

# Palliative Care Volunteers Have High Workload but No Burnout: A Questionnaire Survey from Tanzania

Reino Pöyhiä, MD, PhD,<sup>1-3</sup> Anna Jaatinen, MD,<sup>1</sup> Leila Niemi-Murola, MD, PhD,<sup>2</sup> Aida Mtega, RN,<sup>4</sup> Godfrey Mpumilwa, MD,<sup>4</sup> and Paul Mmbando, MD<sup>5</sup>

## Abstract

**Background:** In Africa, the core of home-based care (HBC) in the villages is provided by volunteer helpers, individuals chosen to provide both support to patients and important information to health officers. Yet, voluntary work in palliative care and the burden of being a volunteer have not been studied in Africa.

**Objective:** To study the content and burden of volunteer work in the palliative home care of Ilembula District Designated Hospital (IDDH), a secondary care institution in Tanzania.

**Design:** A descriptive prospective study using semistructured and closed questionnaires.

**Setting/subjects:** The modified Palliative Care Evaluation Tool Kit (PCETK) and Professional Quality-of-Life Scale (ProQOL) were used to study the work content and workload of 47 volunteers in the palliative HBC of IDDH. ProQOL was translated to Kiswahili. Fifty-seven health care professionals and students validated the translation. Factorial analysis and Cronbach's alphas were calculated for reliability.

**Results:** Responses to PCETK and ProQOL were received from 34 (72%) to 20 (42%) volunteers, respectively. The Kiswahili translation of ProQOL appeared to be highly reliable. On average, a volunteer worked 20 hours/month and had 22 patients. The main activities included helping with daily tasks, preparing meals, assisting with transport, and reporting the patient's clinical condition to the health care officers. The volunteers reported high satisfaction ratings (average 4.2, standard deviations 0.38) and had higher scores than the validation group in the compassion fatigue scale (2.42 vs. 1.55,  $p < 0.01$ ) but no burnout.

**Conclusions:** The volunteers had high commitment and workload. Even so, coping strategies for dealing with suffering and death should be better addressed in training.

**Keywords:** home-based care; palliative care; relationships; volunteer; vulnerability; women

## Introduction

AN ESSENTIAL PART of palliative care internationally is voluntary work.<sup>1-4</sup> There is plenty of consistent information available from Western societies describing how rewarding and important the volunteers' work is in end-of-life care.<sup>5,6</sup> Voluntary work in Africa differs largely from that in Western countries.<sup>5,7</sup> African palliative care volunteers are most commonly recruited from their home villages. A common practice is that the local leaders of the wards and villages choose the volunteers. Although a chosen volunteer can de-

cline the offer, working as a chosen volunteer is considered to be an honor. In sub-Saharan countries, volunteers work mostly in home-based care (HBC).

African volunteers are trained to provide both physical and psychological support to their patients. They are trained to identify other related medical problems and provide reports to health officers,<sup>7</sup> making the volunteers' role an important liaison between the community and health care provider.

However, stressors such as dealing with the loss of a patient, role ambiguity, individual disillusionment, or working with paid staff have also been identified among volunteers.<sup>8-13</sup>

<sup>1</sup>Department of Clinical Medicine, Oncology and Radiotherapy, Division of Palliative Medicine, University of Turku, Turku, Finland.  
<sup>2</sup>Department of Anaesthesiology and Intensive Care Medicine, Helsinki University Hospital, University of Helsinki, Helsinki, Finland.  
<sup>3</sup>Kauniala Hospital, Kauniainen, Ilembula, Finland.  
<sup>4</sup>Ilembula District Designated Hospital, Tanzania.  
<sup>5</sup>Headquarters of the Evangelic Lutheran Church of Tanzania, Arusha, Tanzania.  
Accepted October 25, 2018.

Secondary traumatic stress (STS), compassion fatigue (CF), and burnout may also be experienced by the volunteers. Burnout is defined by feelings of reduced personal accomplishment at work, diminished work satisfaction, and poorer quality of performance. CF is defined as a state of physical and mental exhaustion resulting from exposure to a traumatized individual rather than from exposure to the trauma itself; and STS as a care provider's stress reaction due to incapability to rescue or save someone from harm and results in guilt and distress.<sup>11,12</sup> The vast majority of previous studies assessing stressor in volunteer work have been executed in Western countries. Yet, there may be culturally sensitive issues in experiencing stress or burnout. As an example, role ambiguity was identified as a major stressor by U.S. but not Australian volunteers.<sup>11</sup> Unfortunately, there are not many studies about STS, CF, and burnout among African palliative volunteers.

The role of Tanzanian volunteers in HBC seems to be rather similar to that in other African countries,<sup>5,14,15</sup> but there are no detailed analyses of the *palliative care* volunteer work from African countries. To understand better the culturally sensitive issues in the presumed work burden of voluntarism, we have undertaken a study assessing volunteer work in an area of a rural hospital in Tanzania.

## Methods

The study was performed in the Palliative Care Department of Ilembula District Designated Hospital (IDDH), Tanzania, after receiving approval from the hospital administrative board and the District Medical Officer of the Njombe Region and consulting the National Ethics Committee. Informed consent to participate in the study in Kiswahili was received from 34 of 47 volunteers actively working in the HBC palliative care to participate in the study. In IDDH, volunteer work is coordinated by the palliative care team, which consists of a coordinator, an assistant coordinator, nurses, doctors, a pastor, and a social worker. A total of 1163 patients were registered in the hospital palliative care in January 2015. Sixty percent of the patients suffered from HIV infection at different stages. The rest of the patients had various end-stage diseases; cancer, diabetes, and cardiovascular diseases being the most common ones. The data consist of both qualitative and quantitative data.

## Qualitative data

The qualitative data were collected from discussions with the coordinator (A.M.) of the palliative care team in IDDH. In the discussions, information about the volunteer organization, selection of volunteers, their education and support, practices of voluntary work, and the hospital staff's monitoring of the volunteers' activity was collected. The volunteers fill a notebook about the diseases and symptoms of their patients during each visit. The notebooks were examined and discussed with the coordinator.

## Questionnaire survey

Two different questionnaires were used to study the characteristics of volunteers and their work. The palliative care nurses delivered the questionnaires to all volunteers and received filled sheets either in the palliative team's weekly

village meetings or in the volunteers' monthly meetings. The first questionnaire (A) was a modified version of a previously validated inquiry instrument, Evaluation Tool 2.2 "Volunteers Currently Working in Palliative Care," from the Palliative Care Evaluation Tool Kit of the University of Wollongong<sup>16</sup> and collected information about the demographics, practical work, motivation, and future plans of the volunteers. In this semistructured questionnaire, the volunteers could both choose predefined items and also write free text about their feelings and thoughts. The experienced burden and satisfaction of the volunteers were measured with another questionnaire (B), the Professional Quality-of-Life Scale (ProQOL).<sup>17</sup> The ProQOL is a 30-item self-report scale, which consists of three subscales: compassion satisfaction (CS), burnout, and CF. CS describes the pleasure the work gives to the volunteer. Feeling that a person can be effective as a caregiver or do good for society usually gives greater scores. Burnout scale measures the risk of burnout in helping others. It can be associated with feelings of hopelessness about one's workload or the feeling that one is not able to work as well as one would like to.<sup>18</sup>

## Translation of the questionnaires

Both questionnaires were translated from English to Kiswahili by three persons. A Finnish pastor with excellent knowledge of Kiswahili provided the initial version, which was rewritten by two health care professionals who spoke Kiswahili as their native tongue. The Kiswahili version of the questionnaire B (Appendix 1) was translated back to English by a Tanzanian translator, who was not familiar with the original English questionnaire (Appendix Table A1). Each volunteer received both English and Kiswahili translations but responded in Kiswahili.

## Validation process

Questionnaire A sought information related to basic demographics, education, practicalities of voluntary work, and reason for volunteering, while questionnaire B presented choices of different types of attitudes.<sup>16</sup> That is why only questionnaire B was validated in Swahili. After translation and retranslation, questionnaire B was presented to 57 students and health care professionals studying or working at IDDH. In the validation group, 88% (50/57) of responders were female and 12% (7/57) were male. Mean age was 28 years (standard deviations [SD] 11).

## Reliability

Reliability of the scales was analyzed using Cronbach's alpha. Factor loading of the questionnaire was made using the maximum likelihood analysis and varimax rotation (SPSS 22; SPSS, Inc., Chicago, IL) to examine the underlying constructs of the survey instrument. According to the factor analysis, some of the burnout items had weak loadings in the original scale but were slightly better on the other two scales. However, the original scales were used in this study.

## Statistics

Data are presented as mean with SD. Correlation coefficients were calculated when appropriate. Statistical difference between pairwise comparisons was assessed with *t* test.

TABLE 1. DEMOGRAPHIC INFORMATION OF THE VOLUNTEERS

No. of respondents	34
Age (SD)	44 (6)
Gender (female/male)	32/12
Unoccupied	23 (68%)
Education	
Primary	27
Secondary	2
College	0
Professional	3

Numbers (and percentages) of individuals are given. SD, standard deviations.

**Results**

**Volunteers' background**

Anonymous answers were received from 34 (=72%) to 20 (=42%) volunteers to questionnaires A and B, respectively. The demographics of the volunteers are given in Table 1. The majority (68%, 23/34) of the volunteers did not have any occupation, and only few of them reported to be a farmer, an HBC worker, a teacher, or a laboratory technician by profession.

All volunteers had already worked more than three years as a volunteer. Eighty-two percent (28/34) reported that they also had previous experience of voluntary work. Almost all (97%) had received either formal or informal training to be a palliative care volunteer.

**Content of the voluntary work**

The average time spent on voluntary work was 20 (range 1–60; SD 15.9) hours per month. The number of patients cared for by each volunteer varied from 2 to 60 with an average of 22 patients (SD 10) per volunteer. Volunteer work consisted of various elements: home visits were made by 97% of volunteers and hospital visits by 50%. The main activities of the volunteers were cleaning the patients' home (65%), assisting with visits to the doctor or hospital (56%), washing the patients (53%), dressing the patients (47%), helping with transport (42%), and preparing meals (38%). Only 21% of the volunteers had helped the patients in leisure activities. Less frequent activities of the volunteers were shopping assistance and help with medication.

The volunteers fill a notebook for each visit (Table 2). This notebook is used to compose monthly reports to the hospital. The reports are then delivered to the government and the Evangelical Lutheran Church of Tanzania.

TABLE 2. VOLUNTEERS REPORTED TO THE HOSPITAL, IN EACH VISIT TO THE PATIENT, THE FOLLOWING OBSERVATIONS

Diseases (diagnoses) and changes
General condition of the patient: working, deteriorated, bedridden
Observed/discussed problems in the family
Use of medicines and aids of care
Adherence to CTC
Referrals to health care units (maternal care, advisory services, tuberculosis unit) and responses to the referrals
State of HIV infection: tested, medicated or not
Reason for not seeing the patient

CTC, care and treatment center.

TABLE 3. THE MEAN (STANDARD DEVIATION) SCORES OF SATISFACTION, FATIGUE, AND BURNOUT IN VOLUNTEERS AND NURSING STUDENTS (VALIDATION GROUP)

	Validation (n=57)	Volunteers (n=20)
Satisfaction	3.96 (0.67)	4.01 (0.60)
Fatigue	2.00 (0.42)	1.69 (0.69)*
Burnout	2.26 (0.70)	1.87 (0.48)

The participants answered the items using Likert Scale: 1 = totally disagree, 3 = neither agree nor disagree, 5 = totally agree. \* $p < 0.01$ .

Six volunteers received a monthly allowance and 16 volunteers received compensation for travel expenses. The maximum monetary support was 25,000 Tanzanian shillings (TZS) a month. The volunteers were also provided with a bicycle from the hospital, hospital resources permitting.

**Assessment of the meaning of voluntary work**

Fifty-six percent of the volunteers considered general awareness of palliative care to be the most important factor, 44% valued first aid skills the most, and 32% thought that spiritual issues were the most important issues when working with patients.

**Motivation for voluntary work**

Most volunteers stated that they work as volunteers because they want to help people in their own society. Isolation and social exclusion of sick people were seen as a big problem, and as something the volunteers wish to reduce. Volunteers mentioned that the best part of the work was seeing the pain medication working well and the feeling that they were able to relieve suffering with their comforting visits. Lack of resources, such as money for transportation, lack of medication and medical supplies, as well as the long distances to travel were seen as the worst problems and the biggest source of frustration in voluntary work. In addition, volunteers experienced difficulties if their patients did not take prescribed medication for HIV, or when they witnessed their patients dying.

Volunteers were quite involved in their work, with 74% reporting that they are planning to continue volunteer work. Furthermore, 62% would definitely recommend being a volunteer and 26% would recommend it, depending on the person.

**The experienced burden, fatigue, and satisfaction of the volunteers**

In subscale CF (Table 3), a statistically significant difference between the validation group and the volunteers (scale mean 1.56 vs. 2.46,  $p < 0.01$ ) was seen. No difference was found in the burden and satisfaction scales between the volunteers and validation group. Burnout correlated negatively (-0.514) with satisfaction (Table 4).

**Reliability of scales**

The overall Cronbach's alpha values were 0.773 and 0.535 in the validation and in volunteer groups, respectively. The scales of satisfaction and fatigue appeared valid in both

TABLE 4. PEARSON CORRELATIONS BETWEEN PROFESSIONAL QUALITY-OF-LIFE SCALE VARIABLES

	<i>Group 1 = validation, group 2 = volunteers</i>			
	<i>Satisfaction</i>	<i>Fatigue</i>	<i>Burnout</i>	
Group 1 = validation, group 2 = volunteers				
Correlation	1	0.187	0.384**	0.036
Sig		0.380	0.001	0.790
<i>n</i>	77	24	69	57
Satisfaction				
Correlation	0.187	1	0.322	-0.514*
Sig	0.380		0.134	0.017
<i>N</i>	24	24	69	21
Fatigue				
Correlation	0.384**	0.322	1	0.298*
Sig	0.001	0.134		0.038
<i>N</i>	69	23	69	49
Burnout				
Correlation	0.036	-0.514*	0.298*	1
Sig	0.790	0.017	0.038	
<i>N</i>	57	21	49	57

\*Correlation is significant at the 0.05 level (two tailed).

\*\*Correlation is significant at the 0.01 level (two tailed).  
Sig, significance.

groups. However, the burnout scale had lower Cronbach's alpha values than the validation group (Table 5).

## Discussion

We have shown that the palliative voluntary work in Ilembula region, Tanzania, consists of both helping patients in their daily activities and continuously reporting the condition of the patients to health care professionals. The volunteers are uneducated individuals who are chosen for the role and are very committed to their patients despite a high workload of 20 hours on average per week.

EAPC defines volunteering in hospice and palliative care as the time freely given by individuals without financial benefit, within some form of organized structure other than the already existing social relationships or familial ties.<sup>18</sup> In this perspective, two aspects of volunteering in Tanzania may differ from that in other countries. The first one is the mechanism of selection and the second one is the financial support. In Ilembula, the volunteers were considered and chosen by the village elders. The chosen individuals are thus trusted and considered to be eligible to help sicker people in their community. However, the candidates can freely either refuse or accept the assignment.

TABLE 5. CRONBACH'S ALPHA VALUES

<i>Scale</i>	<i>Validation group</i>	<i>Volunteer group</i>
Satisfaction	0.79	0.83
Fatigue	0.65	0.55
Burnout	0.47	0.12*

\* $p < 0.01$ .

Our Tanzanian volunteers received some financial support, which was not considered a salary. Only some volunteers got a very small amount of money. The sums cannot be compared even to the minimum monthly salaries in Tanzania, which in 2016 varied between 70,000 and 325,000 TZS on average in different occupations.<sup>19</sup> Indeed, financial support did not seem to be an important motivator for volunteers. Rather, the desire to help the poor and sick neighbors and the experience of reducing suffering motivated the most to be a volunteer. Most volunteers planned to continue their work. Appreciation, being chosen, and receiving education were all considered important, but none of them appeared to be the key motivator in the free-text answers of the responders. A high level of personal commitment to volunteer work has also been noted in other studies about African community volunteers.<sup>20-23</sup> High ratings in CS in the current study are in line with the volunteers' reporting of high emotional rewards and are also in line with Western studies.<sup>11,23</sup>

The volunteers in Tanzania have an important role in nursing and medical follow-up of the patients, which differs from the tasks of volunteers in Western countries.<sup>8</sup> In private discussions, many volunteers in our study made critical comments about filling the notebooks, although that part of their job was not addressed as a source of burden. Yet, the higher fatigue scores are in accordance with these private talks and may indicate that the volunteers would need more support in their work and also would need to get better training in coping mechanisms. Not surprisingly, the "nursing" site of the voluntary work is emphasized in the education, perhaps at the expense of coping strategies and mental training. Volunteers in Ilembula were trained according to the national guidelines.<sup>13</sup> Most of the patients in the HBC in IDDH have HIV at different stages and the minority of them suffer from other diseases such as cancer. Dying at home is very common.

The ProQOL has three discrete scales but does not create a composite indicator scale. In the current study, the volunteers had higher rankings in the CF scale than the validation group. Individuals with altruistic desire to help in difficult situations report often high CS and CF scores. The combination of low scores on burnout with a high score on CF is of greatest concern as it may be an indicator for risk of a negative outcome such as depression and posttraumatic stress disorder.<sup>10</sup> In our data, only one volunteer (5%) demonstrated this risk combination. The volunteers of the current study reported a low level of burnout, which is in accordance with the results of a few previous studies outside Africa.<sup>12,24</sup>

We understand that these results must be considered cautiously for many reasons. First, although the ProQOL questionnaire has been used successfully with Western volunteers,<sup>11</sup> cultural differences may apply in Tanzania. Second, only 42% of the volunteers responded to this part of the study. Furthermore, although the Swahili translation of the questionnaire was carefully performed, showed a high reliability, and excellent back-translation to English was achieved, the Kiswahili translation differed from the local dialect spoken in the area. We were aware that the languages may be different in various villages in Tanzania, yet we decided to execute a translation from English to standard Kiswahili. The translation was done in two phases: the English version of the ProQOL was first translated by a former missionary pastor with vast experience and knowledge in the

Kiswahili grammar and it was subsequently corrected by two health care professionals whose native tongue was Kiswahili. However, we estimated afterward that 13 questions of 30 (statements 7, 8, 9, 11, 13, 15, 16, 18, 20, 22, 23, and 28) may have been difficult to comprehend by an uneducated person who speaks only the local dialect in the Ilembula area. In addition, the statements of the BO-scale received the lowest Cronbach's alpha values. Clearly, adjustments for local dialects may be necessary in future studies in Tanzania. However, our observations regarding the stress levels were confirmed in qualitative responses and in private discussions with the volunteers. Finally, our results are in line with previous results of the feasibility of ProQOL in palliative care volunteers and professionals.<sup>25</sup> Different palliative care services can be compared, only if similar assessment instruments are used.

We would recommend further studies addressing the workload and work-related burden of volunteers in Africa. Further studies are also warranted to compare volunteer work in different areas of Tanzania. Palliative care is one of the youngest disciplines of medicine in Africa. Since the second National Multisectoral Conference for HIV/AIDS, which took place in 2002 in Dar-es-Salaam, palliative care services have expanded in the country through many developmental projects and in 2016 the Ministry of Health published national guidelines for HBC services in Tanzania. International comparisons of the intentions, rewards, and work burden would also be welcome. The studies would assist in the development of educational and support mechanisms for volunteering laymen. Finally, more studies are needed to understand the mechanisms of reward for volunteer work, since there are concerns about getting enough volunteers in Tanzania.

### Conclusion

This study provided evidence of the high workload and dedication of the volunteers in palliative care in Tanzania. Volunteers were highly motivated in their work and they did not report burnout. Yet, the results of this study propose that coping strategies for dealing with suffering and death, as well as psychological support, should be added to the training and care of volunteers. Finally, we have provided a validated Kiswahili version of ProQOL to be used in future studies, and Lisa Taras, MD for English language editing.

### Acknowledgments

We thank the Finnish Christian Medical Society for financial support, and Dr. Tapio Pitkänen, MD, PhD, and Rev. Eljas Suikkanen for valuable assistance in planning the study, and Lisa Taras, MD for English language editing.

### Author Disclosure Statement

No competing financial interests exist.

### References

1. Nanney E, Smith S, Hartwig K, et al.: Scaling up palliative care services in rural Tanzania. *J Pain Symptom Manage* 2010;40:15–18.
2. Onyeka TC, Velijanashvili M, Abdissa SG, et al.: Twenty-first century palliative care: A tale of four nations. *Eur J Cancer Care* 2013;22:597–604.
3. Claxton-Oldfield S, Claxton-Oldfield J: The impact of volunteering in hospice palliative care. *Am J Hosp Pall Med* 2007;24:259–263.
4. Candy B, France R, Low J, Sampson L: Does involving volunteers in the provision of palliative care make a difference to patient and family wellbeing? A systematic review of quantitative and qualitative evidence. *Int J Nurs Stud* 2015;52:756–768.
5. Akintola O: What motivates people to volunteer? The case of volunteer AIDS caregivers in faith-based organizations in KwaZulu-Natal, South Africa. *Health Policy Plan* 2011; 26:53–62.
6. Claxton-Oldfield S, Jefferies J, Fawcett C, et al.: Palliative care volunteers: Why do they do it? *J Palliat Care* 2004;20: 78–84.
7. National Guidelines for Home Based Care Services: National AIDS Control Programme (NAPC). The United Republic of Tanzania, Ministry of Health and Social Welfare, Dar es Salaam, Tanzania, 2010.
8. Claxton-Oldfield S: Hospice palliative care volunteers: The benefits for patients, family caregivers, and the volunteers. *Palliat Support Care* 2015;13:809–813.
9. Dein S, Abbas SQ: The stresses of volunteering in a hospice: A qualitative study. *Palliat Med* 2005;19:58–64.
10. Huynh J-Y, Winefield AH, Xanthopoulou D, Metzger JC: Burnout and connectedness in the job demands–resources model: Studying palliative care volunteers and their families. *Am J Hosp Palliat Med* 2012;29:462–475.
11. Brown MV: How they cope: A qualitative study of the coping skills of hospice volunteers. *Am J Hosp Palliat Med* 2011;28:398–402.
12. Slocum-Gori S, Hemsworth D, Chan WWY, et al.: Understanding compassion, satisfaction, compassion fatigue and burnout: A survey of the hospice palliative care workforce. *Palliat Med* 2011;27:172–178.
13. Claxton-Oldfield S: Hospice palliative care volunteers: A review of commonly encountered stressors, how they cope with them, and implications for volunteer training/management. *Am J Hosp Palliat Care* 2016;33:201–204.
14. Cocker F, Joss N: Compassion fatigue among healthcare, emergency and community service workers: A systematic review. *Int J Environ Res Public Health* 2016;13:618–716.
15. Smith-Lunsford S, Fatta K, Stover KE, et al.: Supporting close-to-community providers through a community health system approach: Case examples from Ethiopia and Tanzania. *Hum Resour Health* 2015;28:13:12.
16. Eagar K, Senior K, Fildes D, et al.: *The Palliative Care Evaluation Tool Kit: A Compendium of Tools to Aid in the Evaluation of Palliative Care Projects*. Australia: Centre for Health Service Development, University of Wollongong, 2004.
17. Stamm BH: *The ProQOL Manual. The Professional Quality of Life Scale: Compassion, Satisfaction, Burnout & Compassion, Fatigue/Secondary Trauma Scales*. Idaho: Sidran Press, 2005.
18. Defining volunteering in hospice and palliative care in Europe: An EAPC White Paper. *Eur J Pall Care* 2016;23: 184–191.
19. *Tanzania Labour Market Risk Report Q4, 2016*. Business Monitor International Ltd., BMI Research, London, 2016.
20. Jack BA, Kirton J, Birakurataki J, Merriman A: 'A bridge to the hospice': The impact of a Community Volunteer Programme in Uganda. *Palliat Med* 2011;25:706–715.

21. Jack BA, Kirton JA, Birakurataki J, Merriman A: The personal value of being a palliative care Community Volunteer Worker in Uganda: A qualitative study. *Palliat Med* 2012;26:753–759.
22. Jack BA, Kirton JA, Downing J, Frame K: The personal value of being part of a tropical health education trust (THET) links programme to develop a palliative care degree programme in Sub Saharan Africa: A descriptive study of the views of volunteer UK health care professionals. *Global Health* 2015;11:47.
23. Grant L, Brown J, Leng M, et al.: Palliative care making a difference in rural Uganda, Kenya and Malawi: Three rapid evaluation field studies. *BMC Palliat Care* 2011;10:8.
24. Phillips J, Andrews L, Hickman L: Role ambiguity, role conflict, or burnout: Are these areas of concern for Australian palliative care volunteers? Pilot study results. *Am J Hosp Palliat Med* 2014;31:749–755.
25. Alkema K, Linton JM, Davies R: A Study of the relationship between self-care, compassion satisfaction, compassion fatigue, and burnout among hospice professionals. *J Soc Work End Life Palliat Care* 2008;4:101–119.

Address correspondence to:  
 Reino Pöyhkä, MD, PhD  
 Department of Clinical Medicine,  
 Oncology, and Radiotherapy  
 Division of Palliative Medicine  
 University of Turku  
 Turku 20014  
 Finland

E-mail: reino.poyhia@helsinki.fi

#### APPENDIX 1. QUESTIONNAIRE B

Ukiwasaidia wengine utahusiana na maisha yao moja kwa moja. Yamkini ulivyokwishaona, huruma yako kwa unaoaidia ina kipelengee chanya (mazuri) na hasi (mabaya). Tungependa kukuuliza maswali kuhusu uzoefu kwa pande zote ya chanya na hasi uliyokumbana nayo kama msaidizi. Fikiria kila swali katika orodha ifuatayo mintarafu ya hali ulipo kwa sasa. Katika nafasi mbele ya swali tia namba unayoona ni kweli zaidi kuhusu hali yako katika siku 30 zilizo-pita. 0=Hata kamwe, 1=mara chache sana, 2=mara chache, 3=mara kwa mara, 4=mara nyingi, 5=mara nyingi sana.

- \_\_\_\_\_ 1. Ninaona furaha.
- \_\_\_\_\_ 2. Ninaafikishwa na zaidi ya mtu mmoja ninayemsaidia.
- \_\_\_\_\_ 3. Mimi hupata kuridhika nikiweza kuwasaidia watu.
- \_\_\_\_\_ 4. nahisi nimehusianishwa na watu wengine.
- \_\_\_\_\_ 5. Sauti za ghafula na nisizotarajia hunishtua.
- \_\_\_\_\_ 6. Mimi huwa na nguvu zaidi baada ya kufanya kazi na wale ninaosaidia.
- \_\_\_\_\_ 7. Ni vigumu kwangu kutenganisha maisha yangu binafsi na maisha kama msaidizi wa watu.
- \_\_\_\_\_ 8. Nakosa raha ya usingizi kwa ajili ya taabu kubwa ya kisaikolojia au ya kimwili inayotokana na ninaowasaidia.
- \_\_\_\_\_ 9. Nafikiri nimeambukizwa na fadhaa yao ninaowasaidia.
- \_\_\_\_\_ 10. Najisikia nimenaswa na kazi yangu ya kuwasaidia watu.
- \_\_\_\_\_ 11. Kwa sababu ya kuwasaidia watu, nimehisi nimefika ukingoni kwa mambo mengi.
- \_\_\_\_\_ 12. Napenda kazi ya kuwasaidia watu.

- \_\_\_\_\_ 13. Nina huzuni itokanayo na kuwasaidia watu.
- \_\_\_\_\_ 14. Nahisi kama napitia maumivu ya fadhaa ya mtu niliyesaidia.
- \_\_\_\_\_ 15. Ninayo imani inayonistahimilisha.
- \_\_\_\_\_ 16. Nina radhi na jinsi nimeweza kuendeleza mbinu na itifaki zangu za kutoa msaada.
- \_\_\_\_\_ 17. Nimekuwa mtu Yule Yule ambaye daima nime tamani niwe.
- \_\_\_\_\_ 18. Kazi yangu (ya kuwasaidia watu) yaniridhisha/furahisha.
- \_\_\_\_\_ 19. Nasikia uchovu sana kwa sababu ya kazi ya kuwasaidia watu.
- \_\_\_\_\_ 20. Ninayo mawazo na hisia za furaha kwa wale nisaidiao na jinsi ninavyoweza kuwasaidia.
- \_\_\_\_\_ 21. Nahisi kuzidiwa na kiasi cha kazi au ukumbwa (wingi) wa mambo ninayo shughulikia.
- \_\_\_\_\_ 22. Naamini kwamba naweza kubadilisha maisha ya ninao wasaidia.
- \_\_\_\_\_ 23. Najaribu kuyaepuka mambo au matukio yanayolingana na fadhaa za watu ninaowasaidia.
- \_\_\_\_\_ 24. Nina mpango wa kuwa msaidizi kwa muda mrefu.
- \_\_\_\_\_ 25. Kama matokeo ya kuwasaidia watu, napata mawazo ya ghafula yanayonitisha.
- \_\_\_\_\_ 26. Najisikia nimehoofishwa na mfumo wa kuwasaidia watu.
- \_\_\_\_\_ 27. Najisikia nimepata mafanikio kama msaidizi (Nimekuwa hodari kama msaidizi).
- \_\_\_\_\_ 28. Siwezi kukumbuka sehemu muhimu ya kazi yangu na walioathiriwa na uwewe.
- \_\_\_\_\_ 29. Mimi ni mtu mwepesi sana kwa jamo lolote.
- \_\_\_\_\_ 30. Nina furaha kwamba niliamua kufanya kazi hii ya usaidizi wa watu.

*Original**Back-translation*

Helping others puts you in direct contact with other people's lives. As you probably have experienced, your compassion for those you help has both positive and negative aspects. We would like to ask you questions about your experiences, both positive and negative, as a helper. Consider each of the following questions about you and your current situation. Write in the number that honestly shows how often the statement has been true for you in the last 30 days.

0 = never, 1 = rarely, 2 = a few times, 3 = somewhat often, 4 = often, 5 = very often

- \_\_\_\_\_ 1. I am happy.
- \_\_\_\_\_ 2. I am preoccupied with more than one person I help.
- \_\_\_\_\_ 3. I get satisfaction from being able to help people.
- \_\_\_\_\_ 4. I feel connected to others.
- \_\_\_\_\_ 5. I jump or am startled by unexpected sounds.
- \_\_\_\_\_ 6. I have more energy after working with those I help.
- \_\_\_\_\_ 7. I find it difficult to separate my private life from my life as a helper.
- \_\_\_\_\_ 8. I am losing sleep over a person I help with traumatic experiences (psychological or physical).
- \_\_\_\_\_ 9. I think that I might have been "infected" by the traumatic stress of those I help.
- \_\_\_\_\_ 10. I feel trapped by my work as a helper.
- \_\_\_\_\_ 11. Because of my helping, I have feel "on edge" about various things.
- \_\_\_\_\_ 12. I like my work as a helper.
- \_\_\_\_\_ 13. I feel depressed as a result of my work as a helper.
- \_\_\_\_\_ 14. I feel as though I am experiencing the trauma of someone I have helped.
- \_\_\_\_\_ 15. I have beliefs that sustain me.
- \_\_\_\_\_ 16. I am pleased with how I am able to keep up with helping techniques and protocols.
- \_\_\_\_\_ 17. I am the person I always wanted to be.
- \_\_\_\_\_ 18. My work makes me feel satisfied.
- \_\_\_\_\_ 19. Because of my work as a helper, I feel exhausted.
- \_\_\_\_\_ 20. I have happy thoughts and feelings about those I help and how I could help them.
- \_\_\_\_\_ 21. I feel overwhelmed by the amount of work or the size of my caseload I have to deal with.
- \_\_\_\_\_ 22. I believe I can make a difference through my work.
- \_\_\_\_\_ 23. I avoid certain activities or situations because they remind me of frightening experiences of the people I help.
- \_\_\_\_\_ 24. I plan to be a helper for a long time.
- \_\_\_\_\_ 25. As a result of my helping, I have sudden, unwanted frightening thoughts.
- \_\_\_\_\_ 26. I feel "bogged down" by the system.
- \_\_\_\_\_ 27. I have thoughts that I am a "success" as a helper.
- \_\_\_\_\_ 28. I can't remember important parts of my work with trauma victims.
- \_\_\_\_\_ 29. I am an unduly sensitive person.
- \_\_\_\_\_ 30. I am happy that I chose to do this work

If you assist others you will be directly associated with their lives. As you have already seen, your compassion to those you assist has positive (good) and negative (bad) aspects. We would like to ask you some questions regarding your experience on both positive and negative experiences that you came into contact with as an assistant. Think about every question on the following list as regards your present situation. Write the most relevant number in front of every question in relation to your own views for the past 30 days.

0 = never, 1 = hardly, 2 = rarely, 3 = often, 4 = many times, 5 = very many times

- \_\_\_\_\_ 1. I am happy.
- \_\_\_\_\_ 2. I am appreciated by more than one of the people I assist.
- \_\_\_\_\_ 3. I get satisfied if I can assist people.
- \_\_\_\_\_ 4. I feel I am connected to other people.
- \_\_\_\_\_ 5. Sudden and unexpected voices startle me.
- \_\_\_\_\_ 6. I feel stronger after working with those I assist.
- \_\_\_\_\_ 7. It is difficult for me to separate my personal life from my life as an assistant to people.
- \_\_\_\_\_ 8. I fail to get sound sleep due to extreme body and psychological stress resulting from those I assist.
- \_\_\_\_\_ 9. I think I have been affected by the neurosis of those I assist.
- \_\_\_\_\_ 10. I feel I am trapped by my job of assisting others.
- \_\_\_\_\_ 11. Because of assisting others, I feel I am at the brink of many things.
- \_\_\_\_\_ 12. I like the work of assisting people.
- \_\_\_\_\_ 13. I am sad as a result of assisting people.
- \_\_\_\_\_ 14. I feel that I am experiencing neurotic pains of the person I am assisting.
- \_\_\_\_\_ 15. I have faith that sustains me.
- \_\_\_\_\_ 16. I am satisfied with the way I have been able to develop my strategies and protocol of rendering assistant.
- \_\_\_\_\_ 17. I have become the very same person I have always desired to be.
- \_\_\_\_\_ 18. My work (of assisting people) satisfies/makes me happy.
- \_\_\_\_\_ 19. I feel exhausted because of the work of assisting people.
- \_\_\_\_\_ 20. I have happy thoughts and feelings for those I assist and the way I am able to assist them.
- \_\_\_\_\_ 21. I feel overwhelmed by the amount of work or the magnitude (plenty) of matters I deal with.
- \_\_\_\_\_ 22. I believe I can change the lives of those I assist.
- \_\_\_\_\_ 23. I am trying to avoid matters and events similar to neurosis of the people I assist.
- \_\_\_\_\_ 24. I plan to be an assistant for a long time.
- \_\_\_\_\_ 25. As a result of assisting people, I get sudden horrifying thoughts.
- \_\_\_\_\_ 26. I feel weakened by the system of assisting people.
- \_\_\_\_\_ 27. I feel I am successful as an assistant (I have become brave as an assistant)
- \_\_\_\_\_ 28. I can't remember the most important sections of my work nor those affected by neurosis.
- \_\_\_\_\_ 29. I am a very active person on any issue.
- \_\_\_\_\_ 30. I am glad that I decided to do this work of assisting people.