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The funding of specialised paediatric palliative care in Switzerland: a conceptualisation and modified Delphi study on obstacles and priorities

Stefan Mitterer[a], Karin Zimmermann[ab], Günther Fink[c], Michael Simon[a], Anne-Kathrin Gerber[a], Eva Bergsträsser[b]

[a] Institute of Nursing Science, Department of Public Health, University of Basel, Basel, Switzerland
[b] Paediatric Palliative Care and Children's Research Center, University Children's Hospital Zurich, Zurich, Switzerland
[c] Swiss Tropical and Public Health Institute, University of Basel, Basel, Switzerland

Summary

BACKGROUND: Effective funding models are key for implementing and sustaining critical care delivery programmes such as specialised paediatric palliative care (SPPC). In Switzerland, funding concerns have frequently been raised as primary barriers to providing SPPC in dedicated settings. However, systematic evidence on existing models of funding as well as primary challenges faced by stakeholders remains scarce.

AIMS: The present study's first aim was to investigate and conceptualise the funding of hospital-based consultative SPPC programmes in Switzerland. Its second aim was to identify obstacles to and priorities for funding these programmes sustainably.

METHODS: A 4-step process, including a document analysis, was used to conceptualise the funding of hospital-based consultative SPPC programmes in Switzerland. In consultation with a purposefully selected panel of experts in the subject, a 3-round modified Delphi study was conducted to identify funding-relevant obstacles and priorities regarding SPPC.

RESULTS: Current funding of hospital-based consultative specialised paediatric palliative care programmes is complex and fragmented, combining funding from public, private and charitable sources. Overall, 21 experts participated in the first round of the modified Delphi study, 19 in round two and 15 in round three. They identified 23 obstacles and 29 priorities. Consensus (>70%) was obtained for 12 obstacles and 22 priorities. The highest level of consensus (>90%) was achieved for three priorities: the development of financing solutions to ensure long-term funding of SPPC programmes; the provision of funding and support for integrated palliative care; and sufficient reimbursement of inpatient service costs in the context of high-deficit palliative care patients.

CONCLUSION: Decision- and policy-makers hoping to further develop and expand SPPC in Switzerland should be aware that current funding models are highly complex and that SPPC funding is impeded by many obstacles. Considering the steadily rising prevalence of children with life-limiting conditions and the proven benefits of SPPC, improvements in funding models are urgently needed to ensure that the needs of this highly vulnerable population are adequately met.

Karin Zimmermann, PhD, RN
Institute of Nursing Science
Department of Public Health
University of Basel
CH-4000 Basel
karin.zimmermann[at]unibas.ch

Introduction

The prevalence of children (aged 0–19 years) with life-limiting conditions has been rising steadily in recent years [1, 2]. Extrapolating from hospital admission data from England [2], an estimated 11,400 such children currently live in Switzerland. However, if more comprehensive data from Germany are applied, this number could be as high as 42,400 [3]. While advances in life-extending medical care and technology can partially explain the steady increase [4, 5], improvements in medical coding practice may also have had an effect [2]. Many of these children and their families can benefit from paediatric palliative care (PPC). Generally, palliative care aims to improve the quality of life of patients with severe health-related suffering across all ages, as well as that of their families and caregivers [6]. As a needs-based approach, PPC includes physical, emotional, social and spiritual elements that continue throughout the patient's life and beyond [6, 7].

Although new paediatric palliative care programmes have been implemented in recent years, nationwide access remains limited in Switzerland [8, 9]. Recognising the complexity of care involved, the Swiss Federal Office of Public Health defines PPC as specialised palliative care [10]. Commonly provided by consultative hospital-based programmes, specialised paediatric palliative care (SPPC) is delivered in dedicated settings, i.e. the team works exclusively in PPC [11]. Ideally, these teams are comprised of physicians, nurses, therapists and other professionals specialised in PPC [11, 12].

Specialised paediatric palliative care offered within a consultative model of care contributes to primary care provision and incorporates elements of medical treatment, care coordination, psychosocial support and other consultative services [13]. Care and support is offered as and where necessary – both in and out of hospitals (mobile services such as home visits), through the phases of palliation, end of life and bereavement to patients, their families, primary care teams and other healthcare professionals [13]. The level of mobile support offered varies between programmes, depending on service mandates and available resources [14]. Additionally, SPPC teams may engage in paediatric palliative care-related education, training and research [13].

Although federal healthcare laws and regulations apply [15, 16] and most cantons have formally recognised the promotion and provision of palliative care [17], specialised paediatric palliative care is currently much less established than adult palliative care [8]. In the context of the Swiss healthcare system's complexity, for which federal and cantonal bodies assume different tasks, ongoing resource shortages are likely to challenge the full provision of SPPC. In the Swiss healthcare system, resources to pay for eligible services, including palliative care, are collected mostly through compulsory insurance premiums and taxes [18]. In addition, patients who use insured services are subject to cost-sharing in the form of deductibles and co-payments [18]. And while patients under the age of 18 are exempt from deductible payments, their families are still liable for co-payments [19].

Activity-based funding is the dominant payment method for reimbursing healthcare providers in Switzerland [18]. While inpatient services are reimbursed via Diagnosis-Related Group (DRG) payments, outpatient medical services are reimbursed via the *tarif médical* (TARMED), a fee-for-service system [18]. Reimbursement of inpatient costs is subject to cost-sharing between cantons (at least 55%) and health insurers (at most 45%) [18]. Under certain circumstances, e.g. when a child has a birth defect, Swiss disability insurance covers part of the related healthcare expenses [20]: it reimburses 80% of inpatient treatment costs, with the canton of residence bearing the remaining 20% [21]. Payments for medical devices and items, laboratory and diagnostic services and medications are specified in standard fee schedules (i.e. so-called *positive lists*) [18]. Although reimbursement via standardised payment systems, e.g. SwissDRG and TARMED, may work well in most healthcare settings, this is not always the case for hospital-based consultative specialised paediatric palliative care programmes. Considering the complexity of these programmes, with care and support provided in various settings and across the phases of palliation, end of life and bereavement, adequate reimbursement of related costs may constitute a major challenge.

Information on models of specialised paediatric palliative care funding and their practical implementation remains scarce. Even in adult palliative care, few studies describe such models [22]. The available evidence suggests both that reimbursement mechanisms tend to undervalue care input and that funding models are often characterised by a combination of public, private and philanthropic funding [22]. However, it has been recognised that analyses of payment and financial strategies based on programme types and funding systems are highly important to this field's progress [23]. Therefore, this study's primary aim was to develop a conceptual model describing the funding of hospital-based consultative specialised paediatric palliative care programmes in Switzerland. Its second aim was to identify obstacles to and priorities for funding these programmes sustainably.

Materials and methods

In this study, two separate methodological approaches were employed to address each of the study's objectives. First, to develop a conceptual model describing the funding of hospital-based consultative SPPC programmes in Switzerland, we followed a 4-step conceptualisation process, including a document analysis. Second, to identify obstacles and priorities regarding SPPC funding, we conducted a 3-round modified Delphi study.

Conceptualisation process

Conceptual models provide visual illustrations of causal linkages (often visualised as arrows) among sets of concepts (often visualised as boxes) believed to relate to particular target points [24, 25]. To conceptualise the funding of hospital-based consultative specialised paediatric palliative care programmes in Switzerland, we used a 4-step process: (1) define a target point, (2) choose a conceptual basis, (3) conduct a literature search and (4) propose a conceptual model [24].

Target point

For this conceptualisation, we decided to set the focus on hospital-based consultative SPPC programmes, as they are a common model for providing paediatric palliative care and have been implemented at several children's hospitals throughout Switzerland [8, 9].

Conceptual basis

Deber et al.'s blended service and funding flow model [26] provided the theoretical basis upon which we conceptualised the funding of hospital-based consultative SPPC programmes in Switzerland. Their model illustrates the complex relationship between provider organisations, service providers, service recipients and third-party payers, all of which are connected by payment and reimbursement structures [26]. To design our model, we focused on assessing the current sources of funding, systems of payment and mechanisms of reimbursement in terms of direct financial flows and funding arrangements.

Document analysis

To explore and describe the funding of Swiss specialised paediatric palliative care programmes, we performed a document analysis. Such analyses are widely used in health policy research to review documents, provide context and supplement other data types [27]. The aim of the document analysis was to identify funding sources, payment systems and reimbursement mechanisms and to uncover areas where challenges to SPPC programmes' funding are encountered.

Due to the limited number of specialised paediatric palliative care-specific documents and the fact that healthcare financing policies do not distinguish between palliative care for children and adults, we widened our search to include documents on the funding of palliative care in general. The READ approach (Ready materials; Extract data; Analyse data; and Distil findings) for document analysis in health policy research provided the necessary methodology for this document analysis [28].

Documents were identified by conducting web searches (Google search engine) for grey literature, browsing for documents on institutions' and non-governmental organisations' web pages and tracking references. The search was conducted in German between 6and 20 August 2021 by the first author (SM) and discussed with two other authors (KZ and EB). Documents about palliative care funding in Switzerland were included if they reported funding sources, payment systems and reimbursement mechanisms and/or areas where challenges to that funding are encountered. To account for the implementation of SwissDRG, documents had to be published in 2012 or later. Documents reporting solely on the funding of non-hospital-based palliative care programmes (e.g. geriatric long-term care, home care agencies) were excluded. Included documents were analysed using qualitative content analysis [27]. Information was coded, summarised and tabulated into three predefined categories: funding sources; payment systems and reimbursement mechanisms; and challenging areas.

Conceptual model

The findings of the document analysis were used to visualise the funding of hospital-based consultative specialised paediatric palliative care programmes in Switzerland. The resulting conceptual model is presented in figure 1.

Modified Delphi study

To identify obstacles and priorities in the funding of Swiss SPPC programmes, we used a 3-round modified Delphi approach [29]. The Delphi technique is a well-established, iterative series of steps to survey experts on a particular issue and develop individual opinions into a group consensus [30–34]. Since its inception in the 1950s, numerous versions of the Delphi technique have been developed, differing mainly in how consensus was reached or measured [35]. In this study, consensus was measured by asking participating experts to indicate their agreement or disagreement with specific statements on a 4-point Likert scale.

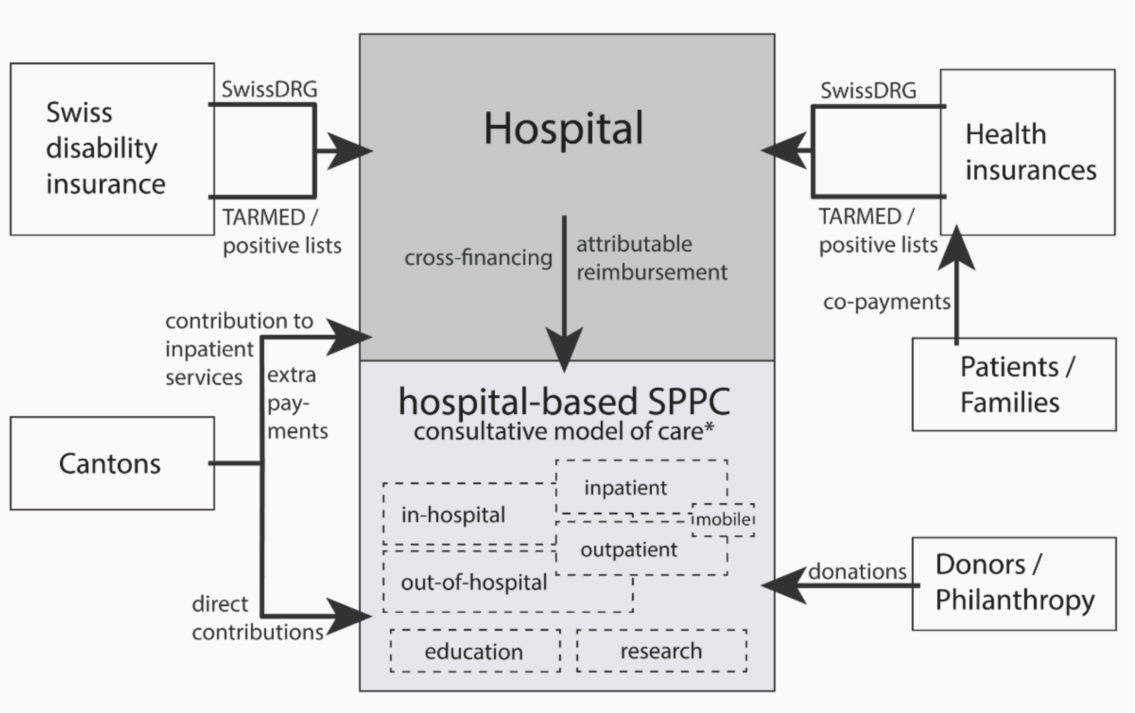
Procedures

Before study start, we purposefully compiled an initial list of experts. We selected potential participants based on two inclusion criteria: either they had professional experience in establishing, managing or leading Swiss SPPC programmes (e.g. programme directors) or they had direct professional knowledge about sources of funding, payment systems or reimbursement mechanisms related to palliative care funding in Switzerland (e.g. researchers, health economists, public health officials, insurance professionals). All eligible experts were first invited via e-mail to participate in this study, then asked to name two to three other experts who might also qualify for participation. The modified Delphi study took place between 23 May and 3 October 2022. Online questionnaires were provided in German via Google Forms. Reminders were sent towards the end of each round.

Round one

All experts who had consented to study participation received a link to an online questionnaire. This asked them to provide minimal demographic data (i.e. profession, affiliation) and, using free-text fields, to list and describe obstacles and priorities regarding SPPC funding. To provide the necessary context for their responses, challenging areas identified via the document analysis were provided. In discussion with two study team members (KZ and EB), the first author (SM) compiled, summarised and merged the

Figure 1: Conceptualisation of direct financial flows and funding arrangements regarding hospital-based consultative specialised paediatric palliative care programmes in Switzerland. * The consultative model of care refers to the provision of medical treatment, care coordination, psychosocial support and other consultative services that contribute to primary care provision. Care and support is provided to families, primary care teams and other professionals in and out of hospitals, i.e. inpatient, outpatient/mobile services. Specialised paediatric palliative care teams may engage in paediatric palliative care-related research and education.



expert's answers into two lists, one of obstacles, the other of priorities.

Round two

In round two, the generated and anonymised lists were sent to everyone who had participated in round one. Experts were encouraged to comment on identified obstacles and priorities, as well as specify any more that might have emerged or occurred to them during the second round. Their answers were again compiled, summarised and merged. The results were used to update the lists of obstacles and priorities.

Round three

To measure consensus, the updated lists were sent to all experts who had participated in the first two rounds. In the third questionnaire, experts were asked to indicate their agreement or disagreement with each identified obstacle and priority on a 4-point Likert scale: strongly agree, agree, disagree, strongly disagree. In cases where participating experts did not feel adequately informed on a topic to indicate agreement or disagreement, they were given the option to answer "Don't know". In addition, each respondent was asked to indicate what they considered the three most pressing obstacles and the three most urgent priorities.

Data analysis

Descriptive statistics (i.e. counts and percentages) were used to provide an overview of the characteristics of participating experts and to analyse consensus. Analyses were performed in Microsoft Excel. The thresholds of consensus vary widely between Delphi studies, with 75% being the median [36]. Considering the diversity of our participants, we chose a slightly lower cut-off, defining consensus as >70% agreement ("Strongly agree" and "Agree").

Ethical considerations

As no health-related personal data were collected, the study was not under the jurisdiction of the Swiss Human Research Act and no ethical approval was obtained.

Results

Document analysis and conceptual model

We included a total of 15 documents in our analysis: 10 reports [8, 9, 14, 16, 17, 37–41], three technical articles [42–44], one directive [45] and one review [46]. Twelve were obtained through web searches and three by backward reference tracking. Only two were paediatric-specific; the other 13 focused on palliative care in general. An overview of included documents is provided as a supplementary resource (see appendix). Figure 1 shows our conceptual model of hospital-based consultative specialised paediatric palliative care programme funding in Switzerland.

Funding sources

Figure 1 illustrates how the Swiss disability insurance fund, health insurance funds, cantons, donors and philanthropists, patients (i.e. their families) and hospitals all hold stakes in the funding of hospital-based consultative specialised paediatric palliative care programmes [8, 9, 14, 16, 17, 41]. Alongside curative and preventive services, compulsory health insurance covers inpatient and outpatient palliative care services, at least partially [16]. Depending on patient characteristics (e.g. age, diagnosis) and service type (e.g. medical aid, treatment), certain costs are reimbursed (partially) either by the Swiss disability insurance fund or by health insurers [14, 16].

In addition to partially reimbursing inpatient service costs and providing financial grants to service providers (e.g. extra payments, deficit coverage), some cantons provide direct financial contributions to fund palliative care [8, 9, 14, 16, 17]. In these cantons, special service mandates with hospitals regulate palliative care provision and related cantonal funding [17]. For instance, the canton of Vaud commissioned a cantonally funded consultative mobile specialised paediatric palliative care programme to provide care in various settings, e.g. hospitals, long-term care institutions, patients' homes [8, 9, 16].

Very limited information is reported about payments made by patients or families (in case of children). Leaving aside their tax payments and insurance premiums, however, they are also involved in the financing of palliative care services through their co-payments [14].

For hospital-based palliative care programmes, hospitals act as both funders and distributors of funds generated through service provision [41], i.e. payments made by the Swiss disability insurance fund, health insurance funds and cantons are collected at the hospital level and distributed under the sovereignty of the hospital [41]. Our document analysis showed budget deficits of palliative care programmes had to be either cross-financed by their operating hospitals [37, 46] or covered by donations and philanthropic contributions [8, 17, 37, 46].

Payment systems and reimbursement mechanisms

In terms of the payment systems and reimbursement mechanisms outlined in figure 1, the reviewed documents primarily reported on SwissDRG and TARMED. The responsibility for further developing, adjusting and maintaining the SwissDRG system belongs to SwissDRG AG, a non-profit public organisation and joint institution of healthcare provider associations, health insurers and cantons [42]. Within the National Strategy for Palliative Care 2010–2015 [40], SwissDRG AG was commissioned to develop a national tariff structure for reimbursing inpatient palliative care services [42]. Via a multiyear process, they developed Swiss Classification of Operations (CHOP) codes for palliative care procedures [16, 41–43, 46]. In this context, to ensure uniform, high-quality service provision, minimum structural and personnel requirements were set as performance criteria [16, 41–43]. Only when these criteria are met can a hospital code and bill for the associated palliative care procedure codes [41, 42].

Despite these provisions, analyses showed that certain characteristics of palliative care patients were not being considered optimally regarding reimbursement [42]. For instance, in terms of length of stay, treatment costs and number of hospitalisations, palliative care patients differed significantly from other patients in the same DRGs [42]. Therefore, SwissDRG AG conducted a fundamental "grouper" restructuring and classified palliative care as a pre-Major Diagnostic Category [9, 16, 42]. By the end of 2016, palliative care had been allocated a separate diagnosis group – one independent of the patient's main diagnosis, with its own DRG codes (codes A97A–G) – defined in terms of medical treatment, procedure, length of stay and other criteria [42–44]. Concerns about adverse incentives regarding inappropriately shortened hospital stays were addressed by a two-pronged strategy: on the one hand, additional payments were allowed for extended hospitalisations [45]; on the other, case consolidations were prevented by recognising readmissions as new, separate hospitalisations [16, 43].

Outpatient medical palliative care services are reimbursed on a fee-for-service basis via TARMED [14, 41]. Services listed in this tariff structure are covered by compulsory healthcare insurance. However, our document analysis suggests that certain palliative care services, e.g. care coordination and case management, are not fully reimbursable via TARMED [16, 41]. Alongside TARMED, standard fee schedules – positive lists – regulate and ensure the reimbursement of diagnostic and laboratory services, medical devices and items, medications and other expenses (e.g. therapies) [16]. Our document analysis also drew our attention to essential palliative care services, including support and relief for relatives and social counselling, that were not covered by formal payers [14, 16, 41]. Instead, these services must be financed by public service contracts, grants, donations or cross-financing [14].

Challenging areas

The reviewed documents indicate that funding challenges are a major barrier to the implementation, sustainability and further development of specialised paediatric palliative care programmes [8, 40]. Difficulties attached to charging for services/covering costs lead to deficits and funding gaps [8, 9, 17, 46]. Areas where funding challenges are encountered include both the SwissDRG and the TARMED system [9, 14, 16, 37, 38, 40, 41, 43, 44]. Our document analysis suggests that variations between cantonal funding regulations hinder the provision of inter-cantonal mobile palliative care services [17, 37, 40]. In addition, dependencies on external funding (e.g. donations, philanthropic contributions) pose a risk to long-term financial stability [17, 41].

Modified Delphi study

Thirty-one experts were invited for study participation, of whom 22 had been purposefully identified by the study team and 9 recommended by initially contacted experts. Overall, 21 experts participated in the first Delphi round (68% response rate), 19 in the second (10% dropout rate) and 15 in the third (21% dropout rate). Demographic characteristics of the original 21 participating experts are presented in table 1. The participants were mostly female (n = 11, 52%), aged 50–69 years (n = 11, 52%) and working in (university) hospitals, clinics or other healthcare providers (n = 14, 67%). Ten (48%) worked in medical/clinical professions, including specialised paediatric palliative care programme leadership.

At the end of round one, one list each of obstacles (n = 22) and priorities (n = 28) regarding the funding of specialised paediatric palliative care programmes was generated. After additional obstacles and priorities suggested in round two, round three began with lists of 23 obstacles and 29 priorities. Obstacles and priorities were grouped inductively into six categories: (1) Political and structural, (2) Funding and tariff structures in general, (3) Inpatient tariff structures, (4) Outpatient tariff structures, (5) Mobile palliative care and (6) Other. All identified obstacles and priorities are presented in tables 2 and 3 respectively.

Obstacles

Using our predefined consensus definition of >70% of experts either strongly agreeing or agreeing (level of agreement), consensus was obtained on 12 of the 23 identified obstacles. A level of agreement of >85% was obtained for four obstacles: "Absence of a holistic health policy approach", "Cantonal differences in service mandates and cost coverage", "Lack of palliative care-specific reimbursement codes in outpatient tariff structures" and "Existent consultation time limitations in the reimbursement of certain palliative care outpatient services in TARMED". Zero disagreement was recorded regarding difficulties arising from cantonal differences in palliative care service mandates and cost coverage. The distribution of the level of agreement of identified obstacles is shown in figure 2.

Asked to indicate the three most pressing obstacles, participating experts indicated 18 obstacles as most pressing at least once. The obstacle most frequently named – six times – was "Absence of a holistic health policy approach". "Fragmentation of palliative care funding" and "Lack of guaranteed funding for developing and implementing new specialised paediatric palliative care programmes" were indicated four times each. Obstacles indicated as one of the most pressing fell predominantly within the political and structural category (table 2).

Table 1:
Demographic characteristics of participating experts.

Characteristics		**Experts, n = 21**
Sex, nº (%)	Female	11 (52%)
	Male	10 (48%)
Age, nº (%)	30–49	10 (48%)
	50–69	11 (52%)
Primary profession, nº (%)	Medical, clinical, specialised paediatric palliative care programme leadership	10 (48%)
	Health policy, health economics, public health	5 (24%)
	Specialist in medical coding, payment systems, service reimbursement	4 (19%)
	Research	2 (10%)
Primary place of employment, nº (%)	(University) hospital, clinic, healthcare provider	14 (67%)
	Federal office, (semi-)governmental organisation	3 (14%)
	Association (e.g. hospital / insurance association)	2 (10%)
	Other	2 (10%)

Priorities

A level of agreement >70% was measured for 22 of the 29 identified priorities. Three priorities had consensus rates of >90%: “The development of financing solutions to ensure the long-term funding of specialised paediatric palliative care programmes”, “The provision of funding and support for integrated palliative care programmes” and “Sufficient reimbursement of inpatient service costs in the context of high-deficit palliative care cases”. Zero disagreement was recorded for two priorities: “Establishing a valid nationwide database on palliative care provision and offering funding and support for integrated palliative care programmes, well-performing treatment pathways” and “Closer cooperation and coordination among service providers”. The distribution of agreement levels of identified priorities is shown in figure 3.

When asked to indicate what they considered the three most urgent priorities, participating experts noted a wide range of priorities (n = 20). Most experts’ top priorities fall within the political and structural category: “Inter-cantonal harmonisation of palliative care regulations” was indicated five times; “Development of financing solution to ensure long-term funding of specialised paediatric palliative care services”, “Legislative integration of palliative care” and “Financing and support of integrated palliative care programmes” were indicated four times each. Additionally, experts indicated four times that they considered the establishment of a valid nationwide database on palliative care provision one of the most urgent priorities (table 3).

Discussion

Our conceptualisation of the funding of hospital-based consultative specialised paediatric palliative care programmes in Switzerland (figure 1) shows that funding flows and financial arrangements surrounding the provision of SPPC are highly fragmented. In many cases, donations and philanthropic contributions are required to supplement funding from formal structures. Several obstacles impede the funding of SPPC. Overall, our modified Delphi study identified 23 obstacles and 29 priorities regarding SPPC funding. Consensus was reached on 12 of the obstacles and 22 of the priorities. The large numbers of both identified obstacles and priorities are notable, as both lists are samples of issues encountered in the funding of hospital-based consultative SPPC programmes. The contributing experts considered many of both lists as very pressing, suggesting that, while no single specific obstacle or priori-

Table 2:
List of obstacles encountered in the funding of specialised paediatric palliative care, sorted by category and most-to-least pressing.

Category	Obstacles encountered in the funding of specialised paediatric palliative care	Most-to-least pressing
Political and structural	1. No holistic health policy approach to the financing and funding of palliative care*	6×
	2. Fragmentation of palliative care* funding rendering the establishment and maintenance of integrated and well-performing treatment pathways more difficult	4×
	3. Lack of guaranteed funding to develop and implement specialised paediatric palliative care programms	4×
	4. Lack of legal definition of palliative care* (e.g. services, providers and funding needed to meet patients' palliative care*demand)	3×
	5. Dependency on charitable funding, compromising long-term continuity and sustainability of specialised paediatric palliative care programmes	2×
	6. Cantonal differences regarding palliative care* service mandates and cost coverage (e.g. financial contributions, coverage of residual costs)	1×
Funding and tariff structures in general	7. Gaps in palliative care* funding when patients transition between care settings (e.g. inpatient, outpatient, home, rehabilitation)	3×
	8. Insufficient compensation, billing limitations and lack of tariffs regarding certain palliative care* services (e.g. roundtable meetings, case management, care coordination, support for relatives)	2×
	9. Patient classification and reimbursement difficulties arising from existing tariff structures that fail to recognise the heterogeneity, multimorbidity and complexity of the palliative care* population	–
Inpatient tariff structures	10. Insufficient reimbursement of inpatient service costs in the context of hight-deficit palliative care* cases or palliative care* patients with complex case constellations (i.e. high-deficit outliers)	1×
	11. Difficulties in meeting the minimum criteria required for the palliative care Complex Codes of the Swiss Classification of Operations (CHOPs)	1×
	12. Funding challenges due to gaps between remuneration and hospital operating costs in view of above-average operating costs, non-optimised processes, low base rates or gaps in tariff structures	–
Outpatient tariff structures	13. Lack of palliative care*-specific reimbursement codes in outpatient tariff structures	2×
	14. No reimbursement of bereavement support services or follow-up home visites to bereaved families and caregivers	2×
	15. Time limitations in the reimbursement of outpatient palliative care* services (i.e. consultation time limits in TARMED for cases not reimbursed via the Swiss disability, accident or military social insurance funds)	–
	16. Lack of clarity on whether TARDOC, as a potential successor of TARMED, will improve palliative care* service reimbursement (TARDOC contains tariff positions for palliative care services provided by general practitioners and paediatricians)	–
Mobile palliative care	17. Difficulties in funding mobile palliative care* services, particularly non-direct patient services (e.g. care coordination, consultations with other healthcare professionals)	3×
Other	18. Lack of financial support and relief for families and informal caregivers	3×
	19. Challenges to palliative care* service reimbursement in long-term and home-care settings	2×
	20. Inconsistent definitions of palliative care cases and populations (e.g. neonates, children, adolescents, adults, elderly) in discussions of funding issues	1×
	21. Lack of educational and training opportunities in specialised paediatric palliative care	1×
	22. Insufficient evidence on specialised paediatric palliative care's (cost-)effectiveness in the Swiss setting	1×
	23. Lack of national regulations about the inclusion, status and funding of (paediatric) hospices	–

CHOP = Schweizerische Operationsklassifikation.

*including but not limited to specialised paediatric palliative care ty emerged as most important, a set of each require urgent action.

This study’s findings also bolster the results of a previous investigation on funding models in palliative care [22]. It was shown that a high degree of fragmentation in funding sources can increase administrative complexities and create ambiguity in responsibilities [22]. The fragmentation in funding sources, payment systems and reimbursement mechanisms has several important implications for the development, implementation and sustainability of specialised paediatric palliative care programmes.

First, high levels of administrative complexity associated with SPPC funding are likely to hinder the development and implementation of new SPPC programmes and may, at least partially, explain why nationwide coverage of SPPC has not yet been achieved in Switzerland [8, 9]. Stable funding, with a streamlined system of payment and reimbursement, may greatly facilitate the establishment of new programmes [47].

Second, reliance on annual grants to cover operating costs can actually endanger a programme’s long-term survival. For example, as both charitable foundations’ and cantonal governments’ budgets can freeze or dry up, dependence on

Table 3:
List of priorities in the funding of specialised paediatric palliative care, sorted by category and most-to-least urgent.

Category	Priorities in the funding of specialised paediatric palliative care	Most-to-least urgent
Political and structural	1. Harmonisation of palliative care* regulations (e.g. service mandates, financing) and closer inter-cantonal cooperation and coordination in palliative care* provision	5×
	2. Funding and support for integrated palliative care* programmes, well-performing treatment pathways and closer cooperation and coordination among service providers	4×
	3. Development of specific, feasible and viable funding solutions to ensure long-term funding of specialised paediatric palliative care programmes	4×
	4. Legislative integration of palliative care* into the Swiss Federal Health Insurance Act (KVG) and the Swiss Health Care Benefits Ordinance (KLV)	4×
	5. Initiation of a nationwide working group (including decision-making bodies) for securing long-term funding in specialised paediatric palliative care	3×
	6. Provision of financial resources (initial funding, core funding) to establish specialised paediatric palliative care programmes and facilitate nationwide coverage	2×
	7. Comprehensive analysis of palliative care* demand, supply and funding, including the identification and disclosure of potential gaps	2×
	8. Establishment of a legal framework for the reimbursement of consultative palliative care* services	1×
Funding and tariff structures in general	9. Amendment of palliative care* services (including psychosocial, spiritual services) as standard benefits in the Swiss Statutory Health Insurance (OKP) scheme	1×
	10. Clarification of open questions regarding the reimbursement of palliative care* services provided when patients transition between care settings (e.g. inpatient, outpatient, home, rehabilitation)	1×
	11. Revision, further development and supplementation of services provided in the patient’s absence in established tariff structures (e.g. interprofessional meetings, case management, care coordination)	–
	12. A comprehensive, palliative care-specific revision of payment systems and reimbursement mechanisms to improve palliative care* funding conditions in the medium term	–
	13. A flexible application of tariff rules, explicitly approved by formal payers, to improve palliative care* funding conditions in the short term (e.g. via analogous positions)	–
Inpatient tariff structures	14. Sufficient reimbursement of inpatient service costs in the context of high-deficit palliative care* cases or palliative care* patients with complex case constellations (i.e. high-deficit outliers)	1×
	15. Assuring the quality of data supplied by service providers to SwissDRG AG (when adequate data becomes available, palliative care* patient and service classification improvements in inpatient tariff structures can be realised through system maintenance)	–
	16. Broader application of palliative care DRG complex codes through the respective certification (quality label) of specialised paediatric palliative care programmes	–
	17. Consideration of structural factors not currently considered regarding SwissDRG at the hospital and patient level in setting base rates	–
Outpatient tariff structures	18. Sufficient, cost-covering reimbursement of outpatient palliative care* services (e.g. interprofessional meetings, travel time for home visits)	2×
	19. Reduction of quantity and time limitations in the reimbursement of outpatient palliative care* services (e.g. reduction of consultation time limits in TARMED)	2×
	20. Introduction of palliative care*-specific counselling and coordination fees in outpatient tariff structures (i.e. tariff codes for palliative care* case management)	1×
	21. Reimbursement for bereavement support services provided to families and caregivers	1×
Mobile palliative care	22. Establishment of mobile palliative care* funding regulations in all cantons	–
	23. Funding of mobile palliative care* services based on the area’s palliative care* demand, not contingent on fluctuating case numbers	–
Other	24. Establishment of a valid nationwide database on palliative care* provision, in coordination with the *Spitalstationäre Gesundheitsversorgung* (SpiGes) project of the Federal Office of Public Health and the Federal Statistical Office	4×
	25. Financial support/relief for palliative care* patients’ families and informal caregivers	3×
	26. Development of educational and training opportunities in the field of palliative care* (including medical curricula)	2×
	27. Facilitation of research on specialised paediatric palliative care's (cost-)effeciveness	1×
	28. Furthering knowledge and understanding of tariff structures to optimise the coding and billing of palliative care*services	1×
	29. Ensuring cost-covering financing of palliative care* services in non-hospital settings (e.g. hospices, psychiatric clinics, long-term institutions)	–

KVG: Bundesgesetz über die Krankenversicherung; KLV: Krankenpflege-Leistungsverordnung; OKP: Obligatorische Krankenpflegeversicherung; DRG: Diagnosis-Related Groups.

*including but not limited to specialised paediatric palliative care either can pose serious risks to the long-term sustainability of SPPC programmes.

Figure 2: Distribution of the level of agreement of identified obstacles encountered in specialised paediatric palliative care funding in Switzerland, sorted by level of agreement. Obstacle numbers refer to the numbered obstacles provided in table 2. PC: palliative care.

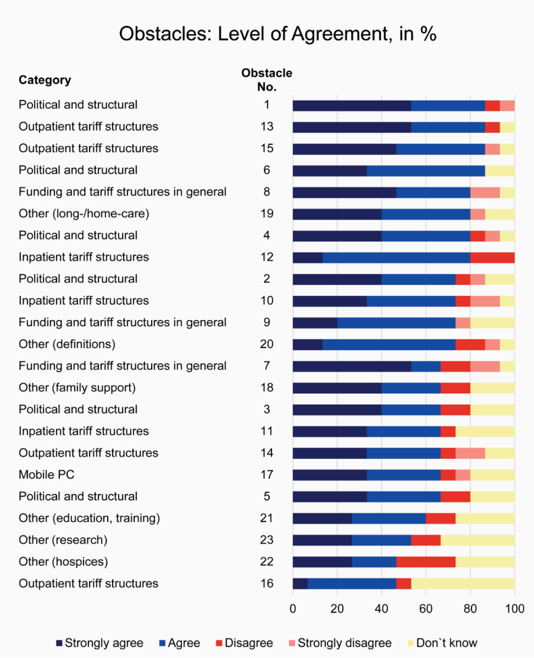
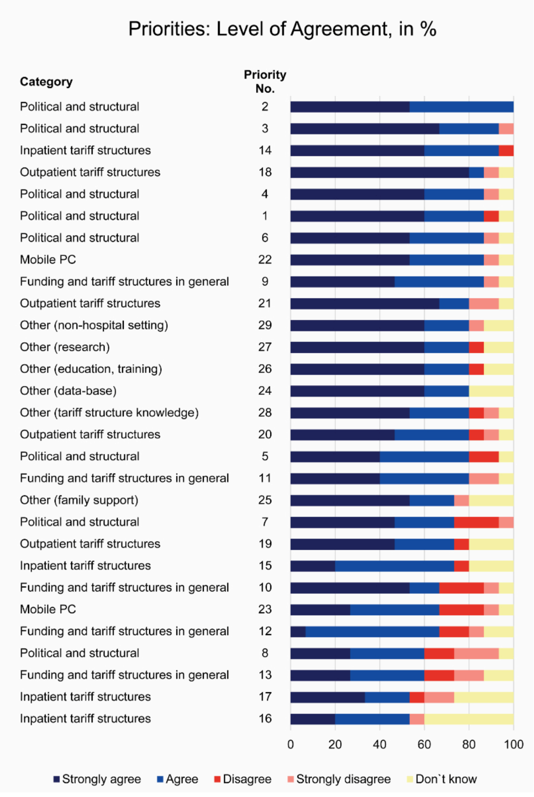


Figure 3: Distribution of the level of agreement of identified priorities for specialised paediatric palliative care funding in Switzerland, sorted by level of agreement. Priority numbers refer to the numbered priorities provided in table 3. PC: palliative care.



Third, fragmentation and complexity in funding of specialised paediatric palliative care programmes may make it more difficult to estimate how and where funding sources, payment systems and reimbursement mechanisms act as policy levers. Palliative care funding has recently become the focus of growing political attention in Switzerland [41]. In June 2021, parliamentary motion n° 20.4264 on palliative care financing was passed, instructing the Federal Council to establish a statutory basis to guarantee needs-based palliative and end-of-life treatment and care for all people [48].

Politically and structurally, the findings of our modified Delphi study suggest that further legislative integration and specification regarding palliative care funding is needed. Parliamentary motion n° 20.4264 [48] provides a unique opportunity to clarify open legal questions. Moreover, participating experts agreed that a nationwide working group should initiate work on securing long-term funding for SPPC. When executing parliamentary motion n° 20.4264 [48], the Federal Office of Public Health established two dedicated working groups: one for palliative care supply and demand, the other for palliative care financing. Ideally, these groups will commission a comprehensive analysis of SPPC demand, supply and funding. In addition to identifying potential gaps in SPPC supply, such an analysis would facilitate development of viable long-term funding solutions.

Additionally, experts participating in our modified Delphi study agreed that differences in service mandates and funding regulations among Swiss cantons are an obstacle. Although most cantons have established legislation to promote palliative care [17], the details of these measures are rather heterogenous. Therefore, even though tailored canton-level solutions for specialised paediatric palliative care funding may provide flexibility in establishing new programmes, local differences may hamper the provision of inter-cantonal SPPC services (e.g. mobile SPPC teams).

Our findings also indicate that charitable sources contribute disproportionately to the current funding of hospital-based consultative specialised paediatric palliative care programmes in Switzerland: a recent report suggests that donations and philanthropic contributions cover up to 50% of annual SPPC programme budgets [8]. In our study, participating experts warned that reliance on donations and philanthropic contributions compromises long-term continuity and sustainability.

Regarding inpatient tariff structures, participating experts agreed that, in the context of high-deficit palliative care cases, i.e. high-deficit outliers, improvements in the reimbursement of inpatient stay costs are required. Generally, compared with the total number of hospitalised patients, high-deficit outliers are a small number of patients that cause a substantial proportion of total inpatient stay costs [49–51]. Considering that specialised paediatric palliative care cases are often highly complex [52], high-deficit outliers can be expected to be more prevalent in this patient population. Sufficient reimbursement of these patients' treatment costs should thus be ensured.

Several obstacles and priorities identified in this study further indicate that certain palliative care activities are reimbursed insufficiently. These include but are not limited to care coordination, case management, consultations of other healthcare professionals and psychosocial and spiritual support. Previous research suggests that insufficient financing mechanisms constrain access to specialised paediatric palliative care [53, 54]. This issue is particularly evident in outpatient palliative care. One identified obstacle is that certain palliative care services are only partially billable, if at all, via outpatient tariff structures. Besides the services outlined above, those provided to family members and other informal caregivers, including psychosocial and bereavement support, are especially prone to reimbursement failures. Related issues regarding these services have also been documented previously [14, 16, 38, 41]. Whether TARDOC, as a potential successor of TARMED, will improve the reimbursement of outpatient services provided by hospital-based consultative SPPC programmes remains unclear.

Strengths and limitations

The conceptual model developed provides a systemic understanding of how hospital-based consultative specialised paediatric palliative care programmes are funded. While informing clinical and administrative leaders regarding the development and implementation of new SPPC programmes, it serves as a point of reference regarding funding issues, e.g. how to address them through policies and regulations. Given that, with high levels of agreement among experts, we have identified a broad spectrum of obstacles, we believe that our findings accurately reflect the issues encountered in SPPC funding. Initiatives aiming to improve SPPC funding models should focus on addressing the priorities identified above.

Several notable limitations affect this study. First, it was not always possible to strictly distinguish between specialised paediatric palliative care and overall palliative care information. Therefore, we included documents on the funding of both SPPC and palliative care in general in our document analysis. Second, several experts participating in the modified Delphi study were experts not in SPPC but in palliative care funding. Third, our approach to conducting the modified Delphi study precluded us from defining the identified obstacles and priorities in greater detail. As a result, a number of obstacles and priorities are stated rather broadly. In addition, as this study aimed to quantify neither funding flows nor the financial impacts of identified obstacles and priorities, we recommend both topics as the subjects of further research. Future research may also explore funding issues in other paediatric palliative care settings, e.g. home care or children's hospices.

Conclusion

Current funding of hospital-based consultative SPPC programmes in Switzerland is highly fragmented and characterised by a complex combination of public, private and charitable funding. With new SPPC programmes currently being developed and implemented, a comprehensive review of current funding structures and actual funding requirements is urgently needed.

We hope that the obstacles and priorities identified in this study will help researchers and policymakers develop funding and reimbursement schemes that will appropriately support specialised paediatric palliative care provision in the future.

Data sharing statement

The data that support the findings of this study are available on request from the first author, stefan.mitterer [at]unibas.ch.

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Potential competing interests
All authors have completed and submitted the International Committee of Medical Journal Editors form for disclosure of potential conflicts of interest. No potential conflict of interest related to the content of this manuscript was disclosed.

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Appendix: Overview of included documents

Type (year)	Publisher; author(s)	Title	Content category		
			Funding sources	**Payment systems and reimbursement mechanisms**	**Areas of challenges**
Report (2020)	Swiss Health Observatory; Peter C., Diebold M., Delgrande Jordan M., Dratva J., Kickbusch I., Stronski S.	Gesundheit in der Schweiz – Kinder, Jugendliche und junge Erwachsene: Nationaler Gesundheitsbericht 2020 [8]	X		X
Report (2020)	Amstad H.	Palliative Care für vulnerable Patientengruppen: Konzept zuhanden der Plattform Palliative Care des Bundesamtes für Gesundheit [9]	X	X	X
Report / Strategy Paper (2012)	Bundesamt für Gesundheit BAG, Schweizerische Konferenz der kantonalen Gesundheitsdirektorinnen und -direktoren GDK	Nationale Strategie Palliative Care 2013–2015: Bilanz «Nationale Strategie Palliative Care 2010–2012» und Handlungsbedarf 2013–2015 [40]			X
Report (2020)	Bundesamt für Gesundheit BAG	Bessere Betreuung und Behandlung von Menschen am Lebensende: Bericht des Bundesrates in Erfüllung des Postulates 18.3384 der Kommission für soziale Sicherheit und Gesundheit des Ständerats (SGK-SR) [41]	X	X	X
Report (2019)	Bundesamts für Gesundheit; Liechti L., Künzi K., Büro für arbeits- und sozialpolitische Studien BASS	Stand und Umsetzung von Palliative Care in den Kantonen: Ergebnisse der Befragung der Kantone und Sektionen von palliative ch 2018 [17]	X		X
Report (2013)	Bundesamt für Gesundheit BAG, Schweizerische Konferenz der kantonalen Gesundheitsdirektorinnen und -direktoren GDK; Furrer M.T., Grünig A., Coppex P.	Finanzierung der Palliative-Care-Leistungen der Grundversorgung und der spezialisierten Palliative Care (ambulante Pflege und Langzeitpflege) [16]	X	X	X
Review (2018)	Gudat H.	Der Wert des Lebensendes: am Beispiel der Finanzierung der stationären spezialisierten Palliative Care in der Schweiz [46]	X	X	X
Directive (2016)	SwissDRG AG	Beschluss des Verwaltungsrats der SwissDRG AG: Abbildung der palliativmedizinischen Behandlung im SwissDRG Tarifsystem [45]		X	
Report (2020)	Degen E., Liebig B., Reeves E., Schweighoffer R.	Palliative Care in der Schweiz: Die Perspektive der Leistungserbringenden [37]	X	X	X
Article (2016)	palliative ch; Schlägel F.	Das SwissDRG-System und die Finanzierung der palliativmedizinischen Versorgung [42]		X	
Article (2016)	palliative ch; Gudat H.	Ist das Vergütungssystem der SwissDRG AG für spezialisierte Palliative Care geeignet? Die Pro-Position [43]		X	X
Article (2016)	palliative ch; Borasio G.D.	Ist das Vergütungssystem der SwissDRG AG für spezialisierte Palliative Care geeignet? Die Kontra-Position [44]		X	X
Report (2014)	Wächter M., Bommer A.	Mobile Palliative-Care-Dienste in der Schweiz - Eine Bestandsaufnahme aus der Perspektive dieser Anbieter [14]	X	X	X
Report (2012)	Bundesamt für Gesundheit BAG, Schweizerische Konferenz der kantonalen Gesundheitsdirektorinnen und -direktoren GDK	Stand und Umsetzung von Palliative Care in den Kantonen Ende 2011 [38]			X
Report (2013)	Bundesamt für Gesundheit BAG, Schweizerische Konferenz der kantonalen Gesundheitsdirektorinnen und -direktoren GDK; Wyss N., Coppex P.	Stand und Umsetzung von Palliative Care in den Kantonen 2013 [39]			X