months from 5 November 2008 to 5 August 2009. The length of the period of fieldwork varied between the two hospitals. While I lived at the compound of hospital A during the entire fieldwork period, nine shorter trips were made to hospital B, each lasting one to three days.

Participant observation

The main method of accessing information, particularly in hospital A, was through the collection of observational data, consisting of both participant observation as well as mere observation. Angrosino and Rosenberg (2011, p. 467) quote Adler and Adler (1994, p. 389) when they refer to observation as 'the fundamental base of all research methods' in social and behavioural sciences. To learn as much as possible from the interviews, I needed a solid base of understanding of the context within which the PMTCT programmes were located, and within which the HIV-positive women interacted with the nurses. The context of the CTC and its content was new to me, which made me a novice in this landscape. Hammersley and Atkinson (2007, p. 79) refers to Lofland (1971, p. 100) when they say that, wherever it is possible, ethnographers must 'put themselves in the position of being an "acceptable incompetent"'. My background as a nurse was experienced as a clear advantage familiarising myself with the nursing situation, however, I repeatedly explained that I was inexperienced with this particular clinical context and hoped that I was allowed to ask basic and naïve questions. I used substantial time to watch and listen in order to 'acquire a good sense of the social structure of the setting', to quote Hammersley and Atkinson (2007, p. 79). As an engaged ethnographic researcher – and not merely an interested novice – I tried to follow this advice and to maintain a self-conscious attentiveness to what I learned and to how I learned it, including 'the social transactions that inform the production of such knowledge' (Hammersley & Atkinson, 2007, p. 80).

As I received access to the field in hospital A, became familiar with the main activity at the CTC and established a relationship with the health workers, I was able to move freely as an participant observer within the clinic. To negotiate my role in the clinic I assisted the nurses with small, practical tasks like retrieving and organising files, cleaning and assisting with computer-related documentation. I did not perform any health worker procedures which would require an extended 'health worker permit' which my research permit did not include. As the nurses increasingly learnt about my research interests they became more conscious about inviting and including me in settings they thought would be interesting for me to observe. Some arenas and types of activity were located at the core of my observations. First, I followed the nurses in the *'dispensing room',* where they met all the patients – not merely the HIV-positive pregnant women and mothers – to dispense ART prescribed by the clinical officer. During these sessions I only participated through the collecting of files and perhaps handing over the correct ART if I sat close to the medicine cabinets. Second, I was invited to observe during '*counselling sessions*' – a conversation between the nurse and an HIV-positive woman enrolled in the PMTCT programme with the intention of providing infant feeding advice. These talks took place in the counselling room (see findings, Paper II) – I did not participate in or get involved with the conversation even though the nurses sometimes asked me if I had any questions. I was able to understand the main dialogue in these conversations that took place in Swahili; however, the nuances and details were at times difficult to capture. I was however allowed to write field notes during the counselling sessions, and permission was granted to record many of the conversations (13) in order to gain a detailed picture of some of the dialogues taking place between the nurses and the HIV-positive women. The transcriptions of the recordings largely confirmed my observations and notes. As the fieldwork progressed I was also invited to follow the nurses as they went on *outreach visits* to the homes of particularly vulnerable HIV-positive, women which gave me an opportunity to learn further about interactions between nurses and mothers. Eighteen of the HIV-positive women at hospital A were followed up with one or more home visits (see Table 6). To gain insight in how the HIV-positive women were enrolled into the PMTCT programme I joined the RCHS for one outreach clinic where I was allowed to observe the midwives in charge of the HIV-testing and -counselling of pregnant women. Included in all the observations were a focus on how the nurses talked to the HIV-positive women and I made an effort to listen to the tone of the communication between the two parties in relation to the content of what was communicated. I further observed how the nurses and HIV-positive women interacted through visible signs of interaction such as eye contact and body language, as well as the atmosphere created within the different settings.

Through my restricted visits to hospital B I did, naturally, never achieve the same access to observational data as I did in hospital A. But I was able to observe, to a restricted degree, how nurses and HIV-positive women interacted within the clinic, particularly in the reception area and corricor. How the clinic was organised and how the nurses and patients interacted was vital background information to the informal conversations and more formal interviews. During the last four visits I was also invited for some observation inside the nurses' offices which provided me with valuable insight into how the nurses interacted with their patients, including the HIV-positive women. In hospital B, I also attended *outreach CTC clinics* which gave me an opportunity to observe how the nurses organised such clinics on part of the pregnant HIV-positive women and HIV-positive mothers.

Field notes – with a particular focus on concrete observations – were written on a regular and frequent basis, detailing experiences and information as well as questions for further work. The field notes were organised into various categories: one file with headings and cues for activities throughout each day, and four other files headed 'PMTCT and infant feeding', 'CTC, everyday activities', 'questions that arise during the fieldwork' and the main file 'everyday field notes' respectively. Whenever possible, I took notes during the actual observations, for instance during observations of particular conversations or counselling sessions, while most of the field notes were written down during afternoon and evening working hours, based on short notes taken during the day. In addition to what was observed related to nurses' work and interactions with HIV-positive women within CTC, the locations of the CTC were also drawn and described, and the homestead of the HIV-positive women I visited were described in field notes related to the particular visit so that I would be able to recall the particular context of the actual woman we visited.

Informal conversations and interviews

The dividing line between participant observation and informal conversations in data collection is also hard to discern (Hammersley & Atkinson, 2007, p. 108). As I followed the nurses at hospital A through participant observations on a daily basis, informal conversations were a vital part of our interaction, and an important source of information for the study. In hospital B, even though I was by and large not included in the nurses' everyday practice, I engaged in substantial informal conversations with them during the course of the data collection. Before each field trip to hospital B, I prepared particular topics and questions to be discussed with the nurses, and used these as an entry to engage in informal conversations about the topics. Only four in-depth interviews were carried out with the nurses, two at each hospital, as the informal conversations made up an immensely important approach to the kind of knowledge I was looking for. Many themes that could hardly be raised during formal interviews emerged spontaneously during the activity and the informal talks. At hospital A, these interviews were carried out at the end of the fieldwork to discuss the main study findings, to clear up misunderstandings, and to increase the details and nuances of the main findings. At hospital B, the two interviews with nurses were carried out to provide more substantial information on how the nurse counsellors approached the HIV-positive women with regard to infant feeding and the national PMTCT guidelines as seen from their perspective.

Regarding the HIV-positive women, the bulk of the information was, in addition to participant observation, collected through more formal interviews. Fifty-four HIV-positive women at hospital A and 22 HIV-positive women at hospital B, a total of 76 informants enrolled in the two hospitals' PMTCT programmes previously or currently, were interviewed.

Table 6.

Interviews and follow up, HIV-positive women	Hospital A	Hospital B
A formal, 1st interview	54	22
Follow up conversation(s) and/or observation in clinic consultation	22	1
Home visit(s)	18	0

In hospital A, the in-depth interviews with the HIV-positive women were carried out in an office located through a separate entrance at the back of the CTC. The office provided a calm, quiet and shielded atmosphere free from interruption and, as such, was suitable in terms of providing the necessary privacy. After the first interview, the informants knew where the office was located, which allowed them to appear for follow-up conversations when they visited the CTC for consecutive consultations. At hospital B the interviews were carried out in an office inside the clinic that was less shielded. It was however located in the interior part of the corridor to ensure that the talks remained as private and undisturbed as possible.

The first meeting with the women was planned as a so-called in-depth interview. This data collection method presupposes individual interviews with the intention of getting the informants to openly explore their experiences and perceptions on the topic of interest (Malterud, 2011, p. 129-131). We used an interview guide (appendix XII) that was developed to be employed in a flexible manner to allow the opening up of informants' histories and experiences, preferably offering details to allow the researcher to grasp the dynamics at work. The interview guide and techniques in how to present the questions or topics and how to relate to the informants during the interview were thoroughly discussed with the supervisory team and research assistants who attended the interviews.

As detailed above, infant feeding is among the vital challenges that HIV-positive women encounter when they enter motherhood. Because of the 'foreshadowed problem', experiences with infant feeding and the emotions related to infant feeding were well covered in the interview guide. Interviews with HIV-negative women in RCHS, carried out before we interviewed HIV-positive women in CTC, as well as a review of the literature on local infant feeding practices, provided essential background knowledge and guided the development of the interview guide. During the course of the research this interview guide was revised several times, adding and deleting questions to allow for a follow up on importantly emerging issues.

The interview was carried out in the language chosen by the informant. Most interviews were carried out in Swahili, while some informants preferred to speak their local languages, Iraqw or Datoga. Most of these interviews were recorded with the permission of the informants. During the interview the research assistant and I took notes – the research assistant on the information being communicated, mine concerning non-verbal communication not captured by the audio recordings. To the extent possible, the research assistants and I reviewed the interview the same day it was carried out in order to discuss its content, our impressions of the talk and our preliminary interpretations which were written down in a separate file for the particular interview. When the transcripts were ready, the text was carefully reviewed so that apparent patterns, ambiguities or contradictions could be clarified with the assistants. Sometimes the research assistants and I listened directly to the audio recording before the interview was transcribed, noting down core phrases and discussing particularities of the information provided.

During the early fieldwork period in hospital A, the first interview, a talk usually lasting from 30 to 90 minutes, which was also the first meeting with the HIV-positive woman, often turned out not to provide sufficient in-depth knowledge of the women's experience with the PMTCT programme. Because of the foreshadowed problem with a focus on HIV-positive mothers' experience with infant feeding guidelines and infant feeding practices many of these first meetings and talks were thus, in time, viewed more as an introductory conversation in order to map knowledge on the mothers' background and history with the PMTCT programme, and to assess whether the women should be politely asked to be followed throughout the fieldwork period. To gain in-depth information and a more complete understanding of the HIV-positive women's experiences, we found, as the fieldwork progressed and the foreshadowed problem evolved, follow-up conversations at the office to be fruitful and complementary to the observations of the clinical consultations, the counselling sessions and the home visits – all parts of the CTC's PMTCT programme. As presented in Table 6, 22 of the 54 interviewed HIV-positive women in hospital A were followed more closely through such follow-up meetings. Some of these talks provided in-depth and rich data for the study. The follow-up conversations were more informal than the first interview, but we tried to prepare some central questions for informants who expressed that they would return. In particular, women with children aged 0-6 months who were followed through the exclusive breastfeeding and the weaning process provided rich and in-depth information linked to the interaction and relationship with the nurses and PMTCT programme.

The HIV-positive women in hospital B did provide relatively detailed information during the first interview. Generally, the women at this hospital conveyed less scepticism and were more open about their experiences from the very start. This may also have been a consequence of our previous interview experience from hospital A – we were simply better trained on how to approach the women with appropriate, good and pertinent questions. These informative interviews were vital at hospital B, as we did not have the opportunity to follow the women for home visits or during clinical consultations, and were hence dependent upon the information provided during the individual interviews.

ANALYSIS

In the present study the process of analysing the collected data has been informed by an inductive approach and has followed Hammersley and Atkinson's (2007) work. They state that there is not one 'formula or recipe for the analysis of ethnographic data. There are certainly no procedures that will guarantee success' (Hammersley & Atkinson, 2007, p. 158). They do however propose some general and potentially fruitful ways or principles to draw upon in the process of making sense of the material. At a very general level, the purpose of data analysis is to 'organise, provide structure to, and elicit meaning from research data' (Polit & Beck, 2004, p. 570). As Hammersley and Atkinson (2007, p. 160) note:

> Ethnographic research should have a characteristic ‘funnel’ structure, being progressively focused over its course. Over time the research problem needs to be developed and may need to be transformed; and eventually its scope must be clarified and delimited, and its internal structure explored. In this sense, it is frequently well into the process of inquiry that one discovers what the research is really about; and not uncommonly it turns out to be about something rather different from the initial foreshadowed problems.

The analysis of ethnographic data requires an ongoing analysis process, and the search for concepts and themes starts from the moment the researcher begins to collect data (Polit & Beck, 2004, p. 570). The analysis process is thus not a separate stage of the research (Hammersley & Atkinson, 2007, p. 158).

The material collected during the fieldwork consisted mainly of interview transcripts and field notes. Throughout the fieldwork period, I continuously discussed the emerging data with the research assistants, while the main group of informants (nurses and HIV-positive women) were asked about the preliminary findings as the collecting of data progressed. In the field notes I recorded thoughts and reflections from these discussions, reflections that proved to be vital in the process of enhancing the understanding of the information gathered. During the fieldwork, the aim of the analytic process was, as Hammersley and Atkinson (2007, p. 163) express it ‘[t]o use the data to think with. One looks to see whether any interesting patterns can be identified; whether anything stands out as surprising or puzzling.’

After leaving the field I started the process of further analysis by reading through all the collected data, a so-called overview reading, to gain a renewed sense of the main contents running through the material. Hammersley and Atkinson (2007, p. 162) write about this phase, saying that ‘[u]nderpinning the process of analysis is the necessity to *know* one’s data. Detailed and repeated readings are necessary.’ Based on the overview reading, some of the transcrips clearly did not provide information of relevance and a concluding summary was written at the end of the transcript. The rest of the transcripts and field notes were manually coded; codes were marked in the right-hand margin, while preliminary and concrete ‘categories’ were labelled in the left-hand margin. This process was highly time-consuming because of the voluminous material based on the field notes and interview transcripts. The next step was to work on the preliminary categories which seemed likely to be central to the analysis. The purpose at this stage was to clarify their meaning and explore their relationship with other categories (Hammersley & Atkinson, 2007, p. 165). The preliminary categories were hence viewed together and condensed into new sub-categories.

Examples of codes in the right hand margin could be: (1) mother upset, (2) 'we are here to help' [nurse] (3) dispute [between two mothers], (4) tries to conciliate [nurse]. The preliminary category in the left hand margin in this particular example was 'nurse helping out' and 'nurse worries for mothers' and 'private matter' [between the mothers] which was later condensed to a category labelled 'problem solvers' which were included within the theme 'Care' (see Paper I). Several preliminary categories, together with raw data, were read and discussed within the supervision- and co-author team. All supervisors and co-authors of the three papers are fluent in Swahili and have conducted extensive research in Tanzania. Based on the discussions within the team, proposed categories were eventually grouped into the major themes that in the process became the topics of the three articles that comprise this thesis: care (Paper I), counselling, choice (Paper II) and confidentiality (Paper III).

REFLECTIONS ON METHODS

Reflexivity

In qualitative research the researcher is 'the research instrument' and the researcher's background and position will necessarily affect the choices made throughout the project. The concept of reflexivity acknowledges that social research cannot be carried out unaffected by personal or social processes and characteristics, including the background of the researcher and 'rather than engaging in futile attempts to eliminate the effects of the researcher completely, we should set about understanding them' (Hammersley & Atkinson, 2007, p. 16). Malterud (2001, p. 484) states that the importance lies with the researcher to account adequately for all steps of the research process; for his/her effect on the research process. The problem of subjectivity will only arise if the effect of the researcher is ignored. In this section I make an attempt to reflect upon what seem to be particularly relevant aspects of my position, perspectives and pre-conceptions as a researcher in this study.

Reflexivity starts by looking at the pre-conceptions the researchers brings with them into the field (Malterud, 2001, p. 484) which has partially been addressed in the section 'situating the researcher'. In hospital A, my background as a nurse seemed to be of substantial value in my approach to the health workers during the early periods of the fieldwork, and my position as a researcher with health-related experience appeared to make it easier for the nurses to include me for observation in their everyday work at the clinic. It is likely however that my presence in the clinic, particularly during counselling sessions, to some extent influenced the nurses' conduct. As most people are likely to show the best parts of their behaviour and actions when they are observed, the ways in which they related to their patients might have been impacted. My interaction with the nurses on a daily basis for nine months, and the fact that this setting was used to having foreign health workers and foreign researchers around, probably to some extent reduced the likelihood of modifying conduct in the presence of the researcher. The observation of the interaction and communication between the nurses and the HIV-positive mothers was noted to be largely similar when comparing field notes from the early with the later parts of the fieldwork, which indicates that the researcher influence may not have been very strong.

From the HIV-positive women's point of view, I was clearly a foreigner. From their perspective, I was not familiar with their culture and background. In a situation where education and biomedical health care is connected to 'modernity' and 'knowledge', this most likely affected their encounters with me in a number of ways, and the degree to which they chose to openly and honestly express their experiences and sentiments through interviews, follow-up conversations and home visits. In this context it was experienced as vital to work with research assistants who were competent both socially, culturally and linguistically. The length of my stay in the field, and the fact that I followed many of the informants for months and through a number of encounters, might have made our 'relationship' somewhat less coloured by my outsider status, but there is no doubt that I remained 'a stranger', and it is essential to recognize the immeasurable impact such 'otherness' had on the research process.

As the fieldwork proceeded, I got to know the nurses in hospital A quite well, which made me reflect on the challenging borders between a researcher, friend and colleague. I worked closely with the nurses in the clinic and they knew, as did I, that I was dependent on their benevolence to gain information. Being a guest and a European associated with wealth in the present study contexts moreover demands a few reflections. During the first weeks, my status as researcher was tested as one of the nurse informants asked me to support her with a loan. When I explained this would be difficult because of my position as a researcher in the clinic, I found that, for the next few days, she avoided me and refused to include me in her clinical work. However, the issue soon seemed to be forgotten, and her presence in my material and her co-operation as a central informant throughout the fieldwork remained clear and appreciated. The HIV-positive women might also have seen me as a person they could profit from in one way or another. As compensation and gratitude for their time spent during the interviews at the office, the women were each given sugar as well as a soda during the interview, culturally acceptable tokens. News of this small-scale, though for some important, compensation seemed to be quickly spread among the women in the clinic, and might have contributed to some informants' willingness to participate in the study. In the present fieldwork area, a guest who visits someone's home customarily brings a small gift, and, as I was invited for home visits, I also provided minor gifts (such as sugar, butter or flour) when I entered the home of any informant.

In hospital B my presence and relationship to the nurses working in the CTC was quite different. Hammersley and Atkinson (2007, p. 60) write about how the previously-mentioned 'gatekeepers' 'will operate in terms of expectations about the ethnographer's identity and intentions', and they note that: 'the expectation of expert critical surveillance may create anxieties, on the part of gatekeepers and others' (Hammersley & Atkinson, 2007, p. 60). This point is to some extent relevant to the context of the nurses at hospital B, as they seemed to be in doubt about whether or not they should give me access to their field. This was expressed through their reluctance in letting me observe their work and through a hesitancy to engage in interviews and more formal talks, etc. Two of the nurses who was present at a quite regular basis in the clinic was asked to participate in interviews but laughed, smiled and turned away, clearly uncomfortable about the question, and the nurse in charge said: 'You know, they are so shy – maybe later'. My background as a nurse did not seem to play a substantial role; the nurses seemed to relate to me far more as a researcher than as a nurse, and non-verbally communicated being a bit stressed by my presence. This clearly affected my access to information on observed nurse-patient interaction within the programme. In retrospect, I have reflected on to what extent I informed the nurses in hospital B appropriately about my intentions, and on the reasons for the clearly different inclusion of me within their daily work compared to my experience in hospital A. My shorter and more restricted visits might be the easiest and most obvious explanation; that the last visits were far more productive in terms of communication than the early trips seems to be a clear indication of the importance of presence over time, and of what the time dimension does in terms of getting to know people and in terms of trust. That the health workers at hospital B were more unfamiliar with European visitors, whether health workers or researchers, might have added to the more complicated working relationship at hospital B.

As previously mentioned, I chose to enter the field through the CTC and recruit informants from this vantage point in stead of approaching the HIV-positive women in their communities, outside the hospital compound. This might have affected my relationship to the HIV-positive women and, even more their impression of me, as they met me for the first time in the reception area of the clinic as a European health worker. Moreover, even though I spent time in the reception area talking with the patients in both hospitals, my approach to get in contact with the HIV-positive women was through the CTC. In hospital A, my close connection to the clinic and to the nurses working there was evident to the enrolled HIV-positive women. This may have affected how they expressed themselves during interviews, anticipating that I was closely associated with the nurses' and the clinic's point of view, and they may hence have to some extent questioned my loyalty towards their own expressions and experiences. Conversely, the lack of close connection to the nurses at hospital B might explain how we experienced the HIV-positive women as being more open and talkative during the first round of formal interviews than the women in hospital A. The smoothness and relaxed atmosphere during the initial interview at hospital B might also, however, as indicated above, be a result of our accrued experience from hospital A in terms of the relevance of the questions asked and the manner in which they were asked, etc.

Reflections on language, translation and research assistance

Knutsson (2004, p. 68) writes from her fieldwork in Ethiopia about how translations intervened in the data collection, as the data when it is translated is no longer first-hand because the translator 'has already made a first interpretation of what the informant means when she chooses what words to use in the translation.' This point also seems to be of relevance in the present study. In this connection the recordings were found to be of particular importance: the transcribed and translated data were thoroughly reviewed with the research assistants and were compared with the hand-written notes from the interviews.

Experiences from the first formal interviews with the HIV-positive women showed that the interview guide seemed not to work as intended. Several of the first interviews did not provide in-depth information, experiences and personal histories. Through discussions with the research assistants we found that the interview guide included particular words and phrases that the HIV-positive women seemed not to be familiar with – and hence led to confusion and uncertainty in the interview setting, which clearly contributed to a tense and insecure atmosphere on part of the HIV-positive women. Examples of such words and phrases were 'PMTCT', 'guidelines', and questions of a more general character, like 'What do you think of how HIV-positive pregnant women and HIV-positive women are supported at this hospital'. The interview guide was thus gradually revised, which led to the talks that provided far more detailed information, and an atmosphere that was more relaxed.

A note is necessary on the presence of a researcher with assistants during interviews. In this case, one or two research assistants and I were present during the interviews. In particular situations, when the informant expressed feeling vulnerable or stressed during the introduction of the interview, the second research assistant and I left the room, and the elder research assistant and the informant carried out the interview on their own. Research carried out in the same area (Songstad, 2012, p. 41) has found that some informants seemed uncomfortable being interviewed on their own, and that the most valuable data was collected during focus group discussion, and that the participants seemed to feel more comfortable when discussing in groups. That some informants seemed a bit uncomfortable with the individual formal interview was also seen in the present study. I conducted a few group discussions with the HBCs in both hospitals – discussions that were characterized by open informants willing to share their viewpoints within the group. Focus group discussions might thus have been a fruitful data-collection method that I did not consider in relation to the HIV-positive women who I only interviewed individually.

Interviews involving an interpreter are clearly not comparable to interviews where the researcher and the informant have a common language. I gained some experience, particularly in the early periods of the fieldwork, where I listened to the audio recordings and found details in the HIV-positive women's experiences that I had not picked up on or had explained to me during the interview. Hence, I had not been given the opportunity to ask essential follow-up questions which could have provided more in-depth information in the actual interview. A couple of times the audio recordings also revealed that the assistants, without me noticing it, had interrupted the woman to move on to the next question before she was through with her story. Such episodes were discussed with the research assistants to highlight the importance of in-depth explanations and personal histories.

Hammersley and Atkinson (2007, p. 114) note: 'As important as who is present at an interview, and who carries it out, often, is where and when it takes place.' As described above, the interviews with the HIV-positive women in both hospitals took place in an office inside the hospital area. The HIV-positive women might possibly have provided more in-depth information if the interviews were carried out outside the hospital compound. Home visits and follow-up conversations that took place outside the hospital grounds, some of them without the CTC nurses, facilitated encounters in different surroundings. These situations gave them the opportunity to open up in different ways, and some of them grabbed the opportunity, which gave us rich data. It was also easier for us to understand each mother's challenges when we visited her at home and got a touch of insight into her daily life.

Trustworthiness

Qualitative research, as with any other type of research, has to question whether the methods chosen are adequate in terms of generating relevant data on the study topic. In qualitative research, trustworthiness refers to methodological soundness and adequacy (Holloway & Wheeler, 2010, p. 302). To achieve trustworthy findings indicating methodological soundness, the present study has considered the four central categories: (1) credibility (2) dependability (3) confirmability and (4) transferability, employing Lincoln and Guba's (1985) concepts.

Credibility refers to the 'truth' of the findings, i.e. that the findings should reflect the social reality of the participants and be 'compatible with the perceptions of the people under study' (Holloway & Wheeler, 2010, p. 303). In qualitative research, the findings are based on data communicated by the informant which are received, perceived, analysed and eventually constructed into text by the researcher. Lincoln and Guba (1985, p. 301) refer to three aspects that may increase a study's credibility, namely: (1) prolonged engagement, (2) persistent observation and (3) triangulation – all of which were attempted in the present study. Prolonged engagement and persistent observation was attempted through lengthy ethnographic fieldwork and systematic follow up over an extended period of time. The nine months of fieldwork allowed me to build what I experienced as substantial trust among at least some of the informants, both nurses and patients, at hospital A. This allowed me to relatively thoroughly explore everyday interaction between nurses and patients.

Methods triangulation is an integral and inherent part of ethnography through its use of numerous modes to collect data. The present study collected data through observation, participant observation, informal conversations, individual interviews and through informal group discussions, which allowed me to approach the study topic from diverse angles. Source triangulation is also employed in the present study, as the study collected data among diverse categories of informants – the main informant categories being nurses and HIV-positive women. Data analysis took place as an ongoing process while still in the field, and unclear research findings were continuously clarified through feedback from the informants. Lincoln and Guba (1985, p. 314) refer to this process as 'member checks' and hold that this is '[t]he most crucial technique for establishing credibility.' That the research assistants represented the same ethnic groups as the large majority of the informants, and possessed cultural and social competence, is also perceived to have enhanced the credibility of the research findings.

How the credibility of this study was enhanced throughout the lengthy fieldwork, methods triangulation in data collection and close interaction with the informants might be exemplified through how the constant analysis of the data resulted in a gradual and amended understanding of the relationship between the nurses and mothers in the two programmes. Many of the findings presented in the three papers represent settings where, in the immediate situation where it was observed or communicated, I was surprised by the direction the interaction between the nurses and HIV-positive women took – a theme reflected upon in Paper I. However, as I gradually became more familiar with the context and as the fieldwork progressed, the cases were interpreted against a backdrop characterized by a further degree of understanding, which led to reflections that moved beyond the immediately observed action or communication. The early observations of nursing care which, from my assessment, indicated a paternalistic approach on part of the nurses – the instruction like communication, the strictness of the messages – were, with time, located within a wider social and cultural context where my enhanced knowledge about the experiences, wishes and needs of both nurses and HIV-positive women became part of the overall analysis. Questions such as why the HIV-positive women continued to return to the clinic, follow the programme, follow the nurses' instructions, why they brought up personal problems and welcomed the nurses to their private homes became a part of the understanding of the relationship and trust that evolved between the nurses and the patients over time, particularly emerging in data from hospital A. The understanding of the manner in which the interaction between the nurses and patients was socially- and culturally constituted developed over time.

Dependability refers to whether or not the findings of the study are dependable, consistent and accurate (Holloway & Wheeler, 2010, p. 303). Lincoln and Guba (1985, p. 316) say that there can be no credibility without dependability, and that 'a demonstration of the former is sufficient to establish the latter', although they themselves state this to be a weak argument. Dependability is said to imply detailed description of the context where the research has been carried out as well as a detailed description of the research process itself (Holloway & Wheeler, 2010, p. 303). In the methods section I have attempted to give a relatively detailed account of the field sites and hospital settings. What are perceived to be the main steps of the research process in this study are, moreover, described in some detail in the sections comprising the chapter 'Ethnography in the present study'. I did however enter a field setting that, despite my previous fieldwork, was by and large new to me – a foreign culture, a new health care context, which was organised in an unknown way and with health workers I did not know – therefore I cannot be certain that all aspects of relevance for the study are described or accounted for. Indeed it is likely that relevant and important aspects have been left out.

One of the steps to assure *confirmability* is 'the confirmability audit' (Lincoln & Guba, 1985, p. 318) which entails a third party to carry out an audit trail or a coding check. In the present study only the research assistants and I listened to the audio recordings. However, during the early parts of the analysis, as the material was coded and later categorised, which Lincoln and Guba (1985, p. 319) refer to as the process of 'data reduction', parts of the raw material were read by the co-authors in order to assess the coding and preliminary categories. The post-fieldwork analysis was carried out in a continuous manner through discussion within the group of co-authors as well as in research meetings with a larger group of PhD students affiliated to the same department as the co-authors and me. Through discussions and feedback on early drafts, the preliminary categories evolved into summarized sub-categories and major themes, as presented in the three papers. Furthermore, the confirmability of the findings was attempted to be strengthened through the combination of written field notes, including written notes on non-verbal communication made during interviews and conversations, and audio recordings of interviews and counselling sessions that were transcribed in Swahili and translated. Thus the researcher, research assistants and co-authors could check the written notes and compare them to the transcripts to ensure quality and, later, sound analysis. To ensure the quality of the translated interview files, a research assistant with no connection to the project was hired to re-translate eight of the transcribed and translated interviews after leaving the field. These translations were found to be highly consistent with the original translations and no new data emerged.

Transferability refers to whether the findings of a study may be transferred to similar contexts or participants (Lincoln & Guba, 1985, p. 316). It is difficult to assess to what extent the present findings are transferable to 'similar contexts' because it depends on the definition of 'similar contexts'. Hammersley and Atkinson (2007, p. 234) say that it is hard to produce general conclusions based on ethnography, first and foremost because 'it cannot physically control variables so as to reveal associations that are likely to indicate causal relations'. The findings from this study are collected within two PMTCT programmes located within the same Region of Tanzania; however, the geographical locality was different, the hospitals were run by different administrative structures and the PMTCT programmes accessed different economic resources. Because the PMTCT programme in hospital A was externally funded this may affect the findings' transferability to similar, non-supported programmes in low-income settings while the general context of PMTCT programmes might decrease the transferability because such programmes in most low-income settings are run as vertical programmes. This study also show that the present programmes were highly dependent upon a few, dedicated single individuals which together with the practical context and ecomonic and human resources has to be taken account for when reflecting on transferability. Interestingly, Lincoln and Guba (1985, p. 316) say about transferability that, strictly, it is impossible because it is an empirical issue whether the findings will hold in other contexts, or even at some other time in the same contexts, and that the researcher in such studies as this can 'provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility' (Lincoln & Guba, 1985, p. 316). In this study I have attempted to give account for what I find to be thick descriptions on nurses-mother interaction through caring behaviours, and because the discussion of the findings of this study tries to draw on the more general debates on nurses' caring behaviours and how HIV-positive women expect and experience these through the nurse-patient interaction, I will argue that the findings of this study might, at least to some degree, be transferrable or have some relevance to other low-income contexts within Tanzania or even in other parts sub-Saharan Africa

ETHICAL CONSIDERATIONS

This study has adhered to the ethical standards of the Declaration of Helsinki (World Medical Association, 2009). In Tanzania, the project was granted ethical clearance from the National Institute of Medical Research[38] (appendix I). A research permit was granted by the Tanzania Commission for Science and Technology[39] (appendix IIa). The Tanzania Commission for Science and Technology referred an introduction letter (appendix IIb) to the Regional Administrative Secretary, who gave the project permission (appendix IV) and further introduced the project to the District Administrative Secretaries in the two districts where the study was carried out. The two District Administrative Secretaries gave their permission (appendices V and VI) and introduced the study to the hospitals where the Director (hospital A) and Medical Officer in charge (Hospital B) gave verbal permission for the data collection to take place. A residence permit was obtained from the Immigration Office (appendix III). In Norway, the project was approved by the Norwegian Regional Committee for Medical and Health Research Ethics[40] (appendices VIIa and VIIb) and the Norwegian Social Science Data Services[41] (appendix VIII).

All informants received information about the study through verbal and written information available in both English and Swahili (appendices IX and XI). A consent form was prepared in English and Swahili (appendix X). Voluntary participation was emphasised, and all informants were guaranteed confidentiality and the right to withdraw from the study at any time without consequences. The participants gave their consent verbally or in writing prior to the interviews or observation. All the nurses at the CTC ward at hospital A agreed to participate in the study while three HIV-positive women in hospital A declined to participate in the study because of practical issues. In hospital B, no HIV-positive women refused to participate, while three of the five nurses did not wish to participate in individual interviews, but with time engaged in informal talks and later in observations of their work.

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[38] ref. NIMR/HQ/R.8a/Vol.IX/762, dated 10 October 2008.

[39] ref. No. 2008-314-NA-2008-50, dated 10 November 2008.

[40] ref. 192.08.

[41] ref. 20209/2/JE.

4.0. STUDY FINDINGS

This section provides a brief summary of the core findings of the study. This summary will merely be able to provide a few central glimpses of the extensive material the present study holds. How nursing care is expressed and experienced within the nurse-mother interaction is the overarching topic of all three papers. In addition to the findings presented in the three papers the chapter contains a brief section which adds information on the nursing care encountered in hospital B.

PAPER I

Rethinking nursing care: An ethnographic approach to nurse-patient interaction in the context of HIV prevention programmes in rural Tanzania

The findings of this paper have a particular focus on how nursing care is expressed and experienced in the interactions between nurses and HIV-positive women enrolled in a PMTCT programme in a rural Tanzanian setting. In a context where nurses have been attributed a hallmark of low-quality care, the present findings based on material collected from one hospital in northern Tanzania (hospital A) imply a different assessment, suggesting how nurses and HIV-positive women met within a common frame of understanding of what were expected behaviours, and encounters that resulted in trusting relationships between the two parties. The findings are presented under the following four headings: (1) ‘Giving instructions’, (2) ‘Stop thinking’, (3) ‘Just checking’ and (4) ‘Solving problems’.

The first theme ‘Giving instructions’ provides insight into how nurses handled what was labelled the counselling session in a one-way and instruction-like manner, guided by clear communication on how the HIV-positive women should handle the feeding of their children in order to avoid the transmission of HIV. During early fieldwork periods the researcher experienced these interactions between the nurse and woman as being rather rough and harsh, but the women themselves expressed that they were satisfied with the clear instructions provided. Both nurses and patients showed, verbally and non-verbally, this kind of interaction to be an expected and appreciated practice. The nurses, moreover, expressed that they acted in a way that was best for the women and their children, and they were convinced that, if the HIV-positive women followed their instructions on infant feeding, it would ensure the HIV-free survival of their children. The HIV-positive women on their part communicated that they were in no doubt about how to handle the infant feeding as they had understood the strict but clear messages presented to them by the nurses. The women's revelations and adherence to the programme further indicated a trust in the nurses' work, in their instruction-like counselling and in the overall programme. These interactions and communications were analysed to be an expression of expected, accepted and appreciated behaviour from the nurses on part of the enrolled HIV-positive women.

The nurses in the present study interacted with the HIV-positive women during ordinary clinic consultations and during follow-up activities like home visits. The remaining three themes, 'Stop thinking', 'Just checking' and 'Solving problems' reveal how nurses seemed to communicate a general and overall concern for the HIV-positive women enrolled in the programme. The seemingly genuine concern for the women's well-being and their everyday life challenges of being an HIV-positive mother was expressed and observed in diverse settings and emerged through diverse activities. The nurses expressed that the challenges of every-day life could, and often did, affect the women's ability to carry out their intended infant feeding practice – a method which was vital in preventing HIV transmission from the mother to the child. The nurses were particularly concerned with the women's well-being during their child's first six months of life and through the critical weaning process which, in accordance with the nurses' instructions and, in line with the hospital guidelines at the time, should be carried out with a rapid cessation of breastfeeding to avoid a mixed-feeding practice. This weaning practice was, however, not in accordance with the national guidelines applicable at the time of the fieldwork.

Conversations of informal talks in the clinic and during home visits revealed that when the HIV-positive women expressed frustration and challenges in life, the nurses' were seen to divert the women's negative thoughts, and bring focus back to her resources and to positive aspects of her life. Cases of such conversations are presented under the heading 'Stop thinking'. The nurses were seen to approach the women in a manner that often brought humour and laughter into the conversations and a positive atmosphere. Another aspect of the nurses' apparent concern for the women in the programme emerged through how they constantly checked on vulnerable women during their outreach trips and home visits, as presented in 'Just checking'. Such home visits were, by and large, greatly appreciated by a majority of the women who received the visits, and the nurses expressed that they found it important to check on the most vulnerable women to see how they were faring. The nurses stated that the women were more relaxed in their own homes than in the clinic, and it was thus easier to assess her true situation. Even though the nurses had agreed upon which of the women they should visit during each outreach, they always made quick stops to greet HIV-positive mothers who lived in the area, and sometimes made small detours to facilitate the visit to a mother they were worried about.

The last theme, ‘Solving problems’, is based on observations and communication suggesting how the nurses became engaged with and even intervened in the patients’ private life and private challenges and matters when they worried that such problems could interfere with the women’s intended infant feeding practice. The nurses in many settings were observed to be ‘problem solvers’, requiring both creativity and skills in their interaction with the women and their relatives. The nurses and the enrolled HIV-positive women were seen to interact within what was, to the outsider, a ‘blurred sphere’ between professional and private practice, and this also emerged through accounts of how mothers’ brought their children to the house of the nurse after the clinic had closed. These findings document a caring interaction that differs quite sharply from what is referred to as ‘professional nursing care’ within dominant nursing milieus represented in Europe and North America. The study findings indicate the importance of locating nursing care within its socio-cultural context in any attempt to assess its expression and content.

PAPER II

Reflections on informed choice in resource-poor settings: The case of infant feeding counselling in PMTCT programmes in Tanzania.

The findings of this paper have a particular focus on nurses’ and HIV-positive women’s communication during the *counselling session* linked to infant feeding information and patients’ rights. It is based on research findings from two PMTCT programmes in rural and semi-urban areas of Tanzania. In the wake of the growing emphasis on patient involvement and informed patient choice in health care contexts, the findings of this paper reflect on how the nurses’ approach to the counselling of infant feeding practices affected HIV-positive women’s understanding and actual infant feeding practices as well as their experience of trust in the PMTCT programme. The findings are presented through four major themes, two from each hospital setting: hospital A: (1) ‘There is no choice’ and (2) ‘They follow instructions’, and hospital B: (1) ‘Diverging messages’ and (2) ‘I was so scared about the infection’.

The findings from hospital A show that the nurses chose a counselling strategy that included only one option: exclusive breastfeeding followed by abrupt weaning and a replacement milk strategy, implying the use of cow's milk and complementary foods from six months of age, i.e. on the weaning of the baby. The nurses' strategy was based on thorough knowledge of the meaning of motherhood as well as of the economic and hygienic conditions in the area. The nurses expressed that alternatives to breastfeeding for the first six months of the infants' lives were not available, feasible, affordable, sustainable nor safe (AFASS) for the large majority of the enrolled HIV-positive women ('There is no choice'). The nurses at hospital A were seen to practice an explicit, clear and direct strategy; through instruction-based counselling sessions a 'no-choice' approach related to infant feeding practice was communicated, a message which did not reflect the 2007 national PMTCT and infant feeding guidelines current at the time of the study, but a strategy that had been decided upon by the hospital adminsitration. The nurses communicated a strict conviction that the instructions they provided for the women were the only alternative in terms of infant feeding, and a strategy that would reduce confusion and increase the probability of the women adhering to safer infant feeding practices ('They follow instructions'). The women enrolled in the programme confirmed to a substantial degree the nurses' version of a strict and clear 'no choice' strategy, a strategy which seemed to lead all the interviewed women from hospital A to be clear and concise on how they were advised to feed their children. This does not mean that every woman managed to follow the instructions, but the message presented to them was clear.

In hospital B, the nurses stated that they adhered to the 2007 national PMTCT guidelines and hence provided the HIV-positive women with a choice in terms of how to feed their infants. The nurses did not however have a strict and common strategy. The HIV-positive women enrolled in the PMTCT programme of this hospital on their part did not experience being given a choice during the infant feeding counselling sessions but, rather, that they were provided with different messages and conflicting advice ('Diverging messages'). The advice seemed to be based on the respective nurse's own view of the best option for preventing HIV transmission to the child. The women in hospital B to a large extent seemed to be saying that they made their own decisions regarding infant feeding. The decision was not based on choice since most of them did not have a choice beyond breastfeeding their babies. The mixed messages led women at hospital B to express fear of infecting their children ('I am so scared about the infection') to a stronger degree than did the women at hospital A.

The findings problematize how guidelines developed by global institutions (in this case by WHO and affiliates) may articulate poorly when transferred relatively unchanged to contexts for which they are not suited – in this case the concept of infant feeding guidelines based on informed choice. In settings where patients' access to information and economic resources is scarce, and patients depend to a greater degree on health-worker knowledge and decisions, choice scenarios may be experienced as highly problematic. The findings highlight that patients in the present context expect and want clear advice from the nurses, who are perceived as knowledgeable and 'modern'. Where such expectations are not met, confusion and frustration arise.

PAPER III

Boundaries of confidentiality in nursing care for mother and child in HIV programmes

The findings of the present paper have a particular focus on nurses' care and follow-up of HIV-positive women and their HIV-exposed children linked to confidentiality and third-party dilemmas. The ethical principle of confidentiality has been established as the cornerstone of health worker practice in order to establish a trusting and caring relationship between nurses and patients. In the present context, nurses and HIV-positive women faced challenging dilemmas in their common goal of ensuring the HIV-free survival of the third party – the child. The findings draw attention to three main challenges presented within three highly interrelated themes: (1) 'Keeping it a secret', (2) 'Everything is so open at this clinic', and (3) 'They are open and have no fear'.

Many of the women enrolled in the two programmes expressed having experienced the HIV-related stigma linked to disclosure of their diagnosis ('Keeping it a secret'). That stigma was found to still be extensively present in the study areas, was exemplified in a number of ways – from abandonment by husbands to negative reactions from family and friends and being chased from their homes. Hence the majority of the women in the PMTCT programmes were afraid to disclose their HIV status, and generally wished to keep their diagnosis a secret. Only very few of the mothers expressed to have disclosed to the wider community, while most of them had disclosed only to one or two in a close relation to them. Quite a few had indeed not disclosed to anyone at all, and hence kept their HIV status a secret. Both PMTCT programmes included in the study strongly recommended that the women disclose to at least one close kin in order to receive care and support during difficult periods, like the months of exclusive breastfeeding and the trying period of abrupt cessation of breastfeeding.

Observations and expressions from interviews revealed continuous challenges pertaining to the nurses' handling of confidentiality within the clinical settings in the two PMTCT programmes studied. Women said that their status was hard to hide when they entered the clinic for consultations ('Everything is so open at this clinic'). The information was also hard to keep confidential between the HIV-positive patients at the clinic. At one outreach clinic all consultations with doctors and nurses were held inside one large room, which was the same room as the general patients' waiting area, with the doctor and nurses during consultations with patients, shielded only by folding screens. Inside the hospital clinics, observation revealed how nurses seemed to be unconcerned in their handling of confidential information; for example, they were seen to share confidential information with colleagues from other wards without any emphasis on the patients' rights to privacy.

A vital finding arose from the nurses' follow up during home visits, which in themselves were particularly challenging situations in terms of maintaining the HIV-positive women's confidentiality vis a vis their community, family and friends. In these contexts the women's children – the HIV-exposed third party – raised particular dilemmas because the nurses seemed to worry strongly about the health of some of the children who were found to be particularly vulnerable. Different ethically-challenging situations were observed and experienced during such home visits. While some of the women who received home visits had no problem with the visit, with the hospital car and one or two health workers arriving at the house; other situations created substantial confidentiality-related challenges. Such situations generated ethical dilemmas for the nurses: they wished to care for both the woman and her child, but nonetheless had a particular focus on the the third party, the HIV-exposed child. The nurses' approach to many of these situations indicated that they did not alwas recognize or acknowledge particular situations as ethically challenging or as compromising confidentiality.

In the present situation the HIV-positive women's ability to practice safe infant feeding for the first six months as well as their adherence to ART was vital to protect the child from being infected with HIV – a substantial focus in Tanzanian health policy. The nurses thus found it to be their duty, as well as a prime good for the mothers, to ensure the health of the women and their third-party children through home visits to provide a picture of their overall life situation and thus facilitate optimal support. The study findings, however, provide a picture of how the nurses' desire to care for and ensure the health of the women and their HIV-exposed children led to direct or indirect breaches of confidentiality, particularly through home visits.

COMPLEMENTARY STUDY FINDINGS

Paper I draws merely on the extensive material from hospital A and a few findings on nurse-patient interaction should therefore be added from the data collected in hospital B. As mentioned above, the access to observational data were considerably less in hospital B, however, the material, particularly the four last field trips to hospital B provided glimpses of how the nurses interacted and related to their patients within the CTC on a general basis, however, not in particular settings like home visits and counselling sessions as in hospital A. The picture that emerged from the limited observations at hospital B indicate that the nurses handled the situation of care within the CTC in a calm and quiet atmosphere. While I was present in the corridor and on a few occasions observed the nurses' work within their offices, I never heard any arguments or loud disputes between nurses and their patients. One nurse was heard to sing and hum all day long as she walked through the corridors to find files or talk to patients or colleagues. As I commented on her song, she said: 'You know, there are so many challenges in the lives of my patients, and I try to keep up their hope and spirit. Singing makes difficult thoughts to disappear.' The general picture of the nurses in hospital B was that they encountered their patients in a friendly and respectful manner. In my field notes, I reflect, for example, on how an elderly nurse handed out medication and met her patients with respect and with clear instruction. Another example was of the nurse quietly asked the woman and her mother to repeat her instructions in how to take the medication: 'Repeat after me', the nurse said – and the young woman and her mother repeated in unison to assure her that they had understood. A third case was when a young patient had a couple of questions about the diagnosis and the nurse leaned towards the patient and quietly explained. At the same time the nurse ensured that her patients understood what she had told them, and frequently asked them to repeat what she had said. I wrote in my field notes:

> What struck me is how nicely the nurse approached the patient. She talks calmly and quietly. Whether it is so patients outside do not hear the conversation I am not sure, but she leans towards them, sits close, and makes sure they understand her messages. The message is instruction-like as in hospital A, and she keeps repeating the questions – have you understood – what did I tell you to do? A young girl comes

> in together with her mother – they have to repeat in unison how the young girl is supposed to take her medication.

I asked one of the nurses in the clinic about how she experienced her work situation to be and she said: ‘I have been working at this hospital for 30 years. I have never been sick – I love my job and praise the Lord for keeping me in good health.’ One day I observed this nurse in her work and she added:

> The patients call me ‘*bibi’* (grandmother), you know, because I am so old they trust me and tell me everything and they can tell me their secrets. There is a difference between the young nurses and us who are old. With me, the patients are not afraid I will tell anyone because I am so old.

In hospital B, the nurse-patient interaction was also pictured through the expressions of the interviewed HIV-positive women. In paper II findings on how the mothers expressed to be given diverging advices in infant feeding practice and hence felt insecure about how to feed their children, and were scared to transmit the HIV, was presented. However, on questions about their overall experiences of being enrolled in the PMTCT programme, several of them communicated that the nurses and their interaction gave them hope in a demanding life situation. One HIV-positive mother said that ‘the nurse gives me hope, she says that I am not allowed to worry and that I will live well with this disease.’ Another informant said: ‘The nurse gives me hope, she asks me how I am – it makes me feel well.’ Several of the informants said they were scared and afraid when they received the HIV positive test results, particularly about how it would affect their pregnancy and unborn child. However, many of them were encouraged by the nurses, and one informant stated: ‘The nurse told me that this disease is not the end of my life, and that I should not worry. I can live with this disease just like any other person.’

The nurses in the present study rarely complained about their working conditions, even though some diversity between the two clinics was observed in this regard. In hospital B, the nurses on a few occasions complained about the lack of resources to attend courses as well as the lack of stability among the personnel working in the clinic. One informant said: ‘Who wants to open up to a new person every time he visits the clinic?’, referring to how the patients frequently had to relate to new health personnel during their clinical consultations. The nurses in hospital A, however, were heard to discuss their salary and complained about long working hours as they compared themselves with other departments within the same hospital. None of the nurses in the two programmes expressed feeling unfairly blamed by the patients, and, on the contrary, expressed pride in their work and in doing the best they could for the HIV-positive women enrolled in the programmes.

5.0. DISCUSSION OF CORE FINDINGS

The major aim of this dissertation was to scrutinize care in nurses' everyday practice in low-income contexts in Tanzania. In the light of clinical research and theories within nursing science and medical anthropology about caring interactions within nursing practice, the discussion will shed light on the core findings of the study. The discussion is organized into two main sections: (1) the social and cultural constructions of care in nurse-patient interactions based on the experiences by nurses and HIV-positive women, and (2) the essence of care in nurses' and patients' everyday health-care interaction.

Let us first remind ourselves of the fact that the overwhelming majority of studies published on nursing care in sub-Saharan Africa have been based on 'things said' by nurses and patients during interviews or reported in questionnaires – as seen in the general critique of studies on 'care' as presented in the introduction section. In addition, 'care' is frequently neither defined nor specified in many of the studies referred to from sub-Saharan African countries, which is a challenge particularly linked to the complexity and wide variety in the understanding of what care may embrace. From previous studies on nursing care in sub-Saharan Africa we have also seen that there is a marked difference between how patients and nurses argue when they are asked about how they experience and handle caring behaviours and -interactions within clinical settings. At a general level, patients refer to harsh and inhuman treatment while nurses feel unfairly blamed and over-burdened by poor working conditions in a context where health-related resources are scarce.

THE SOCIAL AND CULTURAL CONSTRUCTIONS OF CARE

This section will draw upon the distinction Jecker and Self (1991) make between expressive and instrumental care, and also add reflections from Roach's (1990) theory on care, with five caring attributes – the five Cs – as described in the introduction. The central focuses of *caring actions* as found in the reviews as presented in the introduction will moreover be drawn upon.

'Caring about' – compassion and commitment

First, we will discuss caring behaviours and -interactions as they are expressed and experienced by nurses and HIV-positive women, as they emerged in the present study, in the light of Jecker and Self's (1991) element of 'caring about' and Roach's (1990) caring attributes of ‘compassion’ and ‘commitment’. As described in the introduction, ‘caring about’ is linked to the expressive elements of caring. Jecker and Self (1991, p. 295) write that

> a health professional who *cares about* a patient makes a cognitive or emotional decision that the welfare of the patient is of great importance. Caring about requires keeping the patient’s best interest in the forefront of mind and heart.

Roach (1990) says that compassion cannot be referred to as a skill but, rather, a gift of human response which is defined as including ‘a relationship, lived in solidarity with the human condition’ and ‘a simple, unpretentious presence to each other’ (Roach, 1990, p. 20).

The findings overall, give a picture of nurses with a fundamental and clear concern for their patients. Looking at findings from hospital B first, the nurses were, based on my observations, found to treat their patients well. They were, within the CTC, observed to approach and interact with their patients in a respectful manner. One nurse thanked God for her opportunity to serve the patients which reveals a profound and humble presence on behalf of the patient, as found in Roach’s (1990, p. 20) definition of compassion. Another example is how a nurse communicated that she tried to keep up the hope and spirit in the challenging lives of her patients. The HIV-positive mothers confirmed the nurse’s statement in how several of them expressed that their interaction with the nurses gave them hope; as this HIV-positive mother said: ‘the nurse gives me hope, she asks me how I am – it makes me feel well’. Such expressions strengthen the picture of nurses who ‘cared about’ their patients.

In hospital A, as I followed the nurses for home visits, they repeatedly expressed being concerned about the women’s living conditions, which they found to be crucial for their ability to fulfil the intended infant feeding practices. The nurses knew that the women enrolled in the programme were dependent upon information, material and psychological support in order to succeed with the challenging infant feeding instructions provided to avoid HIV transmission to their infants. If the women had not disclosed their HIV status to anyone, and hence could not expect support from family members, the exclusive breastfeeding period, and even more the weaning process at six months, would be difficult. The nurses hence found it within their own area of responsibility to involve themselves and support the women during this period. The nurses’ inherent concern for the enrolled HIV-positive women and their HIV-exposed children was, in both hospital settings, expressed and observed through uncommonly long working hours and through continuous statements such as ‘I worry so much about this mother’, ‘I know they struggle in that family’, ‘we have to do the best we can for them’, ‘I am worried about that child’, ‘we have to keep up their hope’, etc. Paper I describes how the nurses in hospital A had a general concern for the mothers’ enrolled in their PMTCT programme. Even though Paper III has a prime focus on challenges of confidentiality, the underlying aspect of these findings is the nurses' inherent concern and care for the HIV-exposed child – the third party – which in particular situations resulted in challenging behaviour and interactions in the light of the HIV-positive women's right to a confidential handling of their diagnosis.

Paper I suggests that nurses in this study were found to stretch the boundary of what in many nursing contexts would be referred to as professional nursing behaviour, as they were observed to involve themselves personally in the HIV-positive women's life situations. A particular aspect was the apparent blurring of the borders of professional and personal involvement that emerged through experiences of how HIV-positive women sought help in the private homes of the nurses' outside clinic opening hours. Likewise, the nurses engaged themselves in attempts to solve what to me were personal affairs, like disagreements between husband and wife, disputes with neighbours and in situations that could 'disturb the mother while breastfeeding', as one nurse explained. Roach (1990, pp. 19-20) writes that compassion as a caring attribute includes 'a quality of presence which allows one to share with and make room for the other' and 'a response of participation in the experience of another'. I will argue that the examples of nurses' and mothers' statements and conduct presented in the findings of this study express a caring attitude through compassion found among the nurses in both hospital settings. The nurses were found to be particularly present in their patients' lives in the sense that they participated in the experiences of the mothers, as made manifest in statements and in concrete engagement in the mothers' private lives in processes aimed to enhance the likelihood of an HIV-negative child. These actions seemed to be experienced and appreciated by both parties: both nurses and mothers found nursing roles engaged in the patients' private lives as normal and as an expected part of the caring interaction. How the nurses in this study kept the HIV-positive women's 'best interest in the forefront of mind and heart' (Jecker & Self, 1991, p. 295) is thus powerfully illustrated. The socio-cultural construction of care thus seemed to emerge in a manner where care was communicated through a stronger degree of 'blurring' of professional and private spheres as found elsewhere; it was perceived as natural and relevant to extend caring conduct into both patients' and nurses' own private lives if deemed important for the patients.

Commitment, the fifth of Roach's (1990, p. 25) Cs, is defined as 'a complex affective response characterized by a convergence between one's desires and one's obligations, and by deliberate choice to act in accordance with them.' Swanson (1999, p. 36) similarly refers to commitment as one of the levels of caring and concludes that 'caring in nursing is based on commitments to recognize the dignity and worth of each person.' Commitment as a caring attribute in the present study context also seems to be relevant in connection to how nurses interacted with the HIV-positive mothers, exemplified through the manner in which they made attempts to keep a focus on the positive aspects of the women's lives. One example as referred to in the complementary findings, was how one of the nurses sang while working in the clinic and who explained: 'You know, there are so many challenges in the lives of my patients, and I try to keep up their hope and spirit. Singing makes difficult thoughts to disappear'. Under the heading 'Stop thinking' in Paper I, attention is drawn to nurses' communication as a way of shifting the HIV-positive women's thoughts and attention from the challenges and difficulties to the resources and positive aspects of their lives. This seems to be related to Nordanger's (2007, p. 183) findings from post-war Tigray in Ethiopia where, as a coping strategy, people were encouraged to avoid expressing emotional pain and to concentrate on what they still had left in life, as grieving and crying 'cannot bring back what is lost'. Likewise, de Klerk (2013, p. S489) describes how older caregivers in northwest Tanzania addressed bereaved people with strategies to 'endure loss' and to 'try to focus on the relations that remain.' A similar approach was observed in the conversations and interactions between the nurses and HIV-positive women in the present study. The nurses in hospital A expressed the belief that the HIV-positive women enrolled in the PMTCT programmes needed a clear focus and a belief in the possibility of fulfilling their intentions of exclusive breastfeeding in order to succeed with their infant feeding strategy. They needed to be assured, and the nurses were observed using the strategy of diverting negative thinking to strengthen the women through this part of their lives, providing the energy to endure. This is another manifestation of the expressive elements of care, of 'caring about' in our case of the well-being of the enrolled women indicating at a very general level a nursing care approach that is culturally distinct from the approaches to suffering, saying that challenging memories, rather than being avoided, should be confronted (Nordanger, 2007, p. 174).[42] When the HIV-positive women brought up worries related to problems that could not be solved, the nurses were seen to try to refocus the conversation, directing the attention to the other resources, whether it be other children or family, physical strength, a field with potential for future harvests. How the nurses 'cared about' the HIV-positive women was in these situations seen to be direct, concrete and realistic in continuous attempts to focus upon what the women were actually able to handle or could realistically change, and to abandon thoughts about what was beyond their influence. Through such efforts the nurses seem to have expressed a commitment to assist their patients, in this case through attempts of defining the women's situations and

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[42] Nordanger here refers to: Englund, 1998; Honwana, 1997; Machel, 1996; Summerfield, 1999

lives as filled with potential and possibilities, and thus far from hopeless. 'Hope' was in the present study particularly mentioned in interviews with the HIV-positive women in hospital B, who found that the interaction with the nurses in the programme brought hope into their lives. To convey hope through the nurse-patient interaction, moreover, might be understood as a commitment which Roach (1990, p. 25) states to be a quality of investment of one's self in a person, experienced as a call drawing the self 'to a conscious, willing and positive course of action'.

Alike the findings of this study, Kyakuwa (2011) also links nursing care to commitment and compassion in her study of Ugandan nurses. She writes:

> Despite the many challenges faced, for the nurses in this study care is a tale of commitment (often referred to as devotion, perseverance, and dedication), compassion (kindness, consideration, empathy, and concern), and creativity (inventiveness, initiative, and resourcefulness) (Kyakuwa, 2011, p. 257).

As referred to in the introduction, Kyakuwa (2011, p. 257) also found the nurses in her study to care for their patients 'beyond the call of duty – they went the extra mile', largely in accordance with the present findings. In a context where patients find themselves in a truly marginalized situation, the nurse-patient interactions referred to in this section are found to shed light on how care emerges as socially- and culturally constructed in our case revealing how care is experienced and expressed in this resource-constrained low-income setting.

'Caring for' – competence and confidence

The coming section will discuss caring behaviours and -interactions as they are expressed and experienced by nurses and HIV-positive women in the present settings in the light of what Jecker and Self (1991) refer to as 'caring for', and Roach (1990) refers to as 'competence' and 'confidence' in caring. As described in the introduction section, 'caring for', according to Jecker and Self (1991, pp. 294-5), involves the 'exercise of a skill' and includes engaging 'in a deliberate and ongoing activity of responding to the patient's needs'. Even though 'caring for' is related to more instrumental caring activities, Jecker and Self (1991, p. 294) highlight that 'caring for' is a relational term because it is directed towards someone. Roach's (1990, pp. 22-3) caring attribute, 'competence', is defined as 'the state of having the knowledge, judgement, skills, energy, experience, and motivation required to respond adequately to the demands of one's professional responsibilities' while 'confidence' is 'the quality which fosters trusting relationships'. Moreover, the *caring actions* as found in the reviews of 'care' as presented in the introduction is seen to be relevant in the coming discussion.

As referred to in the introduction to the PMTCT programmes, counselling came up as one of the new tasks introduced to nurses in the rise of HIV in the 1980s and 1990s and is, in this context, referred to as a skill. The concept of counselling was, and still is, located at the core of global guidelines of diverse HIV-prevention programmes. The approach to infant feeding counselling in PMTCT programmes was no exception and how to counsel the HIV-positive women within these programmes has been highly dependent upon such global and national PMTCT guidelines. As referred to in the introduction these guidelines have undergone speedy revisions during the last decades, considerably complicating the nurses' counselling of safer infant feeding practices. At the time of the fieldwork, the global, as well as the national PMTCT guidelines in Tanzania, underscored the importance of counselling comprising individual informed choice in infant feeding practices. The HIV-positive women's individual decisions should be based on rich information provided through patient-active counselling. Throughout the fieldwork, the nurses at the two hospitals were found to handle the counselling session differently with reference to the national guidelines. While the nurses at hospital B vaguely argued that they attempted to follow the informed choice strategy as stated in the guidelines, the nurses at hospital A were clear in the hospital's strategy to opt for exclusive breastfeeding as the only alternative for the HIV-positive women. This different approach to infant feeding counselling was further found to impact on the HIV-positive women's interaction with the nurses, which again was seen to form their confidence and trust in the PMTCT programme overall.

As a part of the 'no-choice' strategy from the nurses in hospital A, the nurses were observed to approach the HIV-positive mothers in a very direct and instruction-like manner during the infant feeding counselling sessions. This kind of communication is brought forth in both Paper I and Paper II as examples of how the HIV-positive women in hospital A were found to clearly understand and adhere to the presented infant feeding strategy. Even though a few nurses in hospital B communicated opting for a choice strategy, the interviewed HIV-positive women at this hospital presented a quite different picture of the infant feeding counselling they received. They expressed to have been provided with highly differing information, exemplified by one mother who received three different strategies in infant feeding from three different nurses. Several of these mothers said they had ended up making a decision on infant feeding practice based on their own interpretation of the different information provided on transmission risks of HIV through the various infant feeding methods advised to them. They expressed not to have received a clear strategy in infant feeding to adhere to, and, moreover, communicated that they were insecure about their infant feeding strategy and scared of transmitting HIV to their children. Based on the HIV-positive women's histories, the information they received from the nurses often turned out to be improperly interpreted, which resulted in sub-optimal infant feeding practice.

Two focuses are found interesting to discuss in this setting: (1) how the information was communicated between the nurses and HIV-positive women in the counselling session, and (2) reflections on informed individual choice in infant feeding in the present health care context.

HIV-positive women from both hospitals expressed that the nurses talked to them in an instruction-like manner during the counselling on safer infant feeding practices. Such communication was also confirmed during observations of several counselling sessions in hospital A. These interactions were found not to be in line with how the literature refers to the concept of 'counselling', which should be characterized by active listening, respect, empathic understanding and dialogue (Nelson-Jones, 2005, p. 9), where in particular the 'active listening' and 'dialogue' parts were missing in the 'infant feeding counselling session' between the nurses and the HIV-positive women. However, somewhat surprisingly, none of the HIV-positive women at either of the two hospitals at any time problematized this kind of communication, which, to me, in early fieldwork periods, appeared as typical top-down communication based in paternalistic nurse-patient interactions. The nurses at both hospitals also clearly expressed their infant feeding counselling was based on 'instructions' and in 'telling' the women how to feed their children. This, of course, might be assigned the nurses' lack of understanding of the nature of counselling and, as such, questions their competence in counselling. Still, the two remaining characteristics of counselling, respect and empathy, need in the present settings to be viewed within the wider socially- and culturally-embedded context within which the present study was carried out. In addition, and importantly, Roach (1990, p. 22), specifies that within the caring attribute of 'competence' lies how the nurse needs to handle the situation with the competence 'required to respond adequately to the demands of one's professional responsibilities'. 'One's professional responsibilities' also has to be viewed within the wider context in which the nurses of this study were practicing their counselling and caring interaction with the HIV-positive women. As argued in Paper I, my growing understanding of instruction-like and paternalistic communication became more nuanced during the course of the fieldwork. As referred to in Paper II, the immense knowledge gap between most of the HIV-positive women enrolled in the two PMTCT programmes and the educated nurses who held 'modern' and biomedical knowledge, seemed to lend authority and expectation to nurses' communication in health-specific topics. This point is spelled out in the findings of Leshabari et al. (2007a, p. 6) where nurses found their role as counsellors challenged because the patients expected them to provide straightforward and correct answers on what was best for their health – as had previously been done through the classical health education approach. Sprague et al. (2011, p. 7) report from a PMTCT setting in South Africa that the enrolled women looked for information and answers to their many challenges as HIV-positive mothers. The nurses in the present study indeed spoke of this instructive communication as 'counselling' – the clinic in hospital A had a separate 'counselling-room' and the nurses invited me to join them as they were going to 'counsel' the HIV-positive women. The nurses moreover expressed with pride how they instructed the women in infant feeding practices and not the least how they found the HIV-positive women to followed their instructions. They hence seemed to find it to be their 'professional responsibility' to provide the women with clear messages in which they realistically could follow and adhere to. With this reference we can see that the nurses in the present study adhered more to the classic health education approach than to the counselling approach, but they did so because they knew that their patients expected and appreciated such health-related instructions when they entered the hospital. When the patients expressed to appreciate such clear communication we might also deduce that the nurses held competence in caring for their patients within their common view of the skill of counselling in the present setting, based on social- and cultural expectations to of the nurse-patient interaction.

A vital aspect of the above reflections on how this instruction-like communication, which we may label a caring competence in culture-specific health-related communication, has to be accompanied by confidence and trust in *what* is communicated. Roach (1990, p. 23) states that the caring attribute of confidence – 'the quality that fosters a trusting relationship' – is a critical attribute of professional nursing care. When we look at how the nurses in the two hospitals approached the infant feeding counselling, it is within the *quality* of what is being communicated that the findings from the two hospitals differed, based on what the enrolled HIV-positive women experienced as the consequence of the instructions they received. Jecker and Self (1991, p. 295) specify that their view of 'caring for' is concerned with the activity of responding to the patients' particular condition and needs, in which the two caring attributes of competence and confidence are seen to be closely interrelated. While the nurses in hospital A had one 'no-choice' strategy for the instructions of infant feeding practices for the HIV-positive women, the nurses in hospital B were said to communicate highly different strategies in infant feeding to their enrolled women. As a consequence, the HIV-positive women in hospital A were found to adhere to the unambiguous instructions from the nurses, while the mothers in hospital B expressed themselves uncertain and scared by the diverging instructions they received from the nurses. None of the women questioned the way in which the nurses talked to them, in an instruction-like manner, but the quality of *what* was communicated was clearly different. The unified message from all the nurses that they spoke to in hospital A was perceived by the HIV-positive women as fostering a trusting relationship between the women and the nurses and the overall PMTCT programme. The mothers in hospital B expressed the opposite related to the infant feeding counselling, even though several of them communicated that the interaction with the nurses on a general level brought hope to their lives. The nurses in hospital B also expressed, during informal conversations, to be insecure about the infant feeding guidelines and, on several occasions, explained how they had not attended the relevant PMTCT courses. This might add to the understanding of why the messages they provided to the mothers were unclear and diverging, which resulted in HIV-positive women not experiencing the quality that leads to a trusting relationship, and hence communicating having limited confidence in the interventions connected to infant feeding and PMTCT.

The second focus that will be reflected on related to competence and confidence as attributes of caring is how the findings of the present study highlight a challenge within the choice-strategy found in global and national guidelines at the time of the fieldwork. Already at that time the choice-strategy was problematized within international research, and in the set of guidelines issues in 2010, indivudal informed choice was toned down and more responsibility was left with authorities on the country level to decide on the most appropriate infant feeding method to be recommended to HIV positive women (WHO et al., 2010, p. 3). As referred to in Paper II, the Tanzanian authorities changed the 2007 PMTCT guidelines that highlighted the HIV-positive women's right to choose infant feeding strategy (URT, 2007, p. 49) to the 2013 version of the guidelines which state that '[q]uality infant feeding counselling should include information that assists women and their families in making informed decisions about how and what to feed their children' (URT, 2013a, p. 66). 'Informed choice' is thus replaced with 'informed decisions'. As described above, the nurses in hospital A did not provide the HIV-positive women with any informed choice – a strategy that was held by the entire hospital. A few nurses in hospital B expressed to opt for a choice strategy, while none of the enrolled and interviewed HIV-positive mothers expressed to have received any choice-related information in infant feeding practices. Doherty (2011, p. 185) and Moland and Blystad (2009, p. 459), writing about infant feeding practices of HIV-positive women, highlight that the intended choice in infant feeding practices brought forward by international guidelines in PMTCT typically carries a burden of responsibility which the women mostly carry alone. In Paper II, such a responsibility is discussed in relation to the authoritative knowledge (Jordan, 1997, p. 154) the nurses are found to hold within this context. The nurses at hospital A, expected by the HIV-positive women to hold 'modern' knowledge, expressed that they found the mothers' particular need in this setting to be to 'know how' – i.e. to receive information and a clear procedure on how to practise safe infant feeding, while still trying to appear not to differ from the cultural and social norm, to ensure adherence. When the nurses in hospital A gave the HIV-positive women no choice and instructed them how to feed their children they indirectly took on the responsibility for the outcome of such infant feeding which might be viewed as a nurturing and caring aspect on part of the HIV-positive women in search for clear advices. Indeed, the HIV-positive women in hospital A expressed, and were observed to demonstrate, confidence and trust in the nurses and the overall programme, as they adhered to the instructed infant feeding strategy and approached the nurses for advice in case of any misunderstandings or questions. Desclaux and Alfieri (2011) also write about how HIV-positive women in low-income contexts experienced the choice in infant feeding as presented by the nurses:

> [M]any women had the feeling that what was labelled as 'choice' by health workers was instead a decision made under constraints, since the cost of formula and its preparation prevented many of them from considering this option. (Desclaux & Alfieri, 2011, p. 201)

Paper II also draws upon the writing of Mol (2008) and her reflections on 'the two logics': 'The logic of care' and 'the logic of choice', and how she questions the highly-celebrated ideal of patient choice, and whether the lack of choice is necessarily opposed to good care. She writes that 'choice might be a great ideal, but only in situations in which people are indeed able to make their own decisions' (Mol, 2008, p. 6). Within 'the logic of care' the health worker tries to identify a suitable target to achieve that is actually possible for the patient, while 'the logic of choice' tries to separate facts from values (Mol, 2008, p. 46). These reflections seem to be of relevance when making sense of the present study findings, as the nurses, based on hospital A's policy, argued that 'there is no choice in this area – there is only breastfeeding' (Paper II). Based on this policy, they found the 'no-choice-strategy' to be 'best practice' for the HIV-positive women, and the safest way for them to reach the goal of an HIV-negative child. A relevant target that is possible to reach in this particular setting also has to take the socio-economic context into account and to join it with the assessment of local values (Mol, 2008, p. 46), which in the present context implies the value of infant feeding from a social and cultural perspective. The nurses at both hospitals knew how mothers who did not breastfeed could experience stigma and challenges within their community, which coincides with what Leshabari (2007b, p. 549) writes about how breastfeeding is viewed in a neighbouring area: 'All good mothers breastfeed their children' and that '[t]he study findings reveal breastfeeding as the only culturally acceptable infant feeding method, and the only way to fulfil ideals of being a good mother' (Leshabari, 2008, p. 64). Once again we draw on Roach's (1990, p. 22) caring attribute of competence and the nurse's judgement om how to 'respond adequately to the demands of one's professional responsibilities'. The findings of the present study show that the nurses in the two hospitals made differing judgements on how to adjust or adapt the national guidelines to their particular context. While all the nurses I talked to in hospital B expressed that very few of the mothers enrolled in the PMTCT programme could afford any alternative to breastfeeding, quite a few of the interviewed HIV-positive women expressed to have been told to avoid breast milk and buy formula milk or cow's milk to reduce the risk of HIV transmission. Without drawing any conclusion on which of the hospitals chose the 'right approach' to infant feeding counselling, it seems clear that the manner in which hospital A communicated one unambiguous and clear message regarding infant feeding practices resulted in HIV-positive women who expressed confidence and trust in the nurses and the programme overall. The nurses in hospital B lacked a common basis on how to relate to the PMTCT guidelines, and thus communicated diverging and unclear information to the HIV-positive women during the counselling session. *What*, in addition to *how*, particular information is communicated to patients is thus found to intervene in how the HIV-positive women in this study experienced being 'cared for' and accordingly how they expressed, and were observed to show trust and reliance on the nurses and the overall PMTCT programme, based in the nurses' combination of competence and confidence as vital attributes of the provided care.

Another vital nuance to bring forth when discussing the manner in which the nurses in the two PMTCT programmes 'cared for' the HIV-positive women is the two programmes' unquestionably different access to external funds. Instrumental activities within nursing, as Jecker and Self's (1991) 'caring for' refers to, is frequently dependent upon resources – the PMTCT programmes being no exception. As described in the section 'Field sites', hospital A received external funding, which for the HIV-positive women became evident through the nurses' home visits and how the hospital was able to support the women economically with one litre of cow's milk on a daily basis when they weaned their children from exclusive breastfeeding. In hospital B there were no such regular support systems for the enrolled women. Again, we draw attention to how Jecker and Self (1991, p. 295) talk about 'caring for' as nurses, through the execution of practical skills, responding to the patient's particular needs. In the present context, such particular needs were, among others, found to be how to solve the practical and economic challenges related to safe infant feeding. The nurses in hospital A saw their ability to visit the HIV-positive women in their homes as of particular importance during the first six months of exclusive breastfeeding in order to ensure that the mothers adhered to the instructed infant feeding practice. For the women, the economic subsidy for cow's milk was expressed during interviews to be crucial in order to fulfil their intended infant feeding practice of weaning at six months. Desclaux and Alfieri (2011, p. 197), based on their study from Burkina Faso, Cambodia and Cameroon, write about how infant feeding practices are greatly determined by material and economic constraints. It must not be underestimated how such access to economic support as found within hospital A had a substantial influence on the overall PMTCT programme, and that it might also influence other parts of the nurse-mother interaction. The HIV-positive women at hospital A indeed expressed that the food support, even though it was limited, was important to them, and seemed to provide signals beyond the mere practical aspects – it made them feel cared for. In hospital B, with no possibility of sustaining the women with incentives like food support, a health worker, when asked if HIV-positive women in the programme brought up their practical problems at the clinic, responded: 'Why should they bring up their problems? There is nothing the nurse can do about it – why should they bother to tell her?'

In the above section we have discussed the caring attribute of compassion as connected to 'caring about'. Roach (1990, p. 22) connects compassion and competence by saying:

> While competence without compassion can be brutal and inhuman, compassion without competence may be no more than a meaningless, if not harmful, intrusion into the life of a person or persons needing help.

She also writes about how competence requires a strong constitution and 'more than kindness' (Roach, 1990, p. 22) from the nurses. Even though this part of the discussion has focused on instrumental activities and skills, the caring attribute linked to competence in Roach's perspective is a concept wider than mere technical skills. She includes cognitive *and* affective skills within the competence-concept, and argues that professional caring demands competence within all of these areas (Roach, 1990, p. 22). Roach's (1990) view of caring competence is thus in line with the caring actions referred to in several of the most well-known reviews on the content of care within nursing, such as that by Swanson (1999, p. 41), who says that caring actions include competence in physical and technical care as well as affective care, and Morse et al. (1990, p. 6), who specify caring actions as 'attentive listening, patient teaching, patient advocacy, touch, “being there”, and technical competence’. These reviews, and Roach’s (1990) attribute of caring competence, point to the challenge of creating an artificial distinction between the instrumental and the expressive dimension of caring conduct: the ‘caring for ’ versus the ‘caring about’. This point leads the discussion into its last section where we will look at how we might interpret the essence of care within this particular context.

THE ESSENCE OF CARE – A HUMAN MODE OF BEING

We have in the previous sections discussed how nursing care, as divided into ‘caring about’ and ‘caring for’, emerges within the present social and cultural context of the nurse-patient everyday interactions. However, the previous paragraph brings attention to a challenge which is also brought forth in the care debate within nursing as stated by Benner (1984), who refers to Skipper’s (1965) belief that ‘[w]e do violence to caring when we separate in our practice the distinction we are able to make conceptually between the “instrumental role” and the “expressive” role’ (1984, p. 170). The last part of the discussion will hence return to the discussion of the essence of care which Roach (1990) refers to as ‘the human mode of being’. We shall make an effort to shed light on the essence of care – trying to merge the above various aspects of caring behaviours and -interactions in nurses’ practice while simultaneously locating it within the particular study context. The central focus of caring as a *human trait* as found in the reviews on ‘care’ as presented in the introduction is also found to be closely connected to how care is viewed as a human mode of being.

To recall the introduction section, the essence of nursing care has been discussed within nursing science particularly from the vantage point of whether ‘care’ is unique to nursing practice or ‘is ubiquitous among all professions and does not reflect the uniqueness of the knowledge and practice of nursing’ (Smith, 1999, p. 14). A brief reference back to this discussion shows that most of the theorists of the 1980s and 1990s argued that nurses could not claim caring as specific or unique to their profession (Huch, 1995, p. 38; Smith, 1999, p. 15; Smith, 2013, p. 3) but argue that care is seen to be central to nurses’ practice (Dunlop, 1986, p. 665). This is also the core message of Roach’s (1990) theory of care, which is seen to be greatly influenced by the philosophy of Heidegger (1962), who writes about care (sorge) as ‘being in the world’, and Mayeroff (1971), who holds that caring is what provides meaning and order into one’s life (Roach, 1990, pp. 5-7). Even though Roach (1990, p. 2) holds that caring behaviour is explicitly manifested through the five caring attributes, the five C's, her overall stance is that caring is a total way of being, of relating, of acting:

> A quality of investment and engagement in the other – person, idea, project, thing, or self as the 'other' – in which one expresses the self most fully, and through which one touches most intimately and authentically the meaning of human. (Roach, 1990, p. 2)

The *human trait*, emerges in good nursing care through nurses' views of the patient as a 'fellow human being worthy of dignity and respect' (Brilowski & Wendler, 2005, p. 645). Referring to Benner and Wrubel (1989), Swanson (1999, p. 34) phrases it this way: 'concern and caring are at the essence of being, a claim that human wholeness is characterized by the capacity for concern, loving, and caring.' Also Morse et al. (1990), within their category 'caring as a human trait' refer to Benner and Wrubel's (1989, p. 389) view on care as 'the "basic way of being in the world" from which all nursing practice evolves' (Morse et al., 1990, p. 4).

We have seen from the findings of the present study that the nurses' prescribed roles and professional boundaries in their nursing practice may be stretched far beyond the walls of the hospital clinic – into people's homes and well beyond regular working hours. The example illustrate that caring as a way of being in the world cannot in this context be seen merely as a professional role that is turned on and off inside and outside working hours or inside and outside the work arena. Rather it must be understood as a responsibility that has been accorded to nurses through their education and the authoritative knowledge they embody in the local community in which they live and work. Examples were abundant and emerged through the ways in which nurses welcomed patients into their private homes, provided practical help during the difficult weaning process, engaged in private conflicts within the women's families and worried about their crops. The episodes described above were not spoken of as special or unique at all, and emerged in natural settings during the course of the fieldwork. The nurses did not seem to operate with a very clear boundary between the private and the professional arena. In northwester parts of Tanzania, de Klerk (2012) found that family caregivers had a strong notion of what they consider to be 'good care'; 'It includes tactfulness, closeness, love, duty and suffering' (de Klerk, 2012, p. S36) – much the same expectations to care as found among and between the nurses and the HIV-positive women in this study. As such, it makes sense that the nurses' caring behaviours on part of the HIV-positive women appeared as a naturally given way of acting on part of one's fellow human beings, or as Roach (1990) says 'a human mode of being', and, lies at the core of the essence of care. In Paper I we argue:

> [A]s the fieldwork progressed, a different interpretation of a nursing identity evolved, one that was not limited to certain locations or specific times but to a larger extent was a personal identity valid in all settings at more or less all times (Våga et al., 2013, p. 1051).

Even though we have, in the previous sections, discussed nurses' caring behaviours- and interactions from how they are explicitly manifested through Roach's (1990) five caring attributes, the five C's, it is possible to consider the 'essence of care' as a natural merging of 'caring about' and 'caring for' their patients. This seemed to be central to a nursing identity among the nurses in the present thesis and was intimately connected to, or possibly even an integral part of, being a fellow human being. Morse et al. (1991, p. 125), quote Brody (1988, p. 92), and highlight how the expressive and instrumental aspects of nursing care are both aspects of what is perceived to be the essence of care:

> It is not just the competent performance of technical skills that evokes the image of caring, but the compassionate attitudes and feelings of the nurses toward the patient as they perform their tasks that is the essence of caring. (Morse et al., 1991, p. 125)

That the essence of care cannot be understood without a recognition of both the expressive and instrumental elements of caring behaviour is clearly not an original thought; however, how the essence of care is expressed and experienced in the present setting seems to add a dimension to this body of work in the sense that it reveals how these elements of nursing care emerge as to some extent culturally distinct. The findings also seem to reveal in particularly illuminating ways the manner in which these two dimensions of care are inextricably intertwined in a manner where the one can hardly be understood without the other, and how we can only make sense of the nursing care emerging in this study by viewing the essence of care as a human trait, or a human mode of being. A few published sources hint at this direction. Moland (2002a, p. 55) writes that nursing in Tanzania is perceived as a 'clean and self-sacrificing occupation' and continues: 'Clean (*safi)* in this context, refers to the humanitarian basis of nursing rather than to its practice. It refers to nursing as goodness, rather than as a means of earning a living' (Moland, 2002a, p. 55). Bell (2004, p. 82), in her study carried out in the same area as the present project, quotes a nurse as saying: 'Nursing comes from the bottom of your heart'. Even if these studies do not refer directly to nursing care theory, their writings indicate that nursing is understood as a human mode of being with a sincere desire for goodness.

A referral back to the literature presented in the introduction section reminds us that the *relationship* between the nurse and the patients is said to both express and define caring, and some authors even state that the nurse-patient relationship *is* the essence of caring, according to Morse et al.'s (1990, p. 6) review. Hartrick (1997, p. 524) emphasises the failure of a behavioural approach in the discussion of care and caring within nursing, referring to the 'significance of relationship as a foundation for human caring.' Roach's third caring attribute, 'confidence', which was drawn upon in the 'caring for' section, was defined as the quality of the caring attribute that 'fosters a trusting relationship' (Roach, 1990, p. 23). As such, trust is also highlighted in the caring interaction between a nurse and a patient. Sherwood's (1997, p. 38) meta-synthesis on care also highlights the trusting relationship. Confidence and trust is hence seen to be closely connected to a caring relationship, and Jecker and Self (1991, p. 297) link confidence to 'caring about' and says that, on the nurses' part, this includes '[a] manner which expresses concern and involves efforts to reassure and gain the patient's confidence'. As the findings indicate, mothers and nurses at hospital A seemed to develop a close relationship where mothers in many settings brought up personal problems and sought advice from the nurse and expressed their acceptance of the programme as they claimed to follow instructions. The findings concerning caring behaviours that are discussed in both of the previous sections about the interaction at hospital A are seen to be one part of how the nurses and the patients developed a relationship based on care which resulted in confidence and trust. At hospital B, however, the HIV-positive women expressed uncertainty about the information they received from the nurses, which made them feel insecure. However, the few, but important, observations of the nurses' general approach to their patients, provided a picture of how nurses tried to make the best of the situation in a more resource-constrained setting than hospital A. Even though the nurses in hospital B were not able to provide the mothers with economic support, this does not have to imply that the patients did not trust them. However, a real challenge to the nurse-patient relationship in hospital B was how the mothers experienced receiving unclear and differing messages about infant feeding practices. However, this is merely one of many areas in which the nurse and the mother interact and on which they base their relationship. The quote by one of the nurses in hospital B of how she experienced her patients' trust of her provides a picture of a nurse who relates to her patients as being fellow human beings, which was also confirmed through the small number of observations.

The last section of this discussion has tried to merge the previous two sections and place a focus on how the essence of care is viewed as a merging of the different caring behaviours referred to in the literature and that such merging, in its desired outcome, results in a caring relationship based on trust and confidence from the parties involved in the nurse-patient interaction. Roach (1990) emphasises that her five caring attributes have to be merged and be considered as a whole to represent care as the human mode of being.

6.0. CONCLUDING REMARKS

The present study aimed to generate knowledge on nursing care in nurses' everyday practice in Tanzania. Previous research has frequently referred to a picture of deteriorating quality of care among nurses in sub-Saharan African settings. Data collected through ethnographic fieldwork revealed an understanding of nursing care as culturally- and socially constructed and as produced, re-enforced and changed within the nurse-mother interaction. The way nursing care is constructed in the example provided in this work is an important comment to the dominant discourse on nursing care which emanates from nursing in Europe and North-America where the socio-cultural, professional and health system context is very different. As illustrated through the findings of this study, this does not imply that patients in the PMTCT programme in Tanzania feel less cared for. On the contrary, the care given to them is expressed as resonating with their desires and strengthening their trust in the nurses. In light of relevant nursing care theory and literature, the study has revealed how care cannot be understood independently of the social and cultural contexts that constitute care, and that the assessment of what good care implies will vary between social settings and provides nuances to the existing picture of low-quality nursing care in the present context. It is argued that the focus on the diversity of ways in which nursing care may emerge in various cultural settings has shed interesting light on the debate about what care as a concept and as a practice may or possibly may not entail in diverse contexts. The implications drawn from the study are that although nurses globally aim to relieve pain and suffering, their approach should be allowed to evolve in local contexts of authority, knowledge and legitimacy.

7.0. AREAS FOR FUTURE RESEARCH

Several recommendations can be made to direct future research in the area of nurses' everyday practice and handling of challenges linked to caring behaviour and how that interferes with their interaction with patients in Tanzania:

- There is an unequal distribution of health worker access between rural and urban areas in Tanzania which makes it of interest to explore nurses' everyday practice and interaction with patients in urban areas of the country in the light of the present findings.
- Future research should examine how health-related resources affect the nurses' ability to 'care for' and 'care about' their patients
- Shayo et al. (2014) highlight challenges in implementing national guidelines of infant feeding in a PMTCT setting, and indicate a gap in how national and local health authorities communicate the changes in such guidelines. Future research should provide in-depth knowledge of nurses' understandings of national guidelines and how their working conditions are organised so as to be able to carry through the expected challenges.
- While there are studies (Bland et al., 2007, p. 289; Fassin, 2008, p. 269) that called for further qualitative observational studies to explore nurses' work nearly ten years ago, there is still a considerable knowledge-gap on this topic and future research should hence devote attention and effort to providing more in-depth understanding of the everyday work of nurses among patients in low-income and resource-constrained settings.

In the light of scarce qualitative literature on nursing care in sub-Saharan Africa, future research is needed to make the understanding of everyday nursing practice more nuanced and thorough. The present study is a modest attempt at approaching this void. I will end by quoting Watson and Smith (2002), who shed light on the challenges in research on concepts such as care and caring, and who also highlight the importance of continuing to seek thorough knowledge and understanding of such concepts:

> [J]ust because concepts such as caring, suffering, love, beauty, God and so on are 'elusive' we struggle to capture their essence because of their importance. We always fall short, and will continue to fall short. Nevertheless, we strive to know them through many different methods and approaches, we seek descriptions, qualities, attributes, etc. as well as how they are experienced. (Watson & Smith, 2002, p. 455)

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RESEARCH PAPERS

APPENDICES

Appendix I	Clearance certificate for conducting medical research in Tanzania, National Institute for Medical Research (NIMR), The United Republic of Tanzania, ref. NIMR/HQ/R.8a/Vol.IX/762
Appendix II a	Research permit, Tanzania Commission for Science and Technology (COSTECH), No. 2008-314-NA-2008-50
Appendix II b	Research permit, introduction letter, Tanzania Commission for Science and Technology (COSTECH), No. 2008-314-NA-2008-50
Appendix III	Residence permit Class C
Appendix IV	Support letter from Regional Administrative Secretary, Region
Appendix V	Support letter from District Administrative Secretary, Hospital A
Appendix VI	Support letter from District Administrative Secretary, Hospital B
Appendix VII a	Ethical approval, Norwegian Regional Committee for Medical and Health Research Ethics, ref. 192.08, Norwegian
Appendix VII b	Ethical approval, Norwegian Regional Committee for Medical and Health Research Ethics, ref. 192.08, English
Appendix VIII	Recommendation for processing of personal data, Norwegian Social Science Data Services, ref. 20209/2/JE
Appendix IX	Information about the study, English and Swahili
Appendix X	Informed consent form, English and Swahili
Appendix XI	Question about participation in the PhD-project, English and Swahili
Appendix XII	Initial interview guide HIV-positive women
Appendix XIII	Initial interview guide nurse counsellors

APPENDIX I

THE UNITED REPUBLIC OF
TANZANIA

National Institute for Medical Research
P.O. Box 9653
Dar es Salaam
Tel: 255 22 2121400/390
Fax: 255 22 2121380/2121360
E-mail: headquarters@nimr.or.tz

Ministry of Health and Social Welfare
P.O. Box 9083
Dar es Salaam
Tel: 255 22 2120262-7
Fax: 255 22 2110986

NIMR/HQ/R.8a/Vol. IX/762

10th October 2008

Bodil Bo Vaga
Department of Public Health and Primary Health Care
University of Bergen
C/O Dr Sebalda Leshabari
Muhimbili University of Health Sciences
P O Box 65001
Dar es Salaam

CLEARANCE CERTIFICATE FOR CONDUCTING MEDICAL RESEARCH IN TANZANIA

This is to certify that the research entitled: How to feed an infant: Exploring HIV positive mothers' and nurses' experiences with prevention of mother-to-child transmission of HIV (pMTCT) programmes, Babati and Haydom, Tanzania (Vaga B B *et al*), has been granted ethics clearance to be conducted in Tanzania.

The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is made available to the Ministry of Health and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine.

Name: Dr Andrew Y Kitua

Signature

CHAIRMAN
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Dr Deo M Mtasiwa

Signature

CHIEF MEDICA L OFFICER
MINISTRY OF HEALTH, SOCIAL
WELFARE

CC: RMO
DMO

APPENDIX II a

TANZANIA COMMISSION FOR SCIENCE AND TECHNOLOGY (COSTECH)

Telegrams: COSTECH
Telephones: (255 - 22) 2700745-6
Director General: (255 -22) 2700750 &
Fax: (255 - 22) 2775313
E-M: Rclearance@costech.or.tz

Ali Hassan Mwinyi Road
P.O. Box 4302
Dar es Salaam
Tanzania

RESEARCH PERMIT

No. 2008 –314 - NA–2008-50

Date 10th **November 2008**

1. Name : **Bodil Vaga**

2 Nationality : **Norwegian**

3 Title : **How to Feed an Infant: Exploring HIV Positive Mothers and Nurses Experiences with Prevention of Mother to child Transmission of HIV(PMTCT) Programmes, Babati and Haydom, Tanzania**

4 Research shall be confined to the following region(s): **Arusha and Manyara**

5 Permit validity **10th November 2008 to 9th November 2009**

6. Local Contact/collaborator: **Dr. M. Malecela, NIMR, P.O. Box 9653, Dar es Salaam**

7. Researcher is required to submit progress report on quarterly basis and submit all Publications made after research.

H.M. Nguli
for: DIRECTOR GENERAL

APPENDIX II b

TANZANIA COMMISSION FOR SCIENCE AND TECHNOLOGY
(COSTECH)

Telegrams: COSTECH
Telephones: (255 - 22) 2700745-6
Director General: (255 - 22) 2700750
Fax: (255 - 22) 2775313
Telex: 41177 UTAFITI
E-M: Rclearance@costech.or.tz

Ali Hassan Mwinyi Road
P.O. Box 4302
Dar es Salaam
Tanzania

In reply please quote: **CST/RCA 2008/50/230/2008** **10th November 2008**

Director of Immigration Services
Ministry of Home Affairs
P.O. Box 512
DAR ES SALAAM

Dear Sir/Madam,

RESEARCH PERMIT

We wish to introduce to you **Bodil Vaga** from **Norway** who has been granted a research permit **No. 2008 –314 - NA–2008-50** dated **10th November 2008**

The permit allows him/her to do research in the country "**How to Feed an Infant: Exploring HIV Positive Mothers and Nurses Experiences with Prevention of Mother to child Transmission of HIV(PMTCT) Programmes, Babati and Haydom, Tanzania**"

We would like to support the application of the researcher(s) for the appropriate immigration status to enable the scholar(s) begin research as soon as possible.

By copy of this letter, we are requesting regional authorities and other relevant institutions to accord the researcher(s) all the necessary assistance. Similarly the designated local contact is requested to assist the researcher(s).
Yours faithfully

H.M. Nguli
for: DIRECTOR GENERAL

CC: 1. Regional Administrative Secretary: **Arusha and Manyara**

2. Local contact: **Dr. M. Malecela, NIMR, P.O. Box 9653, Dar es Salaam**

3. Co-researchers: **None**

JA 27/340/081 VOL TID/DOK.01/F. 01

NORWEGIAN FG.

APPENDIX III

17 NOV 2008

DAR ES SALAAM TANZANIA

THE UNITED REPUBLIC OF TANZANIA

TIF 4B

The Immigration Act, 1995
(Section 20)

No. 0061839

RESIDENCE PERMIT CLASS C

Mr./Mrs./Miss BOOIL BO VAGA.
P.O. BOX MBULU - MANYARA.

is hereby authorised to enter Tanzania and to remain therein for a period of ONE YEAR VIU 16=11=2009 for specific employment with ~~MUCHS~~ ~~MUHIMBILI UNIVERSITY~~ COSTECH

and subject to the provisions of the Immigration Act, 1995 and to the following conditions:-

(a) (i) Place of work MANYARA
(ii) Place of residence MANYARA

*(b) the holder shall not engage in any employment, trade, business or profession other than RESEACHER

*(c) wife and children whose names have been endorsed on this permit are not allowed to engage in Employment

*(d) (other specific conditions) NO CHANGE OF IMMIGRATION STATUS.

Description of Passport :-
Country of issue NORWAY No. 26567413
Date of issue 18.09.08 20

Fees: US $ 160 received *vide* E.R No. 33452560 33452562 of 17.11.08
Issued at D'SALAAM HQ

17 NOV 2008

Director of Immigration Services

All persons entitled to enter the United Republic under this permit must on entering the United Republic report to an Immigration Officer without undue delay (Reg. 18)

(Section 25)

Full Name	*Relationship to Holder*	*Age*
OLE VAGA	SON	2007
LAURITS VAGA	SON	2007

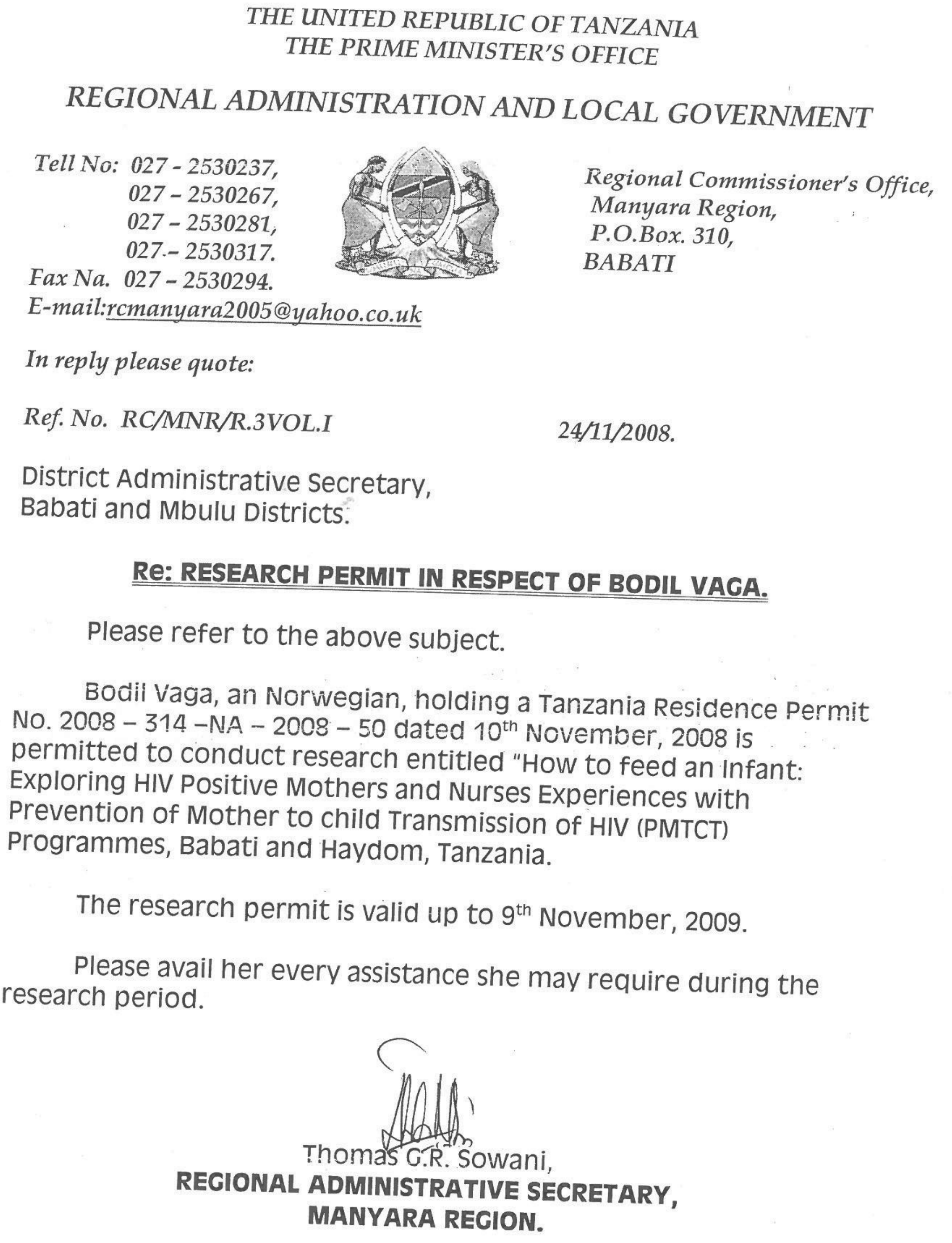
17 NOV 2008

Date .... *20* ....

Director of Immigration Services

*Delete if not applicable

APPENDIX IV



THE UNITED REPUBLIC OF TANZANIA
THE PRIME MINISTER'S OFFICE

REGIONAL ADMINISTRATION AND LOCAL GOVERNMENT

Tell No: 027 - 2530237,
027 - 2530267,
027 - 2530281,
027.- 2530317.
Fax Na. 027 - 2530294.
E-mail:rcmanyara2005@yahoo.co.uk

Regional Commissioner's Office,
Manyara Region,
P.O.Box. 310,
BABATI

In reply please quote:

Ref. No. RC/MNR/R.3VOL.I

24/11/2008.

District Administrative Secretary,
Babati and Mbulu Districts.

Re: RESEARCH PERMIT IN RESPECT OF BODIL VAGA.

Please refer to the above subject.

Bodil Vaga, an Norwegian, holding a Tanzania Residence Permit No. 2008 – 314 –NA – 2008 – 50 dated 10th November, 2008 is permitted to conduct research entitled "How to feed an Infant: Exploring HIV Positive Mothers and Nurses Experiences with Prevention of Mother to child Transmission of HIV (PMTCT) Programmes, Babati and Haydom, Tanzania.

The research permit is valid up to 9th November, 2009.

Please avail her every assistance she may require during the research period.

Thomas G.R. Sowani,
REGIONAL ADMINISTRATIVE SECRETARY,
MANYARA REGION.

APPENDIX V

THE UNITED REPUBLIC OF TANZANIA
PRIME MINISTER'S OFFICE
REGIONAL ADMINISTRATION AND LOCAL GOVERNMENT

Tel. No: ***027-2533019***
027-2533036

District Commissioner's Office,
Mbulu District,
P.O. Box 1,
MBULU

In reply please quote:

REf. NO. DC/MB/M7/0/107

2 nd December, 2008

Divisional Secretaries
MBULU DISTRICT

REF: RESEARCH PERMIT IN RESPECT OF BODIL VAGA

Please refer the above subject.

Bodil Vaga, a norwegian is permitted to conduct research entitles "how to feed an infant exploring HIV positive mothers and nurses experiences with prevention of mother to child transmission of HIV.

Please avail him any assistance he needs to enable him to conduct his research. His research is valid up to 9th November, 2009.

D. Mwanicheta
DISTRICT ADMINISTRATIVE SECRETARY
MBULU

APPENDIX VI

THE UNITED REPUBLIC OF TANZANIA
PRESIDENT'S OFFICE
REGIONAL ADMINISTRATION AND LOCAL GOVERNMENT

Tel. No. *027 2531035*
027 2531071

District Commissioner's Office,
Babati District,
P.O.Box 11,
BABATI.

In reply please quoet:

Ref. No. DC/BBT/R.30/167

26TH March, 2009

Town Director,
Babati Town Council,
P.O. Box 383,
Babati.

RE: RESEARCH PERMIT IN RESPECT OF BODIL VAGA

This is to introduce to you MS. Bodil Vaga, a Norwegian, holding a Tanzania Residence Permit No. 2008 – 314 – NA – 2008 – 50 dated 10th November, 2008 who is permitted to conduct research entitled " **How to feed an infant: Exploring HIV Positive mothers and Nurses experiences with prevention of mother to child transmission of HIV (PMTCT) Programmes.** She has chosen to conduct her research in Babati.

The research permit is valid up to 09th November, 2009.

Kindly, avail her every assistance she may require that will enable her to complete her research successfully and in time.

M.A.R. Musa
DISTRICT ADMINISTRATIVE SECRETARY
BABATI

DISTRICT ADMINISTRATIVE SECRETARY
BABATI DISTRICT

C.C. District Commissioner,
Babati District.

" District Security Officer
Babati District.

" Ms. Bodil Vaga

APPENDIX VII a

UNIVERSITETET I BERGEN
Regional komité for medisinsk og helsefaglig forskningsetikk, Vest-Norge (REK Vest)

Astrid Blystad
Universitetet i Bergen
Det medisinsk-odontologiske fakultet
Institutt for samfunnsmedisinske fag
Forskningsgruppen ”Global helse”
Postboks 7804
5020 Bergen

Deres ref	Vår ref	Dato
	2008/10026-CAG	22.12.2008

Ad. prosjekt: Korleis ernære eit spedbarn: Ei undersøking av HIV-positive mødre og sjukepleiar-rettleiarar sine erfaringer med "Prevention of mother-to-child transmission of HIV" (PMTCT) program i Babati og Haydom, Tanzania (192.08)

Det vises til tilbakemelding datert 31.10.08 som vi oppfatter som en klage på komiteens vedtak fra 28.08.08.

Komiteen behandlet klagen i møte den 16.12.08.

Det forelå sakkyndig vurdering som sendes søker til orientering.

Prosjektleder hevder i klagen at overrekking av symbolske gaver til deltakerne er i tråd med den lokale kulturen og understreker at det kun er snakk om mindre, lokale gaver som for eksempel litt sukker eller mel. REK Vest legger vekt på at veilederne i prosjektet har god kjennskap til den lokale kulturen og har bodd mange år i Øst-Afrika. Vi merker oss også at prosjektet skal godkjennes av National Institute for Medical Research og Commision for Science and Technology, Tanzania som vil vurdere også dette spørsmålet ut fra tanzanianske forhold. En gir derfor prosjektleder medhold i klagen på dette punktet forutsatt at den symbolske gaven er en mindre gave som det er naturlig å overrekke i den gitte situasjonen.

Komiteen gjentar argumentet om at intervju med familien til kvinnene som er åpne om sin HIV-positive status, kan representere en bias i data. Det er grunn til å anta at antall kvinner som ønsker å inkludere familiemedlemmer vil være lavt og at tilfanget av ny kunnskap dermed blir begrenset og tilfeldig. Ettersom det kun hentes informasjon fra familier til kvinner som står fram som HIV-positive, mener komiteen at prosjektet vil få begrenset informasjon fra tilleggsstudien. Det er videre uklart for komiteen hvilke seleksjonskriterier som ligger til grunn for rekruttering av disse deltakerne.

Ideelt sett vil det gi mer kunnskap om utfordringene knyttet til ernæringsregimene dersom man inkluderer informasjon om det sosiale miljøet til kvinner som ikke er åpne om sin HIV-positive status. Slike intervju vil imidlertid åpenbart gi store etiske utfordringer som er uforenelig med kravet om samtykke.

Prosjektleder viser til at utfordringene knyttet til PMTCT-programmene i stor grad henger sammen med kvinnenes sosiale miljø og at intervju av familiemedlemmer kan gi viktige bidrag til å kartlegge utfordringene. Komiteen legger vekt på dette argumentet og ser at det er vanskelig å rekruttere andre deltakere som kan gi bedre kunnskapstilfang. En ser også at informasjonen som vil framkomme fra deltakerutvalget likevel kan gi et kunnskapsbidrag.

For øvrig vil prosjektsykepleierne som skal dybdeintervjues og som kjenner familiens betydning for kvinnens valg sannsynligvis gi mer relevant informasjon om problemstillingene knyttet til kvinnens sosiale miljø.

Etter en helhetsvurdering gir komiteen klager medhold i at familiemedlemmer kan inkluderes. Komiteen setter imidlertid som vilkår at kvinnen selv må samtykke til at familien inkluderes, og at det blir sørget for tilstekkelig informasjon slik at kvinnen har forstått konsekvensene av deltakelsen.

Vedtak:

1. *Klagen tas i hovedsak til følge.*
2. *Prosjektet godkjennes på vilkår av ovennevnte merknad tas til følge.*

Komiteen ber om å få tilsendt sluttrapport evt. trykt publikasjon for studien.

Vennlig hilsen

Jon Lekven
leder

Camilla Gjerstad
førstekonsulent

Vedlegg: Sakkyndig vurdering

De regionale komiteene for medisinsk og helsefaglig forskningsetikk foretar sin forskningsetiske vurdering med hjemmel i Forskningsetikklovens § 4. Saker vedrørende forskningsbiobanker behandles i samsvar med Biobankloven. Saksbehandlingen følger Forvaltningsloven.

Komiteenes vedtak etter Forskningsetikklovens § 4 kan påklages (jfr. forvaltningsloven § 28) til Den nasjonale forskningsetiske komité for medisin og helsefag. Klagen skal sendes REK-Vest (jfr. forvaltningsloven § 32). Klagefristen er tre uker fra den dagen du mottar dette brevet (jfr. forvaltningsloven § 29).

APPENDIX VII b

UNIVERSITY OF BERGEN
Regional Committee for Medical and Health Research Ethics, Western Norway

To whom it may concern

Your ref	Our ref	Date
	192.08	22.12.08

Confirmation;

We hereby confirm that the project "Prevention of mother-to-child transmission of HIV" (PMTCT) program in Babati and Haydom, Tanzania", by Professor Astrid Blystad, Department of Public Health and Primary Health Care, University of Bergen, is reviewed and approved by the Regional Committee for Medical and Health Research Ethics, Western-Norway (Institutional Review Board).

Our approval is however conditioned upon the following:

- Traditional gifts to the participants must be of a small, symbolic character.
- All necessary information must be given to the participants (purpose of the project, the inclusion criteria, practical consequences of participation and whether or not the project is intended to benefit the participants directly).

Sincerely yours,

Jon Lekven
Chairman, REK Vest

Camilla Gjerstad
Committee secretary

APPENDIX VIII

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Bodil Bø Våga
Institutt for helsefag
Universitetet i Stavanger
Ullandhaug
4036 STAVANGER

Vår dato: 12.12.2008	Vår ref: 20209 / 2 / JE	Deres dato:	Deres ref:

TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 13.10.2008. All nødvendig informasjon om prosjektet forelå i sin helhet 10.12.2008. Meldingen gjelder prosjektet:

20209	*How to Feed an Infant: Exploring local infant feeding practices and relevant infant feeding programmes, Babati and Haydom, Tanzania*
Behandlingsansvarlig	*Universitetet i Bergen, ved institusjonens øverste leder*
Daglig ansvarlig	*Bodil Bø Våga*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/forsk stud/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/prosjektoversikt.jsp.

Personvernombudet vil ved prosjektets avslutning, 31.03.2011, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Bjørn Henrichsen	Janne Sigbjørnsen Eie Janne Sigbjørnsen Eie

Kontaktperson:Janne Sigbjørnsen Eie tlf: 55 58 31 52
Vedlegg: Prosjektvurdering

Personvernombudet for forskning

Prosjektvurdering - Kommentar

20209

Hovedgruppen av informanter vil være HIV-positive mødre og sykepleierveiledere som er tilknyttet to PMTCT programmer, ca 20 HIV-positive mødre og 20 sykepleierveiledere.

Ved rekruttering av HIV-positive mødre er det sykepleierveilederne som tar førstegangskontakt. I etterkant av veiledningssamtale vil sykepleierveilederen informere om studien og forespør den potensielle informanten om deltakelse.

For sykepleierveilederne er det prosjektleder Bodil Bø Våga som vil opprette førstegangskontakt ved å informere om studien i PMTCT-gruppen, men selve rekrutteringen er det forskingsassistenter som vil gjøre.

Det gis skriftlig og muntlig informasjon og innhentes skriftlig samtykke. Den muntlige informasjonen er identisk med den skriftlige. Muntlig informasjon gis fordi noen av de potensielle informantene ikke kan lese eller skrive. Informasjonsskrivet oversettes også til swahili.

Ombudet har ingen merknader til revidert informasjonsskriv av 10.12.2008.

Hovedmengden av informasjon skal samles inn via dybdeintervju. Ut over dette vil data også samles inn via ustrukturerte samtaler ved hjemmebesøk, oppfølgingsintervju og observasjon. Ombudet legger til grunn at alle deler av data som samles inn, også hjemmebesøk og observasjon, er basert på samtykke fra deltakerne.

Det registreres sensitive opplysninger om helseforhold, jf. personopplysningsloven § 2 punkt 8 c).

Prosjektet vil inkludere to forskningsassistenter som skal fungere som tolk i intervjusituasjonen og hjelpe til med transkribering av datamaterialet.

Prosjektet skal avsluttes 31.03.2011. Senest innen denne dato skal datamaterialet anonymiseres og lydopptak slettes. Anonymisering innebærer at direkte og indirekte personidentifiserende opplysninger slettes eller omkodes (grovkategoriseres), navneliste/koblingsnøkkel slettes.

Det er sendt søknad til Regional komité for medisinsk og helsefaglig forskningsetikk (REK) samt søkt etisk godkjenning og forskningstillatelse i Tanzania gjennom National Institute of Medical Research (NIMR) og Tanzania Comission for Science And Technology (COSTECH). Ombudet legger til grunn at alle nødvendige tillatelser innhentes og ber om at kopi av REKs godkjenning ettersendes når denne foreligger.

APPENDIX IX

Centre for International Health

University of Stavanger

INFORMATION ABOUT THE PhD-PROJECT:

‘How to feed an infant’: Exploring local infant feeding practices and relevant infant feeding programmes, Babati and Haydom, Tanzania.

Background

The present project has a general focus on local infant feeding practices in two districts of Manyara Region, Tanzania. The project will also explore experiences with infant feeding practices related to prevention of mother-to-child transmission of HIV (PMTCT) programmes and how different follow-up systems affect the mothers’ lives as well as choice and adherence to infant feeding options.

Methods

The information is to be collected through individual in depth interviews. The information about local infant feeding practices will be collected from lay people in the communities and health personnel. Nurse counsellors and women affiliated with PMTCT programmes will be interviewed about infant feeding practices related to PMTCT programmes. If the informant is willing, there will also be informal follow-up conversations at a later stage. Data will furthermore be collected from health personnel and administrative personnel at Haydom Lutheran Hospital (HLH) and Babati Regional Hospital (BRH) as well as from regional and district authorities.

Ethical considerations

Participation in the project is voluntary and the participant can withdraw from the project at any time without any consequences. The informants will remain anonymous, and any information given will be kept strictly confidential. With the informants’ permission the interview will be recorded. The recorded material will be deleted as soon as the tape has been transcribed, and all personal information will be anonymous. The principles of anonymity and confidentiality do also apply to the research assistants/interpreters of the project. The informants can also refrain from replying to questions that they do not wish to answer.

Outcome

The information gathered through this PhD study will be presented to both academic audiences, to health programmes and to policy makers with the aim of contributing to increased knowledge on local infant feeding practices, knowledge that can contribute to improved PMTCT programmes and services.

Research team

PhD-student:	Bodil Bø Våga, University of Stavanger, University of Bergen
Main supervisor:	Astrid Blystad, PhD, Professor, University of Bergen
Co-supervisors:	Sebalda Leshabari, PhD, Assistant Dean, Muhimbili University of Health and Allied Sciences Karen Marie Moland, PhD, Postdoctoral fellow/Associate Professor, Bergen University College/University of Bergen Bjørg Evjen-Olsen, MD, PhD, Haukeland University Hospital/University of Bergen

If you have any questions, please feel free to contact me.

Sincerely yours,

Bodil Bø Våga

UNIVERSITY OF BERGEN
Faculty of Medicine and Dentistry
Global health: Ethics, economics and culture

CIH Centre for International Health

University of Stavanger

MAELEZO KUHUSU SHAHADA YA UDAKTARI WA FALSAFA:

'Jinsi ya kumlisha mtoto mchanga': Kuchunguza jinsi ulishaji wa watoto wachanga unavyofanyika katika eneo husika na programu za ulishaji wa watoto wachanga zinazofaa, Babati na Haydom, Tanzania.

Utangulizi

Mradi wa sasa unachunguza kwa ujumla jinsi watoto wachanga wanavyolishwa katika eneo la wilaya mbili za mkoa wa Manyara, Tanzania. Mradi pia utachunguza uzoefu wa jinsi watoto wachanga wanavyolishwa kuhusiana na programu za kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa mtoto (PMTCT) na jinsi mifumo tofauti ya ufuatiliaji inavyoathiri maisa ya wamama pamoja na uchaguzi na kufuata njia za kulisha watoto wachanga.

Taratibu zitakazotumika

Taarifa zitakusanywa kwa njia ya usaili wa kina wa mtu mmoja mmjoja. Taarifa kuhusu jinsi watoto wachanga wanavyolishwa katika eneo zitakusanywa kutoka kwa watu wa kawaida kwenye jamii, na kutoka kwa wahudumu wa afya. Wauguzi washauri nasaha na wanawake waliopo kwenye programu za kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa mtoto watafanyiwa usaili kuhusu jinsi watoto wachanga wanavyolishwa kuhusiana na programu za kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa mtoto. Kama mtoa taarifa atapenda, kutakuwa pia na namna isiyo rasmi ya kufuatilia maongezi katika hatua za baadaye. Maelezo zaidi yatakusanywa kutoka kwa wahudumu wa afya na kwa uongozi wa hospitali ya Haydom Lutheran (HLH) na hospitali ya mkoa ya Babati (BRH) pamoja na mamlaka za mkoa na wilaya.

Uzingatiaji wa maadili

Kushiriki katika mradi ni kwa hiari na mshiriki anaweza kuondoka kwenye mradi wakati wowote bila athari. Watoa taarifa wataendelea kutojulikana kwa majina, na taarifa zozote zitakazotolewa zitatunzwa kwa usiri mkubwa. Kwa ruhusa ya watoa taarifa usaili utarekodiwa. Maelezo yatakayorekodiwa yatafutwa mara mkanda utakapobadilishwa kwenda kwenye maandishi, na maelezo yote binafsi hayatajulikana ni ya nani. Kanuni ya kutojulikana kwa jina na usiri itawahusu pia watafiti wasaidizi/wakarimani wa mradi. Watoa taarifa wanaweza pia kujizuia kujibu maswali ambayo hawataki kujibu.

Matokeo

Maelezo yatakayokusanywa kupitia utafiti huu wa shahada ya udaktari wa falsafa yatatoelewa katika mikutano ya kitaaluma, kwenye programu za afya na kwa watunga sera kwa lengo la kuongeza ujuzi kuhusu jinsi ya kulisha watoto wachanga katika maeneo husika, elimu inayoweza kuchangia kuboresha programu na huduma za kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa mtoto.

Timu ya watafiti

Mwanafunzi wa shahada ya udaktari wa falsafa:	Bodil Bø Våga, Chuo kikuu cha Stavanger/Chuo kikuu cha Bergen
Msimamizi mkuu:	Astrid Blystad, shahada ya udaktari wa falsafa, Profesa, Chuo kikuu cha Bergen
Wasimamizi wenza:	Sebalda Leshabari, shahada ya udaktari wa falsafa, Dean msaidizi, Chuo kikuu cha afya na Tiba Muhimbili Karen Marie Moland, shahada ya filosofia, Profesa mwandamizi, Chuo kikuu cha Bergen Bjørg Evjen-Olsen, Daktari, shahada ya udaktari wa falsafa, Haukeland University Hospital/Chuo kikuu cha Bergen

Kama una swali lolote, tafadhali jisikie huru kuwasiliana na mimi.

Wako mwaminifu,
Bodil Bø Våga

UNIVERSITY OF BERGEN
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Global health: Ethics, economics and culture

Centre for
International Health

University of
Stavanger

INFORMED CONSENT

INFORMED CONSENT FOR THE PhD STUDY:

‘How to feed an infant’: Exploring local infant feeding practices and relevant infant feeding programmes, Babati and Haydom, Tanzania.

I hereby confirm that I have received information about the focus and the conditions of the coming research project. I understand that I am under no obligation to participate, and that I am at liberty to withdraw from the study at any time without any consequences. I also understand that all information will remain strictly confidential. I hereby agree to participate as an informant in the project.

Name……………………………………………………………………………………

Signature or thumbprint………………………………………………………………

Date……………………………………………………………………………………

Witnessed by…………………………………………………………………………

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RIDHAA YA KUSHIRIKI

RIDHAA YA KUSHIRIKI KWENYE UTAFITI WA SHAHADA YA UDAKTARI WA FALSAFA

‘Jinsi ya kumlisha mtoto mchanga’: Kuchunguza jinsi ulishaji wa watoto wachanga unavyofanyika katika eneo husika na programu za ulishaji wa watoto wachanga zinazofaa, Babati na Haydom, Tanzania.

Hapa sasa ninathibitisha kwamba nimepata taarifa kuhusu lengo na masharti ya mradi wa utafiti huu. Ninaelewa kwamba silazimishwi kushiriki, na kwamba nina uhuru wa kujiondoa kwenye utafiti wakati wowote bila athari yoyote. Pia naelewa kwamba taarifa zote zinabaki kuwa siri kwa umakini. Hapa sasa ninakubali kushiriki kama mtoa taarifa katika mradi.

Jina………

Sahihi au alama ya kidole gumba……………………………………………………………………………………

Tarehe……

Imeshuhudiwa na………

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APPENDIX XI

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QUESTION ABOUT PARTICIPATION IN THE PhD-PROJECT:

'How to feed an infant': Exploring local infant feeding practices and relevant infant feeding programmes, Babati and Haydom, Tanzania.

Background

We hereby ask if you are willing to participate as an informant in the present project which has a focus on local infant feeding practices in two districts of Manyara Region, Tanzania. The project will explore experiences with infant feeding practices both in the general population as well as among women enrolled in prevention of mother-to-child transmission of HIV (PMTCT) programmes.

Methods

The information is to be collected through individual in depth interviews. At the interview, you as informant, the PhD-student as interviewer and an interpreter, will be present. If you are willing, there will also be informal follow-up conversations at a later stage.

Informants

The information will be collected from lay people from the communities, nurse counsellors and women affiliated with PMTCT programmes. Data will furthermore be collected from health personnel and administrative personnel at Haydom Lutheran Hospital (HLH) and Babati Regional Hospital (BRH) as well as from regional and district authorities.

Ethical considerations

Participation in the project is voluntary and you can withdraw from the project at any time without any consequences. You, as informant, will remain anonymous, and any information given will be kept strictly confidential. With your permission the interview will be recorded. The recorded material will be deleted as soon as the tape has been transcribed, and all personal information will be anonymous. The principles of anonymity and confidentiality do also apply to the research assistants/interpreters of the project. You can also refrain from replying to questions that you do not wish to answer.

Outcome

The information gathered through this PhD study will be presented to both academic audiences, to health programmes and to policy makers in order to increase knowledge on local infant feeding practices with the aim of contributing to improved PMTCT programmes and services.

Research team

PhD-student:	Bodil Bø Våga, University of Stavanger/University of Bergen
Main supervisor:	Astrid Blystad, PhD, Professor, University of Bergen
Co-supervisors:	Sebalda Leshabari, PhD, Assistant Dean, Muhimbili University of Health and Allied Sciences Karen Marie Moland, PhD, Postdoctoral fellow/Associate Professor, Bergen University College/University of Bergen Bjørg Evjen-Olsen, MD, PhD, Haukeland University Hospital/University of Bergen

If you have any questions, please feel free to contact me.

Sincerely yours,

Bodil Bø Våga

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University of Stavanger

SWALA KUHUSU KUSHIRIKI KATIKA MRADI WA SHAHADA YA UDAKTARI WA FALSAFA:

'Jinsi ya kumlisha mtoto mchanga': Kuchunguza jinsi ulishaji wa watoto wachanga unavyofanyika katika eneo husika na programu za ulishaji wa watoto wachanga zinazofaa, Babati na Haydom, Tanzania.

Utangulizi

Hapa tunataka kujua kama ungependa kushiriki kama mtoa taarifa katika mradi unaoendelea unaochunguza katika eneo husika jinsi watoto wachanga wanavyolishwa katika wilaya mbili za mkoa wa Manyara Tanzania. Mradi utachunguza uzoefu wa jinsi watoto wachanga wanavyolishwa katika jamii kwa ujumla na pia kwa wanawake walioandikishwa katika programu za kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa mtoto (PMTCT).

Taratibu zitakazotumika

Taarifa zitakusanywa kwa njia ya usaili wa kina wa mtu mmoja mmjoja. Wakati wa usaili, wewe kama mtoa taarifa, mwanafunzi wa shahada ya udaktari wa falsafa kama mwendesha usaili na mkarimani, mtakuwa pamoja. Kama utapenda, kutakuwa pia na namna isiyo rasmi ya kufuatilia maongezi katika hatua za baadaye.

Watoa taarifa

Taarifa zitakusanywa kutoka kwa watu wa kawaida kwenye jamii, kwa wauguzi washauri nasaha, na kwa wanawake waliopo kwenye programu za kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa mtoto. Maelezo zaidi zitakusanywa kutoka kwa wahudumu wa afya na kwa uongozi wa hospitali ya Haydom Lutheran (HLH) na hospitali ya mkoa ya Babati (BRH) pamoja na kutoka mamlaka za mkoa na wilaya.

Uzingatiaji wa maadili

Kushiriki katika mradi ni kwa hiari na unaweza kuondoka kwenye mradi wakati wowote bila athari yoyote. Wewe kama mtoa taarifa utendelea kutojulikana kwa jina, na taarifa zozote zilizotolewa zitatunzwa kwa usiri mkubwa. Kwa ruhusa yako usaili utarekodiwa. Maelezo yatakayorekodiwa yatafutwa mara mkanda utakapobadilishwa kwenda kwenye maandishi, na maelezo yote binafsi hayatajulikana ni ya nani. Kanuni ya kutojulikana kwa jina na usiri itawahusu pia watafiti wasaidizi/wakarimani wa mradi. Unaweza pia kujizuia kujibu maswali ambayo hutaki kujibu.

Matokeo

Maelezo yatakayokusanywa kupitia utafiti huu wa shahada ya udaktari wa falsafa yatatolewa katika mikutano ya kitaaluma, kwenye programu za afya na kwa watunga sera ili kuongeza ujuzi kuhusu jinsi ya kulisha watoto wachanga katika maeneo husika kwa lengo la kuchangia kuboresha programu na huduma za kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa mtoto.

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<u>Timu ya watafiti</u>

Mwanafunzi wa shahada ya udaktari wa falsafa:	Bodil Bø Våga, Chuo kikuu cha Stavanger/Chuo kikuu cha Bergen
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Kama una swali lolote, tafadhali jisikie huru kuwasiliana na mimi.

Wako mwaminifu,

Bodil Bø Våga

INITIAL INTERVIEW GUIDE HIV-POSITIVE WOMEN

The introduction to the PMTCT programme

- Can you please tell me about how you first got in contact with CTC?
- When you became pregnant, can you tell us about the meeting with the CTC personnel - what did they tell you?

Medical support

- When did you start ART? Before pregnancy? Or: At what time in pregnancy?
- What does your family know about your participation in the PMTCT programme?

Infant feeding counselling

- Who has been counselling you about infant feeding; a nurse, medical doctor, clinical officer?
- How many counselling sessions have you attended?
    - During what time in pregnancy/after delivery?
- What have the counsellor told you about how to feed your child?
- What was difficult about what the counsellor told you?
- Did you ask questions during the counselling?
    - Can you tell me what kind of questions you had?

How to feed your child:

- What are common infant feeding practices in your area?
- At what time do the mothers start complementary food?
- Can you tell me what you understand by ‘exclusive breastfeeding’?
- Are/were you able to feed the child the way you want?
- Are/were you able to breastfeed exclusively?
- Can you tell me about the first days of the child’s life
    - How did you start to feed your child?
- Did you experience any problems during the first 6 months of breastfeeding? What kind of problems?
- Did you have control that the baby was not given anything else than breastmilk? How?
- How do your family and relatives respond to the way you feed your child?
- Have you received questions about how you feed your child?

Weaning the child: (if the child is more than 6 months)

- Can you tell me about the days when you stopped breastfeeding?
    - How did the child react?
    - How did you solve the problem of engorged breasts?
- How did your family react?
- How did you feed your child when you stopped breastfeeding?
- From where did you get cow's milk? How much milk did you get each day?

The follow-up through PMTCT

- What kind of follow-up care have been given to you?
    - Home-visit, meetings, practical support?
- Has the follow-up care been helpful for you? How?

The PMTCT program in general

- What do you think about how HIV-positive pregnant women and HIV-positive mothers are supported at this hospital?
- What parts of the PMTCT programme have been most important to you?
    - Medication? Counselling? Transport? Food? Home visits? Meetings for people living with HIV/AIDS?

INITIAL INTERVIEW GUIDE NURSE COUNSELLORS

About the introduction to PMTCT (for nurse counsellors working in RCHS/MCH)

- Can you please tell me what happens when a pregnant woman comes to the clinic and has not yet taken an HIV-test?
    - Pre-test counselling – what is discussed?
    - Post-test counselling – what is discussed?

- How is the pregnant woman taken care of if the test is positive?
- How is the pregnant woman enrolled into the PMTCT programme?

About the introduction to PMTCT (for nurse counsellors working in CTC)

- Can you please tell me what happens when a HIV-positive pregnant woman comes to the CTC clinic for the first time after being tested at the RCHS/MCH clinic?

About medical support

- What kind of ART-regimen are the HIV-positive pregnant women offered?
- What is your impression of whether the women adhere to the ART regimen?

About infant feeding counselling

- When are the HIV-positive women counselled about infant feeding practices?

- Can you please tell me about a typical infant feeding counselling session?
    - Choice in infant feeding?
    - Breastfeeding or infant formula?

- What are your experiences about how and what the HIV-positive women feel about feeding their children?
    - Infant feeding in general
    - Infant feeding in their situation as HIV-positive

- What do you think are challenges for the HIV-positive women according to infant feeding practices?

- What are your thoughts about the national PMTCT infant feeding guidelines?

About weaning your child: (if the mother is breastfeeding)

- How is the HIV-positive woman followed through the weaning process if she is breastfeeding?
- What are your experiences of how the HIV-positive women experience the weaning process?

About the follow-up through PMTCT

- What kind of follow-up is provided for the HIV-positive women through the PMTCT programme at this hospital?

About the PMTCT program in general

- What are your experiences with the present PMTCT programme, overall, how does it work?
    - On part of the nurses and health workers at the CTC/RCHS?
    - On part of the HIV-positive women who are enrolled?