A review of the volunteer movement in EAPC countries

Claude Fusco-Karmann and **Gianna Tinini** report on a study that assessed the importance of the voluntary services that support palliative care in EAPC member countries

The volunteer movement has played an important role in palliative care from the start, and in the early days, the pioneers of this ‘new’ and ‘untrusted’ medicine often relied on voluntary service groups that had been created specifically for this purpose. These volunteers were strongly motivated and were determined to provide support – in both human and financial terms – for the professionals who had chosen to act to relieve the suffering and the state of neglect endured by patients with terminal illness.

The first palliative care physicians acknowledged the essential support that voluntary services provided and consulted their organisations in operative choices. They also gave them the recognition they deserved and included volunteers in the multidisciplinary caring team. For its part, voluntary service has evolved from its somewhat disorganised beginnings, introducing management and education and providing organisation and experienced staff. Now, after 20 years of struggle, the significant co-operation that resulted from the synergy between these ‘special’ doctors and ‘special’ volunteers has been established throughout Europe.

Outlining the study process

The aims

Although each of the member countries of the European Association for Palliative Care (EAPC) could provide a ‘map’ of the palliative care centres or units open in their respective countries, very little data were available regarding the non-profit organisations (NPOs) supporting these. The main aim of this study was, through the use of a specially prepared survey, to assess the importance of these organisations and to establish a Europe-wide network of NPOs, with the intention of putting the survey data at the disposal of EAPC. In addition to this, the study aimed to:

- Enhance the lobbying force of both European and local palliative care movements
- Share the results/information with patients looking for support
- Improve communication and exchange of information between NPOs supporting palliative care.

The volunteer movement has played an important role in palliative care from the start

The proposal

A proposal for the implementation of a network of NPOs active in palliative care was submitted to the Federazione Cure Palliative (a collective member of the EAPC, currently representing 38 Italian NPOs). When the proposal was accepted, an easy-to-complete questionnaire was drafted, which took into consideration the very different environments and situations faced by the NPOs in various countries.

The questionnaire

The questionnaire investigated the importance of volunteer movements in palliative care from a quantitative standpoint, looking at the:

- Number of associations
- Number of volunteers
- Number of patients

Key points

- The first palliative care physicians acknowledged the essential support that voluntary services provided ... and gave them the recognition they deserved.
- When dealing with direct care, the ratio of patients to volunteers is about one volunteer to every five patients.
- The available resources are still inadequate in relation to the number of deaths, but when compared with the situation 20 years ago, a great deal of progress can be seen.

- Funds raised to finance the activity (expressed in local currency, and converted into euros when processing the data).

The information collected should also provide some idea of the kind of activity performed (whether it be direct care or be through agreements with the national health service institutions), as well as assessing the importance given to volunteer education by the associations in each individual country.

Collecting and analysing the data

The 18 EAPC member countries were divided into four large geographical areas in which representatives collected data:

- Israel, Italy, Spain, Switzerland
- Belgium, France, Luxembourg, the Netherlands
- Germany, Great Britain, Republic of Ireland, Norway, Sweden
- Croatia, Cyprus, Greece, Hungary, Romania.

Looking at the findings

It should be noted that the data collection process relied on the goodwill and capability of the people contacted in the various countries. It was not carried out on an official or institutional level, and therefore, could not pretend to be exhaustive. The work, started with great enthusiasm, proved to be difficult and would not have been possible without the extraordinary help received by colleagues in the various countries.

It was not possible to collect data relating to 1999 from all 18 member countries (co-ordinators for Great Britain and Norway had to pull out), but 733 NPOs from 16 countries did respond (18 of which were not active in palliative care). Tables 1 and 2 present the data collected, and some key points are outlined in brief below.

- Seven hundred and fifteen NPOs are active in supporting palliative care (63% of

Table 1. Data showing the total number of respondents and the main activity areas

		Area of activity of associations			Type of care provided			
Country	**Total no. of respondents**	**Only PC**	**Not only PC**	**Non-PC**	**Own PC teams**	**PC units in agreement with NHS**	**Own volunteer education**	**Total fund-raising (euros)**
Belgium	185	47	138	0	128	93	69	124,166,263
Croatia	1	0	1	0	1	0	1	26,339
Cyprus	5	1	4	0	2	5	3	2,800,586
France	200	199	0	1	11	46	199	5,030,776
Germany	9	6	1	2	4	4	6	780,940
Great Britain	na	na	na	na	na	na	na	na
Greece	5	2	1	2	1	1	3	391,170
Hungary	7	5	2	0	2	5	4	204,150
Rep of Ireland	5	4	1	0	4	3	5	5,588,437
Israel	12	7	5	0	7	4	11	1,217,281
Italy	131	52	71	8	61	57	101	31,913,228
Luxembourg	1	1	0	0	0	0	1	na
Netherlands	96	96	0	0	0	0	96	na
Norway	na	na	na	na	na	na	na	na
Romania	4	2	2	0	3	0	2	6,421
Spain	20	10	6	4	16	12	15	300,320
Sweden	na	na	na	na	na	na	na	na
Switzerland	52	22	29	1	14	21	36	11,079,495
Total	**733**	**454**	**261**	**18**	**254**	**251**	**552**	**183,505,406**

PC = palliative care **na = not available** **NHS = National Health Service**

Table 2. Data showing the division of volunteers and patients

Country	Volunteers			Patients		
	Direct care	Other	Total	Home setting	Hospice setting	Total
Belgium	1,416	5,483	6,899	2,630	7,047	9,677
Croatia	32	0	32	38	0	38
Cyprus	137	995	1,132	1,010	145	1,155
France	3,140	620	3,760	5,400	12,600	18,000
Germany	1,567	569	2,136	331	291	622
Great Britain	na	na	na	na	na	na
Greece	24	20	44	700	0	700
Hungary	66	10	76	422	318	740
Rep of Ireland	538	1,732	2,270	2,667	1,030	3,697
Israel	307	666	973	912	913	1,825
Italy	2,700	4,102	6,802	18,421	1,122	19,543
Luxembourg	50	na	50	na	na	na
Netherlands	2,000	na	2,000	na	na	na
Norway	na	na	na	na	na	na
Romania	17	17	34	218	1,276	1,494
Spain	156	752	908	1,787	845	2,632
Sweden	na	na	na	na	na	na
Switzerland	774	1,214	1,988	744	2,772	3,516
Total	**12,924**	**16,180**	**29,104**	**35,280**	**28,359**	**63,639**

na = not available

these are active exclusively in palliative care and were formed with this sole aim, while the remaining 37% also operate in additional fields).

- Two hundred and fifty-four NPOs provide palliative care through their own multidisciplinary teams, and 251 through agreements with their country's national health service (some – for example, Belgium – operate in both ways).
- In France, only 57 out of 200 NPOs provide palliative care, while 199 out of 200 associations provide education.
- The vast majority of associations (77%) supply volunteer education and training.
- In 1999, a total of 63,639 patients were assisted by volunteers; 35,280 in a home setting and 28,359 in a hospice setting.
- The total number of volunteers reported is 29,104, of which 12,924 are involved in direct care, and 16,180 have some other role within their NPO.
- The total fund-raising reported amounts to euros 183,505,406 (this information was provided by 423 NPOs – 59% of the respondents).

Comments from the co-ordinators

Some of the local co-ordinators made noteworthy comments specific to their geographical area:

- Collection of data in Luxembourg and the Netherlands was difficult, and combined data were supplied for these two countries
- The picture in France results from only three federations (grouping about 200 associations), whose main task is the education and introduction of volunteers into existing palliative care units
- In Switzerland, many small associations operate inside hospitals, and it is only possible to trace the associations through the hospitals
- Volunteers in Sweden appear to be active only in private hospices and their inclusion depends on the organisation's willingness
- In Israel, there is no clear recognition of the contribution of volunteers to palliative care, and their inclusion depends on the organisation's willingness to accept them
- The palliative care movement in Hungary is in its early stages.

The issue of turnover

The critical issue of the turnover of the associations was not answered by 36% of Italian, 51% of Swiss and 87% of Spanish NPOs – even though it was stated clearly that this information would only be made public as a collective figure for each country, with the sole objective of assessing the economical importance of NPOs operating in palliative care. As a result, the figure obtained is merely indicative, but it does lend itself to some considerations, while certain figures stand out and require some explanation.

- In Belgium, where the declared turnover is extremely high in comparison to other countries, it must be stressed that 128 NPOs (69%) treat patients through their own units.
- In Italy and Switzerland, it appears that the role of NPOs is essential in providing palliative care directly or in supporting palliative care units.
- In France and the Netherlands, NPOs do not tend to provide palliative care directly, but support its provision through a large number of volunteers, and the role of NPOs is mainly to educate volunteers.
- Great value is clearly attributed everywhere to education for volunteers – it is provided by 77% of the respondents.
- When dealing with direct care, the ratio of patients to volunteers is about one volunteer to every five patients. When the total human resources involved in NPOs (including volunteers who do not provide direct care but support their associations in other ways) are considered, this ratio increases to one volunteer for every two patients.

What does it all mean?

This study represents the first step of a long journey that NPOs will need to undertake if they are to achieve the co-operation and ever increasing cohesion they strive towards. It has been an attempt to measure our force and to place another brick in the huge framework we started building 20 years ago. 'Globalisation' is still a long way off as far as NPOs are concerned, but this is what we should now be aiming for. In some countries, groups of NPOs have united to form federations, which have, in turn, become members of the EAPC, thus strengthening the palliative care movement.

Despite the fact that only 59% of respondents declared their turnover, and that many questionnaires were not returned, the figure representing fund-raising is high, meaning that NPOs are a force to be reckoned with.

The internet will be an important source of information – facilitating communication and enabling experiences to be shared. The results of this survey have been collated in the form of a database – reporting information about more than 700 NPOs in 16 countries. Names and locations of the NPOs surveyed will be available on the Federazione Cure Palliative website (www.fedcp.org) and the data will be put at the disposal of the EAPC. The questionnaire will also be available online, to allow constant updating of the database. Any patient in any country will be in a position to consult this information and find the organisation that might help him or her through his/her struggle with terminal illness. Any association will be in a position to contact other associations sharing the same problems.

The picture that has emerged, though incomplete, shows that the available resources are still inadequate in relation to the number of deaths. However, when compared with the situation 20 years ago, a great deal of progress can be seen, and many patients have received the help they so desperately needed. This is enough to inspire us to continue our struggle with renewed force and determination, to offer solidarity and to spread the culture of palliative care.

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