Contributing and protecting factors to moral distress
A qualitative study amongst nurses meeting patients with HIV/AIDS in primary healthcare in Swaziland

Bidragande och skyddande faktorer relaterade till moralisk stress
En kvalitativ studie bland sjuksköterskor som möter patienter med HIV/AIDS inom primärvården i Swaziland
Sammanfattning


Syfte:
Att beskriva moralisk stress bland sjuksköterskor som arbetar med personer som lever med HIV/AIDS i Swaziland.

Metod:
En kvalitativ semi-strukturerad intervjustudie genomfördes på två hälsokliniker i Swaziland. Fem sjuksköterskor intervjuades som i sitt dagliga arbete kommer i kontakt med patienter som lever med HIV/AIDS. Innehållsanalys med induktiv ansats enligt Elo och Kyngäs användes för att analysera data.

Resultat:
Resultatet delades upp i bidragande och skyddande faktorer. Bidragande faktorer var: påfrestning av tung arbetsförda och bristande resurser, maktlöshet över ens arbetssituation, skuld över att inte göra tillräckligt, förväntningar att vara den perfekta sjuksköterskan och att inte uppskattas för sitt arbete. Skyddande faktorer var: att ge gynnsam vård skänker mening samt att ha ett arbetsklimat som stöttar och uppmuntrar.

Diskussion:
Studiens resultat diskuteras utifrån ett livsvärldsperspektiv. Sjuksköterskornas upplevelse av identitet, höga förväntningar, maktlöshet samt skyddande faktorer såsom meningsskapande och stöd från kollegor diskuteras.

Nyckelord: Moralisk stress, HIV/AIDS, omvårdnad, Swaziland
Abstract

Swaziland, a country in Sub-Saharan Africa, with an HIV prevalence of 26% amongst 15-49 year olds. The nurses work conditions are heavily affected by the high prevalence of HIV/AIDS and of the increasing workload. Moral distress can have implications on the nurse’s social, physical, emotional and psychological wellbeing and can also serve as a wake-up call in morally questionable situations.

Aim:

To describe moral distress among nurses working with people living with HIV/AIDS in Swaziland.

Method:

A qualitative semi-structured interview study was carried out at two health clinics in Swaziland. Five nurses who in their daily work interact with patients living with HIV/AIDS were interviewed. Data was analysed using content analysis with an inductive approach as presented by Elo and Kyngäs.

Results:

The results were divided into two main themes of contributing and protecting factors. Contributing factors were: strain of heavy workload and shortages, powerless over ones work situation, guilt over not doing enough, expectations on being the perfect nurse and work not being recognised. Protecting factors were: providing beneficial care brings meaning and having a supportive and appreciative work environment.

Discussions:

The results of the study are reviewed in the light of the lifeworld perspective theory. Nurses’ sense of identity is discussed as well as experiences of high expectations, powerlessness and protecting factors such as meaningfulness and peer support.

Keywords: Moral distress, HIV/AIDS, nursing, Swaziland
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1 Introduction
When we got the opportunity to do a Minor Field Study we both wanted to go to a country in the Sub-Saharan Africa region. The field of HIV/AIDS is a common interest of ours and as we had contacts in Swaziland and the country is heavily burdened by HIV/AIDS we thought this was a suitable place to do our study. We did some research into the healthcare system in Swaziland, the work environment and the role of the nurse. We wanted to write about a moral or ethical aspect of nursing since this is an area thoroughly integrated into our education. Eventually we came across research on the concept of moral distress that prompted our curiosity. As we learnt more about moral distress in the Sub-Saharan region we began to wonder if the heavy burden of HIV/AIDS might affect the nurses’ experiences of moral distress.

2 Background
2.1 Swaziland and HIV/AIDS
The Kingdom of Swaziland is a small country in Sub-Saharan Africa, landlocked between South Africa and Mozambique and measuring 17,364 km². The capital Mbabane is located in the north-west of the country in the Hhohho region, one of Swaziland’s four administrative regions (National Emergency Response Council HIV/AIDS [NERCHA], 2010). The population of Swaziland is approximately 1.2 million with 40% living in severe poverty and survive on less than $1.25 a day. The majority of the population is Swazis with a Zulu minority. Only 21% of the population lives in urban settings. In Swaziland there are a few traditional African religions but the majority of the population consider themselves Christians (Landguiden Utrikespolitiska Institutet, 2012).

Swaziland is a country heavily affected by the HIV pandemic, with the highest prevalence of HIV in the world (World Health Organization [WHO], 2011). The prevalence of HIV amongst 15-49 year olds is 26% and the average life expectancy is 50 years for men and women respectively (WHO, 2013a; WHO, 2013b). As a result of AIDS and HIV, 78,000 children have been orphaned in Swaziland (United Nations Program on HIV and AIDS [UNAIDS], 2012a).

The Swaziland government declared AIDS a national disaster in 1999, and in 2001 it appointed the National Emergency Response Council HIV/AIDS (NERCHA) to come to terms with the pandemic (Kamiru, Ross, Bartholomew, McCurdy & Kline, 2009). The goal of NERCHA is to organise and coordinate the work done in the country, both on local and
national level, on the war on HIV/AIDS (NERCHA, 2014). A way to accomplish a better organised and more accessible healthcare system is to decentralize care and staff rural health clinics with nurses only, as proposed by Wright, Walley, Philip, Petros and Ford (2010). In order to enable this transition responsibilities traditionally assigned to physicians are transferred onto nurses. This will be further elaborated on when presenting the healthcare system in Swaziland.

2.2 Healthcare in Swaziland

The health care system in Swaziland consists of two different sectors; the informal sector mainly made up by traditional healers who have large credibility among the population, and the formal sector (The Government of the Kingdom of Swaziland, 2013). The formal sector operates on three levels; primary health care consisting of health clinics, outreach stations and community based healthcare workers. The secondary healthcare sector consists of the health centres with both inpatients and outpatients departments and who operate as referral points for some of the clinics. On tertiary level are the country’s eight hospitals, six of which are government hospitals and two that are mission hospitals operated by private entities (The Government of the Kingdom of Swaziland, 2014).

A large part of the population of Swaziland lives in rural areas with limited access to the main hospitals and the health centres. Local clinics and outreach sites play vital roles in the provision of health services. There are 76 clinics and 187 outreach sites in the country, which are staffed mainly by nurses and nurse assistants. In addition to the clinics and outreach sites there are approximately 4,000 home based caregivers, rural health motivators and community birth attendants working out in the communities, many on a voluntary basis (Swaziland Ministry of Health, 2014). This effort to decentralize services has brought healthcare closer to the communities making it more accessible to those living in rural areas (Bicego, et al., 2013).

Since most clinics are staffed only by nurses, due to the shortage of healthcare staff in the country, The Ministry of Health has recognised the need to equip and train nurses in providing quality care for people living with HIV/AIDS (PLHA) (Kamiru et al., 2009). The health care provided to PLHA consists of a range of different organisations and actors from the government, development and donor agencies, faith based actors, non-governmental organisations, communities and organised groups of PLHA (UNAIDS, 2012b).

In Swaziland the healthcare workforce consists of 1,911 nurses and 241 physicians (WHO, 2010). Work conditions for nurses are heavily affected by the high prevalence of HIV/AIDS.
They run a high risk of being stigmatized, being infected and dying from HIV/AIDS (Baleta, 2008; Haber, Roby & High-George, 2011). This, together with the high workload and low pay, is causing many nurses to consider leaving the country for work elsewhere or leaving the profession all together. The main reason for this is not to receive a higher salary but to obtain better working condition; working with HIV/AIDS in Swaziland is considered dangerous and the work morale is low (International Council of Nurses [ICN], 2011). The healthcare workforce in all of Sub-Saharan Africa makes up for only three percent of the global healthcare workforce, though the medical needs in this region are great. The majority of countries experiencing a critical shortage of healthcare workers are located in Sub-Saharan Africa (WHO, 2006a). Many of the countries in the region are experiencing substantial brain drain with healthcare workers leaving the country for better work opportunities elsewhere (Kamiru et al., 2009).

The ICN (2006) has done an inventory of global nursing shortages and points out that shortages are experienced differently between countries. In Swaziland there is a large discrepancy between the number of people seeking healthcare and the number of nurses available (Kamiru et al., 2009; WHO, 2011). Being short-staffed is one example of a stressful factor that can cause nurses to experience what in literature is referred to as moral distress. Studies have shown that moral distress is a threat to the field of nursing (Harrowing & Mill, 2010; Woods, 2013). The burden of HIV/AIDS weighs heavily on the healthcare resources in Swaziland and the challenging work conditions contribute to nurses considering leaving their profession. The concept of moral distress will be discussed further in the following section.

### 2.3 Moral distress among nurses

The definition of moral distress as described by philosopher Andrew Jameton in 1984 is as follows: “…moral distress arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action” (Jameton, 1984, cited in Hanna, 2004). This has been the only and widely used definition of moral distress within the nursing research community. However, Hanna (2004) and Repenshek (2009) have in recent years been re-examining Jameton’s definition and questioned its omnipresence in the field. Both Hanna (2004) and Repenshek (2009) argue that the definition is too simplistic and incomplete. They argue that the definition as established by Jameton is referring to the causes of moral distress rather than its actual definition.
Role morality, “that which nurses do to meet the goal of nursing” (Hanna, 2004), has been discussed as an important factor in determining whether a nurse will experience moral distress. The concept of role morality includes a personal set of moral values as well as a collective, professional value system. The nurse’s role morality includes being an advocate for the patient and raising their voice when morality is compromised, i.e. being the whistle-blower. When nurses fail to act according to the moral values there is a risk of nurses developing an emotional numbness to moral issues, experiencing burnout and moral distress (Hanna, 2004; Repenshek, 2009). Emotional numbness, burnout and moral distress are all factors which have been established to contribute to nurses making the decision to leave the profession (Woods, 2013; Harrowing & Mill, 2010).

Returning to the problem with Jameton’s definition of attributing the cause of moral distress only to external factors such as institutional constraints, what Hanna (2004) argues is that internal factors also contribute to whether moral distress is experienced. Steppe (1996, cited in Hanna, 2004) makes two important points about moral distress by examining the responses of nurses in the Nuremberg trials where nurses admitted to killing people and still claimed their innocence. Firstly moral distress is not caused only by external factors. The nurses’ response demonstrates how external moral constrains, i.e. killing is wrong, can be present and yet moral distress is not experienced. Secondly, morals are not only personal but a combination of personal morality and role morality. The absence of a strong role morality prevents the nurses from experiencing moral distress.

The effects of moral distress can have implications on the nurse’s social, physical, emotional and psychological wellbeing (Schluter, Winch, Holzhauser & Henderson, 2008). Social consequences can be withdrawal from family and friends and disengaging from patients as well as leaving the profession all together. The physical manifestations can be headaches, stomach troubles and tiredness whilst emotionally feelings of frustration, guilt, shame and self-blame are commonly experienced. Psychologically moral distress can lead to loss of self-worth and depression (Schluter et al., 2008; McCarthy & Deady, 2008).

Studies have shown that nurses with a higher education are more prone to suffer moral distress. The same is applicable for experience; with more professional experience comes a higher risk of suffering moral distress (Schluter et al., 2008). Peer support has been found to lessen the impact of moral distress amongst nurses. This only goes for support between nursing colleagues who work on the same level however, support from management and physicians do not have the same protective effect (Schluter et al., 2008). Repenshek (2009) discusses how moral distress and powerlessness are experienced by nurses when they feel
trapped between their own moral values and carrying out medical orders from physicians. Feeling ignored when advocating for patients' wishes and needs can result in these experiences of moral distress and powerlessness.

Shortage of support, lack of time, care which is futile and of low quality are other factors which can cause moral distress (Corley, 2002; Schluter et al., 2009). McCarthy and Deady (2008) add the feeling of personal failure, such as a lack of resolve, as a contributing factor. To promote openness amongst colleagues and encourage conversations regarding moral values and challenging work situations have shown to protect against the experience of moral distress (Schluter et al., 2009).

As much as moral distress might be a difficult experience for the nurse it plays an important role in highlighting morally questionable situations. Moral distress can be the wake-up call for the nurse to initiate change or to take a stand against something that is immoral. Nurses with a well-developed moral competence, sensitivity, commitment and autonomy are prone to take action and be courageous in a morally challenging situation. Acting on moral distress can lead to positive change within the institution, for the patient and for the nurse as it can be an opportunity for personal transformation and growth (Hanna, 2004).

Corley (2002) argues that ethical guidelines can be used as a compass in morally complex situations and where there are no such guidelines nurses are at risk of suffering moral distress. Corley’s argument that ethical guidelines are sufficient in preventing the experience of moral distress is criticised for being a quick-fix which is too simplistic for such a complex problem. Hanna (2004) and Repenshek (2009) argue there is a subjective moral component as well as an objective in the establishment of moral distress. As there is no alternative definition of moral distressed than that by Jameton (1984, cited in Hanna, 2004) this is the definition that will be used in this study, together with the concept of role morality as discussed by Hanna (2004). Thereby both the internal and the external factors are considered as contributors to moral distress.

2.4 Providing care

As discussed through this study, there are ethical codes and principles acting as guidelines for the nursing profession. According to ICN (2012) nurses are expected to advocate for the patient, foresee and prevent complications and provide support to patients and their families. Principles of respecting each person’s autonomy, doing good, doing no harm and the principle of justice aim to guide nurses in how to handle ethically challenging situations and to make
decisions (Bolmsjö, 2005). These principles often come in conflict with each other as the patients’ wishes and beliefs are not always congruent with what is best for him/her. Being faced with these tough decisions is part of nursing everywhere in the world and imposes a challenge on the nurse regardless of the resources at hand.

When it comes to providing healthcare in accordance with the ethical principles it has to be taken into account what good health implies for each and every patient (Dahlberg & Segesten, 2010). Whether the nurse is meeting a patient in Swaziland who has just been diagnosed with HIV, or a patient with a cancer diagnosis in Sweden, the responsibilities are the same; to provide healthcare that is in accordance with the patient needs. The nurse has to see the person behind the diagnosis, where the patient is at and identify the risks and resources for that particular patient in order to make a plan.

In nursing sciences the interaction between environment and health is of great importance. The environment in which nursing is provided has proven to influence how the patient perceives health and well-being (Edvardsson & Wijk, 2009). Another aspect is the nurses’ working environment which also plays an important role, both on an organisational and a personal level. When nurses are content with their working environment they are able to provide a higher quality of care (Delobelle, Rawlinson, Ntuli, Malatsi, Decock & Depoorter, 2010).

3 Problem statement
Swaziland has a high prevalence of HIV/AIDS and a limited number of nurses. The heavy workload makes the nurses vulnerable for the detrimental effects of moral distress. Moral distress in the Sub-Saharan region is a relatively unexplored field. The authors were curious as to whether the heavy burden of HIV/AIDS could affect the nurses’ experiences of moral distress. The work environment of the nurse in Swaziland and the increased workload makes it an interesting setting to do a study on moral distress. Therefore the authors decided to go to Swaziland and interview nurses on the topic.

4 Aim of the study
The aim of this study was to describe moral distress among nurses working with people living with HIV/AIDS in Swaziland.
5 Theoretical framework
The theoretical framework chosen for this study is the lifeworld perspective as presented by Dahlberg and Segesten (2010). The lifeworld perspective focuses on seeing the person as an undivided whole, body and mind in one; the physical, psychological, existential and spiritual all integrated in the body. Each and every person has a unique lifeworld made up by ones experiences, memories and emotions determining how the world is perceived and interpreted. This is true for all humans; nurses and patients alike. However, for the nurse, always meeting patients with their unique lifeworld perspective puts moral pressure on the nurse (Dahlberg & Segesten, 2010). This pressure can be seen as a possible factor contributing to moral distress if the nurse is not able to live up to the expectations experienced. Not being able to explore and adjust to the patients’ lifeworld when providing care can be seen as not meeting expectations on care, not living up to standards and thus compromising care, which are factors that contribute to moral distress.

Adopting a lifeworld perspective comes with a demand on the nurse to be open and accommodative towards the patients’ lifeworld; to understand the world as the patient experience it. In order to maintain an open attitude the nurse must have the ability to be surprised by the unexpected. To be accommodative the nurse must allow the phenomenon to emerge by itself and to approach each patient with curiosity (Dahlberg, Segesten, Nyström, Suserud & Fagerberg, 2003).

In an article by Ellis-Mill (2011) the focus on visible and measurable results in a healthcare system striving for efficiency is argued to increase the risk of losing the relational aspect of caring. As healthcare becomes more about making a profit than delivering patient-centred care the humanly sensitive aspect is easily lost. Ellis-Mills (2011) argues that the lack of compassion extracts the relational aspects from the caring and puts the nurse at risk as well as the patient. Nurses are reported to experience isolation as the relational aspect of caring is neglected. Professionalism has become synonymous with not displaying emotions or being compassionate. A gradual “hiding” of one’s emotions during training has been reported by nursing students.

The lifeworld perspective emphasises the importance of a caring relationship between the patient and the nurse where the emotional lifeworld of each party is taken into account (Dahlberg & Segesten, 2010). It can be argued that the lifeworld perspective can bring light on both contributing and protecting factors on moral distress. It is a perspective that focuses on the individual as being more than a patient or a nurse.
6 Method

6.1 Study design

This study has a qualitative design with interviews exploring nurses’ experiences of moral distress in Swaziland. Qualitative interviews were chosen as it is considered the most appropriate method in order to gain insight into the nurses’ experiences of their working situation (Danielsson, 2012).

6.2 Participants

The inclusion criteria for participating in the study were to be a registered nurse working at local clinic in Swaziland, attending to patients living with HIV/AIDS at least once a week, and to understand and speak English. Clinics were chosen over hospitals as the authors’ local contacts argued this was a setting where nurses had a regular contact with patients living with HIV/AIDS to a greater extent.

In order to gain access to the field of interest a gatekeeper is recommended when conducting qualitative research (Polit & Beck, 2010). A local contact person served as gatekeeper introducing the authors to nurses at one of the clinics. Information about the study was handed out to all nurses present during the authors’ first visit. The second clinic was chosen purposively by the authors and during an introductory visit the study was introduced to the director of the clinic who served as the gatekeeper. During a second visit to the two clinics participants were recruited using a combination of convenience and snowball sampling as the nurses present were asked if they wanted to participate. This resulted in three nurses agreeing to participate at one clinic and two nurses at the other. All participants received information about the study prior to the interview date (see Appendix 1).

All five participants worked fulltime and had contact with PLHA on a daily basis. The number of years in the profession ranged from two to 18 years, median was 12. Three of the participants were male and two female. The participants were given a small token of appreciation after the completion of the interview. In order to prevent the participants being influenced in their decisions to take part or not they were not made aware of this gift beforehand.
6.3 Data collection

Data was collected in February 2014. Interviews were conducted at the two clinics during working hours and lasted between 35-45 minutes. At one of the clinics the interviews were conducted in an office space which allowed privacy. At the other clinic the interviews were conducted in the nurses’ consultation rooms. All interviews were done in English since all participants were comfortable expressing themselves in English as it is an official language of Swaziland. A semi-structured interview guide (see Appendix 2) with open questions was used to make sure that all topics of interest were covered and to encourage the participants to talk freely about their experiences (Danielsson, 2012). The interviews were recorded using an Olympus digital voice recorder in order to capture the details of the conversation such as tone of voice and pauses. Before the recordings were started the participants were asked three introductory questions in order to make sure they met the inclusion criteria: How often do you see patients living with HIV/AIDS in your work, do you work full-time or part-time, how long have you worked as a nurse? Both authors were present during the interview, one as the interviewer and the other as assistant being in charge of the technical apparatus, keeping track of time and taking notes.

6.4 Data analysis

The recorded data was transcribed word by word to allow the authors to have manageable texts to work with during the analysis phase. The transcripts included pauses, laughs and repetitions in order to make the text as true to the original recordings as possible. Transcribing the data is the first step in the analysis process as it requires the data is being listened to several times by both authors (Danielsson, 2012).

The data was analysed using the content analysis method as described by Elo and Kyngäs (2007). The first step was to identify units of meaning in relation to the aim of the study. These units can consist of one or more sentences being representative of the greater whole where they are drawn from. Each unit of meaning was then condensed into smaller units where the essence of what was going on in each unit was derived. Throughout this process the aim of study was always guiding the authors. This part of the analysis is referred to by Elo and Kyngäs (2007) as the preparation phase.

In the following organising phase the authors familiarised themselves even more with their data and started the actual coding. An open coding based on an inductive approach was used
to let the data speak for itself (Elo & Kyngäs, 2007). An outline of the analysis process can be seen in Appendix 3.

Through the analysis seven sub-themes were identified and these were sorted into two main-themes; five factors contributing to and two factors protecting from moral distress among nurses.

7 Research ethical considerations
When conducting qualitative interviews it is important to keep in mind the intimate nature of the research method. This study was approved by the Research Ethical Committee at Department of Healthcare Sciences, Ersta Sköndal University College in Stockholm, Sweden (Dnr 1403/A). Before starting each interview the consent letter (see Appendix 1) was read through together in order to ensure that the participant was fully aware of the nature of the study, that participation was voluntary, that the confidentiality would be ensured and that they could withdraw from the study at any time. A written consent to record the interview was obtained from each participant. Participants remained anonymous throughout the interview process and the transcribed interviews were coded to ensure confidentiality.

The local gatekeeper reviewed the topic of the study and the questions in the interview guide in order to ensure questions and formulations, which might be construed as culturally inappropriate or offensive, were eliminated. As it is always a risk when conducting interviews the benefits of the study must be guaranteed to outweigh the risks in order for the study to be justified (Danielsson, 2012).

8 Results
The results of the study are presented in two main themes which are represented by numerous sub-themes (see Table 1). The sub-themes will be discussed below and exemplified with quotes from the participants.
Table 1.

<table>
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<th>Main theme</th>
<th>Sub-themes</th>
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<tr>
<td>Factors contributing to moral distress</td>
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<td>Factors protecting against moral distress</td>
<td>• Providing beneficial care brings meaning</td>
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<td>• Supportive and appreciative work environment</td>
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8.1 Contributing factors

Five sub-themes emerged during the analysis process having to do with factors contributing to the experience of moral distress among nurses. They will each be discussed thoroughly in the following section.

8.1.1 Strain of heavy workload and shortages

Throughout the interviews lack of resources and an overwhelming workload came up as a challenging factor. The participants expressed that their work description has continuously become wider, and they have to do tasks outside of their work description: “our job descriptions have become very wide, yes. We have started doing things for lab technicians, even for doctors. Not forgetting the documentation...*laughter*...it’s clerical work”.

As the clinics in most cases are staffed only by nurses all responsibilities land on them, and as there are only eight hospitals in the country the local clinics have to offer a very wide variety of services:

Cause we are doing a lot of things...we are putting implants [contraceptive implants], family planning, the implants, whereas those who are supposed to be done by that house [clinic] and that, in our settings we find that doctors are only in the bigger hospitals. In the clinics there are no doctors.

The fact that medication and supplies often run out or are out of stock is a stressing factor: “The problem is with the blood test, yeah. That is a very big problem, which hinders our job. Because at times we find that the reagents for testing the blood samples are out of stock, at the national bank.”

The nurses also expressed that their limited time is taken up by other things than providing care and that they feel stressed because of this: “we ended up having this burn-out because of the work we’re doing, it’s becoming too much documentation than the health aspect, yes,
provision of the health aspect, yes”. Having too many clients makes the work stressful and problematic as the nurses feel obligated to attend to each individual client fully even if the queue is getting longer and the patients are getting more restless:

> You have to. The problem is that the clients, the other clients who are in the queue, they become restless, that becomes that shouting ‘ah, you are taking too long, why why why’. That’s the problem. But, che, as a health worker...you have to attend to that client fully.

The nurses have a heavy workload and therefore they get tired. “But, the things that pan out is the workload. Because when you are tired really, you are, you easily get angry”. This can be seen a stressing factor, as the nurses come to work every day knowing the overwhelming challenges they are about to face. The implications of the shortages and the heavy workload are that nurses no longer enjoy their work and consider leaving the profession all together:

> At times I used to like to be a nurse, *laughing*. Now...the workload, it’s too much. Yeah, too much workload. It decreases the, the appetite to work, the joy. If they can say there is another job where I can work, I can quit this one *Laughing* I can quit this one, this challenging.

### 8.1.2 Powerless over ones work situation

This sub-theme includes feelings of powerlessness and helplessness when caring for patients. Nurses expressed they feel powerless when they were not able to help patients who eventually die. This was related to factors outside of their control weighing heavy on them. The nurses expressed a feeling of powerlessness when working with PLHA. For many patients, being diagnosed with HIV is still largely viewed as receiving the death sentence. “Even if you can try to explain, but you know that even if that client can understand, but it doesn’t take away the fact that he’s sick and might lose his or her life”. Telling patients who had come for testing that they are HIV positive was described as a challenge, and handling the fact that many patients are going to die is difficult and can be emotionally draining:

> So when you call this person, you test this person and become HIV+, then what? Then you feel like helpless as a health worker to say: you are positive. And then it will be like saying to this person: then you go home and die.

Having to tell patients that they cannot get the necessary treatment was described as a difficult and stressful event for the nurses. The nurses described the difficulty of facing patients who are struggling economically and facing stigma, discrimination and sorrow.

> Ok, we find that at times there is no medication for the clients, when a nurse, as a nurse you have to explain to the clients. ‘Oh, sorry your BP is high, your blood pressure is high but I don’t have the anti-hypertensive medicine you see’ ( ...) What does that mean? ‘Go and buy
at the pharmacy’. Yet, the Gogo, the old people, they don’t even have the money, you see, to go and buy.

8.1.3 Guilt over not doing enough
This sub-theme includes the nurses’ feelings of guilt and self-blame for shortcomings in the care provided. They explained that they were disappointed in themselves, that the best they could give was not enough and that they were failing their patients.

Nurses talked about the stress and guilt they felt when they could not meet the patients’ needs and they let patients down who had put their trust in them. “At some point in time some [patients] feel like: let me not go back to that facility because they don’t have medication or they don’t have bandages or something”. They talked about the pain of losing the patients’ trust because they could not give a complete care: “when there’s something you didn’t do right, when you were...maybe you can’t do something, ‘cause you were able to do something better, you can’t because of certain reason, so you feel guilty”.

Many of their patients come to the clinic with very complex needs (social, economical, medical and psychological) and the nurses expressed that they felt they did not have the personal resources to handle the situation. “Clients come with a lot of problems, some of their problems you cannot help, with the skill and the knowledge you have, you have maybe to go for...for...a speciality to help that one, yeah it’s a problem.”

The nurses also voiced feelings of working hard for nothing and that their efforts were futile:

you felt like, even though I think I’m trying but it’s like I’m not doing my best. So in a way we are always feeling we are not doing enough, so in that way it brought to us some burden.

8.1.4 Expected to be the perfect nurse
This sub-theme reflects the nurses’ experiences of having to live up to external expectations expressed by the community. The nurses expressed that there are high expectations on them to perform and behave. They have to be efficient and productive at all times and there is little understanding for when they make a mistake. The nurses are not allowed to have a bad day at work; they are expected to commit to their profession. “To be a nurse really is a challenging situation, for every day you have to be productive, you have to give best quality, and the expectations are so high from you as a nurse”.

When sharing their thoughts about and experiences of expectations the nurses mainly used the words “have to” to emphasise that the expectations are very much present and a stress factor in their profession.
We work in communities, so people in communities they look up to you as a nurse, so, as a nurse then you have to act accordingly, yes. So myself I always try, I always apply myself, ‘cause I always treat people with respect, ‘cause I know that people they look up to me, I always try to be a role model.

Nurses described how they are experiencing expectations on availability at all times. Their community knows them by their profession and are expecting them to be available whenever need be:

At some point in time when I was very much exhaustive and when I was taking the last patient, I thought I was taking the last patient...and wanted to go home to rest, then she started crying. And I was like ‘oh my goodness that is counselling’. So it might take a very long time. So I had to get up again and then ‘why are you crying?’ And then you start all over again (... ) putting yourself into the position of being available all the time...

The nurses described that in order to be a nurse they had to compromise on who they are and their feelings. Even outside of the profession they felt they had to modify their behaviour to fit with the values and expectations of the profession. The profession always had to come first. “It’s not a problem of if I’m happy or I am not happy, because sometimes…it’s not, I don’t control it, it’s just the people around. And it puts you in, it gives you in certain pressure, you have to.” There were many things they felt they could not do as nurses, things that were strongly viewed by the communities as not compatible with the conduct of a nurse:

They don’t expect a nurse to smoke in public, they don’t expect a nurse to be drinking alcohol, they don’t expect a nurse to be changing girlfriends, sleeping there and there, you see yeah, those are not good...those are not good...good, these things are not good conduct to be a nurse.

Nurses described situations when they had experienced loss of a loved one and were still expected to come in to work. They were expected to put feelings aside and be productive at work. Being vulnerable and expressing human emotions were not seen as combinable with the nursing profession.

Even if you yourself you have lost someone, or you are also infected or affected. Cause the problem is, we as nurses, even if we are also infected, yes. So that’s the other challenge ‘cause we also get sick, yes, and we are supposed to be at work.

There was a sense that the nurses felt the need to be flawless, super-humans:

Only that maybe we are human sometimes we fail somehow, even though we try to do something good along the way, as human, we fail, (... ) something that is we will regret for the rest of our lives.
One nurse gave an example of a situation when personal instincts were contradicting with the professional expectations. The nurse came on the scene of an accident and didn’t feel comfortable stepping in as a leader of the emergency care, although that was expected from her:

So...if I come in a scene where the people know who am I, professionally, then they expect me to be the leading person to say: hey guys, come let’s do this. And personally I feel like I should be going away. So I feel, yeah the profession is affecting who I am when it comes to issues of my personality ( ...) But at the same time my personality is like: no this one I don’t have to be there or I don’t have to do, and then I have that kind of conflict...within myself, do I run or do I attend?

8.1.5 Work not being recognised and valued

Throughout the interviews the nurses expressed a frustration and sadness over the fact that their work was not valued and they lacked appreciation and recognition for their hard work.

Nobody say thank you or nobody say, pats you on the back, ‘Ah, nurses you are doing a good job, continue’. They are always *making noise by cliquing fingers*: ‘You are not doing good, you are not doing’...yet we try our best.

There was also a disappointment in lack of appreciation from the government: “How I wish our government can...know the power to say thank you.”

The nurses expressed that it is common with patients who do not understand the severity of their condition or who do not want to accept their HIV-status. Many nurses described this as frustrating as they have to work hard to get the patient to fully commit to treatment, and sometimes to no avail.

But at times you find that they don’t keep their appointments, and some are not adhering to the treatment per se, so then you come to wonder what could be the cause, ‘cause this person is knowledgeable about the subject so why is he not or, taking adhering to the rules.

The nurses go to great lengths to educate the patients and to make sure they have all the information needed for the treatment to be successful, yet the patients come back in a worse state and this is both sad and frustrating for the nurses:

And then another challenge would be that much as a nurse put more effort to, to lay that person’s uncertainties aside as far as stigma is concerned...when the person is not complying. Then you give a 10 days: okay come back then, but the person will not come, but then it becomes traumatizing, because...you know eventually this person will be going downwards.
Nurses expressed a frustration over patients not valuing their life. Having to trace patients and convince them of the importance of treatment was a burden for the nurses who had to take responsibility for the patients’ life: “Yeah, it’s hard work...because now you have to beg people for their lives, you see? *Laughing* you have to beg them for their lives”.

Regarding the lack of recognition from funders and supervisors there was a general sense of not being listened to. When nurses received feedback it was more for their failings than for their successes. One example given was when a representative from the government came to inspect the clinic and pointing out their shortcomings rather than their achievements: “You have seen 12 people have come for...antenatal care. So what about the others? Why didn’t you take blood?’ You see? Those comments, they are de-motivating.” This lack of recognition leaves the nurses feeling overlooked and sad:

Respondent: ( ... ) nobody recognises...the job that we do. Hmm.
Interviewer: And how does that make you feel?
Respondent: Bad. *Laughing* it makes us feel bad, it makes me feel bad. Even the people, which are the higher, people, yebo, which are from the government, they don’t see.

Nurses also expressed a general lack of support and a sense of not being looked after by management: “Nobody takes care of the carer. Yes”.

There was also the matter of low salaries, the nurses felt that they were not being paid in accordance with the effort they put into their work: “And we...the work that we do as nurses is just too much and we are being paid...little, you see? The money doesn’t *Laughing* compensate, it is not equal to the work that we do.”

8.2 Protecting factors

Two sub-themes emerged during the analysis process representing a more positive side of the nurses’ work situation, namely how nurses handle the situations they face in their everyday work and what makes work meaningful to them. It has to do with both choosing to focus on the things that are being done for the patients as well as creating a supportive work environment. Taking pride in ones work and the ideals that the profession represents are also important protecting factors.

8.2.1 Providing beneficial care brings meaning

This sub-theme consists of things making the hard work worthwhile for the nurses. The situation with HIV/AIDS has changed over time with the increased availability of treatment. People are not dying of AIDS to the same extent and nurses nowadays see their patients
improve and live healthy lives. Being able to provide treatment that is effective and seeing that some patients recover brings meaning to their work.

In that way it’s even our success ( ... ) what keep us going each day, to say no, the help we do, the help we are giving to our clients, it’s very sufficient, it’s very effective and quite useful. If we are seeing our clients getting well and they are going back to work...

Furthermore the nurses describe the good feeling and the joy they experience as a result of helping patients: “Yeah, you have a good feeling that at least I have managed to make somebody comfortable, make somebody happy, ( ... ) probably this person would have died a long time ago but she’s still here with the family”. They also expressed feeling honoured when patients thank them for saving their life:

‘If it wasn’t for so and so...I don’t think I would have been alive’. So in that way, as an individual and as an institution you feel very honoured to be seeing people who are well and who were sick, who could have died.

To receive appreciation for ones efforts was presented by the nurses as rewarding and motivating. Whilst a lack of recognition for ones work can be seen as a contributing factor, choosing to focus on the acts of appreciation from patients could have a protective effect. Having somebody thank you for caring for them and reinstalling their hope were examples of things that gave the nurses the energy to carry on: “If people they talk good about you then you are more and more motivated to do good to other people, yes”.

Many nurses explained their choice of profession as a calling from God, reserved only for a few chosen ones. Being a nurse was regarded as a fine and highly sought after profession and nurses hold credibility in the society. The nurses described their profession as being integrated with their identity; they saw themselves as nurses even when they were out of uniform and it was something they were proud of.

I’m happy about it, I’m not ashamed about it, I just go with my chest out, knowing that I’m a nurse, it’s not a stigma, it’s not something that I’m ashamed about it. No I’m just a nurse, even at home, they know I’m a nurse, yeah, I’m not ashamed of that ( ... ) I really, really I am a nurse.

From the interviews it became clear that the profession of nursing is viewed as a calling in Swaziland. The nursing profession chose them rather than it being an active choice: “we have got a SiSwati saying which says: some people are, they did not choose their job but the job chose them”.

8.2.2 Supportive and appreciative work environment

This sub-theme reflects the importance of a supportive and accepting atmosphere at work. The nurses emphasised the significance of knowing you have support from colleagues and talked about teamwork as an important factor to help with work challenges. They expressed that it’s important “to know that you are associated, you are surrounded by people who care for you, people who you can report to when you have some problems, is encouraging, it lifts the spirit”.

Nurses expressed the importance of being able to discuss work issues with colleagues. They explained that having debriefing sessions helped them come up with solutions to difficult cases and issues. They talked about the value of being able to ask for advice from colleagues and to utilise each other’s competences.

You come, you say ‘oh, what’s the problem?’ We try to come together as a team, yeah, we do report those incidents, yeah. We come together and we solve them. When there is something that I don’t understand I talk to my colleagues ‘I don’t understand this, how can I do it?’

Being able to share your experiences with your colleagues when faced with a complex case lessens the burden of work. The nurses also emphasised how valuable it was to have support from ones supervisors:

To have good supervisors, people whom you can rely on when you have some problem, when you talk to them, you know they are going to listen to you, when you need an off-day because there is something pressing you, they are going to release you, they will not have any problem. That’s encouraging, yeah.

Furthermore the nursing profession was viewed, both by the nurses themselves and in the public eye, as an important one as it represents good ideals. The community values what the nurses do, and the nurses themselves talked about all the services they deliver as very important: “I think…they know, even those who are our supervisors they know that we are doing a good job, I think we will continue doing a good job, helping the people of XX and surrounding areas.”

9 Discussion

The purpose of this study was to describe moral distress amongst nurses working with people living with HIV/AIDS in Swaziland. The method used in this study and the result findings will be discussed in relation to the theoretical framework.
9.1 Discussion of method

In this section the method of data collection and analysis used in this study will be discussed. This will be done in three steps starting with a discussion of how the selection of participants was done after which the interview process will be discussed. To finish off a reflection of the analysing process will be made.

In the selection process an introductory visit to the clinics was made to present the purpose of the study and the request to participate. This was followed up with a second visit where the nurses on duty were asked to participate. A strength of this course of action was that the clinics and nurses were given time to consider the opportunity to take part. It can however be questioned as to how voluntary the participation in the study was considering that all nurses present on the day of the interviews agreed to participate making them vulnerable to peer pressure (Polit & Beck, 2010).

The method used for this study was qualitative semi-structured interviews. The method proved to be appropriate for the aim which was to describe the individual experiences of the participants. The use of a semi-structured interview guide opened up for the participants to talk freely which they did. A possible limitation of the interview guide is that there were no questions asking about experiences of guilt and powerlessness, factors which are related to moral distress. To formulate such a question however, without prompting a yes or no answer would have been difficult. During the interviews it was noted that questions regarding the nurses personal experience were answered from a “we-perspective” rather than a “me-perspective”. This made it difficult for the interviewers to explore the nurses’ personal opinions and gain access to their lifeworld. The benefits of doing a test interview in order to explore the applicability of the interview guide were discussed with our local contact person. This was decided against, as the tendency to answer questions from a “we-perspective” was attributed to cultural differences. There is a strong culture of consensus in Swaziland which influences how people express their opinions.

A challenge to confidentiality was that colleagues of the participants’ interrupted to ask work related questions at several occasion during the interviews. After these brief interruptions the interviews continued however, there was an element of having to get back on track which was distractive and can be argued to have influenced the confidentiality of the interviews.

When it comes to data analysis it is vital for the researcher to be well acquainted with the data (Elo & Kyngäs, 2007). Through the process of having to modify the method of analysis
several times we got to know our data very well. Even though this resulted in having to expand the time schedule and not meeting set deadlines it did result in a deeper knowledge of the data set.

When performing qualitative interviews the interviewer needs to be aware of preconceived perceptions. The interviewer must be able to put these aside during the interviews in order to absorb all that is being said and to enable a true understanding of the interviewees narratives (Polit & Beck, 2010). An example of this was our preconceived perception of the impact HIV/AIDS would have had on the health system in Swaziland and the nurses working there. During the interview process we came to realize that the impact of HIV/AIDS looked differently than what we had initially thought. Having put aside our preconceptions during the interview process increases the trustworthiness of this study’s results. To ensure reliability of the results the authors went back to the raw data to reanalyse the material on several occasions (Elo & Kyngäs, 2007). Codes and categories were reworked in order to ensure the interpretation of the data was a true reflection of the raw material.

Only a few studies have been done on moral distress in non-western settings and the definition of moral distress is based on research done in westernised countries. This could be a weakness to this study as the definition and the results of many of the earlier studies might not be culturally applicable.

9.2 Discussion of results

The nurses in the study described how they have integrated the professional role into their identity. This was not expressed as problematic but rather as a natural process and something that was expected from them as a nurse. In a study performed by Harrowing and Mill (2010) Ugandan nurses expressed satisfaction in helping their neighbours in their spare time who were in need of medical assistance. The nurses appeared to have no clear boundary between personal and professional. Our study shows similar results with the difference that the nurses did not describe helping their neighbours as satisfactory per se, but rather accepted this as something which was expected from them. This brings up the question as to whether one can step out of one’s nursing uniform and leave the professional identity at work and vice versa. Hanna (2004) discusses separating personal and professional roles in her concept of role morality and poses the question if this is actually possible. Through a lifeworld perspective the process of integrating personal and professional self can be problematic (Ellis-Mill, 2011).
When nurses are expected to always be professional and are never allowed to step out of the uniform, emotions might be suppressed and personal self compromised.

Several nurses in the study talked about the profession choosing them as opposed to it being an active choice. They described that the nursing profession for them was a calling in which they took great pride, rather than just being an occupation. This is confirmed by the results found in Harrowing and Mill’s study in Uganda (2010) where nurses described the profession as a mission from God. In Sweden the general view of the nursing profession has transgressed from a noble calling to a professional choice and talking about the nursing profession as a calling is considered rather old fashioned. In the 19th century, the nursing profession in Sweden prioritised true religious conviction, humility and self-sacrifice over skill and the nurse was expected to serve with no thought of receiving gratitude or pay (Andersson, 2002). The transgression in Sweden from the noble calling to a profit driven healthcare might result in losing the lifeworld perspective. When the focus of healthcare shifts from compassion to profit there is a risk the valued relationship between nurse and patient is lost (Ellis-Mill, 2011).

An interesting point brought up by Hanna (2004) is that most of the research done on the topic of moral distress is from a western setting, on female Caucasian participants. Only a small number of studies have been done in an African setting (Harrowing & Mill, 2010). This raises the question as to whether the results from the western studies are applicable to other cultural settings. There are also cultural aspects of what is considered morally right and wrong which have to be taken into consideration (Hanna, 2004). During the data collection phase in Swaziland we became aware of a culture of consensus which coloured the responses of the participants. When asked a question participants generally referred to “us” rather than “I”.

The positive effect of peer support on the experience of moral distress, as was found in previous research also became evident in the results of this study. Participants described how having an allowing work climate helped them handle challenging situations and contributed to a positive work atmosphere. Seen in the light of the lifeworld perspective this emphasises the importance of acknowledging the nurses’ lifeworld as well as the patient’s (Dahlberg & Segesten, 2010).

In previous studies it has been found that peer support is only a successful protective factor between nursing colleagues who work on the same level whilst work relationship between nurses and physicians can increase the risk of experiencing moral distress (Schluter et al., 2008). However, many of the rural clinics in Swaziland are staffed by nurses only, thus making it a favourable environment which might protect them from moral distress.
The decentralization process of healthcare in Swaziland intends to train and empower nurses to perform tasks which traditionally have been the responsibility of the physician (Wright et al., 2010). This is a strategy to make sure rural clinics are not dependable on physicians being present. However, this puts a lot of pressure on the nurses as their job description becomes very wide, something the nurses in our study confirms as it adds on to their already heavy workload. The added strain takes away the joy of working and contributes to nurses considering leaving the profession. This result is important as it shows the implications this strategy has on the nurses. The increased workload is, as presented in this study, an important risk factor for moral distress. According to Wright et al. (2010) and Schluter et al. (2008) a heavy workload, feelings of powerlessness and moral distress are all risk factors for burnout. With this insight one might argue that Swaziland is vulnerable to brain drain.

Nurses in this study expressed a strong sense of helplessness and powerlessness when they could not provide the quality of care they wanted to. These feelings were connected to situations where the nurse had little control, for example the financial situation of the patients, the lack of supplies and other resources. Having to repeatedly compromise care and feeling like ones efforts are futile have been argued by Repenshek (2009) as leading to moral distress. Not being able to care for the patient from a lifeworld perspective can be experienced as disheartening for the nurse as he/ she is not seeing the patient as a whole (Dahlberg & Segesten, 2010).

Nurses are expected to advocate for the wellbeing of the patient and be respectful of the lifeworld of the patient. The results of this study show that the nurses have high internal expectations and experience high expectations from society. The nurses expressed that these expectations limited their expression of themselves. They had to modify themselves to fit into the perceived image of the perfect nurse. From a lifeworld perspective this might be problematic as there is a risk of them compromising their own lifeworld (Dahlberg & Segesten, 2010).

10 Further research

The result of this study suggests a need for further research into the protecting factors of moral distress and the role of a supportive environment in decreasing its effects on nurses. Research show that peer support is important as a preventing factor whilst management support does not have any such effects. It would be of benefit for managers to increase their understanding of how their support can be adapted to lessen the burden for the nurses.
It would be interesting to look into what the integration of the professional self and private self does with one’s identity and what happens with the sense of identity if you can no longer remain in the profession, in the context of heavy workload and burnout.

11 Clinical implication
The strategy of decentralization of health services, which has been adopted and implemented in Swaziland by the Ministry of Health together with NGO’s, has resulted in an increased workload for nurses and an extensive job description. The results of this study suggest a need to re-examine the decentralization strategy for the benefit of the nurses and the quality of the health care services. In order to prevent burnout and brain drain, the outsourcing of responsibilities from physicians to nurses needs to be done in a responsible way proportionate to the number of nurses at each and every health clinic.

12 Conclusion
The aim of this study was to describe moral distress among nurses working with people living with HIV/AIDS in Swaziland. The results show that factors such as heavy workload, futile efforts and not meeting expectations, identified in literature as contributing to moral distress, were found among nurses in Swaziland. The nurses in this study had developed strategies to handle the challenges at work which seems to protect them from experiencing moral distress. These strategies included finding meaning and taking pride in the profession together with a supportive work environment. We suggest further research into the possible implications of an immersed personal and professional self, what this does to ones sense of identity.

13 References


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Appendix 1, Letter of Consent

Participation enquiry for care staff

This study aims to describe moral distress amongst care staff working with people living with HIV/AIDS in Swaziland. The purpose is to gain more knowledge about the working situation for care staff.

This letter contains information for you who considers taking part in the interview.

If you want to be part of this study you will be interviewed and your answers will be recorded. The interview will take place close to your work and take approximately 45 minutes. During the interview you will be asked questions about your daily work.

Your participation is anonymous and your answers will not be shared with anyone but us conducting the interview. The recorded interviews will be transcribed and both recordings and paper copies kept in a secure manner in order to ensure confidentiality. Your name will not be recorded or kept together with your answers.

It is important to us that you know your participation is voluntary. If you at any time change your mind about taking part in this study you can withdraw without having to give a reason as to why. Before starting the interview we will ask for your consent to take part in the study.

This study has been approved by the Research Ethical Committee at Department of Health and Care Sciences, Ersta Sköndal University College in Stockholm, Sweden 2014, Dnr 1403/A.

The finished thesis will be presented at Ersta Sköndal University College to fellow students and lecturers. Should you be interested in the result we are happy to share the finished thesis with you. Should you have any questions you are welcome to contact us at any time.

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Appendix 2, Interview guide

Introductory questions
How often do you see patients living with HIV/AIDS in your work?
Do you work full-time or part-time?
How long have you worked as a nurse?

Interview questions
1. Could you please tell us about what you do on a typical day at work?
2. Could you tell us about any challenges in your work?
3. Do you experience any expectations in your work? How?
4. How does your work affect how you see yourself?
5. Could you tell us about something that is important to you in your work?
6. Would you mind sharing an experience where you had to make a difficult decision as a nurse?
7. How do you describe your work to others?
## Main themes

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<th>Coded unit</th>
<th>Condensed units of meaning</th>
<th>Unit of meaning</th>
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<td>Strain of heavy workload and shortages</td>
<td>Workload decreases joy of working</td>
<td>Increased workload decreases appetite and joy of working</td>
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<tr>
<td>Powerless over ones work situation</td>
<td>We try our best and yet we fail</td>
<td>We are humans and sometimes we fail even though we try to do good</td>
<td>Only that maybe we are human sometimes we fail somehow, even though we try to do something good __ along the way, as human, we fail, but…it has not to be always, and this must not be something that is we will regret for the rest of our lives.</td>
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<td>Guilt over not doing enough</td>
<td>Feeling guilty when you cannot do what’s right</td>
<td>In such cases when you cannot do what’s right because of some reason you feel guilty</td>
<td>when I have…such cases you don’t feel, you feel guilt, when there’s something you didn’t do right, when you were…maybe you can’t do something, cause you were able to do something better, you can’t because of certain reason, so you feel guilty, yeah…you feel guilt</td>
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<tr>
<td>Expectations on being the perfect nurse</td>
<td>Expectations to be professional</td>
<td>We are always expected to be professional, it’s a challenge</td>
<td>So we are always challenged, and we are always expectant, to be professional...in every way</td>
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<td>Work not being recognised</td>
<td>No recognition for hard work</td>
<td>Nobody says thank you for the work we do</td>
<td>But nobody says ‘thank you’, just a simple thank you. <em>Laughing</em>. Not even giving you a pen or a glass or what, a present. Just thank you. There is no thank you.</td>
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<td><strong>Factors protecting against moral distress</strong></td>
<td>Providing beneficial care brings meaning</td>
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<td>Supportive and appreciative work environment</td>
<td>Importance of teamwork</td>
<td>Being surrounded by encouraging, caring colleagues whom you can talk to motivates you and lifts your working spirit</td>
<td>And also the…good working relationships in the clinic, it also motivates, to know that you are associated, you are surrounded by people who care for you, people who you can report to when you have some problems, is encouraging, it lifts the spirit, your working spirit, yeah.</td>
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