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Public health actions to improve palliative care in Germany: Results of a three-round Delphi study

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ABSTRACT

Background: In previous studies, key targets for public health initiatives to improve palliative care in Germany were defined. The aim of this study was the identification and prioritisation of actions to achieve these targets.

Methods: A three-round Delphi study with 107 stakeholders acting on the meso and macrolevel of the healthcare system was undertaken. First round: proposing actions for each of the key targets; second round: assessment of the actions regarding their relevance; third round: ranking of the actions.

Results: 37 actions were generated (first round) of which 14 actions were rated as relevant (second round). In the third round, the action ranked highest was "close collaboration between specialist palliative care services, general practitioners and community nursing services", followed by "Implementing specialist palliative care in the community consequently" and "Strengthening generalist palliative care through training and education of general practitioners and nursing services".

Conclusions: The range and the ranking of the actions provide an empirical basis to improve palliative care in Germany on different levels of policy, education and clinical practice. A focus should be on strengthening the collaboration between primary health care providers and specialist palliative care services.

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1. Introduction

After palliative care has long been a discipline at the edge of the health care system, in recent years increasing attempts have been made to establish palliative care as an essential part of the German health care and social system. Initiated by the individual commitment of engaged pioneers, palliative care has been developed remarkably

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which is demonstrated e.g. by the number of available inpatient hospices, palliative care units and palliative home care services [1,2]. The development has been fostered by anchoring the legal right to specialist outpatient palliative care (SAPV) in the social security statute [3,4]. Moreover, palliative care has become a mandatory subject in undergraduate medical education [5]. In addition, the German charter for the care of the critically ill and the dying was a crucial step towards improved public awareness for palliative care on different societal levels [6].

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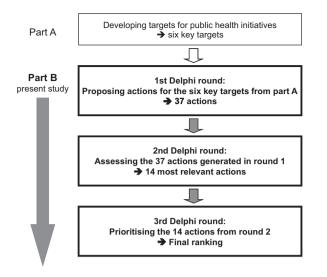


Fig. 1. Project overview.

experts in public health and palliative care, as well as a range of organisations on the macro- and meso-level of the German health care and social system (e.g. health insurance funds, medical and nursing organisation, patient organisation, policy). The six key targets included:

- supporting palliative care as a basic attitude for the healthcare of people in the last phase of life;
- coordinating healthcare for people in the last phase of life;
- establishing cooperation among health professions and disciplines;
- establishing education in palliative care for all professional groups providing care for people in the last phase of life;
- offering support to family members who are caring for someone in the last phase of life;
- reviewing the evidence of palliative care actions.

This article is on the final stages of project part B in which actions should be defined and prioritised to achieve the above mentioned key targets. The overall design of the project is illustrated in Fig. 1.

2. Methods

A three-round Delphi study was undertaken to identify and prioritise actions for the implementation of public health targets for palliative care in Germany. The Delphi method was selected since it allows participants to systematically develop a subject in an anonymous multistage group process where bias by hierarchy or social status can be prevented [8].

The methods and the preliminary findings of the first Delphi round were published elsewhere [9] and will be summarised in the following as to their relevance for the second and third round which are the focuses of the present work (Fig. 1).

2.1. Participants

For recruitment of the participants, we used a sample from project part A [7]. Based on discussion within our research team and with external experts in public health and palliative care, 363 institutions and organisations were included because of their relevance for the study. Main inclusion criteria were (a) acting at national and federal level of the German health care system and (b) involvement with palliative care in the narrow or wider sense, e.g. within the context of politics, science, lobbying, financing, or administration. Initially, we addressed the heads of the organisations. They were asked to forward the invitation to participate in the study to another person within the organisation if they themselves did not feel responsible or qualified to participate.

For the second and third Delphi rounds, only the respondents of the first round were approached again.

2.2. Data collection and analysis

In the first Delphi round from March to June 2010, the six key targets identified in project part A [7] were presented to the participants, asking them to propose up to five actions for each of the targets using free-text answers (postal survey). Reminders were sent after three weeks, followed by a second reminder after another three weeks. On demand the questionnaire was sent via email as a pdf-document.

The free-text answers were analysed using a qualitative descriptive approach [10,11]. For each of the six key targets identified in part A, all meaningful text units were identified and open-coded separately by two researchers (MB, SJ). Continuously comparing codes and text material, the codes were grouped into several sub-categories. These were subsequently summarised into main categories for each of the key targets, followed by a step of data reduction: similar categories were summarised and reorganised into major topics (e.g. "relatives") independently of the original key targets. Finally every category was linguistically revised to phrase an action. The analytic process, the emerging categories and the phrasing of actions were continuously discussed in the study group until consensus was reached. The analysis was technically supported by the software programme Atlas.ti. As a result, 37 actions were defined (details are reported in Section 3 and in Table 2).

The second Delphi round (November 2010-January 2011) included two steps: Firstly, each of the 37 actions was assessed separately with regard to its relevance, using the question: "In your opinion, how targeted is this action in order to ... [major topic inserted, e.g. "support relatives"]?" The actions could be rated on a 5-point-scale ("not at all targeted" to "very targeted"). Secondly, the participants were asked to select and highlight the five most relevant of the 37 actions presented, independently of the major topics. Actions were considered for the next Delphi round if they met two criteria: marked as targeted by a minimum of 65 participants (60%) and selected as one of the five most important actions by a minimum of 15 participants (Table 2). Based on the distribution of the data, these criteria were defined in a consensus decision among the researchers aiming at reducing the number of actions for

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