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African Communality Contributing to the Dignity of the Terminally Ill. : Ujamaa in the Hospice and Palliative Care Program in Tanzania.

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African communality contributing to the dignity of the terminally ill – traditional and political Ujamaa in the Selian Hospice and Palliative Care Program in Tanzania

Tanzania's first president Julius Nyerere's Ujamaa (living together or living as one family) still extends its influence on Tanzanians' understanding of communality. The era of Ujamaa socialism as a political system is now history, but some of its heritage still seems to influence how people in Tanzania regard family as well as community and how they act within their community. In this article I differentiate between Nyerere's political Ujamaa and the traditional Tanzanian communality which was the model for Nyerere's political program. I thus argue, that the Selian palliative care program could be seen as a present-day example of how Ujamaa - both in political and traditional forms - still influences communal life in Tanzania. The results of this study reveal that the Selian Hospice and Palliative care Program uses dimensions of both traditional and political Ujamaa in order to protect the dignity of the dying patients. This is done subconsciously and eclectically. The term Ujamaa was not explicitly used in the data of this study. The Program seems to stress communality and social responsibility in general while clearly utilizing the values of both traditional and political Ujamaa all through its practices.

Key words: Ujamaa, Tanzania, palliative care, communality

Ujamaa ideology influences the values in Tanzania

This research journey began already in the year 2000 when I was teaching at Makumira University College in Tanzania. During morning tea breaks in the faculty lounge, I used to converse with one of my part-time colleagues, Dr Gabriel Kimirei. In addition to teaching at the college, this active retired theologian was involved in a newly founded palliative care program, which had to be organized, he explained, to address the lack of communal care for the vast number of dying AIDS patients in the Arusha region in northern Tanzania. I continued to teach for five more years at the college, and at the same time I followed how a small program with only a few active volunteers could grow to serve thousands of patients across the region.

I revisited Tanzania in 2009 and 2012, during which time I collected the data for this article with my friend Kimirei. I have previously published results from the perspectives of contextual

counselling, religious diversity and gender,¹ but only while analysing the aspect of communality within the Selian Hospice and Palliative Care Program did I come to understand that it is actually the link between these three previously examined aspects. Additionally, I noticed that it was not just a question of any kind of communality, but rather that the discourse used in the Selian program was connected with Nyerere's concept of Ujamaa (living together or living as one family). This model, introduced by Tanzania's first president Julius Nyerere, still extends its influence on Tanzanians' understanding of communality.² The era of Ujamaa socialism as a political system is now history, but its heritage still affects how people in Tanzania regard family, as well as community, and how they act within their community, especially with regard to communal values. During the era of the AIDS pandemic, families and neighbourhood care proved not to be enough. Instead, more formally organized palliative care volunteers were needed, such as those working for the Selian program studied here.

In this article, I differentiate between Nyerere's Ujamaa and the traditional Tanzanian communality which served as the model for the president's political program. When analysing the former, more organized form of Ujamaa, I refer to it as 'political Ujamaa', and when analysing the local communality aspect of Ujamaa I call it 'traditional Ujamaa'. I argue that the Selian Hospice and Palliative Care Program can be seen as a present-day example of how Ujamaa – in both its political and traditional forms – still influences communal life in Tanzania. Ujamaa ideology continues to have importance in present-day Tanzania, especially in the official political discourses of peace and unity of the ruling party Chama cha Mapinduzi (CCM), which Nyerere formed already in the 1960s. This political discourse can be seen in terms of national identification, values and social practices.³

Political Ujamaa emphasized the following: ethnic and gender equality, the equality of all faiths, and indigenous African practices. The history of Tanzania during the time of

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¹ See AUTHOR, 'Contextual Pastoral Counselling among the Terminally Ill AIDS Patients in Tanzania', *Journal of Pastoral Theology*, 22/1 (2012), 1–14; AUTHOR, 'Religious Diversity in Praxis: Muslim Volunteers in a Christian Palliative Care Programme', *Mission Studies*, 31/2 (2014), 171–190; AUTHOR, 'Transforming Masculinities: Male Care Volunteers in Tanzania', *Religion and Development – Nordic Perspectives on Involvement in Africa*, ed. T. Sundnes Drønen. Peter Lang Series of Religion and Society in Africa, 145–159. New York: Peter Lang 2014.

² Maia Green, 'After Ujamaa? Cultures of Governance and the Representation of Power in Tanzania', *Social Analysis*, 54/1 (2010), 15–34.

³ Marie-Aude Fouère, 'Julius Nyerere, Ujamaa and Political Morality in Contemporary Tanzania', *African Studies Review*, 57/1 (2014), 1–24; Hans Olsson, *The Politics of Interfaith Institutions in Contemporary Tanzania*, Uppsala: Swedish Science Press 2011.

independence, however, was unique in its approach towards religious diversity and its search for harmony. Nyerere's ideologies for the Tanzanian nation dictated that religions belong to the private sphere and, following this idea, to this day the official census does not include religious affiliation.⁴ During the Ujamaa period in the 1970s and the 1980s, national identity was strengthened by promoting Swahili as the national language, as well as by the construction of so-called Ujamaa villages, where people from various religious and ethnic backgrounds were resettled. According to general government discourse, Christians, Muslims and African Traditionalists each comprise approximately 33% of the population.⁵ While these statistics are provided to avoid religious competition and conflict, this has not, however, always succeeded in present-day Tanzania.

In Tanzania, as in Africa at large, faith-based organizations and other communities of faith form an essential part of civil society. Communities of faith are significant channels for social support and communality. Thus, they are important actors in promoting the well-being of the members of their community. Both political and traditional Ujamaa stress the need to take care of the vulnerable members of society. These values are important when taking care of the sick and dying, and the goal of palliative care is to give dying patients a possibility to die with dignity. However, only marginal research has evaluated the understanding of dignity at the end of life,⁶ and these few studies have all been done in Western contexts. Jacelon et al. have defined dignity as 'an inherent characteristic of being human, which can be felt as an attribute of the self, and is made manifest through behaviour that demonstrates respect for self and others'.⁷ Street and Kissane argue that 'dignity is relational and constructed through relationships with others'.⁸ Street and Kissane's relational definition of dignity is relevant while studying palliative care patients in Tanzania because it recognizes the importance of relationships to feelings of dignity.

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⁴ Frans Wijsen and Bemardine Mfumbusa, 'Seeds of Conflict. Muslim-Christian Relations in Tanzania'. In *Religion, Conflict and Reconciliation. Multifaith Ideals and Realities*, ed. J. Gort, H. Jansen, and H. Vroom, 316–326. Amsterdam/New York: Editions Rodopi 2002.

⁵ Wijsen & Mfumbusa, 321.

⁶ Gwenda Albers et al., 'Personal Dignity in the Terminally Ill from the Perspective of Caregivers: A Survey among Trained Volunteers and Physicians', *Journal of Palliative Medicine* 16/9 (2013), 1108–1114.

⁷ Cynthia S. Jacelon, Thomas W. Connelly, Rana Brown, Kathy Proulx, Thuy Vo, 'A Concept Analysis of Dignity for Older Adults', *Journal of Advanced Nursing*, 48/1 (2004), 76–83.

⁸ Annette F. Street & David W. Kissane, 'Constructions of Dignity in End-of-life Care', *Journal of Palliative Care*, 17/2 (2001), 93–101.

In this paper I analyse the experiences of patients, community care volunteers and professional palliative care personnel in relation to dying with dignity at the Selian Hospice and Palliative Care Program in Arusha, Tanzania. My research addresses the following questions:

- How do Selian patients, volunteers and team members understand the notion of dignity in palliative care?
- Based on the views of Selian actors, what does it mean to practice Ujamaa in the palliative care context?

Context of the study

The Selian Hospice and Palliative Care Program is run jointly by the Selian Lutheran Hospital and the Arusha Diocese of the Evangelical Lutheran Church in Tanzania (ELCT). This program introduced the 'Tanzanian model', and it is renowned for its success and multidisciplinary approach towards care for dying patients. The number of patients increased rapidly. By April 2012, this program served approximately 5,000 patients. The largest group among the patients is comprised of those suffering from AIDS, but tuberculosis and cancer patients are treated in the program as well. The Selian palliative care team operates extensively in the Arusha region. This multidisciplinary team consists of medical, social and spiritual personnel. The program uses trained volunteers, who make regular home visits and help to provide day care while the multidisciplinary team visits the sick in the villages. Volunteers are expected to visit the sick at least once a week and to regularly report to the professional team about their visits. The professional team is responsible for the training of volunteers.

During the early years of the project, volunteers were selected through the local parishes of the ELCT. Later, when the program expanded and also received support from the Tanzanian government, most of the volunteers were selected through local village governments. The local communities recognise that the chosen volunteers are capable of serving the sick in their community. Thus, the communities suggest the names of suitable candidates to the Selian team, and this team interviews these candidates to determine if they are qualified for the task, both in terms of their personal abilities and to ensure that they have sufficient time to serve the sick in their community.

The first volunteer training course was organized in 2004. The total number of trained volunteers was 250 in April 2012. Out of those, 204 were active in their service, and the number of volunteers who were no longer continuing was very small. My objective was to determine the reasons for the volunteers' strong motivation to continue doing unpaid work, even though they themselves had difficult financial situations. When I asked the team members why some of the volunteers had not continued, they gave a number of reasons for this: volunteers had moved, received full-time work, or died. Others had not been motivated to continue doing unpaid volunteer work, but it seems that this reason pertained to only a few of the approximately fifty volunteers who had resigned.

All volunteers attended a four-week volunteer training course, which uses material produced by the Tanzanian government for caring for HIV-positive patients at home. This training involves basic teaching on the care of sick people, and it also offers, for example, information on hygiene and a nutritious diet. Furthermore, volunteers are taught how sicknesses affect their patients' psychological condition. Most of the volunteers only had a basic elementary school education (the standard seven) as their educational background. During interviews, they indicated that the volunteer training course had taught them important information and had also increased awareness of their need for further education. Evangelists receive further training from the Church after their elementary school education. In addition, one of the evangelists stated that he was attending pastoral training at a local Bible school. Four of the interviewed volunteers had received some secondary school education, two volunteers had attended vocational school, and one interviewee had started his studies at the university (but he had not finished them).

Data and methods

The first empirical data for the present study was collected through interviews and participant observation in the Selian Hospice and Palliative Care Program in June 2009. Eight people (four from each gender) were interviewed. Of these, five were individuals responsible for the Palliative Care Program; the rest were palliative care patients, all of them living with AIDS. Participant observation was carried out in a volunteer training seminar, during day care for the sick, and during the course of home visits. During the seminar and during day care, public

speeches and prayers were also tape-recorded. Private counselling and prayer sessions during day care were recorded only in a field research diary in order to maintain client privacy.

A second, larger body of data was collected in April 2012 when I spent two weeks with the Selian Hospice and Palliative Care team. During this time, I attended day care in two rural villages, one a mining community and one a plantation community, as well as in a semi-urban village outside the town of Arusha. In addition, I visited the sick in the Arusha Lutheran Medical Centre, which is a hospital in the town of Arusha, and attended meetings of the professional team and a monthly meeting that was organized for the volunteers in one of the districts. The total number of interviewed volunteers was 40, out of whom 22 were females and 18 were males. The participants' ages ranged from 23 to 65 years old, and they came from varying ethnic and religious backgrounds. Five of those interviewed – three women and two men – were Muslims. The rest of the interviewed volunteers were members of different Christian denominations, the majority belonging to the Lutheran Church. Furthermore, I was given some statistics pertaining to the volunteers, some teaching materials in PowerPoint format used by the team, and a spiritual guidance book that had been prepared for the patients, covering topics such as bereavement in the Lutheran tradition.

Whereas the original intention was to record all interviews, this was not possible due to malfunctioning of the recording device. Thus, the seven interviews of the fieldwork conducted on the day of the malfunction in 2012 are recorded in my field research diary only. All other interviews were tape-recorded and selectively transcribed. The direct quotations used in this article are all from the tape-recorded interviews. The direct quotations indicate the role of the interviewee (P for patient, T for team member, and V for volunteer) and identify the interviewee by number: for example, T1 was the first professional team member interviewed and P1 was the first patient interviewed. The year of the interview is added in the code to differentiate the two fieldwork periods. The translations from Swahili are mine. All interviewees gave informed consent prior to their inclusion in the study. All details that could identify a volunteer have been omitted. It is possible to identify some of the team members on the basis of the interviews, but as professionals in the program they granted their consent for these interviews to be used in an academic study.

In addition to interview and observation data, I also utilize some of the Selian teaching materials and conference presentations by the Selian team. I refer to these materials in the

article by the name of the presenter (Makule 2010) or by the title of the teaching material if the name of a person is not given (e.g. Cultural issues and beliefs in palliative care 2011). The Selian Hospice and Palliative Care Program has also produced a small booklet for patients on death and dying, and this booklet is also part of the data used in this article.

Theory-based content analysis was used as a method to analyse the data. The Dutch version of the patient dignity inventory was selected as a theoretical tool for theory-based content analysis. The patient dignity inventory focuses on symptoms and experiences that have been shown to influence the sense of dignity in terminally ill patients.⁹ The inventory, which is a quantitative survey, was not used as such, but the contents of the survey helped to organize the findings of my qualitative data. The inventory consists of physical, psychological, social and existential aspects of dignity. These aspects form the main categories of the content analysis. These main categories give the basic structure to the following subchapters of this article.

Physical aspects of dignity central in palliative care

Actual care is a central part of the work of palliative care volunteers in Tanzania. The interviewed volunteers stated that the biggest challenge which they face in their volunteer work is poverty. In their examples, poverty was often connected with the physical dignity of a palliative care patient. Poverty was stated to be a challenge both for the volunteers themselves and especially the poor patients of the Selian Hospice and Palliative Care Program. One way to maintain the physical dignity of patients is through the care that volunteers give in their weekly visits to the sick.

One example of how the Selian team tries to maintain the physical dignity of the patients occurred during my visit to a day care in a plantation community. Three elders from the village, one of them the chairperson of the village in question, attended the day care clinic at a local church. All of these elders were Moslems, wearing special hats that showed their religion. These elders were concerned about distribution of food, a form of assistance which the U.S. agency for International Development (US AID) had made to the HIV-positive patients of the Selian Hospice and Palliative Care Programme. These elders would have preferred for food to also be distributed to some of the volunteers, especially Moslem volunteers, who also had needs

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⁹ See Albers et al.

in their life. This type of assistance was distributed during day care visits to villages, and social workers from the Selian team were responsible for distributing it. The relatively large amount of food, meant to fulfil a patient's needs for three months, was certainly of considerable benefit for HIV-positive patients. The distribution of this aid was controversial, however, as demonstrated here. Food assistance was strictly reserved for HIV-positive patients only, and other patients or volunteers were not eligible to receive it. The argument over food assistance shows the tension and power struggle between the two types of Ujamaa, political and traditional. The village leadership represents Nyerere's local government and the Selian project represents traditional communality via civil society. The village leadership wanted to decide how this assistance was delivered, and it was not happy with the team that did decide. In this case, the civil society type of Ujamaa was stronger and the village elders left the clinic after being defeated.

The physical aspects of dignity discussed above are closely aligned with the human dignity inventory.¹⁰ In these experiences from Tanzanian palliative care, the physical aspects of dignity were connected with the challenge of poverty. The patients were worried about their reduced lack of autonomy and increased need of care. The availability of antiretroviral (ARV) medications has prolonged the period of palliative care, which has further stressed the need to support the physical dignity of the patients.

Psychological aspects of dignity as challenging

Many volunteers told that some of their patients were hard to visit because of the severity of their psychological problems. Volunteers are taught how different illnesses affect their patients' psychological condition. During the interviews, volunteers also explained how they tried to maintain the psychological aspects of dignity of their patients. They did not always find this to be very easy. Psychological problems were also discussed during the volunteers' monthly meetings, and the team tried to supervise the volunteers to help them face the hardships of psychological difficulties. In some crisis situations, one of the team members also visited homes where the sick person was becoming very nervous or feeling despair about his/her situation.

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¹⁰ Compare Albers et al. 1036.

One key psychological difficulty among the patients in Tanzania is feelings of despair. The Selian Hospice and Palliative Care team was prepared to listen to these. At the opening of a day care session in a village, an evangelist on the team preached: ‘There are various experiences of suffering, but do not fear that God is not with you... Do not feel despair so that you would try to find a poison to kill yourself. God who is with us continues to comfort us every day’ (T3, 2009). Before speaking these words, the evangelist had read Psalm 23: 2: ‘The Lord is my shepherd I shall not want...’ The evangelist talked openly about despair, but at the same time comforted the people by reminding them of God’s promise to be with us all and to help us in our daily lives. The audience included patients, volunteers and team members of the Care Programme, approximately forty people in all.

The experiences of psychological aspects point to the lack of dignity in the care of patients. Furthermore, the dignity inventory mainly raises challenges of the psychological aspects of dignity.¹¹ The knowledge and care of psychological problems is limited in Tanzania and the treatment of many severe physical sicknesses further detracts from it, both in terms of time and money. It also seems that the psychological aspects are not well integrated into the training of palliative care volunteers.

Social aspects of dignity as central in Tanzanian context

The Selian volunteers were clearly proud of their service, and they repeated many times during their interviews how blessed they are when they can serve others. One female volunteer (V18, 2012) told that she likes to serve the family and the community; in Swahili this contains a play on words (*kuhudumia jamii na jamaa*). This volunteer stresses the importance of Ujamaa while serving patients, even though she uses only the words from which Ujamaa is derived rather than the political term itself. David Westerlund further differentiates the target of help when he analyses the words *ujamaa* and *ujima*, which means the habitual practice of co-operation of villagers in certain peak season activities or in cases of emergency.¹² Even though the Selian Palliative Care Programme uses the words *jamii* and *jamaa*, it still comes closer to *ujima* as help (help in emergency) rather than *ujamaa* as continued partnership in work or communal

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¹¹ Compare Albers et al., 1036.

¹² David Westerlund, *Ujamaa na Dini: A Study of Some Aspects of Society and Religion in Tanzania, 1961–1977*. Stockholm: Almqvist & Wiksell International, 1980. Dissertation, 31.

ownership, as was central in the political version. Westerlund's analyses above help to understand the difference between political Ujamaa and the traditional communality in Tanzanian societies. Political Ujamaa socialism, which required communal ownership, was proven to be too idealistic, and as a political system it did not work. However, the Selian type of civil society Ujamaa, which calls for help in the case of emergency (or, in this case, taking care of the dying), seems to work better than political Ujamaa.

Various social aspects seem to be important for the personal dignity of the Selian patients. This is seen with all of the actors in the project. One reason why social aspects of dignity are so central to maintaining personal dignity in the program is that many of the patients have AIDS, which is still connected with social stigma. One member of the palliative care team explained, 'One reason is that we also serve others than AIDS patients and this decreases the stigma' (T2, 2012). A great number of the patients are HIV-positive, but there are also those who have cancer and other sicknesses which require hospice and palliative care. Previous research reveals that in some African contexts, the volunteers who serve HIV-positive patients also face stigmas.¹³ Nonetheless, when the stigma of AIDS is not that strongly imposed on the whole program, volunteering is seen more as a privilege.

One social obstacle in maintaining social dignity is especially linked with AIDS as a sickness. One of the interviewees explained: 'I disclosed my status publicly, and as a result, my husband encountered problems at work. Other people at work started saying "Let's not talk to him; he is infected"' (P3, 2009). This woman was ready to announce her condition openly and she had worked through her new identity as HIV-positive, but her public revelation led to her husband being stigmatized at work. One aim of the work of the Selian team is to reduce the stigma of HIV/AIDS. Social stigma seemed to be a bigger problem in 2009 than 2012, although one reason why I heard less stories of stigmas is that in 2012 I did not conduct formal interviews with patients.

Several patients emphasized the importance of support from family members, other patients, and churches. As the following patient expressed it: 'I feel great when I am close to people. Then I always feel comforted. Then I feel that I am fine. I get hope from what I am doing' (P1, 2009). Previous research on peer support found out that such support improved the

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¹³ Kasimbazi and Sliep.

psychosocial well-being of AIDS orphans, while some peer support groups have transformed the lives of their participants.¹⁴ One of the Selian Palliative Care patients said, ‘Do not get tired of visiting us; we get a lot of comfort from these visits’ (P3, 2009). In the context of HIV/AIDS, hope was conveyed not only as an individual experience, but also as a communal expression. Communal expressions of hope gave individuals the chance for a new life. The feeling of not being left alone was an important expression of hope among Tanzanian HIV positive people: ‘I get hope mostly from what you are doing here. I am encouraged by you. I feel that you give me courage’ (P3, 2009). These expressions of palliative care patients in Tanzania show the importance of human relationships for healing. Richard F. Mollica (2006) stresses that healing is most successful within human relationships.¹⁵

The palliative care volunteers clearly identified the challenges of social dignity, as seen in the discussion above. Albers et al. point out that the importance of social support does not seem to change when illness becomes more severe. Patients perceive that social support is important during all stages of their sickness.¹⁶

Existential aspects of dignity are part of holistic palliative care

The dignity inventory uses the term ‘existential aspects of dignity’. In the Tanzanian context, ‘existential’ mostly means spiritual, both in the sense of traditional African spiritualities and Christian or Muslim spiritualities. The spiritual dimension of the Selian Hospice and Palliative Care Program is highly contextual. It always includes praying for the sick and blessing the medicine. This seems to be more of a practical decision, which was made initially when the program began, rather than a clear policy. The contextual approach of the program is confirmed in its training material: ‘According to African culture and religions, human life is a gift from God and death is a normal passage to join with the living dead ancestors.’¹⁷

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¹⁴ Eddie Kumakech, Elizabeth Cantor-Graae, Samuel Maling, and Francis Bajunirwe, ‘Peer-group Support Intervention Improves the Psychosocial Well-being of AIDS Orphans: Cluster Randomized Trial’, *Social Science & Medicine* 68 (2009), 1038–1043.

¹⁵ Richard F. Mollica, *Healing Invisible Wounds: Paths to Hope and Recovery in a Violent World*. New York: Harcourt, Inc., 2006.

¹⁶ Albers et al., 1035–1038.

¹⁷ Cultural issues and beliefs in palliative care, 24 May 2011. Selian PowerPoint slides for volunteer training.

The Selian Hospice and Palliative Care Program serves patients regardless of their religious background. This implies that also in the Selian counselling approach all clients are approached in a similar manner, regardless of their religious background. The patients are informed that the people providing spiritual care have a Lutheran background, but that people of all faiths are nonetheless invited to counselling sessions. Most clients accept this invitation and appear content with a Christian counsellor praying for them. During counselling, Muslim clients are advised to contact their own religious leaders for further counselling. This is also emphasized to health professionals during their training in palliative care: 'Respect patients' belief systems, praying options, refer to religious leaders if necessary.'¹⁸ The way in which religious diversity is dealt with in the studied program seems to strengthen the communality of both patients and volunteers involved in it, regardless of their faith. This demonstrates that the traditional aspect of Ujamaa is fortified through the program.

One part of the Selian holistic approach to gain dignity is the continued search for overall healing. In the data of this study, healing was understood both as a search for physical healing and as reconciliation of relationships. Prayer for healing is regularly available during each day care session through an opening prayer, as previously discussed, in connection to the psychological aspects of dignity. Prayer for the medicine contains both physical and spiritual aspects of dignity. The main focus of my 2009 fieldwork was this healing prayer.¹⁹ The official stance during volunteer training is: 'The holistic and spiritual aspect of the work is integral to the training including daily morning and evening devotions.'²⁰ This spiritual aspect is not only seen during the training course, but also during the volunteers' monthly meetings and in every day care that begins with a morning prayer.

The Selian Hospice and Palliative Care Program has produced a book for patients on existential questions at the end of life. This book is written in Swahili, but its name in English is *God with us, comfort and hope*.²¹ The book contains comforting Bible passages, hymns, meditations and stories of living with HIV. The aim of this book is to comfort the patient and to support her/his dignity. Furthermore, discussions of shame and guilt are included in it. The patient is advised

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¹⁸ Cultural issues and beliefs in palliative care.

¹⁹ See more closely AUTHOR, contextual.

²⁰ Elizabeth Makule, 'Volunteer Retention at Selian Hospice in Tanzania', presentation in the African Palliative Care Association's conference, Windhoek, Namibia, 15–17 September, 2010. Selian PowerPoint slideshow.

²¹ Parmena Nnko, '*Mungu yu nasi; faraja na matumaini*', Selian Lutheran Hospital & Arusha Lutheran Medical Centre. Selian Hospice and Palliative Care Program, 2010/2011.

to confess their sins to God, who will pardon them. The book stresses that hope is found in eternal life with God.²² The themes of the book are clearly seen in the practices of the Selian Hospice and Palliative Care Program. Not a single interviewee talked about this book during their interview, but its themes were included in many of the interviews and observed during morning prayers and volunteer training sessions.

Physically touching AIDS patients is a central part of Selian spiritual counselling. As explained in the interviews, touching – not just talking – breaks the stigma of HIV/AIDS. This reflects traditional African ideals of the value of human encounters. Physical touch is used during prayers for the sick at the end of each counselling session. Another element in contextualizing the counselling in the program studied here is that the counsellor blesses the medicine given to a client already beforehand, when a client consults the medical personnel of the team. The program leaders who were interviewed pointed out that patients had no need to ask traditional healers to bless the medicine because the ailment has already been cured with spiritual power. Instead, the clients feel that they are approached holistically in the Selian Hospice and Palliative Care Program. Previous research has found that many Tanzanian Christians believe that prayer can cure HIV; if faced with the disease, many rely on prayer.²³ In addition, many use ARV treatment.²⁴ Relying on prayer often means having unrealistic expectations of spiritual help and avoiding the use of modern medicine. This appeared to be one reason why counsellors blessed the medicine. It made the medicine part of the holistic approach.

During the three years between my two episodes of fieldwork in Northern Tanzania, a healer called Babu wa Loliondo (Grandpa from Loliondo) suddenly became very famous.²⁵ He was especially understood to be able to heal the HIV virus with herbal medicine. During my second visit, I was also told by the team that many Selian patients visited Babu and drank his medicine. Even though Babu did not advise the patients to abstain from ARV medication, many of them did. It was reported that most of the patients who travelled to see Babu were dead by my second visit. Some of my interviewed volunteers confirmed this, saying that their own patients had died after the trip to Loliondo to see the healer.

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²² Nnko, 1–11, 16.

²³ Felicitas Becker, 'The Virus and the Scriptures: Muslims and AIDS in Tanzania'. *Journal of Religion in Africa*, 37 (2007), 16–40.

²⁴ J. Zou, Y. Yamanaka, M. John, M. Watt, Jan Ostermann and Nathan Thielman, 'Religion and HIV in Tanzania: Influence of Religious Beliefs on HIV Stigma, Disclosure, and Treatment Attitudes'. *BMC Public Health*, 9/75 (2009), 1–12.

²⁵ Mika Vähäkangas, 'Babu wa Loliondo – Healing the Tensions between Tanzanian Worlds'. *Journal of Religion in Africa* 45 (2015), 3–36.

In order for palliative care patients to face a good death, consideration of all aspects of dignity is important, and the role of palliative care volunteers is key in terms of support of dignity for the dying. Selian training materials add one more aspect of dignity for consideration: the cultural needs of the patient.²⁶ This is extremely important in the Tanzanian context, where culture is a vital part of a holistic understanding of a person. This was seen in my previous research on spirituality in palliative care.²⁷ The stress on the importance of dignity is clearly seen also in the Selian material: ‘According to African culture and religions human life is a gift from and is controlled by GOD. Death is normal passage for every person to join the living dead ancestors who behaved well on earth and were proclaimed to be good persons.’²⁸ The living dead mean the deceased loved ones, who according to the traditions live as long as they are remembered and their memory is seen to be important. This natural multicultural and multi-faith approach would also be a good model for palliative care in Western countries where the number of people from various cultures and religions is increasing.

Palliative care research in the European context has discovered that those patients who have a religious conviction approach death with more comfort than those who do not. These patients share a confidence that God decides about life and death.²⁹ The Tanzanian patients and volunteers stressed similarly that God knows the length of a human life. Religious convictions seem to provide both patients and volunteers with the promise of eternal life, which does not end with the death of the physical body.

Volunteers represent Ujamaa in their communities

Previous research on volunteering has not focused on volunteers who are selected by their local communities (instead of volunteering themselves). In this respect, the Selian volunteers are

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²⁶ Makule.

²⁷ AUTHOR, contextual.

²⁸ Cultural issues and beliefs in palliative care.

²⁹ Albers et al., 1036–1037.

clearly unique in the research on volunteering.³⁰ In brief, the Selian volunteers accept the call of their community to volunteer. This practice was explained during one of the interviews, when a volunteer described how three other people had responded negatively to the request by the community and he was only the fourth choice on the list. However, he interpreted this as God's plan, that that place was intended for him instead of the other candidates. Another interviewee explained how she was actively involved in the AIDS committee of her local village and this was the reason why she was also nominated to the Selian Hospice and Palliative Care Program.

As the program expanded and received support from the Tanzanian government, most of the volunteers began to be selected through their local village governing bodies. During this stage, the first Muslim volunteers were recruited. It is interesting, however, that the Muslims were recruited not only through their village governments, but also through mosques. This was explained by a nurse of the Selian Hospice and Palliative Program during her interview. Connection with mosques reveals a keen interest to cooperate with others and serve the community, a position that was further emphasized by the nurse: 'They are recruited in order to serve family and community' (T1, 2012). In Swahili, the previous quotation uses the same two words linked to Ujamaa as discussed above in the quotation of a volunteer: *jamaa* and *jamii*. By highlighting the words 'family' and 'community', the nurse conveys that they are an important part of the project and that the Muslim volunteers participate as equal members of the Selian Hospice and Palliative Care Program.

The communal aspect of volunteers can be explained by focusing on governance as a cultural practice. Green (2010) has asserted: 'Governance as a cultural practice in Tanzania enacts the hierarchical relations between the lower and higher tiers in models premised on the conceptualization of the village as both object and lowest level of government.'³¹ Volunteers in Tanzania seem to participate both as members of the civil society as well as part of the local governance. This service stresses the traditional understanding of Ujamaa, which emphasizes

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³⁰ Henrietta, Grönlund, *Volunteerism as a Mirror of Individual and Society: Reflections from Young Adults in Finland*. Dissertation. Helsinki: University of Helsinki, 2012; Annette Kezaabu Kasimbazi and Yvonne Sliep, 'Unpaid Volunteers and Perceived Obstacles in Ensuring Care and Support of People Living with HIV/AIDS', *Response-ability in the Era of AIDS: Building Social Capital in Community Care and Support*, ed. Wenche Dageid, Yvonne Sliep, Olagoge Akintola and Fanny Duckert, 95–110. Bloemfontain, South Africa: Sun Media, 2011.

³¹ Green, 15.

communality and care of the dignity of the most vulnerable in the community. The unique selection process of the volunteers strengthens the bond between the volunteer and the local governance. The role of the volunteers is somehow in between an official work role and a traditional volunteer role. What makes their role clearly that of a volunteer is that they are not paid for their services.

Ujamaa as promoting gender and ethnic equality, religious diversity and indigenous culture

Ujamaa stresses three different aspects of equality – gender, ethnicity and faith – and it additionally highlights the value of indigenous practices. These three aspects all play a part in the selection process of the Selian palliative care volunteers, as was discussed previously. The involvement of men, ethnic minorities and Muslims was seen to be an important part of community building in a situation where every part of the village had dying patients to be taken care of. A fourth aspect, highlighting the importance of indigenous values and practices, seems to be the predominant philosophy behind the program. The crisis of an AIDS pandemic called for traditional communality to be strengthened. This seems to be one reason why already in the planning stages of the Selian program Ujamaa values were incorporated in it.

The professional team seems to use Ujamaa discourse in a traditional sense in order to motivate volunteers to be responsible in their service. This is clearly seen in the multi-faith greetings used at Selian gatherings. The first greeting is always the evangelical Christian ‘Bwana asifiwe!’, meaning ‘Praise the Lord!’ The response to that is a unified ‘Amen’ from the volunteers and patients attending the gathering in question. The second greeting is a Muslim one: ‘Salaam aleikum’. The response as loud as that to the first greeting: ‘Aleikum salaam’. During my ten-year stay in Tanzania, I had never heard these greetings in succession. I noticed this practice already during 2009 fieldwork, but it seemed that it was even more frequent during the 2012 fieldwork. It seems that the greetings are used deliberately to incorporate various faiths into the Selian community. The Ujamaa literature refers to the use of interfaith strategy.³² The aim of the Ujamaa discourse seems not to be the expression of nostalgia, but the creation of new community, a community needed in a

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³² Olsson; Westerlund.

situation when the old family structure and support system no longer worked. This could be done by stressing the traditional Tanzanian communality aspect of Ujamaa, not returning to Nyerere's political Ujamaa.

Ujamaa discourse also seems to be strongly connected to power and control. The team utilized Ujamaa discourse in order to control and supervise the volunteers. This was also seen as a response to those volunteers who had not attended to their responsibilities (e.g. visiting their patients regularly and turning in their reports on time using the provided form). These volunteers were questioned and their monthly allowance was denied until they turned in their reports. There was also an element of public shame that applied to these people. All others went to receive their monthly allowance, but these few could not join the others. Control and discipline are part of African communality. Nobody apart from myself seemed to be hesitant towards this practice of power and control. I also understood that in order to get the program working properly, the team had to trust that the volunteers would fulfil their duties and not leave patients without care and attention. Power and control are a way to safeguard the dignity of the Selian patients. Traditional communality was also a way to perform social control in the community and to protect the vulnerable members through this control.

Nyerere's notion of Ujamaa cannot be properly understood without reference to the consequences of colonialism. Nyerere stressed that Africans should no longer be ashamed of their indigenous culture.³³ The emphasis on African culture is seen in the various aspects of the dignity provided by the Selian palliative care program. Healing unites physical, social, psychological and existential aspects of personal dignity in a holistic understanding of dying with dignity. This is seen in many practices of the program, as discussed previously. Nobody commented on colonialism while talking of the need for healing and wholeness among the palliative care patients, but they were openly proud of the contextual understanding of healing as practiced in the program.

Four major lines of practices were seen to promote Ujamaa in those villages where the Selian Hospice and Palliative Care Program works. Two of these, the interfaith approach and involvement of both men and women, are already used in the selection process of volunteers, as well as patients, in the program. Additionally, the ethnic balance seems to be a selection

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³³ Westerlund, 31.

criterion, even though it is not as openly expressed as the gender balance. The fourth aspect, which involves various African elements of healing and other indigenous practices, is similarly integrated in many parts of the program. The Selian professional team seems to use the Ujamaa discourse purposefully in order to motivate the community to care for the sick. These four major lines of practices represent political Ujamaa, and they are directly taken from Nyerere's political program.

Conclusion

The aim of this article was twofold. The first aim focussed on analysing ways of enhancing the Tanzanian patients' dignity in palliative care. The patient dignity inventory was used to help to answer the first research question. This inventory is formed from physical, psychological, social and existential aspects of dignity. The physical aspects of dignity were connected with the challenge of poverty. The patients were worried about their reduced lack of autonomy and increased need of care. Experiences of aspects of psychological dignity were found to be mainly negative, and the psychological aspects do not seem to be well integrated into the training of palliative care volunteers. The palliative care volunteers were clear in identifying challenges of social dignity, and they saw them as an important dimension of their work. The Tanzanian patients and volunteers similarly stressed that God knows the length of a human life. This religious conviction seems to be connected to the idea of an eternal life beyond physical death. The spiritual aspects of dignity are also linked to the second aim of this article, the aspect of communality in palliative care through the African understanding of the living dead.

The second aim analysed the practice of Ujamaa in a palliative care context. The results of this study reveal that the Selian Hospice and Palliative Care Program uses dimensions of both traditional and political Ujamaa in order to protect the dignity of dying patients. This is done subconsciously and eclectically. The term 'Ujamaa' was not explicitly used in any of the interviews nor any of the written materials which formed the data of this study. The program seems to stress communality and social responsibility in general while clearly utilizing the values of both traditional and political Ujamaa in all of its practices.