



Conditions of Palliative Home Care: The Case of Family Physicians in Switzerland

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Abstract

Family physicians (FPs) play a key role in the treatment and care for terminally ill men and women. However, little is known about the conditions and challenges of FPs services in this domain. Aim of this article is to identify, how FPs can be supported in palliative home care in Switzerland by the availability of guidelines and advance directives, community-based palliative care structures, education and training, as well as remuneration of palliative home care services.

Case studies in three Swiss cantons, namely Lucerne (LU), Vaud (VD), and Ticino (TI) are the basis of the following investigation. They not only represent French, Italian and German language regions but differ considerably with respect to the history of palliative care. Within and between cantons documents, questionnaires and expert interviews are analyzed thematically with the help of content-analysis.

The results illustrate considerable shortcomings with respect to the backing of FPs palliative home care services. The availability and use of guidelines as well as advance directives is rather small in general practice, and FPs care and treatment at the end of life is only marginally supported by ambulant care structures, especially in rural areas. Also the coordination of services and collaboration between specialists and generalists is poorly developed. Furthermore FPs possibilities to acquire competencies in palliative care are strongly limited, and palliative home care provided by FPs is poorly financed.

The results draw a rather bleak picture with respect to the support of FPs palliative home care services in Switzerland today. Though considerable steps towards implementing palliative care have been made in recent years in general, conditions for FPs medical services have to get improved strongly. Major efforts have to be made to foster the recognition and implementation throughout Switzerland.

Introduction¹

Family physicians (FPs) play a key role in community-based palliative care (CBPC) in many European countries [1,2]. In palliative home care and in nursing homes FPs care not only for oncological patients, but for patients with terminal organ failures, with degenerative neurologic diseases, or for multi-morbid and/or geriatric patients [3]. Best symptom-management, advance care planning, the collaboration with families, ambulant services and medical specialists, as well as the organization of transitions between different care settings (home, hospital, retirement and nursing homes or specialized care services), pose highest demands on FPs' services [4,5]. Demands increase since palliative care services at home constitute a specific work environment: Due to their solitary practice FPs only have restricted opportunities to refer to social guidance by peers, and rely strongly on their very own competencies. The proof and the availability of information and of other medical resources in the environment are therefore highly important factors for the quality of care [6]. However, while specialized palliative care already has gathered attention, the recognition and implementation of palliative home care is still underdeveloped [1].

Community-based palliative care in Europe and in Switzerland

The development of CBPC is crucial to measure up to the expectations and wishes of patients [7], of who most wish to spend their end of life at home. Due to these wishes, but also to the demographic aging of societies, and to the need for cost-effective medical services the intention to increase and strengthen CBPC is an issue that is on

the agenda in many countries. In Europe a 'Taskforce on Primary and Community Palliative Care' exists since 2011[8]. Early efforts to increase and strengthen CBPC are especially known from Great Britain and Ireland. The Golden Standard Framework, established in England in 2000, was one of the first guidelines available on European level aiming on the improvement of end-of-life care [9]. As a recent report shows [10] the reinforcement of CBPC is also on the agenda of other European Countries: Besides England and Ireland also Germany, Scotland, Serbia and Albania have invested into national palliative care strategies with a strong focus on primary or community-based care. Practice-oriented programs to foster CBPC have been established in other European countries as well. But aside from these efforts there are still many countries where palliative care as a part of primary care has to be acknowledged and promoted [10,11].

Community-based palliative care in Switzerland

As in other European countries the promotion of CBPC is an important public health issue in Switzerland [10]. While generally a broad range of activities to establish palliative care can be noted since the 1980ies, the need for new strategies to assure cost-effectiveness

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constantly increases. According to the Swiss Federal Office of Public Health about 75-80% of patients, who require palliative care services in Switzerland can be looked after by means of primary care today [12,13].

However, the establishment of CBPC all over the country is far from being achieved. Quite basically, the Swiss language regions differ remarkably with respect to the information about and the backing of palliative care [14]. The German, French and Italian speaking regions show considerably different attitudes towards life preservation, the alleviation of pain and other symptoms, very similar to those found in Germany, France and Italy [15] and also with respect to palliative care structures a comparison between Switzerland and other European countries reveals Switzerland to be a "Europe in miniature"[14].

Further, the federalist organization of the Swiss health system makes it difficult to define uniform standards. Strong differences across cantons exist also with respect to the legal status of palliative care. While 6 of 26 Swiss cantons do not provide any legal basis for palliative care others mention palliative care as an aspect of public health (e.g. Vaud), or as a patient's right (e.g. Lucerne) [16]. Obviously the legal framing of palliative care affects its development and implementation in the cantons: a legal basis expresses a public interest of the legislative body and empowers cantonal health authorities to take action for installing a comprehensive palliative care system. Of course, measures can also be taken without a legal basis, but a cantonal legislation expresses the officially recognized value of palliative care^{2,3}.

Starting from the profound lack of information and knowledge about FPs as important actors in CBPC, this article aims to highlight some of the specific conditions and challenges for the provision of palliative home care by FPs in Switzerland.

Methods

The empirical study has been conducted by the University of Applied Sciences Northwestern Switzerland, School of Applied Psychology, in collaboration with the University of Basel, the University of Lugano and the University of Applied Sciences and Arts Western Switzerland. In order to identify the backing of FPs services in palliative home care in more depth, the analysis focuses on 3 selected cantons, namely Lucerne (LU), Vaud (VD), and Ticino (TI), which do not only represent French, Italian and German speaking regions in Switzerland but differ considerably with respect to the history of implementing palliative care. Within these cantons most important supply structures for FPs palliative home care services, as they have been used in the course of first general evaluations of palliative care on national level [13], were surveyed. These were defined as a) the availability of guidelines and recommendations for FPs, b) provisional structures in CBPC (such as mobile palliative care teams, ambulatories as well as the number of specialized FPs and nurses), c) the availability of training and further education for FPs, and finally d) the financial backing of FPs services.

In the course of the 3 cantonal case studies a data set has been generated on the basis of (a) documents about health care policies and provisional structures in CBPC⁴, and (b) 10 expert interviews with 7 FPs, 2 nurses and a project leader of a cantonal palliative care project,

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⁴ As numerous documents have been used for the analysis, it is not possible to list all of them. For each canton all the available documents on palliative care have been looked at, as e.g. "Inventaire données sur les soins palliatifs" for the canton Vaud, "Detail Konzept Palliative Care" for the canton Lucerne, and "Rapport Annuelle" for the canton Ticino.

1)	How do you evaluate the conditions for FPs providing palliative care in your canton? Please answer with respect to the following aspects: <ol style="list-style-type: none">degree of information among population on the provision of palliative caredegree of information among FPs regarding medico-ethical guidelines and advanced directives, as well as regarding aspects of palliative medicinearea of coverage and the quality of community based palliative care structures (especially at home)area coverage and quality of specialized palliative care structures / offers (in clinics, nursing homes, and hospices)financing of palliative care provided by FPspossibilities of education and training for FPs and community nurses in the domain of palliative medicinecollaboration between FPs and specialized physicians as well as with institutions of specialized palliative careattitude towards palliative care among the (regional) population (e.g. favourable or negative)Is there a region/a community in your canton, where no/nearly no palliative care is provided (This questions has only been put to cantonal representatives)
2)	Which are the specific challenges/problems for FPs in Switzerland resp. in your canton in community based palliative care?
3)	Which measures can be taken in order to strengthen FPs in the domain of palliative care in Switzerland resp. your canton?

Table 1: Items of the questionnaire.

all of them providing expert knowledge in the field of palliative care. Further (c), data were generated by a semi-standardized questionnaire with open questions for 15 representatives of national and cantonal health care services and policy actors (for items see table 1). all participants got the same questionnaire, but as questions were open, different qualitative data could be gathered.

The questionnaire started from core issues concerning supply structures and asked for a general evaluation of the status quo, while the interview guideline for experienced FPs and nurses concentrated on supply structures, as well as requirements and challenges in palliative home care. Interview guidelines and questionnaires were agreed on by a supervisory board and translated in three languages (French, Italian, German). Collection of data was conducted from February till June 2013. Within and between cantons documents, questionnaires and expert interviews got analyzed thematically with the help of content-analysis [17]. This is an interpretative technique which allows the identification of key issues within text material on the basis of a systematic and controlled reduction and abstraction. Smallest text units got paraphrased, generalized and integrated into core statements in orientation at the above mentioned questions of our study.

Results and Discussion

Low distribution of guidelines and advance directives

Ethical guidelines, professional rules of conduct and standards are known as practical aids for health care professionals making difficult treatment decisions. They aim on assuring an appropriate allocation of medical and nursing care and foster ethical competence among health professionals [18]. Especially advance directives can influence decision-making at the end of life, when eschewing certain medical interventions for FPs [19]. The revised Swiss Civil Code confers a legal status to these instruments from 2013 on [20]⁵.

As our analysis shows, the availability and visibility of

⁵ According to Swiss law physicians have to follow advance directives of patients and the order of possible representatives since January 2013.

guidelines is still rather small for FPs, who report to be rather rarely informed, especially in the French and Italian part of Switzerland. Correspondingly, also the application of guidelines is described as rather rare. Especially the older generation of FPs relies primarily on professional experience, while they assess the practical use of guidelines rather critically. Challenges exist also with respect to the implementation of advance directives in CBPC: information about this tool seems not only low among Swiss citizens [14], but also among FPs as CBPC providers. Neither FPs in the Ticino (TI) nor in Vaud (VD) report a high visibility of advance directives: Quite contrary, the frequency of using advance directives is described as low, even in hospitals. The small degree of implementation seems to explain, why respondents in French and Italian speaking Switzerland report, that advance directives are rarely used. Or, as an expert from canton Vaud (VD) explains: "Advance directives are a problem. Generally FPs are uneasy about them". However, in the German speaking part of Switzerland advance directives seem to be more popular: "What the patient has written in his/her living will is an important guideline for us", claims a FP from Lucerne (LU). The results of the present study reaffirm statements from other publications in Switzerland, where regional differences regarding the dissemination of and dealing with advance directives are described as strong [14,21].

Provisional structures

Marginal supply of FPs by ambulant care structures

To be able to guarantee an extensive palliative service system and to meet the needs of all patients, FPs rely on support by ambulatory and further supporting provisional structures, such as mobile palliative care teams (MPCTs) or specialized nurses [22]. Yet, these supply structures differ strongly across Switzerland: Cantonal health offices evaluate the ambulatory provisional structures in palliative care still as insufficient and provided by too many different actors. Better conditions exist with respect to palliative ambulatories, which are often provided by hospitals. Ambulatory services are provided in several cantons (e.g. Ticino), whereas other regions do not provide palliative ambulatories at all (e.g. Basel or Valais) [15].

The different situation of palliative care in the three Swiss cantons studied here is inter alia attributable to the specific history of its implementation. Switzerland constitutes an intersection of different national European influences, which find their expression in different regional developments. As for Ticino the development of palliative care started already in the late 1980ies: First offers developed in PC concerned palliative home care service, a tradition that seems to contribute to a rather good standing of CBPC in this canton. In canton Vaud (VD) PC started with the foundation of stationary services in 1988; today this canton provides very good specialized PC, and since 2003 also an extensive offer of MPCTs has been realized [12]. In the German speaking canton Lucerne (LU) the implementation of PC started during the last decade: up till today it offers only a poor degree of specialized care in clinics, nursing homes, or hospices, and a rather weak offer with respect to CBPC services [23].

Besides cantonal differences considerable divides exist along urban and rural areas with respect to the provision of PC structures. This applies especially to the canton Lucerne (LU), which is generally worse supplied than the two other cantons. However, experts claim noticeable changes within the last few years: even if in some regions only weakly developed CBPC structures are offered, the positive impact of the Swiss national promotion program for PC starting 2010 [13] can be registered almost everywhere.

Lack of coordination between palliative care services

Well managed and integrated health care services are essential, if efficiency and cost-control, as well as high quality of care for patients shall be achieved [24]. While in the canton Lucerne (LU) support and resources for CBPC as well as specialized care is very rare, the canton Ticino (TI) apparently can rely on good coordination between different actors of primary and specialized palliative care. In the canton Vaud (VD) palliative care supply structures are provided comparatively well, while they are not very well coordinated with the field of CBPC. The case of Vaud shows that even well-established provisional structures in palliative care do not necessarily guarantee well-coordinated health care services. As experts from Vaud (VD) report, the knowledge about MPCTs in general practice is still small, and the division of labor between FPs and mobile teams is quite often unclear: "FPs do not necessarily collaborate with mobile palliative care teams or other peer physicians." Also the coordination of services and collaboration between specialists and generalists is poorly developed due to time constraints and professional attitudes; especially the relation between oncologists and FPs seems rather competitive-dialogue between these professionals in the course of treatment and care is still rare.

The lack of coordination between specialized care providers and CBPC is a problem that is widely reported by interviewees. As a FP claims: "You have to put the pieces together; it is not the case that one team is responsible for everything, as for instance in England. Here, palliative care is not that holistic". Also health care representatives estimate a higher degree of inter-professional collaboration between PC providers as highly important.

Limited education and training opportunities

Since 2010 considerable action has been taken in order to integrate palliative care into the medical curriculum [11]: these initiatives include inter alia the distribution of a guideline for further education programs on national level. However, our document analysis shows that the quality of formation in PC remains very heterogeneous between cantons: While in Ticino (TI) and Vaud (VD) it is possible to attend courses at a university level, in Lucerne (LU) education and training opportunities are mainly provided by hospitals, nursing homes, or NGOs such as CARITAS. And even if efforts are made to homogenize the catalogue of competencies on a national level, the quality of competences generated by education programs is rarely checked, e.g. by certification. Due to a lack of formal education, palliative care is widely practiced still rather individually or 'hands on'.

Especially for FPs possibilities to acquire competencies seem very limited. Mainly three constraints are mentioned by our respondents in this context: Firstly and most important, FPs do have very spare time for further education and training in palliative care due to a large number of medical obligations. Secondly, courses in PC are competing with numerous other offers in further education and training, while at the same time credit points gathered in (further) education in PC are comparatively few. Thirdly, the lack of knowledge about palliative care skills does contribute to a lack of recognition of formally acquired competencies. As experts report, some physicians still define palliative care as a rather 'naturally given' human competence, and therefore not an issue of formal learning. In everyday practice experience and 'tacit knowledge' [25] is considered to be mainly transferred by experienced colleagues and in peer intervention - and constructed in opposition to formal educational contents.

Lack of appropriate remuneration

Finally, while specialized palliative care generates hospital charges, palliative home care provided by FPs is poorly financed; parts of their medical PC services are even not represented in the Swiss tariff for medical activities (TARMED). This cut across to the fact that palliative home care activities are very complex and especially time consuming: As it is stated provocatively by a representative of a Swiss professional medical association: “A washing machine repairmen gets better rewarded for home visits than we do”.

Some interviewees interpret the insufficient financial support for palliative care by generalists as resulting from the dominance of an attitude, which associates medical practice primarily with ‘cure’ [26]. Also in primary care the medical approach seems still based on this paradigm of cure, instead promoting patients well-being primarily by care. An FP states: “It is correct to say ‘we try to cure’ and to work curatively, but it should also be okay to say ‘death is part of life’ and there have to be created financial spaces for this last phase of life to be able to provide good palliative care”.

As our data show, FPs services are not remunerated at all if they are related to activities apart from immediate contact to the patient. These activities include the coordination between care providers, such as between home care nurses, volunteers, social services and psychologists, advice and support for relatives, inter-professional dialogue between FPs and specialized doctors in hospitals or private surgery, as well as many other activities. So for example in canton Vaud (VD) services of MPCTs are financed by a cantonal budget, but administrative expenditures to coordinate palliative home care by FPs and other services lack remuneration.

Conclusions

Our data draw a rather bleak picture with respect to the support of FPs palliative home care services in Switzerland today. Though considerable steps towards implementing palliative care have been made in recent years in general [13] conditions for FPs medical services have to get strongly improved.

To begin with, the shortcomings are related to the lack of a unitary development of CBPC in Switzerland, the cantonal different mixture of law and ‘soft law’ in this field, but also to the absence of guidelines directed to FPs in palliative home care, or the lack of visibility of advance directives for this group of professionals. More than that, our findings highlight the cantonal different backing of FPs services by provisional palliative care structures, especially with respect to MPCTs or professional support and collaboration. In all three cantons surveyed here, palliative care structures do not reflect a continuum of specialization, as it is recommended by the European Association for Palliative Care [27]. Especially in Swiss rural areas FPs are acting rather alone and cannot rely on support by a developed palliative care network. Further, our data show considerable challenges related to the use of training and/or further education in palliative care, which varies regionally and across cantons, while at the same time there exists no specific training for generalists. The lack of knowledge and skills on community level constitutes an important barrier to the quality and recognition of palliative care in general. But also the remuneration of FPs services still is far from appropriate and reflects the lack of recognition.

In 2004 the World Health Organization (WHO) claimed, that high quality care at the end of life must be understood as a basic human right [28]. Our study shows that strong efforts have to be made by health

policy on national, cantonal and municipal level, to promote the public understanding and acceptance of palliative care also in Switzerland [9]. Especially the development of CBPC services seems elementary in order to fulfill expectations and wishes of patients, of whom the majority prefers to die at home [7]. FPs are main target groups for political action if accessibility of palliative care for every patient shall be guaranteed. The availability of and information on guidelines and advance directives in general practice, the support of FPs services by ambulant as well as specialized services, and the development of their competencies and skills therefore have to become highest priority in public health policies. And: FPs services in palliative care have to be based on adequate remuneration, in order to allow recognition and implementation throughout Switzerland.

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