Including personal development in palliative care education to address death anxiety

Carol Gouveia Melo and Jenny Billings

Abstract

Background: Death anxiety may interfere with health care workers' (HCW) relationship with patients and their families. **Aims**: Evaluate an intervention to address death anxiety and improve HCW skills dealing with patients/families in palliative and end-of-life care. **Design**: Quasi-experimental mixed methods approach with a pre-test/post-test design. **Participants**: 208 HCWs receiving the intervention and working in end-of-life care, in and out of palliative care units, were invited to answer quantitative and qualitative questionnaires. In the end, 150 returned with quantitative answers and of these, 94 with qualitative answers as well. Additionally, out of the 150 participants, 26 were recruited for interview. **Results**: Pre- and post-test results revealed a significant reduction in levels of death anxiety, an increase in existential wellbeing, and a significant improvement in HCWs' perception of the quality of their helping relationship skills with patients/families. Content analysis provided an understanding of the difficulties experienced by the HCWs and the positive impact of the intervention. **Conclusion**: An intervention to address death anxiety and help relationship skills can reduce the use of avoidance mechanisms and improve HCW self-perceived psycho-existential support to patients/families.
Key words: ● Death anxiety ● Professional education ● Burnout

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This research conducted in Portugal aimed to investigate whether an intervention combining personal development to address death anxiety and increase existential wellbeing, together with helping-relationship skills, would increase the health care worker's (HCW) inner congruence to face the suffering and death of their patients, reduce burnout and as a consequence, improve their self-perceived capacity to engage in an effective helping relationship with the patient and family. This article expands on a previously published article presenting partial quantitative results of the research (Gouveia e Melo and Oliver, 2011). It presents more detailed quantitative results supported by qualitative data, within the context of a quasi-experimental design and focuses on the results related to death anxiety and self-perceived helping relationship skills, although in the original study, instruments were also used to measure levels of burnout and personal wellbeing.

Although instruments were used to measure levels of burnout and personal wellbeing in the original study, this article focuses primarily on the relationship between death anxiety and helping-relationship skills. The quantitative results show the levels of death anxiety and self-perceived helping-relationship skills in HCWs before and after the intervention and the qualitative results complement these results, showing the effects of death anxiety on HCWs' helping-relationship skills and improvements after the intervention.

This intervention can be considered complementary to training in palliative care, because it addresses an important area of palliative care: giving the HCW the emotional tools and skills to better practise the philosophy of palliative care with less risk of engaging in avoidance behaviours and suffering from burnout. To our knowledge, it is the only intervention of this type in Portugal, and although there have been many similar ones in other countries, none has been found that covers the combination of issues approached under the same kind of pedagogic format that gives individualised attention to each participant.

Death anxiety has been defined as a negative emotional reaction provoked by the anticipation of a state in which the self does not exist (Tomer and Eliason, 1996) or an experience of everyday life, rather than an immediate threat (Neimeyer, 1994; Neimeyer et al, 2003). This may include existential fears (as opposed to existential wellbeing), such as those related to pain, physical degradation and suffering, being alone and not having close and fulfilled relationships, living with uncertainty, not

living a meaningful life, losing one's dignity and being judged by others, and what comes after death (Leloup and Hennezel, 1997). More recently, it has been defined as 'an unpleasant emotion of multidimensional concerns that is of existential origin, provoked on contemplation of death of self or others' (Nyatanga and de Vocht, 2006).

However, evidence has been emerging indicating that nurses and doctors who care for patients with a terminal condition, both within formal palliative care arrangements and outside of these, may suffer from increased death anxiety, triggered by their daily routines with dying patients (Lowry, 1997; Peters et al, 2013a; Anderson et al, 2015). This may affect HCWs' internal congruence (Rogers, 1951) and capacity to engage in an effective helping relationship with the patient and family leading to the use of avoidance mechanisms (Bernard and Creux, 2003; Friedrichsen and Milberg, 2006; Thiemann, et al, 2015). When patients perceive HCWs to be withdrawn, they tend to feel abandoned and without support (Connelly, 2009; Larsson et al, 2011).

Research has suggested that to enable HCWs to help patients on an emotional and spiritual level, it is not sufficient to simply educate them about the patients; HCWs also need to learn how to get in touch with their deeper selves and to be aware of their own spiritual beliefs (Wasner et al, 2005). Although education in palliative care addresses all issues related to patient care, it does not systematically provide modules of personal development to increase the HCW's existential wellbeing and reduce death anxiety.

Methods

Design
Mixed methods approach, with a quasi-experimental pre-test, post test design (Robson, 2002). Quantitative questionnaires and open-ended questions for the participants to answer in writing were used together with 26 semi-structured face-to-face interviews (Robson, 2002) to fully understand the benefits and weaknesses of the intervention.

Participants
Some 208 HCWs, who cared for the dying both in and out of palliative care units (PCUs), received the intervention; of these, 150 (72%) completed both pre- and post-test questionnaires. Of the 150 HCWs, 85 worked within palliative care units and 65 out of these. Exactly 4 months after undertaking the above-mentioned quantitative study, all 150 participants were provided with an open-ended qualitative questionnaire and these were returned by 94 participants (64%). Answers

were anonymous. Subsequently, the head nurse of each of the 10 units that had participated in the intervention group was approached with the aim to recruit some of the 150 participants for an interview. Purposive sampling (critical case sampling) (Marshall, 1996) was carried out and 26 of the 150 participants agreed to participate. This was considered sufficient to obtain data saturation (Green and Thorogood, 2004; Charmaz, 2006) (*Tables 1* and *2*).

Procedure and instruments
Recruitment of participants by invitation through the head nurses of each department, the interventions, data collection and analysis took place between July 2005 and May 2009.

•Death anxiety has been defined as a negative emotional reaction provoked by the anticipation of a state in which the self does not exist.•

Table 1. Participants in quantitative and qualitative questions						
Profession	**Quantitative yes/no**	**Number**	**%**	**Qualitative yes/no**	**Number**	**%**
Nursing aide	Yes	30 (21 in PCU; 9 other)	100	Yes	20	66.7
				No	10	33.3
Nurse	Yes	87 (50 in PCU; 37 other)	100	Yes	53	60.9
				No	34	39.1
Doctor	Yes	8 (4 PCU; 4 other)	100	Yes	3	37.5
				No	5	62.5
Psychologist	Yes	12 (4 PCU; 8 other	100	Yes	9	75
				No	3	25
Social worker	Yes	6 (3 PCU; 3 other)	100	Yes	4	66.7
				No	2	33
Physiotherapist	Yes	3 (1 PCU; 2 other)	100	Yes	3	100
Priest PCU	Yes	1 (PCU)	100	Yes	1	100
Occupational therapist	Yes	1 (other)		Yes	1	100
Secretary	Yes	1 (other)	100	Yes	1	100
Nutritionist	Yes	1 (PCU)	100	Yes	1	100

Table 2. Participants in face-to-face interviews			
Profession	**Nr**	**Place of work**	**Nr**
Nurse	15	In palliative care unit	16
Nursing aide	6	In other units	10
Doctor	3	**Total**	**26**
Chaplain	1		
Unit secretary	1		
Total	**26**		

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Table 3. Structured written questions

1	What was the most important thing you learnt in the training?
2	What was the main help you received from this training?
3	What did you appreciate (or not) in this training, in terms of content, structure, teaching methods, liberty to express feelings etc … ?
4	In what way did the training improve, or not, the following (please specify):
4a	Your relationship with the patient?
4b	Your relationship with the family?
4c	Your relationship with work colleagues?
4d	Your efficiency at work?
4e	Your self-knowledge?
4f	Your internal congruence?
4g	Your daily life and feelings of wellbeing?
5	In your opinion, how could this training be improved?
6	In your opinion, would follow-up workshops be beneficial? If so, what kind of workshops would you like among the following:
6a	Difficulties in communicating with patient and family?
6b	Difficulties in communicating with the team?
6c	Spiritual care?
6d	Health care worker's emotional relationship with the 'body' of the patient (smells, different types of touch, looks, 'symbolic contamination' etc?
6e	The meaning of my life?
6f	Open theme group encounters?
7	Any other theme you would like to mention?
8	Any additional comment you would like to add (optional)?

The intervention

The intervention (AMARA), 'Life and death, the same preparation' (based on Aitken, 2011), consisted of personal development within a setting of group therapy and experiential activities, with the aim to reduce death anxiety and theoretical and practical training in psycho-existential care for patients with a terminal condition. The duration of the course was 36 hours over 6 days, divided into two modules taking 3 days each, with a week interval between each module. The intervention was given to 29 groups with an average of 7 participants per group. The first module of the intervention was given by the first author, a psychologist with a post-graduate qualification in person-centred counselling, and the second by a holistic health counsellor. The contents of the course can be found in a previously published article (Gouveia e Melo and Oliver, 2011). Both the contents of the course and the two facilitators were consistent throughout the research, thereby ensuring the same quality level over time.

Instruments

Pre- and post-intervention quantitative questionnaires

Three questionnaires and a demographic data sheet were given to the participants one week before the intervention. The participants returned the completed questionnaires at the start of the first day of the intervention, and they returned the next set four months after the course ended. It took three months to collect all the post-training questionnaires; from the 208 intervention participants, 150 complete sets of questionnaires were received.

The questionnaires consisted of validated scales to measure levels of burnout, self-perceived helping-relationship skills and personal sense of wellbeing (Gouveia e Melo and Oliver, 2011), although results of burnout are not mentioned in this article. The sum scores ranged from 1 to 6. Construct validation for this population was performed (principal components analysis) and internal consistency (Cronbach's alpha) were

Table 4. Interview schedule for live interviews

A few months ago, you did the AMARA training course. I would like to know what impact the course had on you. Did you notice any change, positive, or negative, after the course?

1	In terms of you as a person and your private life
2	In terms of your professional life:
2a	With work colleagues
2b	With the patients and family
3	Is there anything you would like to say about the course itself
3a	In what way was the course useful
3b	Was there anything you were unhappy about
3c	Do you have any suggestions
4	Any comments you would like to add

assessed (Streiner and Norman, 2008), revealing the factors shown in *Table 6*. (Gouveia e Melo and Oliver, 2011). Death anxiety was assessed in this study by the negative factors, 'avoidance mechanisms', 'fear of dependence and physical degradation', and 'no time for family and meaningful activities'; and the positive factors, 'self-confidence in the face of adversity and illness', 'close personal relationships, and meaning in life' (Leloup and Hennezel, 1997).

Post-intervention open ended questions

These questions were designed by the author to understand the main impact of the training on the participants (questions 1 and 2), to evaluate the structure and teaching methods (question 3), how it affected their relationship with the patient and family and also how it affected their own wellbeing (questions 4a–g), and finally, how it could be improved (question 5). Questions 6 and 7 were asked because there was the possibility at the time to provide further training for these participants after the end of the research. Question 8 was to give them the liberty to raise any other subject they thought relevant (*Table 3*).

Interview

The interviews were carried out at the HCWs' workplace in a room with privacy and only the interviewer and interviewee were present. Although these questions were similar to the qualitative written questions it was considered necessary to explore further the potential impacts through deeper exploratory methods. Filling in questionnaires can be cumbersome, and there is a risk that participants may not give complete feedback. This risk is minimised in a live interview, which also gives the attentive interviewer the possibility to pick up on issues that may otherwise have been missed.

The interview questions were similar to the written questions, but were less structured, allowing for more freedom of expression (*Table 4*). These were carried out by the first author and another independent person-centred trained counsellor. They were audio-recorded, transcribed verbatim and rechecked against recordings. Sounds, pauses and other audible behaviours were not transcribed, unless considered relevant. The interviews lasted approximately 20–30 minutes. The intervention, open-ended questionnaires and interview questions were all pilot-tested prior to the research.

Data analysis

Statistical analysis for all the quantitative data was performed using SPSS 16 (Pallant, 2007).

Assumptions of parametric tests were met. Paired sampled *t*-tests were used to compare the summed scores of participants before (T1) and after the course (T2). All tests were two-tailed and the alpha value was 0.05. Interpretation of effect size ($\eta2$) is as follows: .01= small effect; .06= moderate effect; .14 = large effect. The two cut-off points were calculated by taking the 11 factors from the three questionnaires and separating them into two groups: positive and negative factors. The mean scores for the negative factors and the mean scores of the positive factors were averaged, added together and divided by two (*Table 5*).

The answers to written questions and interview transcripts were imported and stored into the NVivo 8 application (QSR International, 2007) which was used to perform content analysis in the form of thematic analysis (Pope and Mays, 2006). The main categories were pre-defined following the qualitative questions and the interview grid, and their sub categories were created by the author as the text was being analysed. Each relevant sentence was highlighted and dragged to an already existing category or to a new one created at the time. Categories were then re-grouped into themes. Once all the text had been analysed and categories created, all the data was reanalysed to check that no relevant quotations were overlooked. Underlying research materials can be obtained from the author.

Ethical issues

Ethical consent was received from the Research and Ethics Committee of the Kent Institute for Health and Medical Sciences / Centre for Professional Practice at the University of Kent.

❝Nurses and doctors who care for patients with a terminal condition may suffer from increased death anxiety.❞

Table 5. Participants in face-to-face interviews			
Positive factors	**Mean**	**Negative Factors**	**Mean**
Empathy and congruence	4.27	Avoidance mechanisms	2.93
Unconditional acceptance	5	Distance and impatience towards patient	1.87
Self-confidence, dignity and meaning in spite of adversity and illness	4.46	Fear of dependence, physical degradation and loss of control	3.8
Close relationships and personal wellbeing	4.74	Self-criticism regarding no time for family, friends and meaningful activities	3.21
Professional fulfilment	4.44	Emotional exhaustion	3.1
		Depersonalisation	1.81
Total	22.91		16.72
Mean	4.58		2.79
Cut-off point = mean of positive and negative factors:		(4.48+2.79)/2	3.69

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Table 6. Results using paired sampled *t*-tests relating to death anxiety and self-perceived helping-relationship skills of all participants (*n*=150)							
Factors derived from factor analysis using PCA	T1 (pre-intervention) Score 1-6	SD	T2 (pre-intervention) Score 1-6	SD	t (149)	p < (2-tailed)	η2
Empathy and congruence	4.27	0.68308	4.48	0.66514	-4.4	0.001	0.11
Unconditional acceptance	5	0.56051	5.14	0.5295	-3	0.003	0.06
Distance and impatience towards patient	1.87	0.53892	1.72	0.5616	3.2	0.002	0.06
Avoidance mechanisms	2.93	0.67678	2.69	0.6901	4.68	0.001	0.06
Self-confidence, dignity and meaning in spite of adversity and illness	4.46	0.64593	4.73	0.57904	-5.9	0.001	0.19
Close relationships and personal wellbeing	4.74	0.6634	4.86	0.61892	-2.3	0.022	0.03
Fear of dependence, physical degradation and loss of control	3.8	0.88017	3.49	0.88384	5.58	0.001	0.17
Self-criticism regarding no time for family, friends and meaningful activities	3.21	0.72773	3.16	0.6753		Ns	

Results

Quantitative

General analysis of means

The overall results of all participants, both in and out of PCUs, showed a significant improvement in all factors assessed, except for the factor 'self-criticism regarding no time for family and meaningful activities'. Separate analysis of each group showed a significant improvement in all factors for HCWs working in other units, with the exception of 'close relationships and personal wellbeing'. In PCUs, with regard to 'self-criticism regarding a lack of time for family and meaningful activities', the percentage of HCWs above the cut-off point increased from 18.17% to 20.39% after the intervention. Results also showed that most negative factors were already below the cut-off point, especially distance and impatience towards patients, and all the positive factors were above the cut-off point. Fear of dependence and physical degradation was the only negative factor that was above the cut-off point before the intervention; after the intervention this was reduced to just below the cut-off point.

Analysis of Death Anxiety and self-perceived helping-relationship skills in PCUs and other units

Table 7 shows that self-perception of helping-relationship skills showed most significant results in other units, with the exception of empathy and congruence, where results were significant in both groups. Death anxiety showed significant improvements in both groups with regard to avoidance mechanisms and fears related to death and dying and this comparison is further explored in *Table 8*. Whereas in the general results (*Table 6*), paired sampled T-tests

showed no significant changes for self-criticism regarding lack of time for family, friends and meaningful activities, comparison of both groups showed the lack of improvement was only the case in PCUs. Other units showed a significant improvement (*p*<0.007).

Table 8 shows a comparison of means above the cut-off point, of items related to the fear of death and dying in HCWs in and out of PCUs at T1. Results are similar between the two groups, but in HCWs within PCUs, the number one fear is related to personal relationships (*Table 7* shows that lack of time for family and meaningful activities continued to be an issue of concern after the intervention), whereas in HCWs working in other units, the number one fear is related to the process of death: 'If I have to die, may it be quick.' HCWs in other units showed two fears above the cut-off point that HCWs within PCUs did not show: 'I often do not show my appreciation to friends and family and then regret it' and 'The time of dying has no value. It is best to die quickly to end the suffering'.

Qualitative

Thematic analysis revealed four main themes, indicated below.

Main themes
Improvements to feelings of incongruence leading to avoidance mechanisms
Addressing separation with loved ones
Feeling less helpless
Negative feelings still present at work after the intervention

The following will elaborate on each of the themes using referenced quotes extracted from the data to justify analysis.

Table 7. Results using paired sampled *t*-tests relating to death anxiety and self-perceived helping-relationship skills of all participants (*n*=150)

Factors derived from factor analysis using PCA	Mean PCU	Mean other	N PCU	N other	SD PCU	SD other	T1 and T2 PCU			T1 and T2 other		
							t (84)	p < (2-tailed)	$\eta 2$	t (64)	p < (2-tailed)	$\eta 2$
T1 Empathy and congruence	4.19	4.37	85	65	.67	.70	-2.652	0.01	0.08	-3.801	.000	0.18
T2 Empathy and congruence	4.38	4.62	85	65	.71	.58						
T1 Unconditional acceptance and positive regard	5.01	5.14	85	65	.54	.57	Ns			-2.962	.004	0.12
T2 Unconditional acceptance and positive regard	5.14	5.15	85	65	.54	.47						
T1 Distance and impatience towards patient	1.79	1.96	85	65	.54	.53	Ns			3.028	.004	0.13
T2 Distance and impatience towards patient	1.70	1.75	85	65	.59	.52						
T1 Avoidance mechanisms	2.90	2.97	85	65	.64	.73	2.899	0.005	0.09	3.729	.000	0.18
T2 Avoidance mechanisms	2.71	2.66	85	65	.68	.71						
T1 Self-confidence, dignity and meaning when faced with adversity and illness	4.52	4.37	85	65	.59	.70	-3.178	0.002	.11	-5.280	.000	0.3
T2 Self-confidence, dignity and meaning when faced with adversity and illness	4.71	4.75	85	65	.57	.59						
T1 Close relationships and personal wellbeing	4.78	4.69	85	65	.65	.68	Ns			Ns		
T2 Close relationships and personal wellbeing	4.89	4.83	85	65	.58	.67						
T1 Fear of dependence, physical degradation and loss of control	3.80	3.78	85	65	.89	.88	3.833	.000	0.15	4.059	.000	0.2
T2 Fear of dependence, physical degradation and loss of control	3.53	3.43	85	65	.84	.94						
T1 Self-criticism regarding lack of time for family, friends and meaningful activities	3.14	3.29	85	65	.74	.70	Ns			2.799	.007	0.11
T2 Self-criticism regarding lack of time for family, friends and meaningful activities	3.25	3.05	85	65	.63	.72						

Improvements to feelings of incongruence leading to avoidance mechanisms

Fears relating to keeping to trivial conversations or avoiding eye contact were appeased when HCWs had had the opportunity to work on their own personal existential fears during the course. In the following examples, the HCWs realised that their reluctance to allow patients to talk freely could contribute towards the conspiracy of silence. As a consequence, the quality of the helping relationship improved both in and out of palliative care units:

'The relationship with the patient improved, because the course helped me to accept that suffering is part of life, and this allowed me to

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Table 8. Items above cut-off point related to fear of death and dying within PCUs (n=85) and in other units (n=65)			
Fears related to death and dying and avoidance mechanisms (in PCU)	**Mean T1 (score 1-6)**	**Fears related to death and dying and avoidance mechanisms (in other units)**	**Mean (score 1-6)**
If I were to die tomorrow, I would need to talk to some people close to me, to feel up to date with them	4,69	If I have to die, may it be quick	4,64
I feel the need to be informed of everything that surrounds me	4,41	I feel the need to be informed of everything that surrounds me	4,43
I am not at ease until I have everything 'under control'	4,35	If I were to die tomorrow, I would need to talk to some people close to me, to feel up to date with them	4,32
I am afraid of being a burden to others	4,34	I am afraid of being a burden to others	4,23
If I have to die, may it be quick	4,31	I am not at ease until I have everything 'under control'	4,20
I do everything I can to avoid any difficulties or instabilities in my life	4,20	There are times when my outward response to them is quite different from the way I feel underneath	4,02
If I become ill, I would rather die than become dependent on others	3,95	If I cannot be an active and independent person, my life would lose all meaning	3,98
There are times when my outward response to them is quite different from the way I feel underneath	3,94	I often do not show my appreciation to friends and family and then regret it	3,94
If I cannot be an active and independent person, my life would lose all meaning	3,87	I do everything I can to avoid any difficulties or instabilities in my life	3,85
		If I become ill, I would rather die than become dependent on others	3,82
		The time of dying has no value. It is best to die quickly to end the suffering	3,71

stop running away or avoid talking about these things with the patient' (Nurse in other unit)

'I found ways to deal with questions asked by the patient and family related to the progression of the disease, or to death' (Nurse in PCU

Being part of a group expressing empathy, authenticity and unconditional acceptance towards each other seemed to be an effective way for the nurses to gain a better understanding of what the patients are going through and how to better provide a caring atmosphere for them, both in and out of PCUs:

'It gave me more confidence and motivation in my relationship with the patient. More confidence, because I began to understand the experiences they go through with their illness and losses. More motivated, because I understood how much we can do with simple gestures, with love and with 5 minutes of attention.' (Nurse in other units)

'I am more tolerant [now] when the family talks to us aggressively, as a result of their anger.' (Nurse in PCU)

Internal congruence did seem to improve, with a positive effect on the relationship with the patient:

'The main help that the training brought me was the fact that it gave me the possibility to think about myself, and thereby be able to establish a more genuine relationship with my patients.' (Nurse in PCU)

'Not being afraid of showing my emotional and spiritual side, with the aim of helping patients, especially those in a terminal phase.' (Doctor in other units)

HCWs also mentioned they felt more confident exercising what Kearney et al (2009) refer to as 'exquisite empathy'. This can be manifested through an awareness to be present and respectful:

'Professionally, I think I am better in terms of humanity and relationships because I have changed my time management at work and started to give more value to moments of sharing and listening to the patient.' (Nurse in PCU)

'With the patient, what changed was my capacity to listen and accept the silences … ' (Nurse in PCU)

Addressing separation with loved ones
Caring for the dying raised some existential anxieties about life and death and reminded HCWs of what it would be like to never see their own loved ones again. During the intervention, time was spent on reflecting on the meaning of their life and the importance of their relationships with loved ones:

'… it allowed me to give more value to the meaning of life in a way that I hadn't done before, which probably influenced my attitude towards life and other people' (Psychologist in PCU)

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'I give a lot of value to my family. Today I find more time to listen to my children and husband, and I see life in a different way.' (Nursing aide in other units)

Changes also seemed to have occurred through understanding that setting time aside for themselves is not being selfish, but responsible, because feeling rested and fulfilled at home may increase the quality of care to their patients:

'My daily life and sense of wellbeing really got better. Since then, I have organised my work to have more time for me and my family. I have even found time to go to the gym once a week … ' (Doctor in PCU)

However, some HCWs acknowledged the need for continuous support to maintain their wellbeing:

'In the beginning, I felt a big difference in wellbeing, and I am sure that it was due to the calming effect of the training, but unfortunately, this effect didn't last for long, and now I worry even more about the death of my loved ones.' (Nurse in other units)

Feeling less helpless

Feelings of helplessness towards death and patients' frailty and vulnerability were reduced. HCWs felt that a reduction in death anxiety and an increase in inner peace had had a positive effect on the relationship with the patient, and this may have consequently reduced their sense of helplessness:

'… if we accept death better, and that the patient is here to die, but with more quality of life and less suffering … maybe we will be capable of caring for them differently … not that before we cared for them badly … we gave the best technically … but perhaps in terms of relationships, we can help the patient in a different way.' (Nurse in PCU)

Equally important was the ability HCWs gained to trust in the patient's ability to cope, and this improved their own serenity to cope with suffering. If carers do not have this belief, there may be a tendency to overprotect and this may not be beneficial in helping the patient grow (Rogers, 1951).

'The patient has more resources than I thought. The patient can go through many emotional stages and we must respect this. I am continuously trying to understand him.' (Nursing aide in PCU)

Negative feelings still present at work after the intervention

However, despite many improvements, feedback showed that a one-off intervention was not sufficient. HCWs needed continuous emotional support to cope with the suffering:

'We do give, but it is almost a routine … talking to the patient … that's all fine, but there is something missing … everything is so mechanical … ' (Doctor in PCU)

'For many of us, the intervention was like planting a seed in fertile land, but, as everything in life, it would have been important to water the seed and care for it. … perhaps with regularly organised interventions' (Nurse in other units)

Understaffing and work overload also affected HCWs' wellbeing:

'… in terms of efficiency, things are the same. Some things can't be changed with the course, because they have to do with the need for more health care workers … ' (Nurse in PCU)

'The volume of work to do fills our head up in such a way, that we have to just do what is most urgent, and you lose that sense of wellbeing that would lead us to do that bit extra …' (Doctor in PCU)

Discussion

This study showed how an intervention designed to help HCWs cope with their own anxieties towards death and dying and increase their personal existential wellbeing, combined with helping-relationship skills, can increase the quality of psycho-existential care to dying patients and their families.

The study was performed with Portuguese HCWs in and out of PCUs and the quantitative results showed how death anxiety can manifest with regard to the process of death, such as the fear of becoming a burden, of losing control, and issues related to personal relationships and meaning in life (Leloup and Hennezel, 1997). Analysis of the items related to death anxiety before the intervention shows that the main concern of HCWs in PCUs is related to their awareness of the importance of personal relationships in their private lives, whereas HCWs

Caring for the dying raised some existential anxieties about life and death for the health care workers.

in other units were mainly concerned about issues related to dependence and physical degradation. This difference can be explained by HCWs in other units' lack of palliative care education.

The post-intervention quantitative results of this study seemed to show clear improvements with regard to self-perceived helping-relationship skills and death anxiety, with the exception of 'self-criticism regarding no time for family, friends and meaningful activities', which showed a significant reduction in other units, but an increase after the intervention in HCWs working within PCUs. A possible explanation for this is that HCWs within PCUs were already making efforts to spend more time with their family, and these results show that they were not able to do as much as they felt they should, due to understaffing and work overload, and therefore their anxiety increased.

The qualitative results provided a deeper insight into how the use of avoidance mechanisms and feelings of helplessness were reduced through the intervention, and of the way HCWs became aware of the need to bring meaning into their own personal lives and relationships and also how this had a positive impact on the relationship with the patient and family.

A contributing factor to this outcome may have been the benefits of group therapy, which have been well documented (Rogers, 1973; Jones, 2006) and specifically with regard to death anxiety (Nienaber and Goedereis, 2015). HCWs were able to experience how it felt to express their difficulties without being afraid of being evaluated. This enabled them to find the inner resources to face patients' and their families' suffering without resorting to avoidance mechanisms. Furthermore, being part of a group where empathy and unconditional acceptance were present helped them to understand how this atmosphere can benefit patients even when no cure is available and this contributed towards reducing their feelings of helplessness. HCWs were also able to reflect on ways of improving their own personal relationships, and this seemed to increase their personal wellbeing and capacity to enter a quality relationship with their patients.

However, the same did not seem to occur with issues of fear towards dependence and physical degradation (Payne, 1998; Mercadier, 2002) shown in the quantitative results. The absence of qualitative comments relating to this may imply that this difficulty remains at a subconscious level, requiring more attention. A possible reason for this is that although the subject was present in the intervention, it did not occupy a large part of the course curriculum and this aspect of the course has been revised.

Looking at the qualitative results from the point of view of different professions, there is a need to take into consideration that 76% of written answers and 80% of interviews were given by nurses and nursing aides. However, although comments from doctors were scarce, these showed that after the intervention, doctors working out of palliative care units felt more at ease to show their genuine feelings with their patients, increasing the quality of the relationship. Some doctors within PCUs noted that fatigue and work overload resulted in more impersonal relationships with patients, a situation they were unhappy with.

These findings support the need to address these issues in the preparation of HCWs who care for the dying through personal development to improve their personal wellbeing and to help them cope better with death anxiety. By helping HCWs to accept that death is not a failure of medicine, and equipping them with coping strategies for their own existential issues, HCWs can learn to stay present with the patient, even when there is no cure. Personal development to address these issues may have the potential to allow them to accept that after doing all that can be done to ensure comfort, just being with the patient with a different quality of presence is extremely important to help the patient die 'healed', as discussed by Twycross (2005).

However, comments also showed that despite the initial benefits of the intervention, teams need ongoing support in order to maintain these positive results and other studies have shown how death anxiety can affect work engagement (Sliter, 2014). Furthermore, the absence of comments regarding feelings towards dependence and physical degradation shows that a one-off intervention can only go so far in reducing anxiety; other studies have shown that sources of support in the workplace would be considered valuable (Peters et al, 2013b).

Limitations

While efforts were made to gather responses from and involve different disciplines in the qualitative part of the study, as mentioned above, the main respondents were nurses, which gave an ultimate bias to the results. Thus any intervention changes in response to the findings would need to be validated with other professionals. In addition, the lead author not only conducted the intervention but also the research. While the post-intervention qualitative questionnaires afforded some anonymity, the interviews did not and therefore there may have been the potential for respondents to reply in a more positive way

(Robson, 2002). However, the author was aware of this and provided ample opportunity for any negative experiences to be expressed, which were forthcoming, as highlighted in the results. No evidence about the long-term effect of the intervention exists.

Conclusion

Complementing education in communication and psycho-existential support with personal development related to death anxiety may help HCWs within different settings and of different professions, including doctors, who care for patients with a terminal condition, to reduce their need for avoidance mechanisms to protect themselves, resulting in a more meaningful helping relationship. However, an initial intervention should be followed by continuous support to maintain results.IJPN

Supplementary Materials
- For access to statistical data, please contact carolgouveiamelo@gmail.com.
- For access to qualitative data, please contact carolgouveiamelo@gmail.com or the Calouste Gulbenkian Foundation in Lisbon: Processo n° 71773 – Concurso para Financiamento de Projectos na Área da Investigação em Cuidados Paliativos – 'Formação vs Qualidade nos Cuidados Paliativos'

Declaration of interests

The authors have no conflict of interest to declare

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