



MASTER THESIS

The Cost of Caring:
The professional quality of life of Dutch
volunteers in palliative care and
associated factors

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Abstract

Aims

The present study aimed to explore the wellbeing, or professional quality of life of Dutch volunteers in palliative care. Dutch volunteers in palliative care have a unique and important role in palliative care institutions, yet the status of their professional wellbeing remains widely unknown. Therefore, the prevalence of compassion satisfaction, burnout and secondary traumatic stress were investigated. Furthermore, the present study focused on the extent to which personal, work related, and organization related factors were associated with volunteers' professional quality of life.

Methods

A cross-sectional online survey was distributed among the network of the Dutch organization of volunteers in palliative care for data collection (n=107). From a network of 10 000 members, a total of 107 volunteers responded. Questions in the survey included measurements for compassion satisfaction, burnout and secondary traumatic stress (ProQOL), coping strategies (Coping inventory for Stressful Situation), personal situations, general aspects of volunteer work, situations that were most likely to occur during volunteer work and organizational related situations and the Role ambiguity scale. Correlation analyses, Kruskal-Wallis tests and multiple regression analyses were used to examine correlations between the different factors and the outcomes of compassion satisfaction, burnout and secondary traumatic stress.

Results

Demographical characteristics and characteristics of volunteer work such as work experience were not associated with professional quality of life of volunteers. However, it was found that emotion focused and task focused coping, interactions problems with or between the patient and their loved ones, and role ambiguity could be linked to volunteers' professional quality of life. Multiple regression analyses indicated that role ambiguity significantly accounted for 32% ($R^2_{adj} = 27\%$) of the variance in compassion satisfaction scores. For burnout, it was found that emotion-focused coping, task focused coping, and interaction problems involving patients and their loved ones were significantly accounting for 48% ($R^2_{adj} = 43\%$) of the variance in the scores. Lastly, emotion focused coping and interaction problems involving patients and their loved ones were found to significantly account for 43% ($R^2_{adj} = 38\%$) of the scores.

Conclusion

The current study showed that volunteers greatly enjoyed the positive aspects of their work. However, it was also shown that volunteers do feel the costs of caring when experiencing the trauma of loss and grief, even though this is not a loss of their own. Further research is necessary to explain the found links between coping strategies and mental health complaints (burnout and secondary traumatic stress). The

measure of role ambiguity should be repeated using the updated scale. For the current study it can be concluded that the application of the scale seemed feasible with volunteer workers.

Introduction

Volunteers play a vital yet unique role in the palliative care movement. Volunteers are unified by their relational nature of their contribution to qualitative palliative care. Yet, they can divert greatly in (educational, social, economic) background, motivation to volunteer and other aspects, which implies a broad scale of factors that can protect against or expose them to the risk of developing mental health problems that may have negative implications for their (professional) quality of life, a concept that has been used to measure the extent of compassion satisfaction, burnout and secondary traumatic stress in (professional) caregivers. Mental health problems seem to go hand in hand with working in palliative care. Referred to as the “cost of caring” (Figley, 1995) mental health problems can express itself as the literal fatigue of showing compassion, empathy and/or sympathy when caring for another person. However, research on volunteers regarding the prevalence of mental health issues such as compassion fatigue has been sparse and/or has shown conflicting results. The present research aims to examine the prevalence of mental health complaints among Dutch volunteers in palliative care. Furthermore, this research aims to clarify the relationship between compassion fatigue and contextual factors, which include the volunteer as a person, the nature of volunteer work in palliative care, and how this work is organized.

Palliative care in the Netherlands

The aim of palliative care is to ease symptoms of physical illness and uphold quality of life as much as possible, when the cure of an illness is no longer an option. Furthermore, patients and their loved ones receive emotional, social and spiritual support in the grieving process (Eizenga, De Bont, Vriezen, Jobse, Kruijt, Lampe, Leydens-Arendse, Van Meggelen, & Van den Muijsenbergh, 2006). Thus, palliative care is characterized by a continuous, active and integrated way of caring (Eizenga, et al., 2006) in which it is a priority to provide emotional and psychological support for both patient and family (Algood, 2014). The “Being there”-philosophy (Goossensen, 2016) is a widely embraced core value in palliative care settings, according to which all palliative care workers, including volunteers, are expected to apply their own empathic, sympathetic and compassionate capabilities when comforting patients and their families through the mourning process (Goossensen, 2016; Claxton-Oldfield, & Claxton-Oldfield, 2007).

Hospice volunteers in the Netherlands

As umbrella organization for volunteer work in palliative care, Vrijwilligers Palliatieve Terminale Zorg (VPTZ), there are about 10.000 active volunteers per year (Goossensen, 2016;

VPTZ, 2017). With palliative care being a rather recent development in the Netherlands (van Staa, Visser, Van der Zouwe, 2000), the group of Dutch palliative care volunteers poses an especially interesting yet sparsely researched case. As volunteering culture differs among European countries (Goossensen, 2016), it is safe to assume that Dutch volunteering culture will differ from British volunteer culture that have been in the focus of research so far, as well as Canadian and American volunteer culture. In the Netherlands, palliative care is provided by the general practitioner, district nurses and, if needed, multidisciplinary palliative teams for further consultation. (Eizenga, et al., 2006). Volunteers are considered an additional workforce to the professional (general practitioners, nurses) and informal care (social relatives of the patient) in palliative care institutions. Despite its uniqueness, the position of volunteers in palliative care seems to have been neglected by most of the research so far (Testoni, Faletti, Visintin, Ronconi, & Zamperini, 2016).

The range of tasks performed by volunteers is rather broad and the role, including its boundaries, has yet to be made clear (Payne, 2001; Goossensen, Somsen, Scott, Peltari, 2016).

Role of the volunteer

The role of volunteers can be regarded as rather unique. Being neither part of the professional health care (such as nurses, general practitioners, etc.) nor informal care (social relatives of the patient) volunteers seem to hover somewhere in between (Pesut, et al., 2014; Goossensen, 2016; Goossensen et al., 2016) At the same time, volunteers constitute a substantial part of the palliative care workforce. The work of volunteers has often been characterized as relational because volunteers get to know the patient and their families on a personal level fulfilling the role of a companion, as they tend to the patients' and family's personal needs (Claxton-Oldfield, & Claxton-Oldfield, 2007; Claxton-Oldfield, & Claxton-Oldfield, 2008; Pesut, et al., 2014; Goossensen, 2016; Testoni, Faletti, Visintin, Ronconi, & Zamperini, 2016).

The support that volunteers provide thus can be emotional (e.g. sitting quietly with the patient or family, holding their hand) as well as practical (e.g. picking up mail, walking the patient's dog, running errands) (Claxton-Oldfield, & Claxton-Oldfield, 2007). In doing so, they contribute a great part to the satisfaction of the patients' (family's) hospice experience (Goossensen, et al., 2016).

Tasks of a volunteer

In general, volunteers have to refrain from unwanted initiative taking, when it comes to tasks related to professional healthcare (Goossensen, 2016) but even then, there is a broad

variety of tasks that volunteers can carry out which allows a categorization of volunteers into three different volunteer types: D-volunteers (professionals working within their discipline without being paid such as physicians, nurses and chaplains), C-volunteers, subdivided into care-focused roles (involvement with patients and their loved ones) and indirect facilitative roles (supporting hospice organization or clinical team by performing office duties, domestic services, gardening, catering etc.) and B volunteers (such as unpaid board members of hospice palliative care services) (Smeding, 2013). Volunteers are a welcome addition to paid employment as they offer support on tasks that are normally executed by paid employees which can save costs and efforts (Payne, 2001; Claxton-Oldfield, & Claxton-Oldfield, 2008; Goossensen, et al., 2016). Goossensen et al. (2016) has furthermore proposed a distinction between task-oriented and comfort-oriented tasks and . However, the actual perception of volunteers concerning their own role has only been sparsely accounted for, especially for the case of the Netherlands.

Becoming a volunteer

While volunteers face the same encounters as professional healthcare, they do so with a different educational background and preparations than professional health caregivers do (Pesut, et al., 2014). This has also been noted by Fox (2006), who found that training for medical staff was focused on maintaining a professional distance to emotionally burdening experiences, including death and dying (“detached concern”). As a contrast, training for hospice volunteers rather focused on participation in the mourning process and being there for the patients and their families, which implies a rather “attached concern” and therefore more involvement with the patient. The process of becoming a hospice volunteer follows a well-organized path. Volunteer organizations usually provide a generic training course including topics such as the philosophy and goals of palliative care, information about the different workforces and roles within a palliative care institution, information about the dying process, communication skills, and the grieving process (Payne, 2001; Claxton-Oldfield, & Claxton-Oldfield, 2007). During their first volunteer shifts, a novice volunteer receives training on the job by an experienced peer volunteer. A final post-training interview with the volunteer coordinator follows, in which experiences will be reflected upon and where both volunteer candidate and coordinator make the final decision if the is fit to be a volunteer (Claxton-Oldfield, & Claxton-Oldfield, 2007).

Motives

Volunteers, generally perceive their work in palliative care as rather rewarding (Claxton-Oldfield, 2016; Edit et al., 2016) and stress-free (Pesut, et al. 2014). Among the

motives that drive people to go volunteer in palliative care, personal experience with loss in one's social environment has constantly been named. Further motivations were the wish to continue previous work experience in health care (e.g. nursing) after retirement, to gain more volunteer experience after previous volunteer work in other institutions, or to take the possibility to work in the field of health care at all (Payne, 2001; Claxton-Oldfield, & Claxton-Oldfield, 2007). Furthermore, volunteers emphasized on the opportunity to provide service and contributing to society (Brown, 2011a; Phillips, Andrews, & Hickman, 2014), with freedom to do so on their own terms being a prominent motivator as well (Guirguis-Younger, & Grafanaki, 2008). Another motivator to be mentioned is the amount of positive experiences, such as personal growth, learning how to keep things in perspective (Payne, 2001; Claxton-Oldfield, & Claxton-Oldfield, 2007; Guirguis-Younger, & Grafanaki, 2008; Claxton-Oldfield, & Claxton-Oldfield, 2012). The confrontation with finality of life has been perceived by volunteers as a way to find greater meaning in life and personal growth in spiritual matters, self-disclosure and beliefs in continuity of life (Guirguis-Younger, & Grafanaki, 2008; Sinclair, 2011). Positive experiences were also related to the contact with the patients and their families, that is, being appreciated as a volunteer, bonding with patients and learning from their experiences and stories (Claxton-Oldfield, & Claxton-Oldfield, 2012; Phillips, Andrews, & Hickman, 2014). Even though volunteers have described their experiences as highly rewarding, it may be burdensome at times.

The cost of caring

Definition

Caring comes at a certain cost that may have implications for volunteers' (professional) quality of life. Professional quality of life refers to how a person perceives their work as a helper and is used to describe its positive (from now on referred to as compassion satisfaction) and negative aspects (compassion fatigue) (Stamm, 2010), also referred to as the "cost of caring for others" (Figley, 1995). Compassion fatigue incorporates aspects of both burnout and secondary traumatic stress (Stamm, 2010; Abendroth & Flannery, 2006) and indicates a stress response to a person's own desire to help someone who is suffering from traumatic circumstances (Figley, 1995; Abendroth, & Flannery, 2006; Sinclair, Raffin-Bouchal, Venturato, Mijovic-Kondejewski, Smith-MacDonald, 2016). The result is a state of helplessness, isolation and confusion (Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2011) with severe implications for the helper's mental and physical health, including depression and other stress-related mental health complaints in the long run, if not treated (Keidel, 2002; Slocum-Gori, et

al., 2011; Melvin, 2012). Symptoms usually include emotional and physical fatigue and can be accompanied by signs of depression, states of anxiety and intrusive thoughts (Keidel, 2002; Slocum-Gori, et al., 2011; Melvin, 2012). This can lead to emotional devastation at an extent that is comparable to that of a traumatized patient and good quality of care can no longer be guaranteed (Melvin, 2012) or care might even be abandoned (Slocum-Gori, et al., 2011). In the following paragraph, professional quality of life for palliative care workers will be addressed in particular. When discussing its components, this study will refer to burnout and secondary traumatic stress instead of compassion fatigue to address the different facets of professional quality of life.

Regarding secondary traumatic stress, a palliative care worker may experience feelings of fear and trauma related to the nature of their work by the exposure to knowledge about traumatizing events without actually being (threatened to be) physically harmed (Figley, 1988; Stamm, 2010). It has been suggested that palliative care workers may experience the passing of a patient as if it was a loss of their own, (Abendroth, & Flannery, 2006). Due to the parallels between compassion fatigue and secondary traumatic stress, these terms have been used interchangeably (Salston, & Figley, 2003, Stamm, 2010).

The aspect of burnout and how it is manifested in hospice workers' professional quality of life, has also been addressed (Keidel, 2002; Abendroth, & Flannery, 2006; Slocum-Gori et al., 2011). Burnout is a rather broad concept indicating a response to stress in any profession, without taking compassion into the equation (Slocum-Gori, et al., 2011). Compassion fatigue has been used to uniquely address workers in health care professions in particular as a result of exposure to the suffering of others (Figley, 1995; Abendroth, & Flannery, 2006). Common to both burnout and compassion fatigue is an expression of negative attitudes and behaviors such as blaming others, a short temper and a short attention span. These attitudes and behaviors can make it difficult for the palliative care worker to build a relationship with the patient and their families (Keidel, 2002; Slocum-Gori, et al., 2011).

One measure that is thought to counter balance complaints related to burnout and secondary traumatic stress, is compassion satisfaction (Slocum-Gori, et al., 2011), which may function as a resiliency to stress. Referred to as a positive aspect of the work as a palliative care worker, compassion satisfaction can be seen as the emotional reward of caring, where the worker feels good about making a contribution to a good cause (Stamm, 2010; Slocum-Gori, et al., 2011).

When "being there" for patients and their families as they are facing grief and loss, volunteers become witnesses to the trauma of grief of others, while frequently facing loss

themselves (Abendroth, & Flannery, 2006). Therefore, it can be assumed that the (professional) quality of life of volunteers is very likely to be at risk just as much as it has been observed in professional health care staff. Research on the prevalence of mental health complaints, including burnout and secondary traumatic stress, among hospice volunteers has yielded inconsistent results. A number of studies found symptoms of compassion fatigue specifically (Edit, Kegye, Zana, & Hegedus, 2016; Avieli, Levy, & Ben-David, 2016) in hospice workers, including hospice volunteers. On the other hand, there were also studies in which hospice volunteers did not show any signs of mental health complaints (Brown, 2011a; (Phillips, Andrews, & Hickman, 2013; Thieleman, & Cacciatore, 2014; Montross-Thomas, Schreiber, Meier, & Irwin, 2016) and when compared to other professional affiliations, hospice volunteers scored lower on a compassion fatigue scale (Slocum-Gori, et al., 2011).

So far, evidence on the prevalence of mental health complaints as a negative consequence of caregiving has been based on studies mainly involving professional healthcare workers and less so volunteers. Evidence of burnout and secondary traumatic stress in volunteers explicitly has been lacking and has also shown inconsistent results, especially in the case of Dutch volunteers in palliative care. Furthermore, taxonomical inconsistencies between the concepts of compassion fatigue, vicarious trauma and secondary trauma have yet to be solved, as the overall idea of professional quality of life is a rather complex concept (Stamm, 2010). It has further been suggested that the prevalence of burnout and secondary traumatic stress is may be related to a variety of factors, as described below.

Factors related to compassion fatigue in hospice care

There has been thorough research on aspects of palliative care work that may be experienced as stressful, focusing on the experience of volunteers in particular. The relationship between those factors and volunteers' professional quality of life yet remains unclear. The uniqueness of their role as described above, and several qualitative studies involving hospice volunteers have implied several sources of potential stress (Brown, 2011a; Pesut, et al., 2014). The factors can be divided into three groups, personal-related, work-related and organization-related, which has also been suggested by Stamm (2010), who distinguished between factors related to the work environment, the volunteer as a person, and the volunteer's exposure to traumatic events in the work setting. For the current study, factors will be discussed in a likewise manner.

Personal factors unrelated to volunteer work

Personal-related factors concern the volunteer as a person, including the volunteer's characteristics, attitudes and capabilities. Culture, race, sex, sexual orientation, age, stage of

illness, spiritual beliefs, education, and economic situation have been used so far to merely describe the demography of study populations, yet these aspects have also shown possible links to burnout and compassion fatigue, specifically (Keidel, 2002, Dein, 2005; Abendroth, & Flannery, 2006). Several personal circumstances have been linked to a higher risk for stress responses of volunteers (Paradis, Miller, & Runnion, 1987), dealing with one's own fears about death (Pesut, et al.,2014), and not having enough time to volunteer (Brown, 2011a; Pesut, et al.,2014). Furthermore, stress at home, work and/or family environment (Claxton-Oldfield, 2016) have been associated with personally – related stress.

Another factor that has been investigated is how hospice volunteers' way of coping can prevent or even increase the risk of compassion fatigue (Brown, 2011a). Effective coping has proven to be important for ensuring good qualitative care because it has been linked to desirable behaviors of volunteers within the palliative care institution, including high empathetic concern, perspective taking, a need for caring (Lázló, Anita, & Andrea, 2017), having a clear understanding about the own role as a volunteer within the hospice and feeling supported by family and hospice staff (Claxton-Oldfield, & Claxton-Oldfield, 2008). The ways of coping that have been mentioned include striving to maintain a healthy balance between volunteer work, job, family, rest and leisure, and striving to have a personal support system, following a healthy, balanced life style, learning relaxation strategies (e.g. Yoga), learning how to say no (Claxton-Oldfield, & Claxton-Oldfield, 2007; Claxton-Oldfield, & Claxton-Oldfield, 2008; Claxton-Oldfield, 2016), and keeping a distance from clients (Dein, 2005). Several studies have differentiated between general coping strategies, such as problem-focused coping (e.g. seeking assistance from others), and emotion-focused coping (e.g. talking with others to seek emotional support (Claxton-Oldfield, & Claxton-Oldfield, 2008)), meaning making through appraisal (e.g. religious beliefs of death and benefit) and physical techniques (e.g. taking a walk with the pet) (Dein, 2005; Claxton-Oldfield, & Claxton-Oldfield, 2008; Brown, 2011b). The distinction between problem- (or task-) focused and emotion-focused coping is a well-known concept by Folkman and Lazarus (1988) that has been linked to several advantages and disadvantages for (mental) health. For example, research has shown that emotion-focused and avoidance focused coping have been associated with mental health problems such as depression and anxiety while problem-/task focused coping was associated with positive mental health outcomes (Folkman, & Lazarus, 1988; Endler, & Parker, 1990; Cohan, Lang, & Stein, 2006). For the case of (Dutch) hospice volunteers, however, the extent to which coping strategies as mentioned above are related to compassion fatigue, is however unknown.

Factors related to the nature of volunteer work

Work-related factors focus on the nature of volunteer work in the hospice that volunteers encounter during their volunteer time and in the contact with the patients and their families. It has been suggested that years of volunteer experience may be linked to the extent to which volunteer work in palliative care is perceived as stressful (Abendroth, & Flannery, 2002; Brown, 2011a; Phillips, Andrews, & Hickman, 2013). The majority of stressors have been found in the interaction with patients and their loved ones. Even though, building a relationship with patients and their families has contributed for a great part positive experiences, it has also been a source of stress (Paradis, Miller, & Runnion, 1987), such as when a patient is not accepting help (Brown, 2011a; Claxton-Oldfield, 2016) or when there is a fight with/among family members in front of the patient (Abendroth, & Flannery, 2006; Brown, 2011a; Pesut, et al.,2014; Claxton-Oldfield, 2016). After having made a deep connection with the patient, volunteers experienced the passing of this patient as particularly saddening (Dein, 2005; Pesut, et al.,2014; Claxton-Oldfield, 2016). Other patient-related stressors regarded the physical health of the patient, such as witnessing the patient's physical deterioration (Dein, 2005; Pesut, et al.,2014; Claxton-Oldfield, 2016), sounds of a patient dying and when a patient is experiencing a difficult death (Claxton-Oldfield, 2016). Furthermore, the following situations were experienced as difficult: a patient leaving young children behind, a patient not wanting the volunteer to leave (Dein, 2005; Brown, 2011a; Claxton-Oldfield, 2016), a patient sharing similarities with volunteer, such as age (Dein, 2005), and dealing with different expectations regarding the needs of patient and availability of volunteer (Brown, 2011a). Other factors that contributed to an increased experience of stress concerned working with someone with another style of working dealing with the unknown (Brown, 2011a), and interpersonal conflicts (Pesut, et al.,2014) at the hospice.

Factors related to how volunteer work is organized

Organization-related factors concern stressors that are a result of organizational aspects such as communication with colleagues and hospice policies. Early research has pointed towards the critical role of role ambiguity (Paradis, Miller, & Runnion, 1987) and has been confirmed by follow up research on the importance of clearly defined job requirements and responsibilities, frequent communication and feedback as well as flexibility in assignments and providing space to verbalize emotions (Glass, & Hastings, 1992; Payne 2001; Claxton-Oldfield, & Claxton-Oldfield, 2012; Claxton-Oldfield, 2016). Various studies have pointed to lack of communication being a stressor in various situations within the organization was a number of stressors regarding the (lack of) communication within an organization, including being unable

to act because of role restrictions (Payne, 2001; Claxton-Oldfield and Claxton-Oldfield, 2012; Pesut, et al., 2014; Claxton-Oldfield, 2016) and insufficient numbers of volunteers (Brown, 2011a; Pesut, et al., 2014).

Research on stressors has been extensive, yet it also pointed towards possible differences due to culture (Claxton-Oldfield, 2016) and the account of Dutch hospice volunteers has remained widely unexplored. The studies cited above have mainly applied a qualitative approach, wherein the positive experiences seemed to outweigh the negative experiences, it is unclear how often Dutch palliative care volunteers make these negative, which will therefore be investigated in the present study.

Present study

Due to the inconsistent findings on complaints related to professional quality of life in hospice volunteers, the present research is set to explore the case of Dutch volunteers in palliative care. Since research on professional quality of life among volunteers in the Netherlands appears to be missing, the present study seeks to examine the experience for hospice volunteers in the Netherlands in particular. Examining the studies referred to above, in which hospice volunteers did not report signs of distress caused by volunteering, led to suggest that several factors, at individual level, working level and organizational level, might be at play. Past study samples often examined volunteers with a working experience between five and seven years. (Brown, 2011a; Phillips, Andrews, & Hickman, 2013). It has yet also been indicated by Abendroth and Flannery (2006) and Brown (2011a) that working experience might be a mediating factor in how hospice nurses experience working in the hospice, and it would be interesting to investigate the experience of hospice volunteers with regard to working experience. Furthermore, different coping strategies applied by volunteers have been investigated with qualitative methods (Glass & Hastings, 1992; Claxton-Oldfield & Claxton-Oldfield, 2007; Brown, 2011b; Claxton-Oldfield, 2016), yet the effectivity of these different coping styles with regard to compassion fatigue remains unclear. Since a quantitative perspective is missing, in particular, for the case of hospice volunteers in the Netherlands, this will be the applied approach in the present study as well. The aim of the present study is to examine the (1) the status of professional quality of life among Dutch palliative care volunteers and (2) which factors are linked to it.

Research questions

The results of the literature review above result in the following research questions:

1. What is the professional quality of life (compassion satisfaction, burnout and secondary traumatic stress) of Dutch volunteers in palliative care?
2. Which factors are associated with developing complaints regarding professional quality of life of a volunteer?
 - a. Which volunteer-related factors are related to complaints regarding professional quality of life?
 - b. Which work-related factors are related complaints regarding professional quality of life?
 - c. Which organization-related factors are related to complaints regarding professional quality of life?

Method

The present study is a quantitative cross-sectional study to explore the wellbeing of Dutch palliative care volunteers, in the following referred to as professional quality of life, and how personal -, work – and organizational related variables might be related to volunteer’s (professional) wellbeing.

Participants and procedure

Volunteers from the Dutch association of volunteers in palliative and terminal care (VPTZ) were recruited online through VPTZ - affiliated palliative care institutions, in which they were registered. The present study handled the following inclusion criteria: Respondents had to be registered as volunteer in a Dutch palliative care institution. Respondents had to be older than 18 years and be registered in a Dutch municipality. Respondents were excluded when they were working in a palliative care institution in a position other than volunteering. Coordinators of VPTZ – affiliated palliative care institutions were provided with an information letter and an invitation email which was to be forwarded to the volunteers. Coordinators were asked to forward the invitation to the volunteers of their palliative care institution by using the email addresses with which volunteers were registered in the institution. The invitation included an anonymous link to the online survey. The survey had been examined and approved by the commission of Ethics of the BMS faculty of the University of Twente (18526).

The exact distribution of demographic variables is displayed in table 2. In total 135 volunteers responded to the survey. One respondent withdrew consent and two choose to leave the survey after reading the introduction. An additional 25 responses were manually excluded since no further data had been recorded after proceeding to the survey. As a result, the data of 107

respondents was used for further analysis. Respondents were between 41 and 78 years old, with an average age of 62.5 (SD = 8.2) years. The majority of the current sample was women (men = 15.1%). All educational backgrounds were represented in the sample, most of the volunteers had either an MBO or HBO diploma. Half (50.9%) of the respondents had work experience in health care from previous work. The majority of participants was volunteering in the provinces of Gelderland and Overijssel. Nearly half (46.7%) of the volunteers considered themselves spiritual and the majority of volunteers indicated to have personal experience with the loss of a close relative (e.g. partner or parents).

Instrument

A complete overview of the survey can be found in appendix C. The survey was created with the Qualtrics online research tool. The survey was designed to measure the volunteer's professional quality of life, factors concerning personal circumstances, the nature of volunteer work and how volunteering was organized. Below, an overview of the specific parts of the instrument is provided.

Professional quality of life

Professional quality of life of the volunteers was conceptualized as professional quality of life and according to the framework of Stamm and Figley (2002), it is a complex concept encompassing positive (compassion satisfaction), and negative (burnout and secondary traumatic stress) consequences of working as a helper. These three aspects were measured with the Professional Quality of Life Scale (ProQOL) by Stamm (2010). The instrument was translated from English into Dutch according to the WHO method with forward and backward translations (https://www.who.int/substance_abuse/research_tools/translation/en/). ProQOL consists of thirty items in total and assesses quality of life on the three following subscales. Items on each subscale are to be answered on a five-point Likert scale from 1 (= "never") to 5 (= "always"). As a result, the minimum score per subscale is 10, while the maximum score is 50. Each subscale is unique and not to be combined with one of the other subscales. Reliabilities, as stated in the following for each of the subscales, are based on the scores of the current study. Compassion Satisfaction (CS) (10 items, Cronbach's $\alpha = .73$), measures the extent to which one experiences positive effects of his work as a helper. The CS-scale includes items such as "I get satisfaction from being able to help people". Following the instructions of the manual, a sum score was computed from the items for compassion satisfaction. According to the manual, scores lower than 40 are indicative of perceived problems at work or finding

satisfaction from other activities than one's job as a helper. Scores higher than 42 indicate that a great part of one's satisfaction is derived from one's work as a helper (Stamm, 2010).

Burnout (BO) (10 items, a Cronbach's $\alpha = .57$) refers to negative feelings related to the work environment such as unhappiness, exhaustion, and being overwhelmed. The BO-scale includes items such as "I am happy (reversed)" or "I feel trapped by my job as a volunteer". Several items were reversed, as it was suggested by the ProQOL manual (Stamm, 2005; Stamm, 2010). Despite the found low reliability of this scale, and due to the fact that ProQOL is a validated instrument, it was decided to treat the item scores accordingly to the manual, and compute a sum score for the burnout subscale as well. A high score, that is, above 22, on the burnout scale does not diagnose burnout but indicates an increased risk for burnout and doubts about one's own contribution at work (Stamm, 2005). Secondary Traumatic Stress (STS) (10 items, Cronbach's $\alpha = .75$) refers to the feeling of being deeply affected by others' trauma. The STS-scale includes items such as "I am preoccupied with more than one person I help". Scores above 17 can be seen as a need to reach out for help to make adjustments in work and/work environment (Stamm, 2010). Furthermore, sum scores were computed for each of the subscales Compassion Satisfaction (CS_sum), Burnout (BO_sum) and Secondary Traumatic Stress (STS_sum), with the designated items as described in the manual.

Person related factors

Besides demographical information, daily life struggles and coping behaviors were measured as described in the following.

Demographics

Volunteers were asked for demographical information including their gender, age, and highest attained education. Two items assessed if volunteers considered themselves spiritual (yes/no) and if they had personal experiences with loss (closely related / related / remotely close).

Coping

Volunteer's overall coping strategies were measured with a shortened 21-item version of the Coping Inventory for Stressful Situations (CISS (Endler and Parker, 1999)). This scale measures three types of coping as explained in the following, including reliabilities found in the current study Emotion-oriented coping (EOC, 7 items, Cronbach's $\alpha = .72$), aims to regulate one's own emotional reaction and includes behaviors such as self-preoccupation, fantasy, and contemplating (Horn, & Wilpert, 2017). This scale includes items such as "Blame me for having gotten into this situation". Task-oriented coping (TOC, 7 items, Cronbach's $\alpha = .78$) seeks to solve a situation by actively focusing on the problem (Horn, & Wilpert, 2017). Example items

are “Work to understand the situation”. Avoidance-oriented coping (AOC, 7 items, Cronbach’s $\alpha = .73$) is used to withdraw from an unpleasant situation and divert attention to other situations (example item “Treat me to a favorite food or snack”). The present study extracted the items in English translation from another study (Calsbeek, Rijken, Berge, Henegouwen, & Dekker, 2003) and items were translated to Dutch by both the researcher of the current study and a peer student who was a native speaker in Dutch.

Originally, items are to be rated on a 5-point Likert scale from 1 (Not at all) to 5 (Very much). The present study used a 5-point Likert scale from 1 to 5 (1 = never to 5 = always). Volunteers were asked to think of a situation that felt problematic to them in particular. They were then asked to indicate how often they engaged in coping behaviors that were suggested to them and that were related to either task- focused, emotion- focused or avoidance focused coping. Sum scores of each subscale were computed. A high score indicated that a coping strategy was frequently used, a low score indicated rare use of a coping strategy.

Stress in daily life

These types of stressors from volunteers’ daily life were measured with three self-constructed items based upon literature. These items were used to measure how often volunteers were experiencing stress that is rather part of their daily life than part of their volunteer environment. Per item, the maximum score was 5 (“Always”), meaning that a given daily life stressor was experienced at a high frequency, and therefore considered a very likely negative factor for a volunteer’s wellbeing. The lowest score was 1 (“Never”), and therefore considered a less likely experienced factor. Items included daily life struggles such as “stress within close relationships”, “stress at work (not voluntary work)” and “lack of time does not allow volunteering” (for a complete overview over all items, see also table 3). A factor analysis of the scale, based on principle component analysis, indicated one factor to be extracted from the three items, with an Eigenvalue > 1.00 that explained 36% of the variance. A reliability analysis for the three item-scale was performed and demonstrated an insufficient Cronbach’s α of .55. As a result, for further analysis, the items were not combined to a scale but analyzed individually.

Factors related to the nature of volunteer work

Items from this category were self-constructed on the basis of literature research and focused on two aspects, (1) working in palliative care in general and (2) interacting with patients and their families. Regarding the work in palliative care in general, volunteers were asked in which Dutch province, and in which type of palliative care institution (hospice, palliative care unit or home of the patient) they were doing volunteer work. Participants were also asked if they had previous work experience in health care. Further items focused on how much work

experience volunteers as a volunteer in palliative care had (in years), how many shifts per week and how many hours per shift they spent on volunteer work. Two items were used to estimate the intensity of contact that volunteers had with patients (“How long do you on average care for a patient” and “For how many patients have you cared for in the last 2 months?”). One last item investigated to what extent respondents were trained for their volunteer work and which kind of trainings had been absolved.

Regarding the interaction with patients and their families (for a full overview, see table 7) a scale (9 items, Cronbach’s $\alpha = .60$) was composed, based on literature research, on which volunteers were asked to indicate on a 5-point Likert scale (1= never to 5 = always) the frequency at which several described situations involving a patient had happened to them. Items described situations with the patient (not accepting help, visible signs of illness, sharing characteristics with the volunteer), the patient’s family (fighting in presence of patient; not communicating), and the patient’s death (leaving behind young family, difficult death, dying witnessed by volunteer, was close to volunteer). A factor analysis of the scale, based on principle component analysis, indicated three factors to be extracted from the nine items with an Eigenvalue > 1.00 that explained 58% of the variance. The first factor consisted of four items referring to situations where helping seemed hindered or futile: a patient not accepting help, lack of communication about circumstances of the patient, family having a fight in front of the patient, and witnessing the death of a patient.

The second factor included three items referring to the death of a patient: difficult death, leaving behind a young family and having been well acquainted with volunteer. The third factor included two items, referring to a patient’s characteristics: showing visible signs of illness and sharing characteristics with volunteer. Reliability analyses were only sufficient for the first factor (Cronbach’s $\alpha = .68$) and insufficient for the second factor (Cronbach’s $\alpha = .48$) and third factor (Cronbach’s $\alpha = .11$). Therefore, a sum score was created from the three items: patient not accepting help, lack of communication about circumstances of the patient, family having a fight in front of the patient and witnessing the death of a patient. The items of the second and third factor were analyzed individually due to low reliability.

Factors related to how volunteer work is organized

For a full overview of the items, see tables 7 and 8. Two sets of items were used to measure organizational aspects of the volunteer environment, (1) working together with formal care within the institution and (2) perception of the own role as a volunteer (referred to as role ambiguity).

Working with formal care

The first set (7 items Cronbach's $\alpha = .80$) was composed based on literature research that has pointed to communication issues being a stressor to hospice workers (Pesut et al., 2014). Three items addressed communication issues with professional health care (nurses, general practitioners, hospitals), and coordinators within the palliative care institution. Two items addressed issues regarding working together with professional health care. Furthermore, two items measured the extent to which volunteers felt that there was not enough time for being there for the patients and the extent to which volunteers were satisfied with the training facilities offered to them. Each item was to be answered on a 5-point Likert scale from 1 ("Totally disagree") to 5 ("Totally agree"). A high score implied high dissatisfaction of volunteers. A factor analysis of the scale, based on principle component analyses indicated two factors to be extracted from the seven items, with an Eigenvalue > 1.00 that explained 65% of the variance. The first factor consisted of one item regarding the offer of trainings to volunteers. The second factor consisted of six items regarding working together with professional healthcare and the coordinator. After reliability was found to be sufficient (Cronbach's $\alpha = .84$), a sum score from the six items was computed and called "cooperation with supervisors and professional health care".

Role Ambiguity

Role ambiguity was conceptualized as the extent to which volunteers perceived their role as ambiguous. Items were extracted from the subscale 'Role Ambiguity' (see appendix D) by Rizzo, House, and Lirtzman, (1970) (6 items, Cronbach's $\alpha = .54$). The reliability that was found in the current study was lower and conflicted with earlier studies that had found sufficient reliabilities. Closer examination suggested removal of the item "I can divide my time to my own liking", which would result in Cronbach's $\alpha = .82$. However, as this scale was a validated scale, it was decided to treat the items as a scale. The wording of the items was adjusted to fit the context of volunteering in palliative care, such as in the following example "Explanation is clear of what has to be done" became "Explanation is clear of what has to be done for a patient." Each item was to be rated on a 5-point Likert scale from 1 ("Totally disagree") to 5 ("Totally agree"). A high score on the scale indicated high levels of ambiguity. Scores for the first five items of the scale were therefore reversed. A translation procedure in which all items were translated from English into Dutch was applied by the researching student and a peer student. After the initial translation procedure, both translations were compared and for each item, the best fitting translation was chosen. The final choice of items was presented

to a third peer who provided final feedback that resulted in small adjustments to the choice of words for several items.

Procedure

Distribution of the survey started by informing coordinators of regional palliative care institutions about the research. Distribution to hospices farther away was enabled through an internal newsletter within the organization of VPTZ which was sent to hospice coordinators and board members. All coordinators of hospices were provided with a letter with information about the nature of the research project and a short letter for volunteers that included the link to the online survey. Coordinators were asked to distribute the short letter including the link among the volunteers in their organization through email. Data collection took place from June to mid of September. In this period, one reminder was sent two weeks before the deadline for data collection. The reminder included information about the research project and a short letter for volunteers with the link to the online survey. Furthermore, volunteers were informed to not fill in the survey again, in case they had already done so.

Analysis

Analysis employed SPSS versions 23 and 24.

Preliminary analyses

After excluding surveys which had no answers recorded after giving consent and surveys where consent was withdrawn, a missing value analysis was performed on the remaining 107 surveys. Little's MCAR test indicated that the remaining missing values are missing at random ($\chi^2(3128) = 3069.75, p = .77$). The dataset was therefore completed by using Multiple Imputation afterwards.

The distributions of the scores for professional quality of life (compassion satisfaction, burnout and secondary traumatic stress), coping styles (emotion focused, avoidance focused and task focused), work related factors (interaction problems), and organizational factors (role ambiguity, cooperation with supervisors and professional health care) were tested for normality by application of Kolmogorov Smirnov testing. Normality testing resulted in mixed results indicating a normal distribution for burnout, secondary traumatic stress, role ambiguity and interaction problems. For all other variables, the testing turned out significant and therefore non-parametric tests were used for further analyses that did not assume normality (see appendix C).

Data analyses

Descriptive analyses were used to allow inferences about the frequencies at which volunteers encounter the depicted situations and to depict general aspects about the sample and volunteer work. Taking the confirmed non-normality into consideration, correlational analyses using Spearman's Rho were applied to test the extent to which scores of the person-related, work-related and organization-related items were significantly related to each of the outcome variables of the ProQOL (compassion satisfaction, burnout and secondary traumatic stress). Means of the subscales of the ProQOL were compared to comparative scores from the ProQol manual and to two earlier studies which had applied the ProQOL to hospice volunteers. Kruskal Wallis tests were used to explore how the means regarding the scores on the ProQOL subscales differed across demographic variables and variables about volunteer work. Finally, for each subscale of the ProQOL, a multiple regression (forced entry) analysis was executed, including only those factors that had shown significant correlations with the ProQOL subscales, to determine if and how much those factors would explain the variance in the ProQOL scores. Beforehand, it was determined that assumptions about homogeneity of variance and linearity were not violated and application of multiple regression was feasible.

Results

Description of the sample

Respondents were between 41 and 78 years old, with an average age of 62.5 (SD = 8.2) years. The majority of the current sample was women (men = 15.1%). All educational backgrounds were represented in the sample, most of the volunteers had either an MBO or HBO diploma. Half (50.9%) of the respondents had work experience in health care from previous work. The majority of participants was volunteering in the provinces of Gelderland and Overijssel. Nearly half (46.7%) of the volunteers considered themselves spiritual and the majority of volunteers indicated to have personal experience with the loss of a close relative (e.g. partner or parents).

Prevalence of compassion satisfaction, burnout and secondary stress in Dutch volunteers

The mean sum scores of each subscale of the current sample were compared to mean sum scores that had been found in earlier studies, in which the ProQOL had been applied to hospice volunteers. Table 1 shows that the scores for compassion satisfaction were lower and for burnout nearly similar for volunteers in the present study in comparison with the scores of

volunteers in the reference studies. Mean scores for secondary traumatic stress were laying between the scores of the reference studies.

Table 1. Mean scores of the current study and comparison of means with past studies involving hospice volunteers

ProQOL subscale (min.- max. score)	Correlation (Spearman's rho) with			Current study	High score		Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2011 (N=121)	Montross-Thomas, Schreiber, Meier, & Irwin, 2016 (N=390)
	CS	BO	STS	Mean (SD)	n	%	Mean	Mean
Compassion satisfaction (CS) (10 – 50)	-	-	-	41.1 (3.8)		69.2	44.9	43
Scored above 40					74			
Burnout (BO) (10 – 50)	-.626**	-	-	17.6 (3.2)		13.1	17.7	20
Scored above 22					14			
Secondary traumatic stress (STS) (10 – 50)	-.477**	.553**	-	17.3 (4.1)		50.5	16.9	19
Scored above 17					54			

**p < .01. CS = compassion satisfaction, BO = Burnout, STS = Secondary traumatic stress

The mean sum scores of each subscale in the current study were furthermore compared to mean sum scores of each subscale provided by Stamm (2005), in the following referred to as cut-scores. For compassion satisfaction, it was found that volunteers in the current study scored on average slightly above the cut-scores (41.1 vs. 40), implying high satisfaction with their work as a helper. More than half of the volunteers in the current study scored above the comparative score. For burnout, volunteers' mean scores in the current study were lower than the comparative scores (14 vs. 22) and the group of volunteers in the current study who scored above the comparative score, was small.

The scores for secondary traumatic stress of volunteers in the current study were slightly above the comparative mean scores (17.3 vs 17). Here however, about half of the volunteers in the current sample scored even higher than the comparative scores, and thus indicating high scores.

Correlation analyses between the sum scores showed significant negative correlations among Compassion Satisfaction and Burnout, Compassion Satisfaction and Secondary

Traumatic Stress and a positive correlation between Burnout and Secondary Traumatic Stress and therefore confirmed the underlying interrelationships among the three concepts.

Factors related to the occurrence of compassion satisfaction, burnout and secondary traumatic stress in Dutch volunteers

In the following section, the significance of associations will be discussed according to the nature of the factors personal, work related, and organization related.

Personal factors

Demographics

As can be seen in table 2, and contrary to what had been suggested in earlier studies, there were no significant differences found in compassion satisfaction, burnout and secondary traumatic stress when testing for gender, educational background, spirituality and personal experience with loss. Furthermore, age was not significantly associated with compassion satisfaction ($p = -.01$), burnout ($p = -.09$) and secondary traumatic stress ($p = -.14$).

Table 2. Kruskal-Wallis tests on demographic variables and compassion satisfaction, burnout and secondary traumatic stress (N=107)

			Compassion satisfaction			Burnout			Secondary traumatic stress			
	n	%	df	Median (IQR)	χ^2	p	Median (IQR)	χ^2	p	Median (IQR)	χ^2	p
Gender			1		.512	n.s.		1.590	n.s.		.052	n.s.
Men	16	15		40 (39-44)			17 (15-18)			17 (14-19)		
Women	91	85		41.5 (39-44)			17 (16-20)			17 (14-20)		
Educational background			5		6.844	n.s.		4.097	n.s.		2.919	n.s.
VMBO	5	5		42 (40.5-44)			17 (15.5-19)			18 (14.5-21)		
HAVO	9	8		43 (39-44)			18 (16.5-20)			17 (15.5-22)		
MBO	31	29		41.5 (38.75-44.25)			17.5 (16-21)			18 (13-21.25)		
HBO	50	47		41 (39-44)			17 (15-20)			16 (14-19)		
WO	11	10		39 (37-40)			16.5 (15-21)			17 (14-20.5)		
Rather not say	1											
Spirituality			2		4.440	n.s.		2.048	n.s.		.233	n.s.
Yes	50	47		42 (39-44)			17 (15.5-19.5)			17 (14-19.5)		
No	52	49		40 (39-44)			18 (16-20)			16 (14-20)		
Experience with loss			2		.800	n.s.		1.645	n.s.		5.102	n.s.
Closely related (parents, or partner)	81	76		41 (39-44)			17 (15-20)			17 (14-20)		
Related (family, friends, neighbors, colleagues)	22	21		41.5 (38.5-45.75)			17 (16-19)			14 (13-18)		
No or remotely close	4	4		40 (36.75-43.25)			20.5 (17-21)			20 (16.5-22)		

Stress in daily life

Volunteers were asked to indicate how often they felt confronted with a number of daily life struggles. From table 3, we can see that volunteers did not recognize the depicted daily life struggles as struggles of their own in the most cases. However, up to half of the volunteers indicated to experience stress within close relationships, such as having a fight with the spouse or a close friend, on a regular basis. Furthermore, almost half of the volunteers indicated to have experienced the stress of not knowing what would happen during a volunteer shift on a regular basis.

Table 3. Stress in daily life frequency responses, means and correlations with compassion satisfaction, burnout and secondary traumatic stress (per item)

Item	Frequencies (%)					Mean (SD)	Correlation (Spearman's rho) with		
	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Very often (5)		CS	BO	STS
Stress within close relationships	11	33	45	10	1	2.6 (0.8)	-.17	.23*	.20*
Stress at work (not voluntary work)	52	29	16	3	-	1.7 (0.8)	-.10	.11	.08
Lack of time does not allow volunteering	44	35	17	3	2	1.8 (0.9)	-.13	.26**	.25**
Not knowing what will happen during shift	27	21	26	17	9	2.6 (1.3)	-.17	.18	.14
Conflict with colleague at volunteer work	74	20	6	-	-	1.3 (0.6)	-.23*	.34**	.24*

*p < .05. **p < .01.

The next step in analysis was to investigate how the frequency of encountering daily life struggles was associated with volunteers' scores on compassion satisfaction, burnout and secondary traumatic stress each. From table 3 we can see that, from all depicted daily life struggles, the following three showed significant associations with volunteers' scores: volunteers who frequently experience stress within close relationships (such as having a fight with the spouse or close friend) and/or volunteers who frequently feel that they do not have the time to do volunteer work, are more likely to experience signs of burnout and secondary traumatic stress. Contrary to what had been implied by earlier studies, having stress at one's everyday job were not significantly related to any of the subscale scores in the current study.

Coping strategies

Table 4 shows that task-focused coping was the most common coping strategy among volunteers in the current sample, while emotion-focused coping was least common.

Table 4. Coping strategies: means and correlations with compassion satisfaction, burnout, and secondary traumatic stress.

	Mean (SD)	Correlation (Spearman's rho) with		
		Compassion satisfaction	Burnout	Secondary traumatic stress
Avoidance focused coping	16.1 (4.2)	.01	.15	.29**
Emotion focused coping	13.8 (3.3)	-.32**	.37**	.51**
Task focused coping	23.2 (4.3)	.24*	-.19*	-.16

*p < .05. **p < .01.

When examining the relations between coping strategies and volunteers' scores on compassion satisfaction, burnout and secondary traumatic stress, it became evident that emotion focused coping was associated with all three aspects of professional quality of life/wellbeing, while avoidance and task focused coping appeared to be linked to rather specific aspects, as described below.

Volunteers who frequently engage in emotion focused coping are less likely to derive pleasure from volunteering and are also at risk for both burnout and secondary traumatic stress. Volunteers who frequently apply task focused coping, which is known as healthy coping strategy, are indeed more likely to enjoy their work as a volunteer and less likely to suffer from symptoms related to burnout. On the other hand, volunteers who frequently engage in avoidance focused coping, are at risk of secondary traumatic stress.

These results show that volunteers who apply coping strategies that have been associated with negative implications for health are less likely to experience their work as satisfying and more likely to experience the “cost to caring” than volunteers who apply coping strategies that have been linked to positive health outcomes. The results also show that when healthy coping strategies are applied, the risk for stress related complaints is lower than when coping strategies known as unhealthy are applied.

Factors related to the nature of volunteer work

The majority of the volunteers in the current sample was volunteering in a hospice institution and almost half of them had no more than 3 years of volunteering experience (table 5). Spending 6 to 10 hours per week of their time to volunteers work seemed to be the norm, most often during up to two shifts per week. The majority of volunteers had been caring for more than 10 different patients in the last two months (or on average one patient per week). The time of care for one patient varied greatly across the given categories but was usually between

2 to 4 weeks. One can thus suggest that it is typical for a volunteer to see a particular patient 2 times per week across the time span of 2 to 4 weeks.

When testing for the characteristics of volunteer work as mentioned above, there were no significant differences found in compassion satisfaction, burnout and secondary traumatic stress. This was contrary to what had been suggested by earlier research that had pointed to volunteer experience as possible significant factor in particular. The relevant statistics for these tests can be found in table 5.

Table 5. Descriptives of work-related factors and their associations with compassion satisfaction, burnout and secondary traumatic stress (N=107)

	n	df	Compassion satisfaction			Burnout			Secondary Traumatic Stress		
			Median (IQR)	χ^2	p	Median (IQR)	χ^2	p	Median (IQR)	χ^2	p
Palliative care institution		2		1.737	n.s.		3.348	n.s.		1.978	n.s.
Hospice	70										
Patient's Home	27										
Palliative Care Unit	10										
Volunteer experience		4		5.156	n.s.		2.926	n.s.		5.899	n.s.
Less than 1 year	14		40 (37-41.25)			18.5 (15.75-20.25)			18 (14.75-23)		
1 to 3 years	31		40 (37-44)			17 (16-20)			15 (13-18)		
3 to 5 years	16		42.5 (38.25-44.75)			18 (15.25-19.75)			17 (13.25-19)		
5 to 10 years	32		42 (39.25-44)			17 (16-20.75)			18 (16-20)		
More than 10 years	14		43 (39-44)			17 (13.75-18.5)			18 (13-22)		
Hours per week		2		2.963	n.s.		3.554	n.s.		2.474	n.s.
2 to 4 hours per week	13		42 (37-44)			18 (16.5-20)			18 (14.5-20.5)		
4 to 6 hours per week	31		40 (38-43)			17 (16-21)			18 (14-22)		
6 to 10 hours per week	63		42 (40-44)			17 (15-19)			16 (14-19)		

Shifts per week		3		3.441	n.s.		2.774	n.s.		1.789	n.s.
Less than once per week	17	40				18			18		
		(39-43.5)				(15.5-19.5)			(16-20)		
Once per week	35	41				17			16		
		(38-44)				(16-21)			(14-21)		
2 times per week	46	40.5				17			17		
		(38.75-44)				(16-19.25)			(13.75-20)		
More than 2 times per week	9	44				17			18		
		(39.5-47)				(13.5-21)			(13-22)		
Patients cared for in the last 2 months		2		1.387	n.s.		1.682	n.s.		1.210	n.s.
Less than 5	27	40				18			17		
		(38-43)				(16-20)			(15-19)		
5 to 10	37	41				17			17		
		(39.5-44)				(15-21)			(14-21.5)		
More than 10	43	42				17			16		
		(38-44)				(16-19)			(13-19)		
Duration of care per patient		3		4.281	n.s.		1.510	n.s.		2.535	n.s.
Less than 2 weeks	27	40				18			18		
		(37-43)				(16-20)			(16-21)		
2 to 4 weeks	52	42				17			17		
		(39.25-44)				(15-20)			(14-19.75)		
4 to 8 weeks	21	43				16			15		
		(38-45)				(15.5-20)			(13.5-19.5)		
More than 8 weeks	7	41				17			15		
		(37-47)				(16-23)			(13-23)		

Table 6 shows the frequency at which volunteers experienced situations involving patients and their families. Volunteers in the current sample recognized most of the situations on a rather regular basis. confrontations with the visible signs of the patient's illness were encountered the most often followed by sharing characteristics with a patient and cases in which the mourning family was young, and experiencing a patient going through a difficult death.

Table 6. Factors referring to the nature of volunteer work: means and correlations with compassion satisfaction, burnout, and secondary traumatic stress.

Item	Frequencies (%)					Mean (SD)	Correlation (Spearman's rho) with		
	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Very often (5)		CS	BO	STS
Factor "interaction problems"						7.1 (2.3)	-.26**	.38**	.38**
Patient did not accept offered help	66	23	10	-	-				
There was lack of communication by family about patient	44	38	18	-	-				
Family fights were occurring in presence of patient	51	32	16	1	-				
Witnessing death of a patient	31	22	37	8	1				
Deceased patient leaves behind young family	21	18	54	6	1	2.5 (0.9)	.25**	-.26**	-.17
Patient went through difficult death	15	32	50	3	-	2.4 (0.8)	.05	.02	-.05
Patient passing away to whom well acquainted	18	26	44	12	-	2.5 (0.9)	.12	-.11	.07
Patient showing visible signs of illness	1	2	15	52	30	4.1 (0.8)	.13	-.06	-.06
Sharing characteristics with volunteer	6	21	55	11	6	2.9 (0.9)	.14	.03	.14
Not knowing what will happen during shift	27	21	26	17	9	2.6 (1.3)	-.17	.18	.14
Conflict with colleague at volunteer work	74	20	6	-	-	1.3 (0.6)	-.23*	.34**	.24*

*p < .05. **p < .01.

Table 6 shows that from all depicted situations involving patients and/or their families, three were significantly related to volunteers' wellbeing. Firstly, volunteers who frequently found themselves in situation where they were not able to help are less likely to derive satisfaction from their work as a volunteer and are more at risk of facing the costs of caring (burnout and secondary traumatic stress). Secondly, the results show that as volunteers frequently witness the death of a patient, they are more likely to report signs of secondary traumatic stress. Thirdly,

volunteers who frequently experience conflicts with volunteer colleagues are less likely to feel satisfied about their work as a volunteer and are also more at risk for burnout and secondary traumatic stress. Noteworthy however, was the fourth finding according to which volunteers who frequently witnessed the grief of a young family were less likely to report signs of burnout and more likely to derive satisfaction from their volunteer work. Contrary to what had been implied by earlier studies, dealing with the unknown was not related to any of the professional quality of life subscales.

Overall, there were only a few situations regarding the nature of volunteer work that could be linked to volunteers' wellbeing; the majority did not show any links. Among the situations that could be linked, most of them were about interacting the patient and/or their family that implied the volunteer not being able to help (disempowering situations). There were few significant associations with regard to encounters with death or illness. This leads to suggest that while disempowering situations as described above appear to be linked to volunteers' wellbeing this is only partly the case for confrontation with death and/or illness.

Factors related to how volunteer work is organized

The following section distinguishes between factors regarding working with other workforces within the palliative care institution and the definition of the role as a volunteer within the institution.

Working together

As table 7 implies, volunteers overly disagreed with or were neutral about most of the referred to situations where cooperation and communication with other workforces was implied to be lacking. As the scale solely investigated attitudes regarding the absence of cooperation, it can only be speculated if volunteer's disagreement with the statements imply that they feel positively about the aspects of cooperation with professional care and/or the coordinator within the palliative care institution.

Table 7. Working together: means and correlations with compassion satisfaction, burnout, and secondary traumatic stress.

Item	Frequencies (%)					Mean (SD)	Correlation (Spearman's rho) with		
	Totally disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Totally agree (5)		CS	BO	STS
Factor: Cooperation with supervisors and professional health care						12.2 (4.1)	-.39**	.49**	.27**
Lack of communication by hospice coordinator about patient	36	39	16	4	5				
Lack of communication by hospice coordinator about hospice issues	35	35	26	5	-				
Lack of communication by professional healthcare	34	43	19	5	-				
Working together with professional healthcare difficult	36	45	14	5	-				
Working together with GP/hospital difficult	18	33	42	5	3				
Lack of time to "be there" for the patient	35	41	19	6	-				
Lack of training opportunities	33	40	13	8	6	2.14 (1.1)	-.14	.20*	.09

*p < .05. **p < .01.

Despite the low agreement with the different given statements regarding cooperation, (the lack of) communication appeared to be moderately linked to compassion satisfaction, burnout and secondary traumatic stress. Therefore, volunteers who felt communication was lacking, were less likely to feel satisfied with their work as a helper and were more likely to experience symptoms related to burnout and/or secondary traumatic stress. Furthermore, volunteers who experienced that there was a lack of training opportunities were more likely to experience complains related to burnout specifically.

Role Ambiguity

From table 8 we can see that the majority of volunteers perceived their role as volunteer within the palliative care institution to be rather clear. Volunteers appeared to be well aware of

their responsibilities and tasks and what was expected of them within the palliative care institution.

Table 8. Means, frequencies and correlations between compassion satisfaction, burnout and secondary traumatic stress and role ambiguity. (N=107)

Scale (min. – max. score)	Frequencies (%)					Mean (SD)	Correlation (Spearman's rho) with		
	Totally disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Totally agree (5)		CS	BO	STS
Role ambiguity (6 – 30)						11.7 (3.7)	-.41**	.37**	.22*
I feel certain about how much responsibility I have as a volunteer***	-	6	9	51	34				
The goals and objectives of my work as volunteer are clear***	-	6	5	52	36				
I can divide my time to my own liking***	7	8	28	38	20				
I know what my responsibilities are***	4	-	6	52	38				
I know exactly what is expected of me as a volunteer***	-	6	6	56	32				
Clarity of what has to be done for a patient***		8	9	53	29				

*p < .05. **p < .01.*** reversed items (1=5, 2=4, 3=3, 4=2, 5=1)

Table 8 shows that there was a significant correlation between the score for how ambiguous volunteers perceived their role and compassion satisfaction, burnout and secondary traumatic stress each. The less ambiguous volunteers perceived their own role, the more likely they derived pleasure from their work as a volunteer. The results also show that when volunteers perceived their role as ambiguous, they were more likely to experience symptoms of burnout and secondary traumatic stress.

Regression analysis

In table 9, we can see which of the obtained factors (personal, work-related and organization related) could explain the variance in each compassion satisfaction, burnout and secondary traumatic stress. For each of the measures of professional quality of life, a multiple regression analysis (forced entry) was executed, including parameters that were significantly bivariate correlated to the measures as described above. For compassion satisfaction, it was found that emotion focused coping and role ambiguity significantly accounted for 32% ($R^2_{adj.} = 27\%$) of the variance in compassion satisfaction scores. For burnout, it was found that emotion-focused coping, task focused coping, and interaction problems involving patients were significant predictors that could significantly account for 48% ($R^2_{adj.} = 43\%$) of the variance in the burnout scores of volunteers. For secondary traumatic stress, it was found that emotion focused coping and interaction problems involving patients had significant predictive value and accounted for 43% ($R^2_{adj.} = 38\%$) of the variance in the secondary traumatic stress scores.

Table 9. Regression analyses of models for compassion satisfaction, burnout and secondary traumatic stress.

		Compassion satisfaction		Burnout		Secondary traumatic stress	
		B	β	B	β	B	β
Personal related factors	Stress within close relationships	-	-	.23	.06	.65	.14
	Lack of time does not allow volunteering	-	-	.11	.03	.09	.02
	Avoidance focused coping	-	-	-	-	.08	.08
	Emotion focused coping	-.21	-.18*	.24	.25*	.50	.41*
	Task focused coping	.15	.17	-.14	-.19*	-	-
Work related factors	Interaction problems	-.13	-.08	.30	.22*	.46	.26*
	Deceased patient leaves behind young family	.49	-.12	-.44	-.13	-	-
	Conflict with colleague at volunteer work	-.76	-.12	.81	.15	-.02	-.04
Organization related factors	Lack of communication	-.16	-.17	.17	.21*	.01	.01
	Lack of training opportunities	-	-	-.15	-.05	-	-
	Role ambiguity	-.22	-.22*	.12	.14	.20	.18
		R ² = .32		R ² = .48		R ² = .43	
		R ² _{adj.} = .27		R ² _{adj.} = .43		R ² _{adj.} = .38	
		F(7) = 6.736, <i>p</i> < .05		F(10) = 8.954, <i>p</i> < .05		F(9) = 8.103, <i>p</i> < .05	

* *p* < .05

Discussion

The present study aimed to shed light on the professional quality of life of Dutch volunteers in palliative care, and how volunteer work in demanding conditions, such as supporting patients and families in times of grief, would have on the (professional) quality of life of Dutch volunteers. Given the fact that volunteers in the Netherlands are considered a vital part of the palliative care, it seemed feasible to use a measure that has been mostly applied to professional health care. Furthermore, it was investigated which factors, personal, volunteer work related, and organizational, could be linked to the prevalence of compassion satisfaction, burnout and secondary traumatic stress.

Prevalence of compassion satisfaction, burnout and secondary traumatic stress

When investigating the prevalence of compassion satisfaction, burnout and secondary traumatic stress in Dutch volunteers, it was worthwhile noting that, even though the instrument ProQol has been mostly applied to professional health care, its application to volunteers in the present study yielded comparable scores. For compassion satisfaction and secondary traumatic stress, the scores were in similar range, while the scores for burnout were considerably lower than the cut-scores provided by Stamm (2005). The high scores on compassion satisfaction of Dutch palliative care volunteers in the current study reflected the findings from earlier studies that volunteers perceive their work as rewarding and enjoyable (Pesut, et al. 2014; Claxton-Oldfield, 2016; Edit et al., 2016). As volunteers in the current study had rather low scores on burnout, it can be concluded that they do not hold negative attitudes about their work, which would withhold them from forming caring relationships with patients and families (Keidel, 2002; Slocum-Gori, et al., 2011). When examining the scores for secondary traumatic stress, volunteers in the current study scored slightly above the cut-scores by Stamm (2005). However, up to half of the volunteers in the study scored even higher, implying that Dutch volunteers, when confronted with the trauma of facing the definite loss of a loved one, tend to experience the loss of a patient as if it was someone of their own.

Overall, the extent to which compassion satisfaction and secondary traumatic stress are present in the current sample speak to the relational role of the volunteer within the palliative care institution and the extent of their involvement in the care when practicing "being there" for patients and their families (Claxton-Oldfield, & Claxton-Oldfield, 2007; Claxton-Oldfield, & Claxton-Oldfield, 2008; Pesut, et al., 2014; Goossensen, 2016; Testoni, Faletti, Visintin, Ronconi, & Zamperini, 2016).

As far as we know only two studies have previously included hospice volunteers when using the ProQOL. Compared to those studies, volunteers of the present sample scored slightly lower on compassion satisfaction, and to a similar extent on burnout and secondary traumatic stress (Slocum-Gori, et al., 2011; Montross-Thomas, Schreiber, Meier, & Irwin, 2016).

Factors related to compassion satisfaction, burnout and secondary traumatic stress

The current study was able to identify individual, work related and organization related factors that are linked to compassion satisfaction, burnout and secondary traumatic stress more or less likely and can help with the identification of high-risk cases.

Summarizing the results described in the previous chapter, it was thus found that personal related factors and work-related factors were associated with each of the aspects of Dutch volunteers' quality of life, while organization related factors were of significance for compassion satisfaction specifically.

The current study confirmed findings from earlier studies, who had linked coping styles, including emotion focused coping and task focused coping, to mental health complaints including depression and anxiety, or the absence of it (task-focused coping) (Folkman, & Lazarus, 1988; Endler, & Parker, 1990; Cohan, Lang, & Stein, 2006; Brown, 2011a; Melvin, 2012; Lázló, Anita, & Andrea, 2017).

Both burnout and secondary traumatic stress have shown to include aspects of or are accompanied by signs of depression and anxiety (Keidel, 2002; Stamm, 2010; Slocum-Gori, et al. 2011; Melvin, 2012). The findings from the current study have shown that volunteers, who tend to use maladaptive coping (emotion focused coping) are at risk of burnout and secondary traumatic stress, while volunteers who use adaptive styles of coping (task focused coping), showed a low risk for burnout specifically. It is plausible to suggest that feeling overwhelmed, which is a typical symptom of burnout (Stamm, 2005; Stamm, 2010) and the anxiety that is characteristic for secondary traumatic stress are the aspects that emotion focused coping is related to as it incorporates emotion regulation behaviors that aim to regulate intense emotional responses to stress (Horn, & Wilpert, 2017). Since both task-focused coping and compassion satisfaction have been linked to positive outcomes for wellbeing (Folkman, & Lazarus, 1988; Endler, & Parker, 1990; Cohan, Lang, & Stein, 2006), volunteers who are at risk due to their usual coping behavior might benefit greatly from receiving training in how to effectively cope with stressful situations.

The current study did not find any links between demographic variables (age, gender, educational background) and volunteers' professional quality of life. This finding contradicted suggestions from earlier studies (Keidel, 2002, Dein, 2005) and was in line with earlier studies in which demographic variables were not associated with hospice nurses' professional quality of life (Abendroth, & Flannery, 2006). Furthermore, personal related variables such as spirituality and experience with loss were also not related to any of the aspects compassion satisfaction, burnout and secondary traumatic stress. For personal experience with loss, this was especially unexpected as half of the volunteers in the current study had indicated to have experienced personal loss of a loved one and more than a half of the volunteers had scored considerably high on secondary traumatic stress. This finding leads to suggest that it is not the personal experience with loss that makes witnessing the grief of another person grave.

In the current study, it was found that, among all work-related aspects of volunteer work in palliative care, frequent interaction problems with or between patients and their loved ones was linked to the negative aspects of volunteers' professional quality of life, burnout and secondary traumatic stress. These findings were in line with earlier studies (Paradis, Miller, & Runnion, 1987; Brown, 2011a; Brown, 2011b) who had suggested that the relationship that is built with patients and their loved ones may bear stressful aspects as well.

Surprisingly, aspects such as confrontation with death and suffering from illness, that are rather unique to palliative care settings, were not linked to volunteers' professional quality of life, contrary to what had been implied by earlier studies (Brown, 2011a; Melvin, 2012; Abendroth, & Flannery, 2006), who had found a link between work-related aspects around the dying process of a patient, and hospice nurses' professional quality of life.

General aspects of volunteer work, including the work experience as a volunteer, number of shifts per week, worked hours per shift and the average numbers of patients cared for, were also not related to volunteers' professional quality of life. This finding contradicted suggestions from earlier studies regarding the aspect of work experience. Work experience as a hospice worker had been suggested to play a role in how the negative aspects of one's work as a helper might be easier to handle once a helper has gotten more acquainted with the work in general, an advantage that less experienced hospice volunteers might not have (Abendroth, & Flannery, 2006; Brown, 2011a; Phillips, Andrews & Hickman, 2013). The findings from the current study do not confirm the existence of a difference between volunteers with more work experience and novice volunteers regarding their professional quality of life.

Contrary to what had been suggested by Brown (2011b), organizational factors such as communication and cooperation with other colleagues within the palliative care institution could not be linked to volunteers' professional quality of life. However, the current study did find a link between role ambiguity and compassion satisfaction and therefore confirmed the importance of a clearly defined role of the volunteer within the palliative care institution, as many earlier studies had suggested before (Paradis, Miller, & Runnion, 1987; Glass, & Hastings, 1992; Payne, 2001; Claxton-Oldfield & Claxton-Oldfield, 2012; Claxton-Oldfield, 2016). Volunteers who did not perceive their role as clear, were therefore less likely to experience the positive aspects of their work as a helper, an aspect that has been regarded crucial to balance out the negative aspects (Stamm, 2010; Slocum-Gori, et al., 2011).

The findings have identified personal related aspects, such as coping styles, as well as work related aspects and organizational aspects that have shown to be of predictive value when discussing Dutch palliative care volunteers' professional quality of life. Dutch volunteers in particular have a rather unique role in the palliative care environment (Goossensen, 2016), and identification of the factors mentioned above was able to describe which difficulties Dutch volunteers encounter, despite the reward of making a meaningful contribution.

Even though these links were found in a palliative care setting, the nature of the factors might apply to other care settings as well which do not imply frequent confrontation with death, grief and loss. Professional quality of life has been applied to a variety of care settings, and the nature of identified factors do lead to suggest that the group of volunteers

[Strengths, limitations and suggestions for future research](#)

The present study aimed to shed light on the professional quality of life of Dutch palliative care volunteers, through the use of quantitative measures. This made the study unique as previous studies had been mostly qualitative. Through the use of quantitative measures, the present study was able to explore and shed light on factors that can be linked to professional quality of life of volunteers and provide a starting point for further investigations. With all links found, it needs to be emphasized that the results of the current research have yielded correlational insights which can be taken as an indication for further experimental research to investigate for causal relationships to determine causes and effects.

A further notion of caution has to be made regarding the burnout scores, which were really low in the present sample. This was not typical for the scale as earlier studies had found sufficient reliabilities when using the burnout scale in their study (Slocum-Gori, et al., 2011; Montross-Thomas, Schreiber, Meier, & Irwin, 2016).

Considering low reliabilities, the same remarks are true for the role ambiguity scale by Rizzo, House, and Lirtzman, (1970), which had been translated for the use in the current study. Research on the validity of the scale pointed to validity issues regarding the wording of the item “I know that I have divided my time properly” and validity issues (Schuler, Aldag, & Brief, 1977; González-Romá, & Lloret, 1998) and has led to an updated version of the scale (Bowling, et al., 2017) with sufficient reliability that has excluded this item. For future research it is highly recommended to use the most current version of the scale.

The current sample also included only 107 of the suggested 10 000 volunteers that are suggested to be active each year in the Netherlands. In terms of representation of the current study, the current study may be regarded as an explorative study, but further study should be executed that includes a sample of a more representative size. In order to achieve this, it is recommended to make use of the news media to inform more volunteers about the research and to provide a pen and paper version of the survey. Using both mediums to distribute the survey might enable volunteers who are not well acquainted with online surveys to participate after all.

Furthermore, the current study investigated mainly negative aspects of volunteering, namely stressors. However, especially for the case of compassion satisfaction, positive factors such as being acknowledged by the patient and their loved ones or situations in the palliative care setting that imply personal growth, might be more suitable to get a more complete picture of which factors are related to the prevalence of compassion satisfaction, burnout and secondary stress.

Conclusion

The current study has shown that despite the graveness of their work, Dutch volunteers in palliative care reflect a good professional quality of life but are also at risk to suffer from the cost of caring. It has been shown that the assignment to care for others not only comes with the reward of feeling fulfillment but also bears the risk for mental health problems relating to secondary traumatic stress. This finding should encourage more attention to Dutch volunteers in palliative care to shed further light on their unique yet substantial role.

The quantitative approach of the current study has shed light on possible factors that might lead to burnout or secondary traumatic stress, including coping styles, interaction problems with or patients and their loved ones and role ambiguity.

Further quantitative research is therefore highly recommended to examine the explored links and determine possible causes of complaints such as secondary traumatic stress. This would pave the way to the development practical applications that foster healthy coping

strategies, which can help dealing with overwhelming situations, such as not being able to communicate with the patient.

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Vrijwilligers Palliatieve Zorg Nederland

Start of Block: Default Question Block

Beste vrijwilliger,

Hartelijk dank voor uw deelname aan dit onderzoek. Deze brief zal u informeren over de bedoeling van dit onderzoek.

Het werk als hospice medewerker kan intensieve ervaringen met zich mee brengen. Immers zorgt u voor bewoners en hun families in zware tijden. Juist om deze reden kunnen deze ervaringen indrukwekkend en ook zwaar zijn. Met het huidig onderzoek willen wij in kaart brengen hoe u als vrijwilliger dit ervaart en welke factoren daarop van invloed zijn. Eerdere onderzoeken hierover werden reeds uitgevoerd in Engeland, de VS en Australië, voor (Nederlandse) vrijwilligers is dit nog maar weinig onderzocht. Wij hopen dat u mee zult doen, omdat de resultaten ons kunnen helpen om een indruk te krijgen van de situatie van Nederlandse vrijwilligers in de palliatieve zorg.

Het invullen van de vragenlijst zal ongeveer 30 minuten duren. Uw deelname is vrijwillig en u mag op elk moment, zonder opgave van reden stoppen, door uw browser af te sluiten. De tot dan toe opgeslagen antwoorden zullen dan wel gebruikt (kunnen) worden voor de analyses. Uw antwoorden zullen ten alle tijden strikt vertrouwelijk behandeld worden en persoonlijke informatie zal in het rapport niet terug te vinden zijn. De bevindingen van dit onderzoek zullen dan ook een samenvatting van alle antwoorden zijn en niet herleidbaar zijn tot uw persoon.

De vragen hebben betrekking op uw werk als vrijwilliger in het hospice en hoe u dit ervaart, en op factoren die daarop van invloed kunnen zijn.

Dit onderzoek wordt uitgevoerd onder begeleiding van Dr. C.H.C Drossaert, Vakgroep Psychologie, Gezondheid en Technologie aan de Universiteit Twente, en Drs. Mirjam Bosschaart, Stg. Hospice Enschede. De Ethische Commissie van de Universiteit Twente heeft dit onderzoek goedgekeurd.

Als u akkoord gaat met de bovengenoemde voorwaarden, klikt u op 'verder'. Gaat u niet akkoord, klikt u op 'Verlaten'.

Mocht u vragen hebben, verneem ik deze vraag via email, m.mogana@student.utwente.nl, of via telefoon 0618384476.

Met vriendelijke groet,

Miriam Mogana

Verder

Verlaten

Ik verklaar op een voor mij duidelijke wijze te zijn ingelicht over de aard, methode, doel en [indien aanwezig] de risico's en belasting van het onderzoek. Ik weet dat de gegevens en resultaten van het onderzoek alleen anoniem en vertrouwelijk aan derden bekend gemaakt zullen worden, waaronder eventueel beschikbaar gesteld worden voor hergebruik door een andere onderzoeker. Mijn vragen zijn naar tevredenheid beantwoord.

Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud me daarbij het recht voor om op elk moment zonder opgaaf van redenen mijn deelname aan dit onderzoek te beëindigen.

Ja

Nee

Het onderzoek gaat nu starten. Er volgen wat algemene vragen over uw zelf.



Wat is uw leeftijd?

(a.u.b. getal invullen)

Wat is uw geslacht?

- Man
 - Vrouw
 - Geen antwoord
-

Wat is uw hoogst genoten afgesloten opleiding?

- VMBO
 - HAVO
 - VWO
 - MBO
 - HBO
 - WO
 - Zeg ik liever niet
-

Bent u beroepsmatig in de zorg werkzaam (geweest)?

- Ja
 - Nee
-

Bent u gelovig?

- Ja
- Nee
- Zeg ik liever niet

Heeft u persoonlijke ervaring met het verliezen van een naaste?

- Ja, in mijn zeer directe omgeving (bijv. ouders, partner)
 - Ja, in mijn directe omgeving (bijv. familie, vrienden, burens, collega's)
 - Nee, of alleen van wat verder af.
 - Zeg ik liever niet.
-

Hieronder vindt U een lijst met omstandigheden die van invloed kunnen zijn op uw werk. Hoe vaak heeft het zich in de afgelopen 2 maanden voorgedaan dat ...

	Nooit	Zelden	Soms	Vaak	Heel vaak
... er sprake was van stress in uw persoonlijke omgeving?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... er sprake was van stress op uw werk (anders dan vrijwilligerswerk)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... U door gebrek aan tijd niet kon voldoen aan vereiste beschikbaarheid als vrijwilliger?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... U vóór het begin van uw dienst nog geen idee had wat er zou gaan gebeuren in het hospice?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... U conflicten had met hospice collega's heeft gehad?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Vrijwilligerswerk

Er volgen nu enkele vragen over uw werk als vrijwilliger.

Waar doet u vrijwilligerswerk?

- Bijna-thuis hospice
 - Bij mensen thuis
 - Palliatieve afdeling
-

Hoe veel bewoners kunnen in het hospice waar u vrijwilligerswerk doet, terecht?

(a.u.b. getal invullen)

In welke provincie doet u vrijwilligerswerk?

- Groningen
 - Friesland (Fryslân)
 - Drenthe
 - Overijssel
 - Flevoland
 - Gelderland
 - Utrecht
 - Noord-Holland
 - Zuid-Holland
 - Zeeland
 - Noord-Brabant
 - Limburg
-

Hoe lang bent u al werkzaam als vrijwilliger in de palliatieve zorg?

- minder dan 1 jaar
 - 1 tot 3 jaar
 - 3 tot 5 jaar
 - 5 tot 10 jaar
 - meer dan 10 jaar
-

Hoe veel uur per week besteedt u aan vrijwilligerswerk?

- 2 tot 4 uur per week
 - 4 tot 6 uur per week
 - 6 tot 10 uur per week
-

Hoe vaak doet u gemiddeld aan vrijwilligerswerk in het hospice?

- Minder dan 1 keer per week
 - 1 keer per week
 - 2 keer per week
 - Meer dan 2 keer per week
-

In uw werk als vrijwilliger maakt u kennis met veel patienten. Voor hoeveel patienten heeft u gezorgd in uw tijd als vrijwilliger in het hospice in de afgelopen 2 maanden?

- Minder dan 5
 - 5 tot 10
 - Meer dan 10
-

Hoe lang zorgt u gemiddeld voor een patiënt?

- gemiddeld minder dan 2 weken
 - gemiddeld 2 tot 4 weken
 - gemiddeld 4 tot 8 weken
 - gemiddeld meer dan 8 weken
-

Heeft u in het kader van uw werk als vrijwilliger een training gevolgd?

- Nee, nooit
 - Ja, 1 keer
 - Ja, 2 keer
 - Ja, vaker dan 2 keer
-

Welke trainingen waren dat?

Meerdere antwoorden zijn mogelijk

- Basistraining
 - Tiltraining
 - Anders, namelijk _____
-

Onderstaand vindt U een lijst met situaties die wel eens ervaren kunnen worden als stressvol. Het gaat hierbij om het contact met de bewoner/patiënt. In welke mate heeft onderstaande situatie zich in de afgelopen 2 maanden voor gedaan?

	Nooit	Zelden	Soms	Vaak	Heel vaak
Een bewoner heeft zich niet door u laten helpen.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Er was gebrek aan communicatie door familie/naaste over omstandigheden bewoner.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
De familie maakte ruzie voor de ogen van de bewoner.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Een bewoner had een moeilijk overlijden.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
U was getuige van het overlijden van een bewoner.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Een bewoner toonde duidelijke teken van ziekte.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Een bewoner, waarmee u een hechte band heeft gehad, is overleden.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Een overleden
bewoner heeft
een jonge
familie achter
gelaten.

Een bewoner
had dezelfde
eigenschappen
als u (
bijvoorbeeld
leeftijd, afkomst,
...).

Page Break

ProQOL

Als u als vrijwilliger mensen helpt, bent/krijgt/komt/staat u in direct contact met hun leven. Zoals u misschien hebt ervaren, kan de compassie die u voelt voor de mensen die u helpt u zowel positief als negatief beïnvloeden. Hieronder staan enkele uitspraken over uw (positieve en negatieve) ervaringen als hulpverlener/ vrijwilliger. Beschouw elk van de volgende uitspraken over uw en uw

huidige werksituatie. Geef per uitspraak eerlijk aan hoe vaak u dat gevoel hebt ervaren in de afgelopen 30 dagen.

	Nooit	Zelden	Soms	Vaak	Altijd
Ik ben gelukkig	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik maak me druk over meer dan één van de personen die ik help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Het geeft me voldoening dat ik in staat ben om anderen te helpen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik voel me verbonden met anderen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik schrik snel op van onverwachte geluiden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik voel me gesterkt na het werken met de mensen die ik help (bellers, patienten),	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik vind het moeilijk om mijn privéleven te scheiden van mijn werk als hulpverlener/vrijwilliger	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik ben minder productief op het werk, omdat ik slecht slaap van de traumatische ervaringen van de persoon aan wie ik hulp verleen (een beller/patient/bewoner).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Ik denk dat ik mogelijk
aangedaan ben door
de traumatische stress
van de mensen die ik
help/spreek

Ik voel me gevangen in
mijn werk als
hulpverlener/ vrijwilliger

Door mijn werk als
hulpverlener/vrijwilliger
ben ik lichtgeraakt of
snel geïrriteerd

Ik vind mijn werk als
hulpverlener/vrijwilliger
leuk

Ik voel me somber
vanwege de
traumatische
ervaringen van de
mensen die ik
help/spreek

Het voelt alsof ik zelf
het trauma doormaak
van degene die ik
geholpen/gesproken
heb

Ik heb gedachten die
me ondersteunen

Ik ben tevreden over
hoe het me lukt om op
de hoogte blijven van
technieken en
protocollen.

Ik ben de persoon die
ik altijd al wilde zijn

Mijn werk geeft me voldoening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik voel me versleten, uitgeput door mijn werk als hulpverlener/ vrijwilliger	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik heb positieve gedachten en gevoelens over hen die ik help en hoe ik ze zou kunnen helpen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik voel me overweldigd omdat er geen eind aan mijn werk lijkt te komen.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik heb het gevoel dat ik verschil kan maken door mijn werk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik vermijd bepaalde activiteiten of situaties, omdat ze me herinneren aan beangstigende ervaringen van de mensen die ik help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik ben trots op wat ik kan doen om te helpen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Als gevolg van mijn werk, heb ik heb indringende, beangstigende gedachten	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik voel me vastlopen in het systeem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Ik denk dat ik
succesvol ben als
hulpverlener

Belangrijke delen van
mijn werk met
bewoners kan ik me
me niet herinneren

Ik ben een zeer
zorgzaam persoon

Ik ben er blij om dat ik
er voor gekozen heb
om dit werk te doen

Onderstaand vindt U een lijst met mogelijke reacties op een stressvolle situatie. In welke reacties

kunt u zich herkennen? Meerdere keuzes zijn mogelijk.

Denkt u hierbij aan een situatie die zich heeft voor gedaan tijdens uw vrijwilligersdienst.

	Nooit	Zelden	Soms	Vaak	Altijd
Ik neem wat rust en neem afstand van de situatie	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik focus op het probleem en bekijk hoe ik het op kan lossen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik geef mijzelf de schuld voor het belanden in deze situatie	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik trakteer mijzelf op mijn favoriete gerecht of hapje	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik ben bang om de situatie niet te kunnen hanteren.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik denk na over hoe ik vergelijkbare problemen heb opgelost.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik ga een vriend(in) bezoeken	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik bedenk een plan van aanpak n voer deze uit.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Ik koop iets voor mijzelf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik geef mijzelf de schuld voor té emotioneel zijn over de situatie	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik probeer er alles aan om de situatie te begrijpen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik word erg boos	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik neem direct een corrigerende actie	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik geef mijzelf de schuld voor het niet weten wat ik moet doen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik ga tijd doorbrengen met een belangrijk persoon	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik denk na over wat er is gebeurd en leer van mijn fouten	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Ik wens dat ik
zou kunnen
veranderen
wat er is
gebeurd of hoe
ik mij erbij
voelde

Ik ga uit voor
een snack of
een maaltijd

Ik analyseer
mijn probleem
voordat ik
reageer

Ik ga focussen
op mijn
algemene
tekortkomingen

Ik bel een
vriend(in)

Page Break

Onderstaand vindt U een lijst met situaties in het hospice die wel eens ervaren kunnen worden als stressvol. In welke mate doen zich de situaties voor in uw hospice?

	Helemaal oneens	Oneens	Neutraal	Eens	Helemaal me eens
Er worden onvoldoende trainingen aangeboden.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Er is gebrek aan tijd om er voor de bewoner te zijn.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Er is gebrek aan communicatie door hospice coördinator over omstandigheden bewoner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Er is gebrek aan communicatie door hospice coördinator over hospice zaken	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Er is gebrek aan communicatie met zorgteam	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
De samenwerking met het zorgteam loopt stug.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
De samenwerking met de huisarts/het ziekenhuis loopt stug.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

De volgende stellingen hebben betrekking op uw rol als vrijwilliger. In welke mate bent u het eens met deze stellingen?

	Helemaal oneens	Oneens	Niet eens, niet oneens	Eens	Helemaal mee eens
Ik voel me zeker over de verantwoordelijkheid die ik als vrijwilliger heb in het hospice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik weet wat mijn verantwoordelijkheden zijn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik weet precies wat er van mij als vrijwilliger wordt verwacht	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Het is duidelijk uitgelegd wat er door mij moet worden gedaan voor een bewoner.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Er zijn duidelijke doelen en taken opgesteld voor mijn werk als vrijwilliger.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik kan mijn tijd zelf indelen.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik moet 'mijn manier' vinden in het uitvoeren van de taken.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Tot slot, kunt u in enkele woorden aangeven wat u het mooiste vindt aan u werk als vrijwilliger?

Welke dingen zouden er veranderd kunnen worden om het nog beter te maken?

End of Block: Default Question Block

Appendix C Rizzo scale Ambiguity and translation process

Original items/subscale by Rizzo et al. (1970)	Adjusted items	Dutch translation
I feel certain about how much authority I have	I feel certain about how much responsibility I have as a volunteer	Ik voel me zeker over de verantwoordelijkheid die ik als vrijwilliger heb in het hospice
Clear planned goals and objectives for my job	The goals and objectives of my work as volunteer are clear	Er zijn duidelijke doelen en taken voor mijn werk als vrijwilliger
I know that I have divided my time properly	I can spend my time to my own liking	Ik kan mijn tijd zelf indelen.
I know what my responsibilities are	I know what my responsibilities are	Ik weet wat mijn verantwoordelijkheden zijn.
I know exactly what is expected of me	I know exactly what is expected of me as a volunteer	Ik weet precies wat er van mij als vrijwilliger wordt verwacht
Explanation is clear of what has to be done	Explanation is clear of what has to be done for a patient	Het is duidelijk uitgelegd wat er door mij gedaan moet worden voor een bewoner

From: Rizzo, J.R., House, R.J., & Lirtzman, S.I. (1970). Role Conflict and Ambiguity in Complex Organizations. *Administrative Science Quarterly*, 15(2), 150-163

TABLE 1. QUESTIONNAIRE ITEMS AND FACTOR LOADINGS

Item number	Statement	Factor loadings .30	
		Role conflict	Role ambiguity
1.	I have enough time to complete my work.	—	—
2.	I feel certain about how much authority I have.	—	.51
3.	I perform tasks that are too easy or boring.	—	—
4.	Clear, planned goals and objectives for my job.	—	.42
5.	I have to do things that should be done differently.	.60	—
6.	Lack of policies and guidelines to help me.	.43	—
7.	I am able to act the same regardless of the group I am with.	—	.31
8.	I am corrected or rewarded when I really don't expect it.	—	—
9.	I work under incompatible policies and guidelines.	.60	—
10.	I know that I have divided my time properly.	—	.62
11.	I receive an assignment without the manpower to complete it.	.56	—
12.	I know what my responsibilities are.	—	.61
13.	I have to buck a rule or policy in order to carry out an assignment.	.54	—
14.	I have to "feel my way" in performing my duties.	.36	-.35
15.	I receive assignments that are within my training and capability.	—	—
16.	I feel certain how I will be evaluated for a raise or promotion.	—	.34
17.	I have just the right amount of work to do.	—	.32
18.	I know that I have divided my time properly.	—	.59
19.	I work with two or more groups who operate quite differently.	.43	—
20.	I know exactly what is expected of me.	—	.61
21.	I receive incompatible requests from two or more people.	.56	—
22.	I am uncertain as to how my job is linked.	—	—
23.	I do things that are apt to be accepted by one person and not accepted by others.	.41	—
24.	I am told how well I am doing my job.	—	—
25.	I receive an assignment without adequate resources and materials to execute it.	.52	—
26.	Explanation is clear of what has to be done.	—	.35
27.	I work on unnecessary things.	.52	—
28.	I have to work under vague directives or orders.	.59	—
29.	I perform work that suits my values.	—	.39
30.	I do not know if my work will be acceptable to my boss.	.30	—

Items 10 and 18 on this administration were identical, owing to a clerical error.

Appendix C Tests of normality

	Kolmogorov-Smirnov ^a			Shapiro-Wilk		
	Statistik	df	Signifikanz	Statistik	df	Signifikanz
CS_sum	,093	107	,023	,983	107	,180
BO_sum	,136	107	,000	,979	107	,080
STS_sum	,123	107	,000	,953	107	,001
AOCsum	,077	107	,139	,979	107	,088
TOCsum	,101	107	,009	,974	107	,036
EOCsum	,097	107	,015	,967	107	,009
Org_factor1	,087	107	,046	,960	107	,003
RA_sum_final	,138	107	,000	,935	107	,000
W_interaction_problems	,144	107	,000	,934	107	,000

a. Signifikanzkorrektur nach Lilliefors