"God Hey, Now I've Been Through Something"

Moral Resilience of Coordinators in Voluntary Palliative Terminal Care

Gaby Jacobs, PhD

Moral distress arises in the dynamic relationship between personal factors and the organizational and political contexts of care work. Whether moral distress actually leads to a reduced well-being of health care workers or a reduced quality of care in the sector depends to a large extent on how moral tensions are dealt with, also called moral resilience, and the protective conditions available. Research about moral distress and moral resilience within the field of health care has concentrated on staff nurses and physicians. Studies into palliative terminal care and/or about the role of coordinating staff are scarce. A study was conducted to gain insight into the moral challenges that coordinators in voluntary palliative terminal care encounter in their ambition to realize good care, how they deal with these challenges, and the individual and organizational characteristics that foster or hamper moral resilience. Interviews were conducted with 20 coordinators and were qualitatively analyzed. The results brought forward 3 moral challenges in working with volunteers and in collaborating with professional care, namely, striving for connection, negotiating autonomy, and struggling with open communication. However, coordinators seemed to face these challenges effectively. In conclusion, the relational narrative strategies used by coordinators to deal with these challenges, in combination with personal and organizational conditions, foster moral resilience.

KEY WORDS

Palliative care work has the potential for causing moral distress for health care workers and volunteers. The distress may be caused by the confrontation with

Gaby Jacobs, PhD, is professor, University of Humanistic Studies, Utrecht, the Netherlands.

Address correspondence to Gaby Jacobs, PhD, University of Humanistic Studies, Kromme Nieuwegracht 29, 3512 HD, Utrecht, Netherlands (g.jacobs@uvh.nl).

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suffering and dying, which is not compatible with Western values of "leading a good life," and by aspects of trying to deliver good care within restricting circumstances. Maffoni et al[1] described several stressors experienced by nurses and physicians in palliative care, including emotions regarding death and dying, difficulties in communication with patients and relatives, communication of poor diagnosis and prognosis, and decision making about treatment. Protective factors are identified: social support, a positive work attitude and positive value of work and experiences, and work-family balance. In a review study about moral distress, 4 main areas of moral distress were identified: personal factors, patients and relatives, colleagues and superiors, and the organization and environment.[2] These capture categories of distress found in other studies on palliative care.[3-6]

MORAL DISTRESS AND MORAL RESILIENCE

Moral distress arises in the dynamic relationship between persons and the organizational and political contexts of their care work. It is understood "to occur when a health care professional, as a moral agent, cannot or does not act on his or her moral judgment(s) (or what he or she believes to be right in a particular situation) because of institutional or internal constraints."[7] Not being able to practice one's own values of good care can lead to problems with well-being, dropping out of the profession, or a loss of idealism. Nowadays, the view on moral distress is broadened to include other morally troubling situations as well, such as moral conflict, dilemma, or uncertainty.[7,8] In addition, Fourie[8] argued that different groups of health professionals may be prone to different categories of distress.

Whether moral distress actually leads to a reduced well-being of health care workers or a reduced quality of care in the sector depends to a large extent on the ability to cope with the distress. Moral resilience is defined as "the capacity of an individual to sustain or restore their integrity in response to moral adversity."[9(p127)] At an individual level, various dimensions play a role, including knowing one's own values, the ability to self-regulate, being flexible in complex ethical situations, being able to distinguish the boundaries of integrity, the ability to act decisively in morally charged situations, and being able to search for meaning in situations that threaten integrity. At the organizational level, moral

resilience is fostered by a culture of ethical practice that is characterized by reflection on moral issues, collaborative learning, a support program for employees, and a policy that actively facilitates value-based work.[9]

RESEARCH OBJECTIVE AND RESEARCH QUESTION

So far, research about moral distress and moral resilience within the field of health care in general and also in palliative care has concentrated on staff nurses and physicians.[7] Although there is quite a bit research done into nurse managers' moral distress in health care in general,[10,11] only a single study addressed the coordinating role of the nurse within the field of palliative care.[4] In addition, research into voluntary palliative care is scarce. A review study showed that hospice palliative volunteers do not experience high levels of moral distress, although they do report stressors, including role and status ambiguity, factors related to working with patients and families, and personal factors.[12]

The aim of this empirical study was to gain insight into the moral challenges that coordinators in voluntary palliative terminal care (VPTC) encounter in their ambition to realize good care, how they deal with this, and which individual and organizational characteristics support or hinder this. In the Netherlands, a large network of about 200 organizations exists that provides VPTC, alongside professional caregivers, offering additional, nonmedical care. They include hospice care, guest homes, and home care. Coordinators, often having a background as nurses, play a pivotal role in the organization of this care, the supervision of volunteers, and the collaboration with professional caregivers. The research questions included the following: (1) "What moral challenges do coordinators in VPTC experience in their relationship with volunteers and in collaborating with professional organizations?" and (2) "What strategies and conditions support them in dealing with these challenges?" (moral resilience).

METHODOLOGICAL APPROACH

A qualitative study was conducted among coordinators in VPTC, which is well suited to gain an in-depth insight into the experiences and meaning of individuals and to go into depth about subjects that seem to be important.[13] Twenty coordinators were recruited from the 200 volunteer organizations affiliated with the Vrijwillige Palliatieve Terminale Zorg Netherlands, the umbrella organization for VPTC. This sample was selected from 124 coordinators who filled out a questionnaire about moral distress, looking for diversity in biographical and organizational characteristics. All 20 participants were female, and their average age was 55.4 years, with on average 7.4 years of work experience as coordinator. Most participants were employed in guest homes (11) and home organizations (6); 2 participants were working in a high care hospice, and 1 in a palliative care unit.

A semistructured interview was conducted that addressed the 2 main tasks of the coordinators: the relationship with the volunteers and the collaboration with professional care organizations. The questions aimed at getting insight into morally difficult situations in these areas and the way in which coordinators deal with them (strategies that foster moral resilience). Because this is a sensitive area that can be accompanied by feelings of shame or guilt, personal failure or doubts about one's expertise, or the integrity of the organization, the anonymity of participants was warranted, and they were offered the option to withdraw from the study at any time should they wish to do so. All raw data and the analyses were stored on a secured research disk at the university. Ethical review and approval were waived for this study, as ethics approval for this type of study was not required according to the Medical Research Involving Human Subjects Act ("Wet medisch-wetenschappelijk onderzoek met mensen") in the Netherlands.
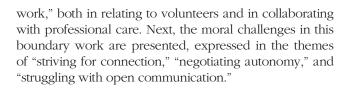
The interviews were fully transcribed and qualitatively analyzed using ATLAS.ti and following the steps of an inductive thematic analysis.[14] This led first to a high number of topics under the headings of "working with volunteers" and "collaboration with professional care organizations," which then were clustered into a few main themes, by using the expressive-collaborative model of morality by Margaret Urban Walker. In this model, morality is "a socially embodied medium of mutual understanding and negotiation between people over their responsibility for things open to human care and response."[15(p9)] Moral challenges arise within a context of different standards that influence care work: institutional and organizational regulations and procedures within the professional care settings, as well as client and volunteer demands, needs, and motives. These aspects may conflict with the coordinators' professional and personal values and those of the volunteer organization, thereby triggering moral questions and dilemmas about good work.

The coordinating work, then, can be seen as a relationship-based practice that requires "boundary work" and "multiactor dialogue,"[16] taking into account different and sometimes conflicting interests, practices, and views regarding good palliative care. The lenses of "boundary work" and an expressive collaborative model of morality show that professional values of coordinators are not unequivocally leading to actions, but that moral challenges and moral deliberations are involved. They also help to see the strategies and conditions that foster moral resilience and learning as key dimensions of relational professionalism.

MORAL CHALLENGES IN COORDINATING WORK

In this section, the results of the first research question are presented. Coordinators work at the interface between professional care and VPTC. They have to do "boundary

work," both in relating to volunteers and in collaborating with professional care. Next, the moral challenges in this boundary work are presented, expressed in the themes of "striving for connection," "negotiating autonomy," and "struggling with open communication."

Striving for Connection

The coordinators value connection highly within their organization, but current health care developments put connection and collaboration under pressure. They want volunteers to feel connected to the organization, to each other, and to the coordinator, almost like a family:

> …And I am actually a connector, like, it must have a family feeling that you take care together, that you also take care of each other, and that volunteers contact each other if there is something wrong and ask questions.

A factor that has left its mark in the past year is the COVID-19 pandemic. As a result, fewer volunteers were available, and coordinators were afraid of losing volunteers:

> …So volunteers now work alone a lot, and they also miss that contact with each other, but I also notice that the mutual connection is less now. That's a pity, yes. So I also have to make more effort to connect that a bit.

COVID-19 has drawn a boundary between volunteers, which requires more effort to sustain or recreate connections. Connection is also threatened on the organizational level between voluntary and professional work because of the ever-increasing demand for health care. The coordinators feel that good care can only be provided by working together as 1 team:

> …[A] team feeling, so being there together for the guests. And then [by] team, I also mean the professional, that we really are a unit, that we complement each other.

However, care requests have become more complex, and volunteers increasingly have to deal not only with the care for dying persons but also with multiple problems within the family. Sometimes pressure is put on the coordinator by professional health care institutions to accept unrealistic care questions that do not fit with the voluntary work:

> And now you [have to] bend over backwards. Because then her husband calls. And then the girlfriend calls. And then the doctor calls. And then…calls, well, you're being manipulated on all sides.… So you have to be clear and very, very clear.

Coordinators try to protect volunteers but at the same time, do not want to leave clients out in the cold.

Negotiating Autonomy

Autonomy is viewed as important in VPTC. It is practiced by informing clients and their relatives about their options and giving them choices in what care they wish to receive:

> Yes, that the guest feels seen and the family and loved ones feel that they are in control, that they can retain a bit of freedom and that the volunteer supports this.

However, volunteers may have problems focusing on the client's wishes and preferences:

> In a complex situation, I sometimes see that volunteers find it difficult to align well with the guest, but we are increasingly successful in guiding them: try to change perspective, see who this person was, how he or she has lived.

In addition, coordinators see various forms of transgressive behavior on the part of volunteers, such as strong personal beliefs that are forced on clients. The autonomy of volunteers is then obstructing the clients' autonomy. On the other hand, sometimes a client refuses help or a client's wishes lead to unsafe situations. The coordinator or volunteer may then have to negotiate the client's autonomy. Furthermore, examples are given that clients or family members may cross boundaries of respect and dignity toward the coordinator or volunteers.

Within the coordinator-client relationship, coordinators sometimes have to draw a line if volunteers become too close, looking for friendship instead of voluntary work, or if they do not function well. Autonomy, and also the boundaries to it, is a diffuse and contested area, which is made even more complex by the voluntary nature of the work:

> You know, to what extent can I say, hey you don't keep the agreement that you schedule a shift every week, or I think you don't act professionally.… Those boundaries are not as clear and rigid as in the professional world, I think.

On an organizational level, the demarcation line between tasks and responsibilities of voluntary and professional caregivers is sometimes not clear:

> I am not responsible for medication distribution by the nurse, but if a guest complains, I need to act on it. Then this should of course be discussed with each other for the benefit of the guest. But sometimes the nurses find it difficult to realize that we as coordinators still have that ultimate responsibility within the hospice. Sometimes that causes some dissatisfaction or tension.

These are all examples of negotiating autonomy, taking place in the relationships between coordinators, volunteers, clients, and professional workers.

Struggling With Open Communication

A third major challenge is open communication. Coordinators attach great importance to open communication among volunteers, among volunteers and coordinators, and in the collaboration with professional caregivers. First of all, volunteers should be able to discuss conflicts and to give feedback to their peers:

> We give it back like: "Gosh, first go and discuss that in the next shift." And if you can't figure it out, then I think we have a role as coordinators.

However, coordinators themselves sometimes have difficulties giving feedback. They may hesitate to address or dismiss a volunteer who is not functioning properly because the voluntary work often has an important meaning in the lives of the volunteers:

> What I find difficult is that you see in volunteers that they themselves are struggling with their health and are deteriorating.… But when will the time come to stop volunteering? And am I the one who has to bring it up, or, I really want to leave it with the volunteer.… I also find that a puzzle.

Secondly, coordinators also value good communication, coordination, and information sharing in their collaboration with professional care providers:

> I want them at least to know what tasks and responsibilities the volunteers have and that they keep an open communication and inform me about things that are important so that the care between volunteers and professionals can be aligned well.

However, in practice, it is sometimes difficult for coordinators to keep their organization on the map with professional health care providers, especially with home care organizations:

> Once we found that they forgot to inform us about the condition of a client and we were then unpleasantly surprised at the decline in health. And on another occasion, they forgot to inform us that someone had died.

STRATEGIES AND CONDITIONS FOSTERING RESILIENCE

In this section, we will present the results on the second research question: the strategies coordinators use to deal with the moral challenges they encounter and the conditions that foster moral resilience (see Table).

A distinction can be made between strategies that help to prevent or solve difficult situations and strategies that

TABLE Strategies and Conditions for Moral Resilience	
Strategies to Deal With Moral Challenges	Conditions Fostering Moral Resilience
Problem-directed strategies: Prevention of problems Seeking dialogue Looking for alternatives **Emotion-directed strategies:** Searching for support Emotion regulation Cognitive reconstruction	Personal strength and wisdom Training and education The meaningful nature of VPTC

Abbreviation: VPTC, voluntary palliative terminal care.

help in dealing with emotions due to difficult situations. The effectiveness of the strategies used by coordinators does not stand on its own but is fostered by conditions fostering resilience. Three conditions for fostering resilience are discussed: personal characteristics of strength and wisdom, training and education, and the characteristics of voluntary palliative work.

Problem-Directed Strategies

The strategy that coordinators most often use when faced with morally challenging situations is an active strategy of "confronting the problem" by seeking dialogue with those directly involved, trying to prevent problems to occur, or looking for alternatives.

Preventing Problems

Coordinators value a good selection process of volunteers by thoroughly examining the suitability of candidates to prevent problems in the future. Moreover, volunteers also receive training after being hired:

> The funny thing is that I don't experience many [problems] nowadays, because in the past 5 years, we have been able to train our own volunteers, and we always had a waiting list. We were able to select, and we actually turned people down because we thought "No, you don't add value to the team."

In addition, coordinators carefully examine whether a care request is appropriate, and they reject it if it is not suitable for a volunteer.

Seeking Dialogue

If confronted with morally difficult situations, coordinators are generally not afraid to discuss these, although there are situations in which they hesitate to communicate openly as outlined in the previous section. They ask questions and encourage volunteers to reflect:

…Because then I'm like "Yes, you are an adult volunteer, you also have your own values and standards so I will reflect with them." Where does that come from?… I'm not going to ban them. I'm just going to try to give them a different insight.

In situations of conflicting interests, coordinators often take a mediating role. However, they are also not afraid to make a decision or to set a clear line when necessary.

Looking for Alternatives

Many coordinators try to think about alternative solutions to a problem. In the example that care requests or volunteers do not fit with the organization, they may refer a care recipient or candidate volunteer to an organization that suits them better:

Because once you know that, you just start looking for how you can help someone by saying, for example, there is a buddy project. So then you refer them.…

Emotion-Directed Strategies

In dealing with emotions in difficult situations, the coordinators also prefer an active strategy: they talk to colleagues to find support. Other strategies used are emotional regulation and cognitive reconstruction.

Searching for Support

Coordinators often enter conversations with colleagues to present a problem to them and to share emotions about the situation with the other person:

…And what you sometimes need [is] to express that with someone like: "God hey, now I've been through something." But the work itself is not such that you are completely destroyed. No.

Colleagues and the management of the organization are most often mentioned as sources of support. In addition, participating in a training, education, supervision, or coaching session can also be a form of seeking support. Coordinators mention that guidance from an external party can be helpful in the case of disturbed relationships or longer-term issues in the organization.

Emotion Regulation

Coordinators identify a number of strategies to regulate their emotions in difficult situations. They try to consciously stay with themselves and their own feelings in difficult situations, not to get carried away by the emotions of their conversation partner, and to keep their calm:

I've been hit, too. I'm also just human. I'm not ashamed of that either.… But then that's just my eyes getting moist, so

to speak. It's not that I'm sitting at someone's bed completely upset; I can still be present for them.

Sometimes they consciously "turn the switch" on themselves, or they apply other strategies to release emotions, such as taking a walk, not answering the phone, retreating to a quiet place, having a coffee, or listening to music.

Cognitive Reconstruction

Coordinators reflect a lot on difficult situations, and in general, they seem to be able to view difficult situations as challenges that make the work interesting and to focus on positive aspects. Mostly, they are also quite capable of separating "mine and thine," thereby not taking matters personally:

I try to see who that person is.… Well, she is like that, and that suits her.

Conditions Fostering Moral Resilience

Several conditions provide a basis for moral resilience, which are personal, relational, or organizational in nature.

Personal Strength and Wisdom

Coordinators show an extensive work and life experience, and personal characteristics of strength and wisdom that fit with their job and provide a foundation for resilience:

Look, I just said…I'm not 25 anymore either. I have been through quite a lot in life by now, without being dramatic and wanting to be. Yes, quite a few situations, from which, fortunately, I have also learned, yes, you know, she does behave that way, but I should be wiser. Like my father always said, "Oh girl, be wise."

Training and Education

The possibility for coordinators to follow a training program, to make use of peer reviews or coaching sessions, or to attend a thematic meeting is promoting professional and personal functioning in the workplace. Sharing experiences and exchanging information in meetings with peers provide new insights and support.

The Meaningful Nature of VPTC

Last but not least, the voluntary nature of the organization is experienced as very positive by the coordinators. In their view, volunteers are very engaged and highly motivated, precisely because they do not work for a salary. Coordinators also find it pleasant and beneficial to work in a nonhierarchical organization; they value their autonomy and freedom, and the lines between them and their volunteers are short. Most importantly, the work allows for special moments that are deeply meaningful:

I also always notice when, for example, I've been on a home visit with someone in a situation where, hey, someone is dying, time runs a little slower. And the moment I drive back I think, gosh, those cars are all speeding. And then you have to get back into the normal world for a while and get into the normal pace. And then I also realize that it is incredibly special that one can get so close with another person.

DISCUSSION

In this last section, we will discuss the findings by relating them to previous research, reflect on some methodological limitations, and give recommendations for further research.

Low Levels of Moral Distress Among Coordinators

It is striking that coordinators in this study seemed to experience few negative emotions because of the morally difficult situations at work. An explanation for this may be the strategies they use to deal with those situations. In addition, their personal strength and wisdom, developed over the years and by training and education, as well as the appeal this work has to them, are contributing to a positive attitude toward their work and the difficulties they meet. This is in line with the framework developed by Rushton et al[6] in which attributes such as perspective taking and high moral sensitivity are supporting emotion regulation and equanimity, and compassionate other-focused responses. In addition, Maffoni et al[1] explained that the same factor can be a stressor for some but a trigger for wellness to others, depending on its meaning to the person. In our study, the coordinators are experienced professionals who use strategies that contribute to a sense of meaning, learning, and development in their job. A positive and meaningful approach to one's work is protective, as reported by Maffoni et al,[1] and is also seen in our study. In other words, the balance seems to be right: the strategies and conditions fostering moral resilience seem to weigh up to the moral challenges involved in the work.

Another explanation may be that coordinators, compared with executive care workers such as staff nurses, experience less powerlessness. Research indicates that powerlessness of nurses is an important factor in the experience of moral distress.[4,11] In addition, Ganz et al[10] in their research about nurse managers found lower levels of distress compared with nurse staff, and the distress was limited to the administrative areas. The coordinators in this study value autonomy and actually have quite some autonomy in making decisions, which might explain their lower levels of moral distress.

Finally, the work in palliative care differs from work in other care settings, resulting in lower levels of burnout in palliative care workers.[17] In addition, the work in the palliative *terminal* phase of life is different from other areas of palliative care. Several important stressors in palliative care that are reported in the literature, such as medical examinations and decisions regarding treatment and the communication of the diagnosis and poor prognosis,[1] are often not relevant anymore in the end stage of life. In this study, we also found that working with highly motivated people in the voluntary sector, a sector that is less affected by the increased emphasis on efficiency and productivity in health care, may add to the high work satisfaction and positive work attitude of coordinators.

Coordinating Work as a Boundary Activity

The study showed that coordinators work at the boundary between voluntary and professional care work, which entails at least 3 moral challenges. The coordinators, then, can be seen as boundary crossers who try to uphold the values of connection, autonomy, and open communication within the different relationships in VPTC. Erikson and Davies[18] also put attention to the stress involved in navigating the personal-professional boundary in their study of nurses in pediatric palliative care. This study had broadened the perspective on boundary work, showing that several boundaries have to be "worked" at the same time in the relationships of clients, volunteers, and professional caregivers, at least for coordinators in VPTC. This requires relational competence and relational agency as conceptualized by Edwards[16] to be able to work within a setting with different stakeholders who all hold their own values and perspectives.

Collaboration with professional care turned out to be an important area of moral challenges, which is commonly not addressed in the literature about moral distress of health care staff, except in a study conducted with volunteers in Belgium.[19] The difficulties they found included ambiguity in tasks and lack of information exchange, which were also confirmed in this study. Volunteers wanted to be more involved in the organization of palliative care, not standing at the sideline, which was also found in this study. It is especially difficult for coordinators of home organizations to stay in the picture with professional care organizations because of the high throughput of staff. This study recommended that professional care providers act as "ambassadors" by making clients and relatives aware of voluntary help, and that information about VPTC is part of training programs of professional caregivers.

Relational Work and Moral Resilience

The coordinators reported various strategies, but "seeking dialogue" and "searching for support" with others involved in the situation—both relational and narrative strategies—turned out to be the most important overarching strategies of coordinators in dealing with morally difficult situations. These strategies enable them to help others or themselves to seek new perspectives and at the same time to strengthen

relationships, connections, and open communication, which are highly valued by the coordinators. It was already known from the literature that seeking contact with others and social support may contribute to the moral resilience of caregivers.[9,11,20] This study stressed the importance of being and staying in dialogue and receiving and giving support as foundations for moral boundary work of coordinators. This moral work is boundary work and a continuous learning process in moral sensitivity and moral acting, thereby contributing to moral resilience. The study also showed that moral resilience is multilevel work, meaning that it is a complex interplay of strategies and conditions on multiple levels (individual, organizational, and institutional), thereby indicating the reciprocity between agency and structure.[7] However, the concept of moral resilience itself is often still defined in individualistic terms as "the capacity of an individual."[9(p127)] On the basis of this study's findings, moral resilience in coordinating VPTC work probably would be better defined as dialogical processes of meaning making at boundaries that contribute to a sense of empowerment, to compassionate and learning work environments, and to new possibilities for interacting and providing "good care."

Methodological Recommendations

This research focused on the perspective of the coordinators on the moral challenges in VPTC, but not on those of other stakeholders, such as the volunteers or professional care providers. Factors that are perceived as hindering or fostering by the coordinators may acquire a different meaning from the perspective of other parties involved. This could be further investigated in follow-up research and specifically for this sector so that a multidimensional view emerges.

In addition, the context is highly influencing the moral difficulties, such as the invisibility of volunteer work, which is more pronounced in home care. More research into specific types of organizations should be conducted to differentiate between contexts, moral challenges, and strategies.

Finally, moral distress as a phenomenon has so far only been investigated in the professional context. It would be interesting to investigate whether and, if so, how this occurs among volunteers in palliative care, for example in relation to what is also referred to as "compassion fatigue."[21]

Acknowledgments

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