Palliative care volunteerism across the health care system

a nationwide survey.

Joachim Cohen
Steven Vanderstichelen

Steven.Vanderstichelen@vub.be
Key points

1) Volunteers across the health care system provide an important capacity for end-of-life care

2) Volunteers provide direct palliative patient care, both in and outside dedicated PC organizations

3) Particularly in nursing homes volunteerism focuses less on palliative care

4) Empowerment of volunteers by organizations is low

5) Developing volunteer capacity by stimulating involvement
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Practical Support

Companion ship

Improving health

Link to community

Medical Oncology wards

Total number?

Volunteer engagement?

Community

Nursing homes

Sitting Services

Dedicated palliative care services

What training?

What tasks?
A survey study to all organizations that provide PC and potentially work with volunteers

<table>
<thead>
<tr>
<th>Organization type</th>
<th>N=334</th>
<th>Response obtained</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Oncology wards</td>
<td>39</td>
<td>25</td>
</tr>
<tr>
<td>Sitting Services</td>
<td>39</td>
<td>33</td>
</tr>
<tr>
<td>Specialized Palliative Care</td>
<td>47</td>
<td>45</td>
</tr>
<tr>
<td>Palliative Care Units</td>
<td>27</td>
<td>25</td>
</tr>
<tr>
<td>PC daycare service</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>PC homecare teams</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Community home care</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>Nursing homes</td>
<td>197/783</td>
<td>145</td>
</tr>
</tbody>
</table>
Definitions

Volunteerism in palliative care
The time *freely* given by individuals, with *no expectation of financial gain*, within some form of organized structure other than the already existing social relations or familial ties, with a palliative approach – i.e. The intention of improving the quality of life of adults and children with life-limiting conditions and their close ones.

Direct patient care
*The immediate treatment of a patient as part of a palliative approach.*
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All organization types have direct patient care volunteers

- Med Oncology: 64%
- Sitting services: 97%
- Dedicated PC services: 98%
- CHC: 80%
- Nursing homes: 73%
The amount and type of tasks to be performed by volunteers differs between organization types.
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Psychosocial and existential care are tasks given to volunteers; medical and nursing care tasks rarely
Nursing homes rarely provide volunteer training in palliative care related aspects.
1/3 of organizations have a mandatory volunteer training
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Volunteer involvement

**INFORM**
To provide balanced and objective information in a timely manner.

**CONSULT**
To obtain feedback on analysis, issues, alternatives and decisions.

**INVOLVE**
To work with the public to make sure that concerns and aspirations are considered and understood.

**COLLABORATE**
To partner with the public in each aspect of the decision-making.

**EMPOWER**
To place final decision-making in the hands of the public.
Volunteer involvement about the organization of care

**Actual involvement:**
Never – Rarely – Often – Always

**Appraisal of level of involvement**
Would like it to be less – is adequate – would like it to be more
Organizations often involve volunteers but seldom collaborate or codesign with them.
Distinguishing organizations by their attitudes towards volunteer involvement

<table>
<thead>
<tr>
<th>Actual involvement</th>
<th>Appraisal of involvement</th>
<th>Would like it to be less</th>
<th>Is Adequate</th>
<th>Would like it to be More</th>
</tr>
</thead>
<tbody>
<tr>
<td>inform – Consult – involve – collaborate – empower</td>
<td>Never</td>
<td>Dismissive</td>
<td>Dismissive</td>
<td>Supportive</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>Dismissive</td>
<td>Dismissive</td>
<td>Supportive</td>
</tr>
<tr>
<td></td>
<td>Often</td>
<td>Dismissive</td>
<td>Supportive</td>
<td>Supportive</td>
</tr>
<tr>
<td></td>
<td>Always</td>
<td>Dismissive</td>
<td>Supportive</td>
<td>Supportive</td>
</tr>
</tbody>
</table>

- Eg, organization who often or always empowers volunteers and thinks this is adequate is supportive of empowerment
Organizations are supportive of involved volunteers but not of empowered ones.
Three degrees of involvement

Cluster analysis based on:
- ‘Inform’
- Low engagement types (‘consult’ + ‘involve’)
- High engagement types (‘collaborate’ + ‘empower’)

Three clusters found:
- **Strong** involvement
- **Restricted** involvement
- **Uninvolved**
Dedicated palliative care services mostly belong to the group with ‘strong involvement’ of volunteers; nursing homes often to the uninvolved.
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Organizations with strong involvement consistently score higher on range of training subjects offered and task performance

<table>
<thead>
<tr>
<th>Range of training subjects offered (0-12)</th>
<th>ADL scores (0-6)</th>
<th>iADL scores (0-8)</th>
<th>PSE scores (0-6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strong involvement</td>
<td>Restricted involvement</td>
<td>Uninvolved</td>
<td>Strong involvement</td>
</tr>
<tr>
<td>7.51</td>
<td>5.3</td>
<td>4.15</td>
<td>4.56</td>
</tr>
<tr>
<td>3.12</td>
<td>2.52</td>
<td>1.76</td>
<td>3.8</td>
</tr>
<tr>
<td>3.12</td>
<td>2.57</td>
<td>2.28</td>
<td>3.53</td>
</tr>
</tbody>
</table>

Graph showing performance metrics for different levels of involvement.
Developing volunteer capacity by stimulating involvement

Investing in organizational volunteer involvement = increasing care capacity of volunteers

more supportive attitudes towards volunteer involvement

Manner to increase their role in nursing homes
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Contact

Steven Vanderstichelen, MSc.
Steven.Vanderstichelen@vub.be
Svdstich@vub.be

http://integrateproject.be/integrate-study-6
http://endoflifecare.be

Twitter: @EoLC_research