

Lay Summary

Decision-making Practice at the End of Life.
The Case of General Practice

Project team

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1. Background

Internationally, little is known about the requirements for prudent decision-making practice at the end of life - as a core issue of high quality care for patients. As a complex process, involving different actors in very different, asymmetrical roles, decision making at the end of life still lacks thorough understanding and practical mastering. This holds even more for decision making in *general practice*. Studies report unmet needs of patients and their relatives, as well as of family physicians (FPs), nurses, and other care providers with regard to decision making at the end of life - for Switzerland as elsewhere.

Family physicians (FPs) play a key role in community-based palliative care in many European countries. In palliative home care and in nursing homes FPs not only care for oncological patients, but for patients with terminal organ failures, with degenerative neurologic diseases, or for multi-morbid and/or geriatric patients. 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.

The present study intends to gain more knowledge and understanding in order to support the decision-making practice of FPs at the end of life.

2. Goals of the project

Objective of this project was to identify most important requirements and challenges related to decision-making practices of FPs. Intention was to draw a whole picture of the complex activities and services FPs provide for patients and families at the end of life, and to identify the individual and institutional resources FPs can rely on in care and treatment of patients. Analytically the project set its focus on **4 core elements of decision-making practice in general practice**, analysing

- the meaning and use of normative regulations and guidelines
- communicative and interactive decision-making with patients/relatives
- the collaboration with health professionals and organizations, and
- ethical considerations and reflexivity of FPs.

Further, the project intended to identify the **backing of FPs services** during end-of-life care by analyzing the **support of their activities** by the availability of guidelines and advance directives, provisional structures in primary and specialized palliative care, by education and training opportunities as well as in form of remuneration of their services.

Decision-making practices of FPs are key constituents for the quality of community-based end-of-life care. Based on detailed knowledge and understanding, we intended to provide **recommendations** for the **development and support of FPs services in this field**. These recommendations shall not only empower FPs and collaborating health care professionals, but inform health care policy and associated palliative care services about necessary improvements and potential approaches in fostering community-based palliative care in Switzerland.

3. Methods

Since internationally knowledge is very limited with respect to this field of research, our project had explorative character and focused mainly on the description and understanding of decision-making practices of FPs in community-based end-of-life care (in nursing homes and at home) in 3 selected cantons in the German, French and Italian speaking part of Switzerland, namely Lucerne (LU), Vaud (VD), and Ticino (TI).

Part I (Oct. 2012 – Aug. 2013) of the project focussed on the identification of the legal context and support for FPs in palliative care (PC) on national level as well as in-depth in **the 3 selected Swiss cantons**. Lucerne, Vaud, and Ticino are not only part of the French, Italian and German speaking Switzerland but differ considerably with respect to their history of implementing PC. Within 3 cantonal case studies a data set has been generated

- (a) on the basis of documents on health care policies and provisional structures,
- (b) by a standardized questionnaire with open questions for 16 representatives of national and cantonal health care services, and health policy actors, as well as
- (c) 10 expert interviews with FPs, all of them providing expert knowledge in the field of PC. Within and between cantons documents, questionnaires and expert interviews got analyzed thematically with the help of qualitative content-analysis.

Part II (Sept. 2013 – March 2015) focused on core elements of decision-making practice of FPs in PC: For this purpose 30 guideline-based group discussions with a total of 91 FPs, 72 nurses and 21 relatives of patients, who have received medical services by FPs, have been conducted in cantons LU, VD, and TI. Since relatives' acceptance for participating in group discussions was very low, partly group discussions with relatives had to be substituted by interviews.

After the full transcription of the material, coding procedures oriented at the 'grounded theory' (Glaser/Strauss) and qualitative content-analysis have been chosen for an in-depth analysis of the data. Some of the interpretations have been supported by qualitative analysis software Atlas-ti. Perspectives of FPs, nurses, and relatives have been triangulated selectively, considering specific research questions. After the regional data interpretation on the basis of French, German, or Italian texts, data and codes have also been triangulated across language regions in order to enlarge and validate the findings and emergent theoretical concepts. For triangulations texts have been selectively translated into English.

Part III (Oct 2014-march 2015) was dedicated to the interpretation of data within and across regions, to the writing of texts for publication, and further activities with respect to the transfer of knowledge. Further, **workshops with FPs, nurses and other stakeholders** of the project have been conducted in the three cantons under study. The workshops served not only for the transfer of knowledge but also for the validation of results. Data gathered within workshops got integrated into the interpretation.

4. Results

In order to evaluate the **support and backing of decision-making of FPs** in 3 selected cantons (LU, VD, TI), we oriented our analysis at four fields of action, which have been defined as most important in the National Strategy for PC 2010-2012. Measured against these fields of action our results illustrate considerable shortcomings with respect to currently available **support structures** for FPs.

- **Availability of guidelines and advance directives (ADs):** Ethical guidelines, standards, rules of conduct are practical aids for health care professionals making difficult decisions. As our analysis shows, the **availability, visibility and use of guidelines** in general practice is still rather small, especially in the French and Italian part of Switzerland. And while the Civil Code confers a legal status to advance directives (ADs) from 2013 on (art. 370 CC), cantonal experts consider the information level of FPs about ADs as rather limited.
- **Provisional structures:** Due to the Swiss federal structure the support of FPs services by specialized and ambulant support structures in PC varies considerably between cantons and can still be considered as insufficient. Further, large differences exist with respect to support structures for FPs between urban and rural areas, with rural areas badly supplied. While in the canton Lucerne FPs get scarcely supported by a PC network, the canton Ticino apparently offers good coordination between different actors in the field (such as FPs and MPCTs). In the canton Vaud PC structures generally are comparatively well established, while experts estimate them as not very well coordinated with FPs.
- **Education and training:** Possibilities to acquire competencies by education and training are insufficiently developed according to our document analysis and to expert opinion. Though a guideline for further education programs exists on national level, the quality of formation is not checked (e.g. by certification) and remains very heterogeneous between cantons: E.g. in Ticino and Vaud it is possible to attend courses at a university level (resp. university of applied sciences), whereas in other cantons (e.g. Lucerne) education and training opportunities are mainly provided by hospitals, associations or NGOs such as CARITAS.
- **Remuneration:** Also financially community-based PC by FPs (including the coordination of actors in health care) is not highly rewarded: important services of FPs are represented in TARMED with a very short time limit or not remunerated at all, if they happen in the absence of patients or relatives.

Our study shows that strong efforts have to be made by health policy on cantonal and municipal level, to guarantee the availability of and information on guidelines and ADs, the support of FPs services in PC by ambulant as well as specialized PC services, and the development of their competencies. FPs services in PC have to be based on adequate remuneration, in order to allow recognition and implementation throughout Switzerland.

Results II: Core Elements of decision-making of FPs

As our explorative data illustrate, that **decision-making of FPs in PC** most often concerns questions related to the transition of patients from home to the hospital, the prescription and dosage of drugs and – more rarely - the interruption of active treatments. Decisions about invasive treatments, such as reanimation maneuverings or artificial nutrition are rarely mentioned, and most of the doctors do signal to patients/families, that assisted suicide is no option for them, and therefore not negotiable.

Based on previous studies on decision-making in PC we conceived four **core elements of decision-making in general practice**: a) the use of guidelines and ADs, b) the communication and shared decision-making of FPs together with patients and relatives, c) FPs collaboration with nurses, hospitals and specialized doctors, and d) the dealing with different values and attitudes at the end of life.

a) Use of guidelines and regulations: The meaning of ‘tacit knowledge’ in PC

Professional experience seems to be highly important when facing the specific demands of decision-making in PC. As implicit knowledge it is confronted with a growing body of formal and explicit normative guidelines and legal regulations, not directly rooted in or linked to medical knowledge. Correspondingly, our data reveal considerable ambivalence in the perception and use of ADs in end-of-life situations. We find three types of perceptions of the usefulness of ADs for decision making: (1) As expected, FPs perceive ADs as a **facilitating tool**. It allows them to make decisions as close as possible to patient’s explicitly stated will (when the patient is conscious through discussion initiated by ADs and when he/she is unconscious through writing directives or through the therapeutic representative). This not only discharges the FP vis-à-vis the patient, but also vis-à-vis the relatives. Accordingly, FPs mention that their decisions are less open to dispute with relatives where ADs exist. (2) Some FPs, on the contrary, think that the formalization of ADs by the Civil Code **does not affect their practices**, because they comply with patient’s will anyway. For them, informal and implicit ways of determining patient’s will are central in managing end-of-life situations, not formalized instruments and paper work. In this category we also find arguments seeing the concrete institutional norms (especially of the nursing homes) as a safeguard for respecting patient’s wishes. (3) The use of ADs also may **make the management of end-of-life situations more difficult**. ADs are perceived as fixed and formal whereas patients may often change their minds. As some elements proposed in ADs are seen as being in the FP’s competencies, ADs may question the medical territory and mislead patients to decide on (technical) objects beyond their (lay) competences.

As we do not find agreement on the instrumental utility of ADs, we also find different opinions about them as a tool for communication and about the relief experienced by the patient in controlling his/her end of life by this legal instrument. Some doctors use ADs to open discussion on patient’s wishes, while others avoid this because they care about ADs cutting the spontaneity of the dialogue with patients. And while some consider ADs as an anxiolytic because allowing patients to talk about end-of-life in a relatively soft way, others perceive fear and anxiety generated by the description of invasive interventions as well as by the complexity inherent in anticipating end-of-life situations.

b) Communication and shared decision-making: The meaning of ‘conversational work’

We found ‘**conversational work**’ in PC to be a highly important means of FPs to evaluate multiple courses of action in the light of clinical data, of fears, desires, and the needs of the patient and by his/her family. The concept describes the ability to explain medical reasons for the proposed actions, calibrating the amount of communicated information and the proper use of language on the base of their long term knowledge about the patient and his/her family. Communication theory describes these processes

as the development of “common grounds”, as conversation in the form of collaborative action. Competences needed to accomplish conversational work seem to be highly rooted in experience.

Further, our research highlighted challenges of **lay-professional communication**, and strategies adopted by FPs to overcome such challenges. Identified challenges reflect some difficulties reported in the literature about end-of-life communication between doctors and patients, including facing denial of the terminal condition from patients and relatives, managing the conflicting desires to sustain hope and to tell the truth, and choosing which role to assume in the conversation with lay interlocutors. However, our study participants reported about **two main strategies adopted by FPs to face challenges in communication**. First, they stress the importance of constructing and maintaining a ‘**communication space**’, namely a space for communication in place, within which patients, relatives and FPs can rely on whenever they need it. Constructing a communication space seems to allow the doctor to understand the patient’s perspective and facilitates shared decision making. Second, our informants underscore the value of **providing information**, as a means to overcome the unescapable distance between lay and professional views. In particular, FPs efforts to provide information relieve patients and relatives from the anxiety provoked by their lay models of knowledge, and help them to accept medical prescriptions aimed at managing symptoms.

c) Collaboration with nurses, specialists and hospitals: Work related disturbances and lack of institutional channels for communication

Our study illustrates a **variety of disturbances** in collaboration between FPs and home care nurses, as well as with care teams in nursing homes. Most prominent factors of conflicts are related to work organization: The **asynchrony of work** of FPs and nurses at the bedside and generally a ‘lack of time for care’ have a major impact on the transfer of information and enforces professionals to rely on written reports or phone calls for collaboration. But also the **ambiguity of responsibilities** in combination with professional rivalries contributes to disturbances of collaboration in PC. FPs quite often **lack strategies to handle leadership** as well as conflicting situations; rather they tend to avoid conflicts what results in a lack of collaboration, small job satisfaction and a reduction of the quality of care.

Also **inter-professional communication** requires specified instruments and expertise, to prevent the **risk of ruptures in the information flow**, which can compromise shared decision making. Our data show that **shared decision-making (SDM)** is highly challenging with respect to **task-related and social aspects in general practice**: Relevant information to make decisions can be fragmented among multiple actors, because PC requires the intervention of a whole network of professional and non-professional care givers. Different actors have partial views and knowledge of the patient, which remain fragmented unless specific communicative practices are implemented. Besides different interpretations of the situation, unclear distribution of responsibilities and a lack of recognition between care providers contribute to conflicting situations, for which FPs have no ‘strategies’ at their disposal. Study participants stress the importance to **further develop information sharing between FPs and other care givers**, namely relatives, volunteers, home and hospital nurses, specialized doctors who work on the territory, and hospital doctors.

Beyond that our data highlight a **lack of institutional channels for inter-professional communication** - this applies firstly for the **communication between FPs and hospitals**: This again is described as main-

ly hindered by features of work organization (e.g. time constraints of FPs to participate in meetings) and the lack of remuneration of FPs. Secondly, barriers of **communication between FPs and specialist** seem caused by different professional visions. The perceived distance between FPs and specialists results in a **breakdown of the information flow**, and – from FPs point of view – in an interruption of the clinical history.

d) Dealing with different values and attitudes at the end of life

Our results show, that the divergence of values between FPs and patients in palliative care situations, can **confront FPs with considerable moral conflicts**, especially when assisted suicide is involved. FPs' personal values and professional experience shape their visions of palliative care, which sometimes is contrary to the patients' views and wishes with respect to the further proceeding. As a consequence FPs find themselves in situations of '**ethical dilemmas**' or '**moral distress**', which can strongly influence the relationship between FP and patient. Our study has identified mainly **three strategies of FPs** to deal with different values: A) if FPs are not able to deal with dilemmas, they tend to draw lines between patient and themselves, which might result into the termination of the relationship. B) FPs also report to adapt themselves emphatically to the patients will. This is mainly due to their respect for the patients' situation; the patient "is on a way" which FPs are not able to follow. This strategy does not endanger the relationship between the FP and the patient, but the moral distress of the treating FP is not necessarily resolved. C) Thirdly, FPs inform the patient about possibilities of further treatment and its consequences, and they inform also about their own personal values and attitudes. This strategy seems to provide a good basis for **negotiation** for FPs and the patient. It enables FPs to overcome their ethical dilemma and achieve shared decision making. However, this strategy depends on a long-lasting relationship with and knowledge about the patient, as well as patients' physical state.

5. Significance of the results for science and practice

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, conditions for FPs medical services have to get strongly improved.

The shortcomings are related to the **lack of a unitary development of community-based palliative care 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. Especially in Swiss rural areas FPs are acting rather alone and cannot rely on support by a developed palliative care network. But also the **remuneration of FPs services** still is far from appropriate and reflects the lack of recognition.

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.

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 in Switzerland. 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. 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.

Education and training of FPs in palliative care is strongly needed: It should include the **practical use of ADs**, including more knowledge about the potential of ADs with respect to their use as a tool in communication in PC situations and - more generally - their implementation in everyday practice of FPs. Also more control of the conditions for the use of ADs is needed (including guidance about the frequency of use, and context descriptions, such as: “the FPs has to see the patient with the relatives 4-5 times”). Education and training of FPs should also include **conversational strategies**, and it should include **meta-communicative** competences. Communication practices of Swiss family doctors could be further strengthened, learning how to recognize **indirect communication** and when to use **meta-communication** in the interaction with patients and their relatives. Due to shortcomings in communication skills many doctors cannot take an active role in end-of-life care yet.

Further, stronger focus on **inter-professional training** of FPs has to be set, which starts already at university level. Strategies and instruments have to be further developed in order to foster knowledge transfer between FDs and other caregivers, namely relatives, paid carers, volunteers, home care and hospital nurses, specialized doctors who work in the community, and hospital doctors. At the same time, a stronger integration of issues of inter-professional collaboration into PC concepts has to be achieved. Most of current concepts and definitions include only implicitly inter-professionalism: they should be more explicit about that topic. Quite basically, the notion of 'leadership' has to be reflected in concepts and the framing of PC home care: FPs do not have to be the case manager, it can as well be the nurse. And FPs have to make use of the competences of MPCTs in order to get advice. Finally, education and training should allow more **self-reflection** with respect to **ethical judgment**, especially when difficult questions - such as assisted suicide - are concerned. The guideline 2004 seems not to provide enough help not to overcome the dilemmas resulting from different views between doctors and patients.