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Volunteering in Palliative Care in France: “A Tough Job”; Patient, Family, Caregiver, and Volunteer Perspectives

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Additional information is available at the end of the chapter

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Abstract

This chapter discusses the place of volunteering in palliative care in the context of hospital services in France, and the meaning each actor gives to that presence. Its aim is to go beyond general normative discourse on the role of these volunteers in order to highlight their actions from a little-explored perspective (awkwardness, fears, reticence their activity can create) but one essential to their development. We attempt to understand how (and within what work settings) personnel and volunteers “work” together, and how that lay presence is perceived by patients and families. This research is based on a literature review and individual semi-structured interviews with patients, families, medical personnel, and volunteers in 10 hospitals. In all, 114 persons were interviewed in three work settings: palliative care units, mobile palliative care teams, and traditional services. The analysis highlighted a diversity of perceptions on volunteering, as a function of the type of actors involved and the work setting. It raises the question of the role of non-professional actors in hospitals, and of what form volunteering in palliative care should take in France, where volunteers explained they “are there” not “to do”, but just “to be there out of human solidarity”.

Keywords: palliative care, volunteering, qualitative research, quality improvement, models of care, France

1. Introduction

1.1. National and international context

As defined by the World Health Organization (WHO), “palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of

early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual". Originating in the United Kingdom and Canada in the 1960s, this care model is based on a multidisciplinary approach, bringing together professionals and volunteers, with a shared view of improving the quality of care and strengthening social relationships. It consists in both alleviating the symptoms from which these people may suffer and putting an end to the image of place of death (often associated with death in institutions) by getting people from civil society involved in the care facilities [1]. While professionals essentially carry out care, hotel, and administrative functions within a salaried and skilled work environment, volunteers offer their time, away from their own family and theoretically through pure "altruism", expecting nothing in return [2]. This is a "free and gratuitous gesture" which "is opposed to the present society founded on wages and profit," and which some authors consider "a higher form of solidarity" [3].

Given its profoundly humanist nature, this care model has expanded rapidly throughout the world. In 2000, there were already 87 countries that have set up palliative care programs, 2/3 of them being middle or low-income countries [4]. Palliative care is found today on the five continents in forms more or less faithful to the original model and varying as a function of national policies, health systems, cultural differences, and local needs [5–7]. According to WHO, there are today 20 million people a year who require palliative care throughout the world (of whom nearly 70% are adults over 60 years) [6]. France has not escaped this phenomenon of acculturation to palliative care; the first palliative care unit (PCU) was opened in 1987—30 years ago [8]. Since the law of June 9, 1999, palliative care is considered a right "for every citizen that needs it" and a public health priority. The first national development plan for palliative care that followed (1999–2001) took the first steps in offering care, which today has become quite significant and diversified, even though the notion of "hospice," dear to the English and Canadians, was not used to bring about this development,¹ with rare exceptions (such as the *Maison Médicale Jeanne Garnier* in Paris, which has 81 beds, all devoted to caring for people needing palliative care). According to recent statistics, in 2016, France had 143 PCUs, 406 palliative care support teams (PCSTs), 5057 "identified palliative care beds" (that is, beds in curative care services, but reserved for patients needing palliative care), 92 home care organizations, 11 coordinated networks, 15 regional pediatric teams, and 350 associations of volunteers [9]. These associations place their activities within a framework of non-abandonment and nonmarginalization of people confronted with a serious illness, old age, death, and grief [10]. In this context, volunteers—estimated at 6000 persons—have the goal of "improving the living conditions of persons who suffer, in a spirit of partnership with health professionals" [11] and of "participating in changing perceptions" concerning death and severe illness [12].

¹Indeed, France chose an original path compared to the pioneering countries: develop palliative care, not in large institutions devoted exclusively to this care, but rather in all facilities where these patients may be found. After having put in place PCUs and mobile teams for 15 years, present efforts are thus aimed at raising awareness for the "palliative approach" among all caregivers caring for people at the end of life, regardless of where they work [13–15].

1.2. Major issues involved in volunteering in palliative care

Although ministerial and association texts encourage caregiving teams to have recourse to volunteers, national and international literature shows that there is a certain contradiction between the attention they are regularly given and the mistrust their presence sometimes provokes in the field [16]. As Godbout emphasizes, "the idea of giving one's time [to strangers] troubles the modern mind [and often seems] suspicious" in our production-driven societies [3]. Being neither caregivers, family members nor paid workers, volunteers raise questions on more than one level for the other actors, as does the public health researcher, anxious to better understand care practices and to analyze their principal stakes.

1.2.1. *Giving/receiving: a delicate balance*

There is a good deal of research on the motivations of volunteers in palliative care [2, 17–24]. These works show that while volunteers are inspired in the first place by a desire to help others and therefore by altruistic and philanthropic values, they are often interested in seeking benefits for themselves as well, with these two types of motivation becoming interwoven, evolving over time and varying according to countries' cultures. Their desire to "give" is often linked (but not always) to the death in a hospice of one of their own family members: future volunteers thus wish to offer to others the quality of care received at that time. "Giving up my time is the least I can do" argues some volunteers. At other times, their system of values and beliefs motivates them to become volunteers, without them necessarily having suffered a loss: it is important for them to ensure that patients do not die alone, to lessen their suffering as much as possible, and to show them warmth and compassion through human solidarity. On other occasion, it is simply a chance discovery of palliative care that leads them to become volunteers. But even if they expect nothing in return for the help, they consciously give, on the other hand, they often admit "receiving" in return sometimes more than they give; the fact of giving does not prevent one from receiving in turn, in a circular dynamic beneficial to all. They evoke their need to feel useful to society, to seek an interruption in their daily routine, to create relationships with other people with the same values as their own, or to acquire new experiences (that they can then use to enhance their professional life, for example). Consequently, some volunteers consider the time spent among people at the end of life as a "gift", even a "privilege", from which they say they gain both enrichment and satisfaction. For Claxton-Oldfield, this relationship should be strongly encouraged as it leads to a "win-win situation" [25]. Indeed, according to him: (1) thanks to volunteers, patients, and families benefit from emotional support, assistance, and companionship in what they are going through; and (2) because of their activities, volunteers experience personal growth, which enables them to choose more easily between what is important in life and what is not. Thus, Beasley concurs that their view of the world may gain in understanding, which can help them better appreciate their own existence [19]. Ferreira considers that palliative care volunteers also contribute some relief in caregivers' busy schedules, to the point of becoming "indispensable" in some places [24].

Thus, the difference between "giving" and "receiving" rests in a delicate balance. This may be a source of stress (even of guilt) for volunteers on the one hand and of unease (even mistrust) for the other actors (patients, families, and caregivers) on the other hand. This potential

stress and unease are related to the fact that the primary motivation of these volunteers is not always unambiguous, and their actions are part of end-of-life situations, a fact which may be disconcerting. In this context, and despite the goodwill of all, tensions may appear, exposing volunteers to numerous emotional challenges and their associations to important training challenges. These include teaching volunteers to maintain limits with the persons visited, to manage the emotions they themselves may be feeling, to learn to offer one's presence without imposing it... These are challenges familiar to associations and necessitate frequent retraining of their teams [16]. Some authors warn volunteers (and not only palliative care volunteers) about the feeling of "negative debt", even "inferiority" that can arise among some beneficiaries (because of the impossibility of being able to repay what the volunteer has given to them) and that may increase the latter's suffering [3]. To rebalance the debt, volunteers are sometimes recommended not to hesitate to tell patients "the extent to which their accompaniment brings just as much to themselves" [16]. Although aiming to be comforting, this parenthetical remark is not without risks and may perplex some patients who are fragile and vulnerable because of what they are going through. In fact, volunteers that have been studied constantly question the nature of their commitment, which may lead them to eventually end it [24].

The ambivalence of many volunteers regarding "concern for the other" and "concern for oneself",² to use the expression of Papadaniel [21], is important and merits further investigations in France, as in other countries. In spite of the challenges it raises, it must be noted that this question is nearly always approached from a single perspective, that of the volunteers and their associations, thus (voluntarily or not) putting to one side the positions of other actors. In fact, the perception patients, their families, and caregivers have of volunteers—whose motivations may sometimes appear vague—remain unclear, despite its major interest. Comparing these perspectives would enable shedding light on an activity with numerous gray areas and stimulate discussion on the question of the "effectiveness" of volunteers' activities, a theme that has recently emerged in the literature because of increasing regulatory policies and the growing importance given to evidence-based medicine [2]. Thus, in spite of the difficulty of evaluating the results of volunteers' contributions to palliative care, research work is increasingly attempting to measure the impact of their presence on patients' quality of life [26–29]. Beyond the question of "giving and/or receiving," it is becoming increasingly important to evaluate the concrete contributions of these people to the quality of care of patients in advanced or terminal stages of illness, contributions that include reduction of patient isolation, more adequate consideration of their emotional needs, an increase in life expectancy, improvement in satisfaction of families, a lightening of the burden on caregivers, etc. This evaluation should be done using proven research techniques (randomization of the study population, use of standardized and validated scales, meta-analyses...). In spite of interest for evaluation studies, routine in the area of medicine and their frequent demonstration of the positive impact of the presence of volunteers, the great majority of studies consulted almost exclusively explore the point of view of volunteers, not looking at (or only indirectly) the much less well-known perspectives of the three other types of actors involved by this care: that of patients (who are at the heart of the care process and of volunteers' concerns), that of

²"Souci de l'autre" and "souci de soi" in the original French text [21].

their families (who entrust their dying loved ones to an institution), and that of caregivers (whether they work in palliative care). And yet, two things appear clear: these people have probably much to say about how they perceive volunteering in palliative care and the methodological and ethical difficulties in gathering this type of information (useful ultimately for improving the quality of care to be given) are perhaps not insurmountable.

1.2.2. Complementarity/substitution: toward professionalization of volunteering

An analysis of the national and international literature brings to light a second type of challenge for volunteering in palliative care: it concerns the place and role of lay actors in hospital departments and the ever-present risk of the substitution of caregivers by volunteers. As Watts emphasizes for the United Kingdom, for example, the years 1980–1990 were marked by a certain professionalization of the volunteer sector in England, following encouragement by successive governments for a more active civil society [2]. In fact, hospices today have “a significant volunteer workforce to help with the care of patients and their families both in the setting of the hospice and in the community” [2, 30], and this increase in unpaid volunteer work resulted in a decrease in the growth of employment in the field [2]. These volunteers ensure a diversity of functions (from welcoming patients and families to grief support and including chauffeuring, reflexology or shop keeping). They are required to take intensive training and go through trial periods beforehand, which give them an increasingly semi-professional role [2]. Like caregivers, they must also ensure the continuity of care and their mission by following high standards of quality. Their work is becoming less and less flexible (for example, for going on vacation or in choosing the department to which they wish to offer their services), and their activity henceforth resembles “paid work, but without the pay” [2]. In addition, the original model of English hospices is increasingly contested [2], and today takes various forms, depending on the regions of the world and the needs of the populations [6]. The differences compared to the original model are especially noticeable in low-income countries, where volunteers—who work primarily in the home within the framework of community programs—may be required to give nutritional advice to patients they see [31] or may receive payment for the time spent on their visit [2]. The absence of a clear line between volunteers and professionals is fully justified in this case by the political, financial, health, and cultural context, which is very different from that in the United Kingdom but is neither wished for nor advisable in other care contexts. We will come back to this below.

The risk of volunteering veering from complementarity toward substitution is very much present in Quebec as well, where volunteer associations are increasingly preoccupied by the difficulty of defining clear boundaries for volunteer action while remaining flexible [16]. Some volunteers have a sanctioned role there, which sometimes creates dissension between volunteers looking for rewarding work and salaried personnel, who are called upon to delegate thankless tasks to them (such as folding laundry, disinfecting toys, or straightening up certain rooms) [32]. Even though it appears delicate to transform relationships that give meaning to life into tasks, the need for a clearer identification of these actions has gradually been imposed on certain association leaders, who are anxious to collaborate effectively with caregivers while staying in a role that is in their own area of responsibility [16, 33]. After having carried out an applied research

project on the question, a group of Quebec researchers recently compiled a list of tasks or roles that volunteers can assume [16, 33]. These tasks or roles distinguish on one hand, those that fall into the category of instrumental acts (shop for patients, offer coffee to their relatives, describe the services offered by their associations...), and on the other, those that belong to social relationships (ensure a presence with the patient, listen to them, be attentive to their family members...). Some negotiation is always possible depending on the patient's and family members' needs for accompaniment. Volunteers should thus always demonstrate pragmatism by adapting on a case-by-case basis, while avoiding encroaching on the work of the caregivers. For them, "Doing" is often a pretext for establishing a relationship with patients and their families and enables them to more easily carry out their work of accompaniment, which is based on "Being"³ [16]. Therefore, there is always the fear among association heads in Quebec that volunteering—given the growing shortage of resources in health care facilities and the ever-increasing need for rationalization of hospital expenditures—becomes "instrumentalized" by health care providers and public authorities, who transform this activity based on the gift of self into a form of "work at a discount" [16]. Consequently, one of the main challenges facing Quebec is neither to seek volunteers with the aim (more or less implicit) of compensating for shortcomings in the health care system nor to use them for complex tasks generally done by paid services [16].

This increasingly frequent tendency to require professional competencies from volunteers and to drift toward unsalaried employment is not specific to the United Kingdom or to Quebec. It is mentioned for many other types of volunteering and in multiple countries, such as Switzerland, where there appears to be an ongoing standardization of the behavior and role of volunteers via a sometimes overly instrumentalized vision of their training [34]. Similarly, in Belgium, hospital volunteers may be charged with running the hospital library, managing the palliative care families' homes, organizing activities, or rendering a multiplicity of services to the caregivers (such as taking the patient to the hairdresser, buying them a newspaper, or carrying the new arrivals' baggage) [35]. While volunteers cost nothing to the institutions that recruit them and automatically increase the efficiency of the facilities where they serve, given all these risks, the boundaries between volunteering and work that should not be crossed are clearly established in France, at once by associations of volunteers, by palliative care professionals, and by policies. Within this framework, it is clearly stated that volunteers must neither take the place of caregivers nor carry out semi-professional duties but limit themselves to accompanying patients and families, who desire it, by offering their presence. Thus, the Public Health Code specifies that "volunteers, trained in end-of-life accompaniment and belonging to associations that have selected them, with the consent of the patient or his or her family and without interfering with the practice of medical and paramedical care, may provide support to the care team by participating in the final accompaniment of the patient and by bringing comfort to the psychological and social environment of the patient and his or her family". In the same spirit, the circular of March 25, 2008, defines the role of volunteers in French palliative care as follows "to propose a presence, an attentiveness, discreetly and with respect for otherness, nonjudgmentally and with respect for the privacy of the sick person and his/her family life [and], on behalf of society, demonstrate kindness to those who are suffering, thereby reinforcing a sense of their belonging to the human community." This model, based purely on

³We will discuss this point in more detail (Section 3.2).

"Being" as opposed to "Doing", is therefore far removed from the English or Quebec models in particular and raises many questions that are rarely or never explored today: how do volunteers experience the missions entrusted to them on a daily basis? What do the caregivers say about this offer of time, which is complementary to their own? How do patients and families talk about the volunteer presence in hospital services and do they take advantage of it?

1.3. Study objectives

Volunteers are largely present in PCUs—where they share the same values as the caregivers in respecting the comfort and dignity of people at the end of life [36]—and to a lesser degree, in traditional hospital services. However, the way they perceive their own activity and are viewed by other actors is rarely addressed in France in official texts (from ministries or associations) or in publications. While some research has looked at volunteering in general [37, 38], other work has been focused totally [21] or partially [1] on volunteer activity as death approaches, and solely from the perspective of volunteers, who are often reticent in discussing the difficulties they encounter in carrying out their missions. Even though international publications in the past 5 years have reported a number of investigations on the volunteer experience in palliative care [2, 17–20, 22, 23], two important questions remain insufficiently studied: (1) that of obstacles and conflicts volunteers may encounter during their activity [39–41]; (2) that of the perception that patients, families, and caregivers have of this type of volunteering, whose main challenges we have described above. At most, some authors arrive at the notion of a game where all the actors are winners, with each one gaining a substantial benefit from volunteer activities [24, 25], and where volunteers say they are satisfied with their activity (in spite of the tensions noted) [24, 39, 41].

In a profoundly changing environment concerning death and the dissemination of palliative care throughout the world, the objective of this chapter is to examine the place and role of palliative care volunteers in French hospitals, in order to enrich existing analyses and provide a forum for dialog with countries where the same issues can arise. These include the following: what meaning does each person (and not only volunteers) give to this time spent in proximity to death? How, why, and within what framework do health personnel and volunteers work together? How is this unusual presence interpreted by patients and their families, that is, by those persons for whom these activities are primarily intended? Our aim is therefore to emphasize volunteers' activities from a little-explored perspective but one essential to their accomplishment—the awkwardness, fears, and reticence their activities can provoke. This entails both highlighting the way each person talks about this activity (with what terminology, what assessments, and what line of reasoning) as well as identifying any friction or dissension. This will enable redefining what is at stake and thus contribute to better care for persons at the end of their life, as well as better support for their relatives. This examination is all the more justified in light of the different volunteer experiences taking place in other countries concerning this activity [6, 42, 43] and in other health care settings in France [44]. Moreover, these examples give rise to lively and more general debate regarding the presence of lay actors in health care facilities, especially in curative services with a high degree of technicity, where the organization of work at the approach of death differs from that of the PCUs and where suspicions held by caregivers concerning volunteers are usually strong [45, 46].

1.4. Methodology: qualitative research among a diversity of actors in palliative care

In an attempt to go beyond broad normative discourse on the role of volunteering in palliative care, and the research that often dwells exclusively on the perspective of volunteers, we have drawn on a body of individual semi-structured interviews carried out in 10 hospitals with volunteers, but also with medical personnel (working in palliative care or not), with patients and families. The hospitals have varied characteristics in terms of location and status (Paris/Province, public/private hospitals, hospitals of varying size, and cancer centers). They all had a PCU or a PCST. They were chosen randomly from a list drawn up by the French Society of Accompaniment and Palliative Care (SFAP) of all palliative care teams in France. This methodological choice to diversify the settings was based on the hypothesis that the volunteer work under examination would be associated with a plurality of perceptions, related to both the types of actors interviewed (volunteers, caregivers, patients, families) and to the specificities of the workplace (PCU, PCST, or traditional service).

In all, five PCUs, five PCSTs, and 15 curative care services working with a PCST were investigated using interviews carried out by an experienced sociologist. The general topic emphasized was that of improving the quality of care in the facilities and meeting the needs and expectations of hospitalized people and their families. After obtaining required consent and ensuring anonymity for participants and teams studied, contact was made with the heads of different teams, with an aim for a diversity of situations. The material collected is composed of 114 interviews: 25 with patients hospitalized in PCUs, 25 with one of their family members (usually the spouse of the patient interviewed), 56 with caregivers (physicians, nurses, nurses' aides, psychologists), and eight with volunteers with good knowledge and experience of this practice (most of them were also responsible for running their association). It should be noted here that, out of the 10 palliative care teams studied, two worked without recourse to a volunteer team, which reduced our sample of volunteers to eight instead of 10. However, this enriched the analysis on the absence of volunteers in some PCUs or PCSTs and on the reasons for this absence.

All of these people were recruited using a purposeful sampling technique adapted to the type of service studied. (1) In PCUs, the four types of actors were interviewed for each site: an experienced volunteer, caregivers (either freely willing or proposed by the head of the team), patients, and families (those present the day of the study, physically and psychologically able to participate in the interview and having given their consent at least the day before to participate, after receiving detailed information on the objective of the research, their right to withdraw and the informal nature of the interviews); (2) In PCSTs, the recruitment procedure was different in two respects: since these were small teams, it was sometimes possible to interview all the personnel; as these were teams that visited traditional services solely on a request to help them out [47], neither patients nor families could be interviewed; (3) In curative care services, the recruitment of caregivers was done in two stages: an initial request made of the PCSTs interviewed to introduce us to three curative care services in their hospital, followed by a request for interviews made to the care supervisor of each of these services. As in the case of the PCSTs, it was not possible to meet patients and families here, with some patients not even aware they were in a palliative stage.

The interviews (face-to-face and recorded) were all fully transcribed and then analyzed using a grid created *a posteriori* using an inductive approach. While our initial research question broadly addressed the work of palliative care teams [48], we observed a high degree of diversity in comments made by different persons concerning volunteering, which led us to consider *a posteriori* this activity as an important dimension for an understanding of palliative care. We, therefore, extracted all references to volunteer service from the general body of interviews to study them separately using content analysis, that is, by the systematic and methodical examination of each interview. It is this analysis that we wish to present here. In order to have sufficient contextual elements and material for discussion, we have also carried out a review of the literature on volunteering in palliative care in France and in the rest of the world. This bibliographic research was done largely at the Documentation Service of the Centre National de Ressources "Soins Palliatifs" (CNDR).⁴ Only the most relevant articles were used to write this chapter, which does not pretend to be exhaustive but rather to suggest several further directions of enquiry.

2. Results: divided opinions concerning a complex and controversial presence

In describing these results,⁵ we will give priority to a presentation by type of actor, first hearing from volunteers, then from those who are at the center of their attention and of professional care (the patients and their families, who give contrasting assessments of this type of volunteering) and finally from health personnel (with often divided opinions depending on whether they work in the area of palliative care). Beyond strong differences in points of view on volunteering in palliative care (notably as a function of the status of the person interviewed and the work setting), the data bring to light several controversial issues that are largely unrecognized and concern the place and role of these nonprofessional actors among hospitalized patients receiving palliative care.

2.1. The viewpoint of volunteers: "being there to be there"

What do volunteers queried about their palliative care activities say and how do they adapt to the realities of the care setting? According to the general description given by a PCST caregiver whom we also interviewed, it's "a tough job" because of the strict guidelines related to this commitment and the concrete conditions for putting them into practice.

⁴This service, located in Paris, has a database of 20,000 references on palliative care, the end of life and death (the database *palli@doc*, accessible on line via the site *VigiPallia*). This database is composed of documents from journals, books, university research, conference proceedings, but also articles found in non "palliative care" journals, obtained either through document tracking or by regular communication with the BDSF (a French document network of information on public health).

⁵Most of the results in this chapter were presented in an article in French [49].

2.1.1. An ambiguous commitment

The heterogeneity in terms of age, place of activities, status, and motivations of the volunteers we met contrasts with the homogeneity of their narratives. Indeed, they described the palliative care model and their missions in quite similar terms: *“represent civil society to show these people that we are not abandoning them”, “ensure a presence and a willingness to listen”, “make oneself useful”, “do things in a humane way for the person”, and “be there to be there”*. Their statements followed associative charters and current texts (that use the terms *“assistance”, “giving”* and *“human solidarity”*), which suggests they had internalized the objectives firmly anchored in the *“Being”* of their association. Similarly, the rules governing this volunteering were directly quoted (*“always knock on the door before entering the room”, “never sit down without being asked to”, “respect the confidentiality of what is heard” ...*), as were the techniques to be used (the more or less spontaneous *“hallway encounters”, “tissues always ready in one’s pocket”* or *“the coffee ploy”* that consists of offering some to people in order *“to more easily create a relationship with them”*).

These standardized narratives, unassumingly expressed at times (*“We don’t contribute much”*), mentioned the challenges to be met such as the initial and continuing training of these volunteers, the fact they are not substitutes for caregivers (following the principle of *“complementarity”*) or the *“proper distance”* to be maintained with the other actors. The rare differences in the narratives were related more to individual modes of functioning or the setting rather than to disagreements about their duties. Thus, while some liked to have a minimum of information before entering a room *“to know what to expect”*, others preferred *“not to have any prior knowledge in order to be fresh for each contact”*. While some go *“to see all the patients without exception, except those not wishing to see them”*, others *“never go into a room without having received an oral transmission from the caregivers”,* who function as filters and informants. While some *“always refer everything to the caregivers, if possible orally and as a precaution,”* others do not want *“to bother them unnecessarily in their work, [preferring] to leave a written record and only when it involves a change in care.”*

As altruistic as their commitment is, it is not without ambivalence, however:

“I am very, very happy to have made this choice, in spite of all I have done in my lifetime. I am lucky to have children, grandchildren, music, lots of things anyway. Well, this really gave a new meaning to my life”.

Conscious of this personal benefit, some felt they receive more than they give, such as this woman:

“We must stop portraying volunteering as this beautiful image of those who give: we simultaneously receive more than we give [...]. I always tell people: wait, I came to see you, but you gave me something as well. I was very pleased to get to know you”.

This ambivalence sometimes leads them to ask themselves: *“What am I doing here?”*, *“Would this person like me to look at them in this way?”*, *“Am I just feeding the beast?”* This last formulation, tinted with *“guilt”*, questions their role among terminally ill patients, and beyond that, the potential and involuntary nuisance created by their presence. The discrepancy between giving and receiving is sometimes so strong that some are forced to suspend their activity:

“It’s clearly something that bothers me a great deal, this part about receiving more than I give. At one time, I even stopped for six months because I felt that it was totally inappropriate of me to feed on that, while they are the ones suffering from an illness”.

One volunteer concluded that what is important is to *"not use that to feel better oneself"* and to continually question one's motivations.

2.1.2. *More or less complicated relationships with health personnel*

Working as a volunteer with palliative care professionals entails building relationships, from simple juxtapositions between the care team and volunteers to true collaboration, depending on what roles the latter are given. In some PCUs, volunteers move around according to requests from personnel, after having been introduced to patients. They play a welcoming and monitoring role and are invited to staff meetings to share their knowledge and are offered training and support sessions. Whether relationships are close or distant, all those interviewed nevertheless repeated the leitmotif that *"they are there to be there"*, *"to listen"* and have a *"common commitment"* with caregivers, not as a substitute for them but to assist them. Some then adopted a clear-cut position between what is their responsibility (*"welcome people at admissions, ensure a presence with solitary patients, give support to families..."*) and what is not (*"make beds, put patients into armchairs, give them bedpans..."*). When patient or family requests are considered outside their responsibility, they tell them they *"don't know how to or cannot"* respond; they then relay the request to the appropriate person. This position of intermediary is also adopted according to how they feel about a situation: for example, when they see particular suffering in a patient, notice unusual behavior of a relative or observe a family with a problem needing to be solved.

The relationships volunteers have with caregivers in curative care departments are more complex than with teams in palliative care and also involve an initial task of persuasion. The narratives reveal two patterns depending on the practices of the department in collaborating with volunteer associations: (1) In the first pattern, volunteers consider themselves well integrated with relatively easy access to rooms, since their role is defined and legitimated by the departmental project. The PCST indicates what patients are to be visited (after informing patients and caregivers concerned), then volunteers go to them after having received some information and checked by the nursing station. Sometimes, caregivers in these departments indicate patients directly to them, independently of the PCST, but volunteers say that in these cases, they have little information available, not even knowing if the PCST has already been by. (2) In the second pattern, access of volunteers to rooms is described as difficult. The *"first reaction"* of caregivers is one of incomprehension (*"Don't go in there; he is at the end of life"*). *"Not being able to impose their participation"* (even when there was a prior contract with the department or even if they were sent by the PCST) generates a feeling of *"transparency"*⁶ and of *"frustration"*. Regretting that too few patients benefit from their presence, they confided that they sometimes take (*"a step to one side [in relation to their code of ethics] for the good of all"*) by going into some rooms anyway using certain tricks (by *"using relationships already established in the departments"* or by *"sneaking around"*). In the face of this resistance by caregivers—which gives them the *"impression of walking on eggshells"* and echoes later statements by some caregivers—they blame external factors such as the *"apprehension"* the caregivers have of them, the compartmentalization of departments or even the strategy of certain units *"to avoid asking for outside help in order to defend their jobs in a difficult financial context"*, thus begging

⁶A feeling of being invisible and useless.

the question of whether caregivers may simply be motivated to protect patients. To overcome this resistance, they work to make themselves better known by the departments, through awareness campaigns on volunteering, for example. In this framework, some volunteers confided in their inability to get the PCST to intercede on behalf of patients that they think are in need, with mobile teams meeting the same resistance. They then underlined the influence of departmental heads and nurse supervisors in properly integrating both the PCSTs and themselves, that is to say, integrating external actors.

2.1.3. Occasionally awkward situations with patients and families

The desire of volunteers to give patients and their families “a space for expressing themselves” is based on the assumption they “need compassion” and that listening to them can “do them a world of good”. Although apparently simple, this position exposes them to awkward situations, sown with paradoxical injunctions, and requires them to constantly watch what they say. Thus, if they introduce themselves at the outset as volunteers, they must also be vigilant to “never pronounce the name of [their] association” (which may “hurt, choke and inhibit people”). While they are alert to “the slightest desires” of patients, they avoid “questioning them” about things considered sensitive (their family situation, their religious beliefs...). If they wish to give them their support, they are also careful to “remain discreet” even when patients and families use them as “buffers” or “ventilate” with regard to caregivers. They can, however, fluctuate between intrusiveness and avoidance in three cases: (1) when a patient confesses to not taking medication and they hesitate between respecting this “secret” and passing it on to caregivers; (2) when a family refuses to let volunteers visit their family member, which sometimes leads them to meet that family to explain their approach; (3) when they ensure a “silent presence” beside the patient in a coma and their mission consists precisely in doing nothing. The following excerpt illustrates the tensions they experience at these times:

“I had a very difficult accompaniment [...]. It was a man I had already accompanied, and he was in a coma. [...] I placed a finger on his arm and said to him: ‘you see, don’t be afraid, it’s me, it’s FIRST NAME, a volunteer, I’m going to spend some time with you.’ I reassured and calmed him. [...] I stayed a very long time next to him. I knew he was very much alone, that he was afraid to die, he had said so. And so I said to myself, ‘I’m going to stay next to him’. But staying silent and respectful for more than 20 minutes is very difficult because you can’t think about your evening dinner. Because thoughts wander about. So at most, you can look at the painting in the room... but not look to see what the weather is like outside. I have to look at the person to really stay with him. [...] And if you look at him, you’re obliged to notice certain things, but I tell myself: ‘I’m being impolite. Would he like for me to look at him so that I see the inside of his mouth, would this man like that?’ [...] And after a time, I tell myself: ‘It would be better if I left, because I don’t think I’m being appropriate.’”

Faced with these dilemmas, some volunteers emphasized the necessity of knowing how “to protect oneself” by avoiding becoming “too attached to people [or] personally investing too much”, and they reformulated various facets of their “guilt”: being “powerless” to relieve some kinds of suffering, involuntarily lacking respect for patients, learning about a death immediately after having left a room, or receiving more than giving. Nevertheless, these considerations do not call into question the content of their missions, which remain strongly in the “Being”.

2.1.4. A significant marshaling of resources

If a volunteer dismisses the idea of evaluating her presence through a tautology ("*One shouldn't think about that, but act as a volunteer should. What use is it to know that 90% of people are highly satisfied?*"), others say on the contrary, "*they always have [this question] on their minds*". They then marshal institutional and personal resources in order to improve their performance.

Institutional resources enable training for accompaniment and reduce deviant behaviors through a rigorous selection of candidates, the obligation to belong to an association, to take occasionally intensive training, and to attend regular meetings supervised by coordinators. "*It's a real uphill battle to become a volunteer and to stay one!*" noted one of them. Some training courses (on how to listen or to manage stress in particular) were described as valuable resources. They take the form of "*simulations*", "*role playing*", or of "*mimes*". They teach them to "*reformulate what people say by acting as their mirror*" and "*to not haul out their own emotions, which would be visible and prevent them being totally present with the person they are with, for the time they are there*". While the objective is to protect caregivers, patients, and families from inappropriate attitudes while shielding volunteers from overinvesting, the result is visible in the homogeneity of the narratives recorded and their correspondence with transmitted norms, without reference to their margin of autonomy.

Personal resources are intellectual and emotional in nature. According to some, they become intertwined and refined with "*experience*". Even if "*situations frequently speak for themselves*" ("*often eloquent*" expressions), "*tools*" help the volunteers adjust the content of their presence: these include the "*observation*" of peoples' behavior when the volunteers arrive, the "*interpretation*" of the signals sent, the "*intuition*" of what should be done or said, their "*feeling*" about the quality of encounters, in a word, "*perceptiveness*" or "*listening to oneself*". The principle is always the same: "*conduct yourself according to the persons and the situations*", while bearing in mind how "*to define oneself as an accompanying volunteer*". One person explained that this implies "*being clear about oneself and one's own past*". Some help themselves by taking personal "*notes*" after each encounter to use as a reminder and to provide guidance concerning the proper attitude to take both with regard to patients and to themselves. Others rely on subtle signs: a patient who "*says it was nice of them to come*", a family that "*demonstrates friendliness*", and caregivers who say they "*are pleased with what the volunteers contribute*". One interviewee thus felt that "*feedback from caregivers [is] a more reliable indicator*" for judging the soundness of their activities than expressions by patients and families since it was a reflection of the quality of "*collaborative partnerships*" with caregivers, and "*it's not just because a patient was aggressive that a visit was not important*". In doing this, she shifts the purpose of volunteer activity toward the caregivers (what is important is that the departments are satisfied).

2.2. The viewpoint of patients and families: a very clear-cut narrative

In contrast to the rather formal and uniform narratives of volunteers, comments by patients and families proved pragmatic and diversified, ranging from praise to disapproval, together with indifference and mistrust. Four groups with differing opinions, independent of the age or sex of the interviewees, stand out: positive, distant, mistrustful, and hostile.

2.2.1. "Volunteers: charming and devoted people"

A first group of patients and families emphasized, sometimes strongly, the relationship qualities of volunteers encountered in the PCU. While the word "kindness" is often mentioned, many terms also evoked volunteers' positive attitudes (*"friendly, charming, likeable, smiling, present, helpful, devoted, considerate, good listeners, discreet, reassuring, big hearted, marvelous, fantastic"*). Some patients said they appreciated the fact volunteers came by to say hello with *"a handshake"*, allowing them *"to chat,"* and sometimes took them on a tour of the hospital grounds. *"It's a plus here, because I saw the sun again, I once more saw several people from outside, and I appreciated that"* (a patient). These narratives highlight the importance to some patients of being listened to and respected, needs that are often mentioned by volunteers and palliative care professionals. For their part, families welcomed the *"idea [of volunteers] devoting some time to others"*, considering that *"their approach [is or must be] beneficial"* at several levels. For example, they enable patients to *"talk about things they like"* and to *"feel free"*; give them *"a helping hand"* such as dialing a telephone number; run the family day room of the PCU and give out coffee there; furnish information; or *serve as intermediaries* with caregivers in order *"not to unnecessarily divert the personnel"* from their work, added the father of a patient.

Whether they come from patients or from relatives acting as spokesperson and protector for their ill family member, these narratives reveal two styles of expression, sometimes based on personal experience, sometimes on abstract considerations. The former referred to concrete experiences. *"We talk with the volunteers about anything that exists in order to think of other things a little, and it feels good"*, and it positively underlined volunteers' commitment:

"They devote themselves to us until 6 pm... Sometimes, I feel bad about that, and I say to myself 'oh my, those poor people'." (a patient).

"They very kindly visited Mama, but they saw she was very well looked after. So, taking the burden off volunteers is also a good idea." (daughter of a patient).

Some families pointed out the *"reassuring"* side of this presence, which does what they themselves cannot do: ensure a permanent presence next to their relatives be a rampart against the harshness of hospital life. This was expressed by three women:

"Volunteers reassure me because I know that my husband is not alone and these are people from outside the medical milieu, they are people like you and me".

"With them, I can leave with peace of mind, knowing that my son will not be abandoned".

"Once, a lady came, my husband was asleep, and I wanted to make a telephone call, but I didn't dare leave him alone. She offered to stay with him while I was gone. And it worked out very well. He didn't realize it, and I was free from anxiety".

These narratives based on experience reflect a contrasting attitude to the mistrust families have concerning the hospital system, felt to be dehumanizing. This suggests that the need for a presence next to patients, often mentioned by volunteers and partisans of palliative care, originates as well in a need expressed by families worried about their ill relative.

The second narrative style is based on hypothetical scenarios—*"I think that if I can't walk anymore, I'll ask volunteers to buy my morning newspaper"*—or on impersonal considerations—*"It's*

valuable to have someone who can give you a hand". This wording borrows much from comments described above and from those of certain caregivers, since they refer to the dominant ideas about volunteering, testifying to the permeability of representations on the subject. It also points out the variety of "little favors" that volunteers can render in addition to their mission of listening and being present, and the more general functions such as their role of third party or informant. People using this style nevertheless proved not to be very talkative about any personal experiences: *"Yes, I met the volunteers, yes, yes, always lots of commitment"*. And some comments were ambiguous: *"They're not really disagreeable"*, *"I'm not lucky because each time they come, I have people here or I sleep some"*. This vagueness suggests that some people accept a volunteer's visit, not because they wish to, but because they do not dare refuse or criticize it.

2.2.2. *"It's for isolated people or for afterwards!"*

A second group of patients or families adhered to the same narrative concerning volunteers but distanced it from their own experiences. While recognizing volunteers' potential value, they insisted on the fact their presence is *"mainly helpful to others"* (those who have few visits) but not to themselves:

"For patients whose family lives far away or is absent or non-existent, I think that it can definitely be positive; for now, I am happy to have exchanged a few words with people who go by, but..." (a patient).

"Volunteers are very helpful in other people's rooms, because you have people here who don't have any family..." (the daughter of a patient).

These narratives, usually succinct as concerns volunteering, show on the one hand that some people do not have a need themselves for this presence, which they do not wish to experience, and on the other hand that, according to them, volunteering activity should be first directed toward isolated patients. Some reserved the possibility of changing their opinion depending on the evolution of their situation, and put off that opportunity for later. *"Perhaps someday I'd be very happy to see volunteer..."*, one patient hinted.

2.2.3. *A position of "mistrust"*

A third group was indifferent to, mistrusted, or was even embarrassed by the presence of volunteers. Not inclined to meet them, three patients spoke in unequivocal terms:

"It doesn't upset me that they come by to see me, but it wouldn't bother me if there weren't any, you see; I don't really want to talk".

"Personally, that doesn't interest me much. The person comes in at any time of the day, and you have to initiate a topic and then keep up the conversation... It's not my thing".

"I don't think I need volunteers. First, because I have difficulty speaking so I don't want to talk. And then, what is it I have to listen to? Their personal history. It's not worth it".

Their reticence is associated with discomfort, something rarely mentioned by volunteers interviewed, even though some caregivers allude to it. This is discomfort at having to accept that people who are not part of the personnel come into their room, often without warning, having to spend time with these people who *"have doubtless personally experienced the death of*

a family member", having to talk with them, even when they do not wish to or have the ability to do so... Volunteers' motivations seem to them *a priori* suspicious, which concurs with the opinions of some of the caregivers in curative care facilities. They even speculated about the impetus behind the volunteer commitment and the safeguards to be put in place, like this patient who worried "*that volunteers commit some faux pas*" that can be harmful to patients, and he raised the question of their supervision: "*I don't know how it happens [he said] but with some... It could have the opposite effect of what is intended, for sure*".

Some families took a similar position. Emphasizing that volunteers should not impose their presence on untalkative patients, they identified with their relatives:

"I'm a little like my mother, I don't really want to talk... I don't really like to describe my life... and besides, it's so personal and so difficult, what we're going through now, that we don't necessarily want to open up to strangers."

Families then put forward their knowledge of their family member's character ("*My father really doesn't want to see volunteers, he's very unsociable and doesn't like to be bothered or have someone come and ask him questions*") or of their preference for getting by without help ("*My mother is someone who has always taken care of herself. So, I don't think she wants to see volunteers*"). For these families, as spokespersons for their relatives, this volunteer presence is secondary, because the essential in their eyes is clinical in nature: "*What's important in a hospital, it's doctors, nurses. Then, the rest...*" (daughter of a patient). A wife stood out here by justifying her mistrust through fear that volunteers prove to be too talkative, due to the fact they have doubtless suffered grief:

"I don't know if volunteers are like that, but people who have lost a loved one, often tell you too many things. Me, I'm not ready to open the doors. There are things I don't want to know, so...."

2.2.4. "A fairly revolting presence"

Finally, a few persons were conspicuous by their caustic remarks, considering this presence as "*fairly revolting*". For one patient, it is "*the black mark, the big problem*" because of their "*systematic infantilizing and disagreeable body language of pity*", their "*manner of more or less forcing themselves into the rooms*" and their "*way of putting patients in a position of inferiority*". She described her impressions at length:

"They're sort of into 'oh, my poor lady, how are you?' [...] They touch you without asking whether you want to be touched. [...] I've even had some take my foot, like for a child, and try to tickle me. [...] The problem is that I left my door open because I'm claustrophobic, so they took that as an invitation. When they came in and I didn't want it, I would say to them: 'what can I do for you?'. It was a sort of joke that should have made them understand I was not interested. And some answered: 'OK, it's you who wants to do something for us?' So, they practically forced me into the position of being sick, of being the poor person that must be helped at all costs".

According to her, they are pursuing "*a kind of dangerous quest for good deed, that is harmful and nonconstructive*", which brings her to question the attitude of "*Being*" without "*Doing*":

"What good is it to visit someone who didn't ask for it, bringing your pity with you, when the person doesn't need it? Volunteering is not a state, but a dynamic process: they need to come with an active approach, like the clowns who go see the children to amuse them, for example. They need to come with

a project and concrete proposals such as activities or some entertainment for example, but not wander from room to room, hoping that at the right moment, the person will want to have their hand patted or be served a cup of coffee".

This rejection of the essence of volunteering based on the gift of presence ("*being there to be there*") is here aligned with a strongly rejected notion of "pity". It is prompted by a lack of "dynamics" where volunteers apparently make a choice beforehand of a territory and mode of intervention. This last excerpt in particular identifies the unintentional annoyance that volunteering can carry with it in palliative care in France. Beyond considerations of the best position to adopt as an accompanying volunteer of the end of life (give/receive, complementarity/substitution), it is the question of what content to give to volunteering between "Being" and "Doing" that is at issue here, and with it, one part of the model of French palliative care. We will discuss this at greater length (see Section 3.2.2).

2.3. The viewpoint of health personnel: contrasting opinions

Narratives recorded among caregivers in palliative care (PCU or PCST) and in curative services are characterized by profound differences depending on the professional setting of those that express them and their concept of end of life care. Indeed, the former, coming from a palliative care milieu, favor volunteering for the most part, while the latter, from outside, are more distant.

2.3.1. Often-convinced palliative care professionals

The perspective of palliative care professionals on volunteers was predominately favorable, especially in PCUs where a positive, even indispensable, place is accorded to them from the outset. The help volunteers provide them, especially if there is a lack of personnel, was thus evoked with qualifiers such as "*full members*" of the team, "*intermediaries*" between patients and caregivers, or "*valuable assistants*" in multiple domains. These include greeting and installing patients in their room, offering a presence and an ear to isolated patients, watching over agitated persons, responding "*to people's need for conversation*", "*being there*" symbolically during dying and transfer of the body, participating in religious rites (if the family asks for this), accompanying mourners to the funeral parlor, ensuring follow-up of grieving (in support groups led jointly by psychologists or in the home), or managing "*solidarity funds*". Their ability to communicate important information to teams was also underlined: observing that "*families talk more freely to volunteers than to themselves*" (because of their "*friendly, attentive and available*" qualities, and the absence of "a white coat" one caregiver adds), some teams invite them to their unit meetings to give their perspective and help them "*refocus*" follow-up care. Sometimes the transmission notebook used for communication between volunteers may be consulted by the caregivers, referral contacts are assigned to them, they are given specific training (in addition to that of their association), and occasional or regular meetings are organized between caregivers and volunteers. While this organization of collective care activity accords volunteers a special place and is a reflection of their positive integration in the units, it raises the question of the blurred and shifting boundary between work and volunteering, mentioned in the case of other countries (see Section 1.2.2).

Contrary to caregivers working in PCUs, those in PCSTs do not have their own space for carrying out their activity. Indeed, they move about, following requests from curative services to provide their skills and are thus subject to the rules in these services, including those concerning recourse to volunteer work. This makes their working conditions insecure and uncertain. Some interviewees regretted that this work organization limits a volunteer presence considered useful for some patients. One caregiver described the effects of a lack of workspace for her PCST, limiting opportunities to meet volunteers: *“We would like to work more with volunteers, but where could we locate a volunteer center when already the psychologists don’t have a place for seeing a patient that isn’t hospitalized?”* While they share the same model as their PCU colleagues, PCST caregivers have to adjust to a work setting that is less receptive and that requires them to be accepted there before negotiating a place for volunteers. The latter would often be *“unwelcome”* in the units, even if they *“try to introduce themselves to explain what they do”* and even when the PCST considers their visit would help certain patients. *“The real problem is that, in the hospital, everyone defends his or her territory, and you’d better not tread on it”* [said a PCST caregiver]. In the departmentalized context of typical services, according to this person, volunteers are seen as trespassers, who are all the less legitimate to intervene because they are at once nonprofessionals, outside the medical milieu, and concerned with the end of life. Therefore, PCST personnel must be vigilant in their use of volunteers to avoid a situation where their own services may no longer be requested by certain caregivers.

2.3.2. *The rare but critical discourse of palliative care physicians*

Unfavorable remarks on volunteering, and thus less expected, were voiced by two physicians rather reluctant to support the place of volunteers in the palliative approach. One was a supervisor of a PCU and one a supervisor of a PCST. Critical of current practices in palliative care, their reflections launched a heated debate and echoed to negative remarks made by certain patients and families.

While the first denounced an *“over-accompaniment”* of patients in PCUs and voiced doubts as to the place to be accorded volunteers, the second *“wondered”* about all forms of volunteering from the moment they are practiced in a hospital. According to him, too many people already gravitate around the patient, it is not proper that *“non caregivers know things about patients, sometimes without their knowledge”* and *“even if people are free to refuse to see them, they don’t always do so for fear of the consequences”*. The volunteers’ motivations also seemed ambiguous to him: *“I even seem to have seen some volunteers who came here because they also felt the need to talk to someone”*. He, therefore, said he was *“skeptical as to the respect for professional confidentiality, to which they are theoretically bound”*, *“conflicted”* as to *“the place they should be given,”* and finally, *“reticent”* to collaborate with them in his PCST, *“except for people who have no family members”*. Noting that some curative care services had *“walls”* that were difficult to get past for people outside the service (volunteers or members of mobile teams), he has decided to let volunteers *“manage by themselves”* in getting in and accessing rooms, solving the problem of the double constraint mentioned earlier.

“I told volunteers: I can’t get into that, you have to go see the supervisors or the physicians, discuss what you do, the agreement made with the hospital, your limits, confidentiality, and see if they agree that you can intervene.”

2.3.3. Often-mistrustful caregivers in curative care services

While caregivers from PCUs and PCSTs described numerous details of their relationship with volunteers, those from curative care departments often had little to say on the subject. This was perhaps due to shorter interviews because of a lack of personnel (the interview then concentrated on their work with patients at the end of life); it was because they said they already had all the necessary resources: *"We have the PCST and a psychologist in the service"* or because they did not know *"how things worked with volunteers"*; or it was because, as a matter of principle, they did not think volunteers had a place among patients in a palliative stage, and they thus avoided directing them to the patients. *"I often hesitate to do it [...]. So if they really want to go there, they go. But I tell them, because I don't think they necessarily have the training for it. It's delicate..."* (a nurse supervisor). The reticence of caregivers can doubtless also be partly explained by the very medicalized, hierarchical, and bureaucratic functioning of many services, where the professional aspect dominates the nonprofessional, and the technical aspect takes precedence over the relational.

Only one caregiver stated, briefly but explicitly, that the presence of volunteers was *"a plus"* for the patients and for their families. Her position of openness breaks with the caricatural image that opposes a curative care milieu—rebelling against accompanying volunteers—to one favorable to palliative care and thus paves the way for genuine collaboration in acute care units.

3. Discussion: redefine the stakes of volunteering in palliative care in France

Two central themes for discussion can be highlighted. The first examines the weak overlapping of comments, representations, and experiences reported by the different actors we interviewed: these differences in discourse relate both to work settings that are more or less favorable to this type of voluntary service and to more or less high expectations concerning volunteers. The second theme concerns perspectives for the development of volunteering in palliative care in France and reexamines the concept of *"being there"*.

3.1. Expectations and work settings more or less suitable for volunteer service

The narratives studied show that there are strong differences in the perception—and therefore in the acceptance—of the presence of volunteers, depending on whether the caregivers work in a palliative or in curative care setting. This is a reflection of two dominant and opposing conceptions of care: one palliative, endowed primarily with human resources and centered on relieving symptoms; the other curative, sometimes very technical and focused on cure [48]. In the first case, volunteers are often considered full members of the care team; in the second case, they are sometimes mistrusted by caregivers, even though the two positions—somewhat overstated here—need to be tempered depending on the sites and people interviewed, as we noted above.

3.1.1. *Palliative care volunteers in PCUs*

There are numerous similarities between France and the countries described above in Section 1.2 of this chapter concerning the meaning volunteers give to their action and the place assigned to them by PCUs. According to statements shared by volunteers and the majority of palliative care professionals interviewed, offering one's time is synonymous with "citizen commitment well beyond the world of health", as noted by R. Aubry, coordinator of the national Program for the development of palliative care 2008–2012 at the Ministry of Health and President of the End-of-Life Observatory [50]. According to the narrative common to most of the volunteers and caregivers interviewed, the time that is offered enables giving support to patients (even if the curative treatments have become ineffective) and brings a "breath of fresh air from the outside", to use the expression of Ferreira [24]. Because of the common values held by the people interviewed, collaboration between caregivers and volunteers is satisfying in most cases. But as the sociologist M. Castra has noted, good integration of volunteers into palliative care facilities may also be explained by the fact that "the PCU personnel quickly understood the advantages to be had by a volunteer presence for their own work comfort", especially at times of heightened activity [1]. Henceforth, and even if volunteering is by definition an unpaid activity, it can sometimes resemble work—for free—resembling in several ways the professional world. This is translated concretely into an expansion of the division of work in peripheral activities, with the more or less formal delegation of caregivers' relationship tasks to volunteers (settling incoming patients into their rooms, informing, being a presence, attentive listening, watching over agitated patients...). In this context, some interviews suggested the idea of a relative professionalization of volunteering in palliative care, an idea all the more compelling in that several interviewees underscored the criteria for selection, training, and strict monitoring (even quasi managerial) that govern them. These elements carry the risk of a political instrumentalization of volunteering in order to make up for the financial shortfalls of care facilities and to thus attempt to compensate for the crisis of the Welfare State. This is reminiscent of fears expressed by association leaders in other countries [16]; that of the potential breakdown of the boundaries between employment and volunteering, fears that in fact exist in a diversity of contexts other than that of palliative care and health [37].

If the risk of boundaries breaking down exists, it should nevertheless be put into perspective by the uniqueness of the object of this accompaniment—the end of life—but also by all the preventive measures taken by French volunteer associations to restrict the activity of their teams as much as possible to the strict accompaniment of patients and their family (listening, presence, limited small favors). Consequently, the people interviewed rejected the idea of work on the cheap as much as that of the professionalization of their activity. They considered that this political and "too categorical" way of reasoning "confined them to techniques that create barriers" between them and those they come to help, and they then evoked a basic principle—that of their complementarity with the caregivers. They also rejected the idea of an instrumentalization of their action by care facilities in order to reduce costs. They justified the many rules to which they are subjected by citing the concern of the associations to train them to adopt the proper attitudes and to "protect" them from risks of overinvestment. These rules—from the world of salaried employment—thus appear to be mainly "safeguards" destined on the one hand to

select "people with sufficient moral qualities" to visit patients at the end of life, and on the other, to "integrate this lay work into a hospital setting", itself highly regulated and hierarchical, as noted by some French authors [1, 43]. The transfer of skills to volunteers would therefore reflect more a "rite of institutionalization" than a professionalization, which again, is not specific to the volunteering we studied, but to all volunteering, from the moment, there is a close relationship between volunteers and those they help [37].

Beyond these considerations, the literature shows that being a volunteer in a PCU or in a hospice is not devoid of stressors, which pose important training challenges to volunteer associations, notably in teaching how to manage one's emotions. Sources of stress may include occasionally ambiguous roles in relation to caregivers and other personnel, unclear status, at times difficult relationships with patients, families, or caregivers, personal problems that can sometimes disrupt the life of volunteers... [39]. Several volunteers in our study thus mentioned several sources of stress: the guilt they felt from time to time at the idea of receiving from patients more than they give them; their regular questioning of their commitment and of their true motivations; their efforts to not deviate from a "position of listening and being present" to one of doing tasks that would be the responsibility of professionals; the awkward situations they can find themselves in (such as a silent presence at the side of someone in a coma); and the whole battery of institutional and personal resources they constantly mobilize. In fact, some palliative care teams today have difficulty in retaining their volunteers [2], and France is no exception. Even though this topic was not addressed as such in our interviews and would thus merit further investigation, it does indeed emerge implicitly in some narratives, such as that of the woman who, although highly dedicated, admitted having suspended her volunteer activities for 6 months because she felt so uncomfortable in certain situations. To limit pressures, some authors emphasize the importance on the one hand of avoiding "unrealistic expectations" that may come from caregivers, patients, or families (through better information on staying within the limits) [16], and on the other hand, the need to reward volunteers more for the social bond they try to re-establish between the patient and society, following the example of what is observed in the world of work [2, 51–54]. Nevertheless, it has been observed that all the volunteers interviewed spoke with enthusiasm about their work alongside caregivers, a result found in other studies, and that some authors explain by the strategies that volunteers use more or less consciously in adapting to stressing situations [39, 41]. According to some research, these coping strategies, in association with proper supervision of volunteers by their association, diminish their feeling of burn out and malaise, to the point they do not always view their activities as stressful in spite of the various tensions identified [39, 40]. It thus appears that the goodwill with which the volunteers studied fulfill as best they can the missions given them constitutes in itself an important resource for the PCUs as well as for hospices, as Watts also observes for the United Kingdom [2].

3.1.2. Palliative care volunteers in PCSTs and in traditional care facilities

As we noted in the introduction (see Section 1.1), France made the original choice of developing institutionalized palliative care, not in large facilities dedicated solely to people needing this care, but directly in hospital departments, where the vast majority of deaths occur.

This was done initially and over a period of 15 years by the creation of palliative care teams (PCUs and PCSTs), considered as expert at improving end-of-life conditions in the hospital. In a second phase since 2004, the “palliative culture” was disseminated among all hospital caregivers frequently faced with the death of their patients [13–15]. Compared with the original model for hospices and what can be observed in many countries, this new direction can be explained by both the concern of French policies to ensure that patients could be cared for in the facility where they were usually hospitalized—and thus by the same caregivers as those that had taken care of them since their first symptoms—and by the critical necessity of rationalizing expenses.

Although the issue of integrating volunteers into PCUs and hospices is well documented, there is still little data on the participation of these lay actors in acute care services, as some authors have recently emphasized [55, 56]. In this respect, this research provides some information, at least for France. First, while these volunteers used the same terms as those attached to a PCU in talking about their commitment and their missions⁷ (attesting to a close proximity between them), on the other hand, they described their access to patient rooms as much more difficult in curative care facilities than in PCUs. This is similar to other research. Thus, a study carried out among Jalmalv⁸ associations shows that their volunteers “are not yet quite at home in the place they are committed to”, and that their action resembles more a “juxtaposition of teams” than a “true collaboration” with unit caregivers [45], because of “misunderstandings and presuppositions” (more than from “frank opposition”) [43]. In curative facilities, these situations revive unresolved tensions concerning the proper moment to change from curative to palliative care [57]. This requires volunteers to work in an uncertain environment and constantly exposes them to feelings of invisibility, of uselessness and frustration, also observed by Finkel [58]. According to some, these difficulties can be explained by a “poor understanding in the facilities of [not only] the notion of palliative care, [but also] of the indispensable help given by volunteers” [43], bearing in mind—as other authors note—that “it takes very little to call into question the [always fragile] cohabitation between caregivers and volunteers” [59]. Some associations attempt to get past this resistance by organizing campaigns to raise awareness of volunteering in order to become better known to caregivers in their hospital [60] and by working to set up “partnership collaborations” with traditional departments [61]. They thus have to think ahead of time about “the optimal placement” of their teams [43] and then actively defend their position, as emphasized by Delaloye in the context of Swiss hospitals as well [56]. However, this is not specific to volunteering in palliative care. The functions of caregiver and volunteer (regardless of what they are) “are in fact sources of misunderstanding [and] conflicts” for several reasons: misunderstanding of volunteering on the part of care professionals, competition around care activities, frequent lack of recognition of each one’s role, the infrequency of shared projects, and the ever-increasing turnover in personnel [46]. Some authors also mention the risk of a lack of continuity of volunteer presence in acute care services, and the necessity for their associations to “invent new functions”, even if it is necessary to “reassess our goals” [46]. Conversely, some volunteers, better integrated into the

⁷Listening to and giving support to patients and their families, human solidarity, the gift of presence...

⁸Jalmalv (“Jusqu’à la mort, accompagner la vie”, “Until death, accompany life”): one of the main French associations of palliative care volunteers.

facilities, mention with regret their inability to get the PCST involved with patients who they think are in need, as these cross-disciplinary teams encounter the same obstacles to intervening as they themselves do [48].

Although work conditions for volunteers in traditional care units are more difficult than in PCUs, the volunteers interviewed were, however, less pessimistic than these authors on the development of their activity. They reported largely satisfactory conditions of collaboration with some acute care units that were more aware of and open to palliative care and volunteering than others were. Some interviewees thus emphasized the influence of heads of departments and supervisory nurses in their proper integration, with the mobilization of all personnel proving to be essential as well, as also stated by Verchère [62]. French publications describe other successful experiments at integrating volunteers outside of PCUs [63–65]. These experiments are doubtless destined to multiply the given political will to disseminate the palliative culture in all facilities that are frequently confronted with the death of their patients. According to Bird—who is interested in volunteer accompaniment in English acute care hospitals—volunteers trained in palliative care, through their careful listening and support, make a substantial contribution alongside caregivers in better responding to the needs of people at the end of life and their families: “when medicine can do no more, a smile, a touch and a friend are the best prescription—this is what our volunteers have in abundance”, she argues [55]. She emphasizes that training programs set up for that purpose are necessary but not sufficient. To be effective, they should be accompanied by both regular support from recruited volunteers and communication activities to make them better known by facilities that are potentially interested. Another direction mentioned simultaneously by American [66] and Canadian [67] authors consists in raising the awareness of future physicians about issues linked to the end of life by proposing they spend several hours as a volunteer in a hospice during their first year of study. This work shows that the students who followed these programs—pilot programs for now—acquired very positive experience for themselves and for their future profession, whether in reducing fear in the face of death, in encouraging their personal reflections, or in learning to better communicate with patients and families.

3.2. Between “Being” and “Doing”: should volunteer service in palliative care be re-examined?

The above results lead us to a reexamination of the place and role—between “Being” and “Doing”—of volunteers in French palliative care and to suggest some avenues of reflection in order to strengthen its development and ensure its sustainability.

3.2.1. “Being there”

The comparison of narratives between volunteers, caregivers, patients, and families in France shows the extent to which volunteering in palliative care is conceptually integrated into “Being”, as the President of Jalmalv also points out [10]. Presence and listening are at the heart of the system, with a clear emphasis on not substituting for caregivers and of discretion concerning patients and their families. As in the Swiss model, volunteers in French palliative care say they are engaged in a relationship with the other, based on not abandoning vulnerable

people and on a civil society determined to care for its members [34]. These social skills (*savoir-être*), sometimes referred to as an “art” due to the multiple “adjustments” involved [68] are appreciated by some patients and families interviewed and by most palliative care professionals, especially when there is a need to go to the bedside of isolated people or play a welcoming or monitoring role. These results reinforce what is already known, as well as the fact that volunteers studied gain benefits from their ethical commitment [1, 12, 21]. But they also reveal several new elements: the intentional absence of volunteers in two palliative care teams interviewed, which is contrary to the prevailing view that “a care facility cannot be palliative if it has not integrated volunteers into its multidisciplinary team” [12]; the reluctance of some caregivers in curative facilities to co-operate with them as a matter of precaution; the numerous efforts of the associations to make their missions known to the acute care staff and thus, to gain access to the rooms of more patients; a mixed or even hostile perception by certain patients and families of this type of volunteering; or the discomfort, often kept quiet, of some volunteers in certain situations (guilt in receiving more than they give, difficult presence with some patients in a coma, use of tricks to access certain rooms in curative care facilities ...).

The concept of “being there”, used by many voluntary associations, is a central notion in several countries, a “precious thing” which consists of “creating value through encounters” [69]. This concept is especially appropriate for French palliative care volunteers, whose recurring position, strongly voiced by their associations, is “to be there” just “to be there” through solidarity. This relationship skill, which rests primarily on presence and active listening, is an integral part of the basic training for people wishing to become volunteers in palliative care, and of continuing education for those who already are. As emphasized by the French association “Accompagnement in Palliative Care” (ASP) in its training pamphlets, “listening is the tool par excellence of the volunteer”. It is what enables them to be truly there, for the time they are there, with the person for whom they are there, and is what shapes them. However, if “learning to listen” is a major challenge for a good accompanying volunteer, other aptitudes are also needed. In France, as elsewhere, these volunteers must therefore participate in several other forms of training in order to fulfill and experience their missions to the fullest. For example, they must learn to manage their emotions—become “hardened” regardless of the empathy they may feel for some patients—and to not go beyond the limits of activity set by their associations [2]. Some studies also note that one of the important challenges faced by these social skills today is to improve taking cultural differences into account, due to the considerable diversification of the patient population in hospices and PCUs⁹ [2, 70, 71]. Indeed, these studies find gaps concerning cultural competencies among volunteers in place and thus an urgent need for remediation. In particular, it is necessary for these actors to learn to “be there” for all people, regardless of their ethnic origin, language, religion, or beliefs, and to offer each one, without discrimination, an appropriate accompaniment. According to Jovanovic, improving this type of skill is “vital, crucial, and imperative” in reducing the social exclusion of some patients [70]. She, therefore, makes several recommendations to achieve this, such as online access for volunteers to certain downloadable documentary resources or the creation of an interactive web site [71]. Although these publications concern the United Kingdom (Watts)

⁹Depending on the country: Muslims, Asians, Africans Hindus, Filipinos, East Europeans...

and Canada (Jovanovic), they can be completely superimposed on the French situation, where the same problems are to be found or soon will be, in a context where social skills are greatly needed.

3.2.2. *"Doing": a pretext for "Being". Toward a more active volunteering in palliative care?*

The position of French volunteers in palliative care, exclusively in the "Being" camp rather than the "Doing" camp, constitutes a source of "pride" for some association leaders [10]. However, it may also constitute a significant obstacle to the development of this activity in France, given the resistance to making a place for volunteers expressed by some health personnel, patients and families in our study. Indeed, in spite of strong institutional recognition, these types of voluntary associations paradoxically suffer today from a "structural fragility". There are "a limited number" of contracts in the field, recruitment as well as fidelity of their members is becoming problematic, the integration of volunteers into facilities is proving "laborious," and volunteering appears to be "disappearing from the preoccupations" of palliative care teams themselves [10], a problem calling for urgent reflection. Our review of the literature shows in particular that there is one important difference between France and most of the other countries studied. In France, palliative care volunteers focus on attentive listening, support and little favors (thus reducing their role strictly to "accompaniment"), whereas elsewhere, "accompanying volunteers" are, but a small group among all active palliative care volunteers. The latter carry out a multitude of quasi-professional tasks (receptionists, secretaries, drivers; reflexologists, fundraisers...), as we have seen in Section 1.2.2 [2, 16, 32, 42, 43]. They can be present with hospitalized patients, as well as with those in day care or in home care, sometimes even offering their professional skills in a wide range of activities (supplementary therapists, hairdressers, spiritual care workers, qualified nurses, doctors...) [72]. In some places, their contribution may be especially beneficial to patients, families, and caregivers alike. This is notably the case in the United Kingdom in pediatric palliative care facilities, where volunteers provide a number of different services, such as organizing recreational activities for hospitalized children and their siblings, playing the role of schoolteachers, providing supplementary therapies, giving support to parents, and managing the families' homes [73]. As emphasized by Sévigny for Quebec [16] and Gérardy for Belgium [35], the "Doing" of volunteers (and not only those in palliative care) is often a pretext for "Being", an excuse to more easily initiate contact with patients and families. More than the task or small favor ("Doing"), what is important above all is the creation of relationships ("Being"). "Doing" provides the possibility to create relationships that would otherwise never have existed to generate an atmosphere of confidence and to keep an expert eye on changes in behavior in case they need communicating to caregivers. In this sense, "Doing" is not necessarily the goal to attain, but the means chosen to better give support to those that need it through the presence being offered.

By improving care without raising costs, this type of action doubtless has a strong development potential for volunteering in palliative care, and can be transferred – at least in theory – to France. Indeed, the literature review and the interviews carried out reveal several avenues for the growth of volunteering in French palliative care. Examples would be of volunteers entering patients' rooms with "concrete proposals" (loaning books or CDs, distributing snacks at various times of the day, doing small errands, organizing entertainment, helping

patients move around inside and/or outside the hospital...). That would give them pretexts considered by some interviewees as more “acceptable” than just “*wandering from room to room, hoping that at the right moment, the person will want to have their hand patted or be served a cup of coffee*” (quoting the disapproving comments of one of the patients encountered). But in return, this implies an extension of their activity to include “service”, similar to what is observed in other countries studied. French experiments are moving toward more active volunteering, such as at *La Maison de Gardanne*, where volunteers are asked (in addition to just being present) to help patients with their breakfast, to go from room to room proposing menus, to help the cooks, or to organize outings [63]. However, such an expansion offends both political (health authorities) and ideological (volunteer associations) sensibilities surrounding the central principle of strict complementarity between professionals and volunteers and creates the risk—considered omnipresent—of seeing this type of volunteering turned into a form of work on the cheap. This probably explains why none of the volunteers interviewed mentioned the idea of expanding their mission to include more concrete activities, thus in a way concealing tensions in the workplace and shunning the potential opportunities mentioned above. We should note here that the restriction in France of volunteer action to a presence and attentive listening constitutes a unique feature of volunteering in palliative care. In other care settings, “Doing” is indeed considered as important as “Being”, in the name of the usefulness and effectiveness of volunteer involvement. This is particularly the case for associations to fight cancer, where volunteers are responsible for doing prevention, collecting funds, or helping to personally redeploy patients [44].

4. Conclusion

While volunteers have a strong presence next to palliative care professionals, their activity remains poorly understood, notably in France. This chapter draws on a literature review and interviews with volunteers, caregivers, patients, and families. It discusses the place and role of these actors and examines their perspectives for development in the French context. Premised on generosity, volunteering is, in fact, a complex activity, sometimes controversial, and often described as a “tough job”. On the one hand, it is clear that the apparent conceptual consensus disseminated by the model of palliative care concerning the beneficial presence of volunteers among hospitalized patients at the end of life becomes fragmented in the field into a wide diversity of perceptions (related to the status of the actors involved, to their concept of care as death approaches, and, where appropriate, to their work setting). On the other hand, it appears that the dominant concept among volunteers interviewed, “being there to be there”, leads to poorly recognized tensions, but which are capable of compromising the sustainability of volunteering and its development in curative care facilities. This raises the question of frameworks and resources needed to overcome resistance and to facilitate the desired dissemination of the “palliative culture” among all health workers confronted with the end of life [13–15]. More broadly, this study shows that the sometimes difficult acceptability of hospital volunteers (and not only those in palliative care) by those persons they wish to help without a prior request (in this case, patients hospitalized in palliative care) depends in part on the fact

that, in France, care is and remains for many people "the exclusive domain of salaried health personnel" [74] (even within the specific framework of palliative care units or teams). This suggests that attitudes change more slowly than policies on this question.

In addition, this analysis highlights similarities and differences between volunteering in palliative care in France and in several other countries. These differences, more or less marked, are due to both palliative care policies carried out in these various countries and to cultural elements that are more or less favorable to the presence of lay actors at the side of caregivers. Depending on the country, this presence may manifest itself in a nearly exclusive attitude of listening and kindness (as in France) or as a semi-professional position where volunteers are responsible for carrying out a multitude of tasks (as in the United States, Canada, and the United Kingdom). While these two positions are justifiable, they give a considerable stimulus to discussion and reflection and suggest directions for fruitful research projects. Beyond the debate on the risk of instrumentalizing volunteering in order to reduce costs, and on the need for better defining the boundary between work and volunteering, we should not forget that concerns are finally always and everywhere the same: improve the care of people at the end of life and their families, for a society each one hopes to make better.

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