



**Universität  
Basel**

Fakultät für  
Psychologie



# **A Qualitative Investigation of Coordination in Swiss Palliative Services: A Quest for Quality in Care**

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von

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Genehmigt von der Fakultät für Psychologie auf Antrag von

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2. Care coordination in palliative care: Who plays a key role? Reeves, E., Schweighoffer, R., & Liebig, B. *International Journal of Integrated Care*, (In press, 2020).
3. Comparing professional and relatives' perspectives of quality of care in palliative care: A qualitative interview study. Reeves, E., Jermann- Degen, E., & Liebig, B. *Journal of Integrative and Complementary Medicine* (In press, 2020)

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I am very grateful for the financial support for this doctoral project, which, together with my salary, was subsidized by the Swiss National Science Foundation (SNF). Moreover, I would like to express my appreciation to the University of Applied Sciences (Fachhochschule Norwestschweiz, FHNW) and the University of Basel for their collaboration. Their partnership made it possible for me to pursue my doctoral studies and provided me with the human resources necessary to undertake these studies. In the same breath, I extend my gratitude to Professor. Dr. Rolf. Stieglitz from the University of Basel, who kindly agreed to be my second supervisor of my doctoral degree and to take the time to evaluate this summation of my work. I also wish to thank the sounding board members of the NRP-74 project for their constructive feedback to the project, which was instrumental in shaping the development of the project. Likewise, I extend my thanks to the master's students and the other researchers who came on board at different points of the project. Sharing the workload with these individuals made for a better joint effort in obtaining and processing the volume of data needed of the project. A special thanks goes to Mrs. Katharina Stieger- Hoffman, student administrator from the University of Basel. Her assistance and clear guidance during my PhD studies was a great help to me.

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Although few of the participants in my research are likely to read this work, I would like to thank them all. During the interviews, the willingness of health care professionals and relatives of palliative patients to share their knowledge and experience was invaluable to my research. Sharing their stories, witnessing their lives, and recording their experiences has been an honor. I trust that this work has been faithful to them.

## **Personal Motivation for Research**

Asides from my personal quest for knowledge, something I am passionate about, both in research and in life, promoting the provision of high-quality palliative care is a topic I care strongly for. During my Master of Science (MSc) degree at Kings College, London, I had the privilege to work with women with breast cancer during a research project which sought to develop an educational booklet to enhance adherence to a leading breast cancer drug, Tamoxifen. The experiences of these women revealed that in many cases, breast cancer survivors preferred to risk the return of cancer than continue to live with the side effects of the breast cancer drug, despite its acclaimed clinical guarantee to prevent the return of cancer by up to five times. The realization that women would rather accept the prospect of dying of cancer than to living their lives with a reduced quality of living was a shocking revelation to me. My motivation for research is that no individual feels that they must compromise their quality of life, so that despite illness, they might live with the best possible care and conditions. This dissertation represents the pinnacle of my formal education and training and is my final, official contribution to this important field, at present. However, I hope that the presentation of the undertaken research presented will serve as much more than a prerequisite for obtaining an academic degree- but will have lasting, meaningful implications for improving palliative care service provision, for the benefit and well-being of public health today, and in time to come.

***“Palliative care cannot remove the impact of a tragedy, but it can ensure that the patient’s voice is heard, and their needs are addressed” – I Finlay, J R Soc. Med. 2001; 94: 437-44***

## Abstract

Ensuring high quality palliative service provision is of utmost importance. In the dawn of the recent pandemic, effective palliative care services have never been more crucial for the 21<sup>st</sup> century. The relationship between effective care coordination and high-quality palliative care provision is highly recognized in literature and supported by empirical findings. However, good coordination of care proves difficult to provide in the demanding context of palliative care and the care coordination of services are often poorly evaluated. Moreover, little is known about care coordination in palliative care services, whilst even less is understood about care coordination between primary and specialized palliative care services. Specifically, in Switzerland, there is an even deeper need for improving coordination of care as the implementation of palliative care is highly fragmented approaches to palliative care service provision, according to regional and cantonal preferences. Thus, high quality service provision in palliative care in Switzerland cannot be guaranteed.

In view of the state of research in the field, three interrelated qualitative interview studies were carried out to explore aspects of coordination and quality of care in both primary and specialized palliative care settings. All studies are based on qualitative interview data from palliative care professionals in palliative care settings in Switzerland. The third study additionally includes data from relatives of palliative patients. All studies were based on palliative care services in four Swiss cantons: Ticino, Vaud, Luzern and Basel-City. These cantons were selected to reflect the rural and urban regions of Switzerland as well as diversly developed policy contexts for palliative care in Switzerland. The studies not only address existing gaps in literature but are also built upon the findings of each study. This was done to ensure that contemporary issues that were indicated in the data were addressed and that important areas for future research were not overlooked. The first study sought to investigate challenges to coordination between primary and specialized palliative care services in Switzerland. The findings of this study shed light on many important, multifaceted challenges to coordination. Amongst these challenges was apparent confusion concerning professional roles, particularly in the context of primary palliative care services. In response to this finding, the second study sought to build on the findings of the first study by exploring who professionals believe to play a key role in palliative home care. The results from this research strongly demonstrated that there was considerable ambiguity concerning the care coordinator role. Based on these results, and the assumption that clearly designated care coordinators are considered a prerequisite for effective coordination and high quality of care, the last study explored perceptions of quality of care in palliative home care. This was done with consideration of the perspective of palliative relatives, as well as the perspectives of palliative professionals, in order to facilitate a broader understanding of quality in palliative care. All findings of the studies contribute substantially, both independently and collectively, to the state of research in palliative care in Switzerland. Importantly, they indicate specific areas for the improvement for policy, practice and future research in the field of palliative care. This cumulative dissertation summarizes the compilation of the scientific manuscripts that were a result of these studies. The summation of these works is of value to; fellow scientific researchers in the scope of public health, policy- makers and palliative care professionals, as well as family care givers in palliative care contexts.

**Key words:** *primary palliative care; specialized palliative care; family caregivers; care coordination; care coordinators, palliative professionals; quality of care*

## Preface

The presented dissertation is a publication-based dissertation, in line with the regulations of the Faculty of Psychology at the University of Basel. It consists of the three manuscripts, listed below. The first has been published and the other two manuscripts are presently in press at the respective journals. The published article, along with two certificates from the respective journals to confirm the ‘in press’ status of the articles can be found in the appendices section of this work (appendix B).

1. Manuscript 1: Reeves, E., Schweighoffer, R., & Liebig, B. (2020). An investigation of the challenges to coordination at the interface of primary and specialized palliative care services in Switzerland: A qualitative interview study. *Journal of Interprofessional Care*, 1-7.
2. Manuscript 2: Care coordination in palliative care: Who plays a key role? *International Journal of Integrated Care*, (In press, 2020)
3. Manuscript 3: Comparing professional and relatives’ perspectives of quality of care in palliative care: A qualitative interview study. *Journal of Integrative and Complementary Medicine* (In press, 2020)

The following publications were also carried out in relation to the work presented here. They are omitted from this dissertation for the purpose of focus but may be referenced throughout:

1. **Reeves, E.**, Schweighoffer, R., & Liebig, B. (2019). Community readiness for palliative care services in Switzerland: Basis for public health strategy for health psychologists. *Psychreg Journal of Psychology*, 3(2), 94-95.
2. Schweighoffer, R., Nagy, N., **Reeves, E.**, & Liebig, B. (2019). Collaboration in Palliative Care Networks in Urban and Rural Regions of Switzerland. *International Journal of Nursing and Health Science*, 13(1), 18-21.
3. Schweighoffer, R., **Reeves, E.**, & Liebig, B. (2020). Collaborative Networks in Primary and Specialized Palliative Care in Switzerland-Perspectives of Doctors and Nurses. *The Open Public Health Journal*, 13(1).
4. Jermann, E. D., Liebig, B., Schweighoffer, R., & **Reeves, E.** Palliative Care in der Schweiz Die Perspektive der Leistungserbringenden, palliative.ch, (2020).

*Disclaimer:* Formal research approval for all of the studies described in this thesis was obtained from the Ethics Committee of Northwestern Switzerland (EKNZ) on 29 August 2018 (Req-2018-00490). Moreover, there were no conflicts of interest to report.

## The Research Project

This section will offer some background information to the research project that made the research pertaining to this dissertation possible. This foreword is intended to provide some contextual understanding for the manuscripts that are featured in this work, as well as the broader scope of the research that will be discussed.

This doctoral thesis, submitted for partial fulfillment of the requirements of the Doctor of Philosophy (PhD) degree from the University of Basel, Switzerland, presents research pertaining to the field of palliative care that I have undertaken over a period of approximately three years, from June 2017 to April 2020. I began the research for this thesis during my time as an associate researcher within the context of the NRP 74 'Smarter Healthcare' Project entitled: "Coordination and collaboration in palliative care: Palliative Care Networks in Switzerland" (NRP 74, Project ID: 407440\_167345, [www.nrp74.ch](http://www.nrp74.ch)), funded by the Swiss National Science Foundation (SNF). During this post, I was enrolled as a student of doctoral studies in Psychology at the University of Basel, where I completed formal training that was complementary to my field of research or contributory to the development of my research skills. The NRP 74 team of this project was headed up by an expert project lead- Prof. Dr. Brigitte Liebig, from the University of Applied Sciences (FHNW). The team was otherwise made up of two core associate researchers (myself and another PhD student from the University of Basel) and one principal research assistant (a master's student from FHNW) (see appendices for details on the research team). The researchers were specialized in different research backgrounds, namely; qualitative and quantitative research. Occasionally, other collaborators were recruited to the project in order to fulfill various supporting functions of research (e.g. to assist with data collection, data processing or data analysis).

*The motivation for this project* was born out of an evident lack of knowledge concerning interprofessional collaboration and coordination in palliative care in Switzerland and responds to the need for understanding and improving interprofessional collaboration and coordination practices in palliative care, both within palliative services, and especially at the interface of primary and specialized care services in Switzerland. In collaboration with my colleagues involved in this project, under the expert supervision of the project lead, Dr. Prof. Brigitte Liebig, we conducted novel research into a broad range of important and highly relevant aspects of interprofessional collaboration and coordination in palliative care services in Switzerland. The majority of the findings of these research efforts have been presented at national and international scientific conferences and published in scientific journals (please see list in appendices). *The basis of our research* was palliative care services in four diverse regions of Switzerland. These cantons were: Vaud, Ticino, Luzern and Basel- city and they were selected to provide an accurate representation of Switzerland, taking into account their diverse palliative care landscapes. Moreover, since the research team was strategically made up of qualitative and quantitative researchers, the team's approach was to investigate the areas of interest from these different research perspectives and techniques, depending on what was considered the most suitable strategy for the specific area of study. This allowed the researchers to gauge a broad, in-depth understanding of complex phenomena relating to our research project. *My primary personal contribution* to the endeavor was to qualitatively investigate the aspects of palliative care that had previously received limited attention in Switzerland with respect to care coordination and quality of care in palliative care more generally. Specifically, in this dissertation, I present the findings from the empirical research that I conducted and developed into scientific, open access, peer reviewed manuscripts, with the purpose of

educating fellow researchers in the field of health care and informing health care professionals and health policy with respect to palliative care services in Switzerland and more broadly.

## **Personal Contributions to Research**

Over the course of the project, I collaborated with my colleagues on various aspects of research, including; knowledge sharing, contributions to conceptual development of research and collaboration on scientific research papers (see appendix C for list of scientific contributions). However, my specific contributions to the research presented in this dissertation include:

1. Development of study materials, including interview guidelines, informed consent forms and recruitment flyers
2. Recruitment of participants for the studies
3. Data collection; including conducting interviews, data transcription and translations
4. Data analysis; including all qualitative analysis of the data
5. Presentation of research at scientific conferences and workshops
6. Academic publications on the basis of research

## **Objectives of the Dissertation**

The main objectives of the present dissertation are the following:

- 1) To present the background and rationale for the research that lay the foundations of this work, as well as to highlight the relevance and novelty of the contributions of this research to the broader scope of scientific knowledge in this field.
- 2) To demonstrate my contribution to scientific knowledge in the field of palliative care.
- 3) To succinctly summarize the manuscripts and discuss the importance of each of the study findings independently, as well as discuss to consider what they collectively contribute to the present state of the research in the field.
- 4) To explain the recommendations for future research, in view of the findings and implications of the present work.

However, on a deeper level, the broader objective of this dissertation is to argue for the significance of these findings for scientific knowledge in the field of palliative care and health care today. Not for the academic accomplishment of novel research, but for the purpose of informing policy makers, health care professionals and fellow researchers. In doing so, the hope is to gain support for better practices and functioning of palliative care services, so that the quality of palliative care may be guaranteed in the future.

## **Structure of the Dissertation**

The subsequent body of this work is divided into three core chapters. The first chapter provides an introduction to palliative care and describes the theoretical background that are the underpinnings to my research. Here, I present the central conceptual foundations, theoretical and empirical work that motivated my research and present dissertation, as well as highlight the key research gaps and questions that emerged from the status of palliative care in Switzerland and the literature. The interrelatedness of the papers, or the ‘story’ of the research undertaken will also be outlined, for reasons of context and for delineating the purpose and relationship of the research presented. Following this, the second chapter

describes the empirical research that I conducted as the basis for this work, as indicated by the manuscripts listed in the abstract. Next, chapter three will offer a discussion of the findings of the studies, including their implications for research and practice. Additionally, limitations, strengths and added value of the studies, as well as implication derived from the research will be given. Lastly, recommendations for palliative practice and future research that are recommended on the basis of the insights of the research findings will be presented. Copies of the manuscripts and certificates of their publication status, as well study materials, additional information about the research project, my personal resume and references can be found at the end of this work and in the appendices section.

## **Chapter 1. Introduction to Palliative Care**

This chapter provides a general introduction to the context of the research field that is the basis of this dissertation: palliative care in Switzerland. Specifically, the background to fundamental aspects of palliative care, such as its objectives and target patient population, history, provisional structures (i.e. available services and related infrastructure) and key characteristics will be described. This will be done not only with reference to Switzerland but also to its broader, international context, in order to depict an accurate picture of Swiss palliative care. Importantly, the state of research in the field of palliative care, as well as the gaps in research and resulting research questions, as well as the theoretical framework which lay the foundations for my manuscripts are described.

### **Palliative Care: Why Care?**

Although many people may associate palliative care specifically with an elderly, even dying population, palliative care is an essential pillar of health care, that for many people is a well-known reality, if not lived personally, then experienced by someone known to them – often a loved one. Moreover, this is progressively becoming the case as the aging population and rapidly changing epidemiology of serious chronic diseases make palliative care services increasingly relevant, particularly in western countries like Switzerland (Connor et al, 2017), where it is expected for the number of individuals aged 65 and over to increase by a staggering 28% by 2050 (Kohli et al, 2015). The growing life expectancy and steady incline in the percentage of elderly people indicates a greater need for the provision of effective, high quality palliative care services in Switzerland. Indeed, this will not only increase the number of patients who are in need of palliative care but also the demands on Switzerland's palliative health services (Seematter-Bagnoud, 2008). Notably, whilst palliative care may be best known for its role in treating oncology patients, it is becoming increasingly utilized in the treatment of a wide variety of conditions, including; kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis (Cherny & Radbruch, 2009). Furthermore, perhaps now, more than ever, is the importance of ensuring high-quality palliative care recognized, as the recent corona pandemic (COVID-19/ SARS-CoV-2) saw an acute rise in palliative care service use, as the demand for palliative care treatment has become critical (Swiss Academy of Medical Sciences, (SAMS), 2020). Before the virus emerged, even the best trained staff and facilities struggled to meet the complex needs of palliative patients (Kim & Kim, 2020). Now, despite tireless efforts to adapt and respond to such needs, palliative care in the coronavirus era is more challenging than ever before. In the face of the present pandemic and its detrimental consequences for so many of our population, particularly those who are especially vulnerable for infection (Kunz & Minder, 2020), the importance of palliative care has been brought closer to home for many in 2020.

## Palliative Care Services

Palliative care describes an approach to patient care that improves the quality of life of patients and their families, who face problems associated with life-threatening illness (WHO, 2019). This involves the prevention and relief of suffering by means of; early identification, assessment and treatment of pain and other problems; physical, psychosocial and spiritual (WHO, 2019). Palliative care services were initially only considered for cancer patients or individuals at the ‘end of life’ when the services were originated in the early 1960’s in the United Kingdom (UK) (Bains, 2010). Consequently, palliative care has often been associated with the negative stigma of death and dying (Zambrano et al, 2020). Yet, today the purposes of palliative care have expanded to aid in the case of any chronic and ultimately fatal illness, regardless of disease stage (Piamjariyakul et al, 2020) and are highly integrated into the medical care, curative and life-long treatment of many health care systems world-wide (Lončarek et al, 2018). Services may be provided across a variety of locations such as; private homes, hospitals, hospices, clinics and nursing homes (Beccaro et al, 2007), ideally within the context of ongoing assessment of physical, psycho-social and spiritual facets of need (Bainbridge et al, 2010). Generally, palliative services are provided by two distinct but interrelated services that cater to specific patient trajectories and health needs, namely; primary and specialized palliative care services. Typically, primary palliative care is provided in an ambulant setting by general practitioners (GP’s), nurses or health care assistants (Von Wartburg & Naf, 2012), whilst specialized palliative care is usually provided in a stationary setting, administered by specialized medical doctors and nursing staff (i.e. staff with specialized training, e.g. oncologists or specialist nurses). However, mobile palliative care teams (MPCT’s), which are made up of individuals who are specially trained in palliative care, but who often operate in an ambulant setting, as an interface between primary and specialized care, are frequently used as an intermediary service for primary or specialized patient care (Wyss & Coppex, 2013). Patients receiving specialized care are distinguished by the greater instability of their condition and the higher complexity of their needs – not just in physical terms, but also in terms of psychological, social and spiritual requirements (Lüthi et al, 2020). Thus, these patients naturally require more specialized and intensive care support (Ostgathe et al, 2019). However, the transition between primary and specialized services of care is very often ‘fluid’, meaning that a patient will often belong to both groups during their lifetime, as his or her condition progresses (Skjoedt et al, 2020). Mostly, a patient’s transition from primary to specialized palliative care is dictated by the complexity and instability of their needs. The degree of instability is reflected by the effort required for evaluating the patient’s condition and by the unpredictability of the patient’s health status, which may incur frequent changes to the treatment plan (Nordly et al, 2016). Likewise, complexity can result from higher levels of comorbidity that demand greater support from meaning that, as the severity of the disease increases, the need for specialized care arises.

It is difficult to discuss palliative care in the context of Switzerland without acknowledging its notorious association with ‘EXIT’. This is a renowned private, “Right-to- Die”-society which stands for: “Exit-Society For a Human Way of Dying” (EXIT, 2000), which enables assisted suicide by providing terminally ill members with a lethal dosage of barbiturates, on request (Frei et al, 2001). This is because, contrary to most European countries, assisted dying (i.e. any action taken to encourage or help somebody to take one’s own life) is supported by Swiss legislation. DIGNITAS is another famous non-profit organization which offers the same services. However, the association between assisted dying services and palliative care services are arguably misguided, given that the purpose of palliative care is to ensure quality of life for patients suffering from progressing diseases (Elsayem et al, 2004), whilst these services facilitate the opposite, i.e. death, or “dying with dignity” as DIGNITAS advertises (Fischer et al, 2008). Nevertheless, some public and professional perceptions are that palliative care is

synonymous with EXIT, or that assisted dying is a continuation of palliative care services (Frei et al, 2001). In line with this, many people, from both Switzerland and abroad, seek out these services when they feel unsatisfied with palliative care (Bosshard et al, 2008). It is not appropriate to discuss the implications or debates concerning assisted dying here. However, it is worth making the distinction that EXIT, or similar services, are not congruent to palliative care services which are discussed in this work and thus have no place in this research. Perhaps, nevertheless, it serves to emphasize how critical it is to continuously improve palliative care services- that is, if we wish to avoid individuals feeling that they must resort to dying, as opposed to choosing to continue living their lives with illness.

### **a) Research Context**

This section is intended to provide some contextual framing for my research by describing the state of palliative care in Switzerland. Moreover, it specifically describes the key problems relating to palliative care in Switzerland and especially demonstrates the status of palliative care in the study setting of the research presented (i.e. four Swiss cantons; Vaud, Ticino, Lucerne and Basel-City).

### **Palliative Care in Switzerland**

Like many European countries, Switzerland has recognized the challenge of the growing population demographic on the health care system and has invested in strategies to foster integrated palliative-care services (Groyenmeyer, 2004). Efforts to promote palliative care can be noted since the 1980's as various strategies and initiatives have been launched on both a cantonal and Federal level in Switzerland. Notably, two "National Strategies for Palliative Care" have proposed guidelines for the implementation of palliative services (Berchtold & Petrymann-Bridevaux, 2011). Moreover, numerous supportive measures regarding; financing, education, research and voluntary work have been implemented in palliative care contexts (Reeves, Schweighoffer & Liebig, 2019), and a national platform for palliative care was also launched to promote the exchange of information and support for palliative services ([www.palliative.ch](http://www.palliative.ch)). Most recently, in response to the corona pandemic, the Association for Geriatric Palliative Medicine (FGPG) have recommended the integration of a palliative care services into the care of elderly and very elderly people – both in the inpatient setting and at home (Kunz & Minder, 2020). Moreover, the current pandemic and the publication of the Swiss Academy of Medical Sciences (SAMS) Guidelines; "COVID-19 pandemic: triage for intensive-care treatment under resource scarcity" (SAMS, 2020) have prompted the FGPG to prepare these recommendations for practice. Such developments in palliative care have been in response to the recognition of the importance of good quality service provision and their growing necessity and have had some positive effects on provisional services for palliative care in Switzerland in the last decade (Sager & Mosner, 2014). However, the nation still has a long way to go in terms of delivering high quality palliative care (Reeves, Schweighoffer & Liebig, 2019). Crucially, experts warn that; without an effort to further improve and support palliative care in Switzerland, it is it will not be able to compete on an international level with countries such as the United Kingdom (UK), Australia, the United States (US) and Belgium (Eychmüller and Pautex, 2019), where palliative care provision is often referred to as the 'gold-standard' (Shaw et al, 2010). Essentially, palliative care services are still comparatively underdeveloped (European Association of Palliative Care, EAPC, 2015) due to the different regional conditions and histories of Switzerland that result in a highly fragmented approach to palliative care (Radbruch & Payne, 2010, Alvarado & Liebig, 2015). In many other European and international countries, there are uniform standards of palliative care service provision that dictate how palliative care services should be delivered in the country. The majority of exiting guidelines originate from the UK, such as the 'NICE' guidelines for palliative care from the National Institute for Health and Care

Excellence, but other standardized guidelines for palliative care can be found in the US, Australia and other European countries like Sweden and the Netherlands (Van Beek et al, 2016). Yet, Switzerland does not share this standardized approach to palliative care but is rather characteristically fragmented in its implementation and delivery of palliative care service provision. Quite basically, the federalist organization of the Swiss health system does not support uniform standards of palliative practice. Whilst general guidelines for palliative practice are found in the “National Strategy for Palliative Care 2013–2015”, the 26 Swiss cantons (Federal Office of Public Health, FOPH, 2016) are free to adhere to or ignore the guidelines, as they consider appropriate. Thus, provisional structures, financing, coordination of care and education for palliative care services have therefore developed differently as they rely strongly on cantonal health care policy and legislations, which differ by region and canton (Schweighoffer, Nagy, Reeves & Liebig, 2019). Consequently, rather than a cohesive approach to palliative care, provisional structures and implementation of palliative care are extremely fragmented (Radbruch & Payne, 2010), with differences not only found between cantons, but also between rural and urban settings (Alvarado & Liebig, 2015). For example, on a regional level, prior literature has identified that rural and remote areas fall significantly behind in terms of infrastructural prerequisites and subventions, whereas urban areas generally have sufficiently more infrastructure at their disposal, both for primary level of care and for specialized and outpatient areas of care (Neuenschwander & Gamondi, 2012).

## **The Research Setting**

In view of the known variations in palliative care services, according to canton and region, four Swiss cantons were selected as the basis for the investigations conducted in the context of the research project. These cantons were; Ticino, Vaud, Basel- City and Lucerne. Importantly, these cantons were selected to adequately reflect rural and urban regions of Switzerland, as well as diversly developed policy contexts for palliative care in Switzerland. As a first step, the researchers of the NRP- 74 team carried out a preliminary document analysis to capture the current status of implementation of palliative care that exist on a cantonal level, in these four Swiss cantons Switzerland (see: Reeves, Schweighoffer & Liebig, 2019). This analysis was guided by the concept of ‘community readiness’, which can be described as a practical tool for assessing the status and change in community health services (Oetting et al, 2001). When applied to the evaluation of health care in the context of palliative care, it implies that important factors of palliative care services, including; the history, financial support, educational opportunity, provisional structures and coordination can dictate how successfully initiatives for palliative care are accepted in a community. Thus, in cantons with ‘high stage’ community readiness, you could expect good financial support for palliative care, many palliative educational opportunities and adequate provisional structures for palliative care. On the other hand, in a community with low stage community readiness, you could expect limited financial support and educational opportunities for palliative care, as well as inadequate provisional structures for palliative care. The key findings from this document analysis clearly illustrate the fundamental differences in palliative care services between cantons and the inconsistent approach to palliative care in Switzerland. Notably, judging from the aspects of care that indicate community readiness for palliative care in the cantons, Vaud appears to have the best chance for successfully implementing palliative care initiatives. Similarly, Basel and Ticino are also well equipped for providing good palliative care services. However, Lucerne has the poorest chance of implementing good palliative care services. An overview of the status of palliative care across the cantons presented next in table 1. This is intended to provide a clear picture of the status of palliative care in the research setting of the studies; i.e. Vaud, Ticino, Basel- City and Lucerne.

<b>Aspects of Palliative Care</b>	<b>Lucerne</b> Poor community readiness	<b>Basel-City</b> Good Community Readiness	<b>Ticino</b> Good community Readiness	<b>Vaud</b> Excellent Community Readiness
<b>History of Palliative Care</b>	Short history since the late 1990s and slow development since.	Fast development of PC	Longest history of Palliative care since 1985	Long history and steady development since 1988
<b>Provisional Structures for Palliative Care</b>	Very few specialized facilities  Only one MPCT	Sufficient specialized, long term and out- patient care facilities	Many provisional structures, including mobile services and specialized facilities	Excellent provisional structures as well as 24/7 care
<b>Palliative Coordination Services</b>	No coordination office/ poor care coordination	Good coordination due to main coordination office and specialized palliative care	Very good coordination due to good care coordination services between primary and	Excellent care coordination facilities due to main coordination office and well
<b>Financial Support for Palliative Care</b>	Some financial support	Very limited financial support	Partial financial support from the canton (e.g. for palliative training)	Some financial incentives from the canton
<b>Palliative Education and Training</b>	Very limited education opportunities for health care practitioners	Few educational opportunities for GPs, some courses offered to nurses via non-profit	Many opportunities offered through universities or hospitals	Most training possibilities available, even for volunteer staff

**Table 1.** An overview of the fragmented approach to Swiss Palliative Care, adapted from: Reeves, E., Schweighoffer, R., & Liebig, B. (2019). Community readiness for palliative care services in Switzerland: Basis for public health strategy for health psychologists. *Psychreg Journal of Psychology*, 3(2), 94-95.

## **b) State of Research**

This section presents the key background literature and state of research in the related field that set the scene for my research, namely with respect to; coordination in palliative care, palliative care coordinators and quality in palliative care. Importantly, the gaps in research are indicated and the research questions are given. Indications of the need for further analysis in research and how the research questions are addressed by the manuscripts are also provided.

### **1. Coordination in Palliative Care**

Good coordination of palliative care services is crucial for ensuring health and high quality palliative care provision (Albrecht et al , 2008). Coordination is strongly associated with interprofessional collaboration in palliative care. However, interprofessional collaboration describes the process of professionals working together to achieve common goals and is often concerned with solving problems (Green & Johnson, 2015), whilst coordination is chiefly concerned with the managing of tasks, resources, and people (Malone & Crowston, 1994). Thus, coordination is a part of collaboration but refers specifically to the activity that is carried out by group members when managing interdependencies. Specifically, good care coordination in palliative care settings primarily constitutes

the effective marshaling of professionals and resources to carry out patient care activities and is usually managed via the exchange of information among providers of different aspects of patient care (McDonald et al, 2010). Palliative circumstances especially require well-coordinated responses because of the complex and frequently changing clinical status or patient needs or preferences for location of care (Agar et al., 2008). The beneficial effects of good care coordination on the quality of palliative care services are well documented in literature and are positively associated with favorable patient outcomes (Pocock et al, 2019). Notably, efficient care coordination has been associated with better patient outcomes; reduced un-wanted hospital admissions, quicker admissions to appropriate care services and overall reduced risk of fatality (Turner-Stoke et al., 2007). Moreover, good coordination has often been shown to lower incurred health care costs in palliative care settings overall (Jawed & Rotella, 2020). Conversely, poor coordination reportedly contributes to an exhaustive list of challenges for ensuring good quality palliative care provision. Notably; poor coordination results in adverse outcomes for patients. As a consequence of poorly organized care patients often; don't receive the appropriate course of treatment, have delayed access to emergency services and die in hospital, rather than in the generally preferred setting for the patient- at home (Dudley et al, 2019).

### **Challenges to Coordination between Palliative Services**

Access to well-coordinated care for all individuals receiving palliative treatment is advocated in policy standards internationally (Senderovic, 2020). Yet, the reality of palliative care often reflects that the coordination of services in this field is insufficient (Peikes et al, 2009). Effective care coordination is not easily met without challenges in palliative care. Firstly, many barriers to coordination can arise from the specific requirements of patient trajectories, which call for the coordination of different palliative care services and combinations of professional competencies (Murray et al., 2015). Moreover, specific patient populations, palliative legislations and policies, as well as the availability of resources can influence the effectiveness of coordinating care (Bainbridge, 2010). In Switzerland, further challenges to coordination may inevitably arise from the availability of provisional structures for coordination and varying approaches to coordinating care that are determined by the region and canton, as discussed. In addition, navigating the course between primary and specialized care is increasingly difficult, for both patients and professionals (Agar et al, 2008). Yet, as discussed, the reality for most palliative patients involves treatment from both primary and specialized spheres of care (Skjoedt et al, 2020). Moreover, the demand for good care coordination between primary and specialized palliative care services is increasingly apparent as the integration of specialty palliative care services into routine care is increasing, even from the point of diagnosis (Zander, 2003). Notably, palliative care has experienced considerable growth in the number of consultation teams, outpatient clinics, community-based palliative care models (Haggerty et al, 2003) and medical specialty societies that recommend the collaboration of primary and specialized care for patient treatment (Woodward et al, 2004). Despite this, the coordination between services has often been poorly evaluated, yet the challenges to coordination in palliative care in Switzerland is still poorly understood (Wittenberg- Lyles et al., 2009). Moreover, the majority of existing literature in the field explores challenges to interprofessional collaboration rather than coordination (Alvarado & Liebig, 2016) or are limited to outpatient or stationary palliative contexts (e.g. Alvarado & Liebig, 2015). Thus, coordination between palliative care services is still very under researched and little is known about the challenges to coordinating care between primary and specialized care services.

## **Current Challenges to Coordination for Palliative Care**

At the time that this research was conducted, the health and political climate was a different one than it is today. However, in order to provide a contemporary understanding of the current state of research in palliative care, some important additional challenges that have arisen in 2019-2020, are described here. This information is relevant for understanding the value of this research and the implications of research that will be discussed in the final chapter of this work. The COVID-19 pandemic is expected to surpass the healthcare system's capacity to provide intensive care to all patients who deteriorate as a result of the disease (Tobler, 2020). This poses a unique challenge to healthcare teams of rationing care during pandemic when resources are scarce. Specifically, physicians and nurses have often been deployed to deliver emergency care for people with COVID-19, who are un-prepared and un-trained for palliative care (Alderman et al, 2020). Many practitioners and even medical students and health care assistants with no palliative training whatsoever have flooded health systems all over the world to support the intense recovery units during the pandemic (Wallace et al, 2020). Moreover, in view of the present resource constraints, priority has been given to saving lives of people with the virus, over palliating discomfort among those who are seriously ill and their families (Borasio et al, 2020). This means that there is more pressure on the health care system and the attending staff to deliver well-coordinated, effective care. Failure to do so can also have a significant impact on carers, who may have to step in and attempt to coordinate health and care staff and services themselves (Alam, Hannon & Zimmermann, 2020). However, these days, when patients fail to receive palliative care services in sufficient time, their transfer to intensive care services may be the last time that their family is able to see them until they are cured, due to policy regarding corona restrictions that requires infected persons to be quarantined (Tobler, 2020). For some, sadly, this may be the last time they see their family member, if the virus proved to be fatal for them.

## **Need for Further Analysis**

The demand for good care coordination between primary and specialized palliative care services is increasingly apparent as patients frequently require transfer from primary to specialized services (Bainbridge, 2010). Yet, coordination between services is often poorly established. Moreover, little is known about challenges to coordination at the interface of primary and specialized palliative care services in Switzerland. Identifying challenges to coordination at the interface between these services is imperative as patients increasingly frequently require a transfer from primary to specialized services and the task of navigating through this transition, for health care professionals, patients and their relatives can be demanding (Liebig & Piccini, 2017).

## **The Research Questions**

The state of research in the field and evidence for the growing necessity for good coordination of care between services primary palliative care services, coupled with the apparent gap in knowledge concerning challenges to coordination between palliative care services motivated the following research questions:

1. What challenges exist between primary and specialized palliative care?
2. What are the areas for improvement for coordination these fields?

These questions were addressed through the following study, indicated by the manuscript title below:

**Manuscript 1:** An investigation of the challenges to coordination at the interface of primary and specialized palliative care services in Switzerland: A qualitative interview study. *Journal of Interprofessional Care*, 1-7. Reeves, E., Schweighoffer, R., & Liebig, B. (2020).

### **Aims of the Study**

The aim of the study was to investigate coordination at the interface of primary and specialized care. Specifically, to identify challenges to the coordination between primary and specialized care services in Switzerland and to indicate areas for improvement.

### **Link to Subsequent Study**

The first study sought to investigate challenges to coordination between primary and specialized palliative care services in Switzerland. The findings of this study shed light on many important, multifaceted challenges to coordination. One of these findings indicated apparent confusion concerning coordinative roles between primary and specialized care. Importantly, the data revealed that this was more the case in primary care settings, where interview responses indicated that professionals were confused about who is responsible for coordinating care between services within their own team. In response to this finding, the second study sought to build on the findings of the first study by exploring who professionals believe to play a key role in palliative home care. The literature that informed the development of the second study will be described in detail below.

## **1. Care Coordinators in Palliative Care**

A person diagnosed with a condition that requires palliative care can receive multiple treatments across a variety of different health care settings over extended periods of time (Murali et al, 2020). During this time, they come into contact with multiple health care providers. For instance, one study revealed that cancer patients with a diagnosis of less than one year had met with 28 doctors on average since their diagnosis (Yates, 2004). In conjunction with the numerous other health professionals with whom palliative patients are likely to come into contact during their illness, a clear picture of the complex maze that can characterise the patient's care journey is palpable. Health care systems worldwide have thus moved to appoint care coordinators as a strategy to assist patients with navigating through their time in care. Care coordinators are clearly identified professionals who are charged with care coordination (Pikes et al, 2009) and are preoccupied with "the regulation of diverse elements into an integrated and harmonious operation" (Stille et al, 2005). Specific examples of official care coordinators in palliative care are case managers or advance practice nurses, who are employed solely to coordinate care within palliative teams (Joo & Liu, 2019). Such positions have evolved from efforts to decrease fragmentation of services, ensure cost efficiency of services and facilitate the provision of high quality of care (Spettel et al, 2009), especially for high risk patient groups where care coordination is usually more complex (Abbasi, 2019). Chief tasks of care coordinators can thus include; outreach to patients by phone or mail; conducting face-to-face patient encounters; providing social support for patients; collecting, managing, and exchanging patient data; supporting physicians; and backing up clinical and administrative staff (Friedman et al, 2016). The benefits for adopting care coordinators in palliative care are extensively advocated in literature. Notably, care coordinators have been shown to aid in the management of patient co-existing problems, providing informational and emotional support, providing education about procedures and self-care, and assisting with activities of daily living

(Kuusisto et al, 2020). Furthermore, families of patients have also been shown to benefit from care coordinators via their support, education and monitoring of their relative's progress (Jennings- Sanders & Anderson, 2003). The coordinator role is thus a rapidly emerging one in palliative care, with a mandate to achieve some potentially far-reaching reforms to systems of care (Yates, 2004).

### **Challenges for Identifying Care Coordinators**

The recognition of professional roles, especially of those in coordinative functions, is important for effective team functioning, interprofessional collaboration and coordinative practices (Rovothis et al, 2017). However, despite efforts to increasingly implement designated care coordinators in palliative care services, care coordinators are often not easily identified by their colleagues (Brant et al, 2019). In palliative home care settings, individuals who play a key role in care coordination often include; general practitioners (GPs), nurses, advanced practice nurses and case managers (Payne, 2006). However, literature indicates that other health care practitioners often perform tasks that go well beyond their usual responsibilities and regulations of their role (Thornley, 2000). Crucially, they can frequently engage in activities that concern organizational and managerial aspects, including care coordination (Carney, 2009). This often occurs as a result of efforts to meet the increasing demands on health services. As such, many care workers can therefore experience "vertical substitution"- which describes the process by which a role that is usually performed by an individual in a higher occupational position is performed by a worker at a lower occupational station (Nancarrow, 2005). Consequently, understandings of professional roles become blurred and evoke confusion regarding identifying official care coordinators (Bodenheimer, 2008). Critically, these factors have been shown to contribute to adverse effects for care coordination as they can result in ambiguity concerning role recognition amongst care providers, i.e. "the situation where individuals do not have a clear direction about the expectations of their role" and also fuel role conflict, where individuals who work together cannot agree about what the expectations are for a particular role are (Walshe, Ewing & Griffiths, 2012). Palliative home care settings increasingly demand well-coordinated services but can present an additionally challenging environment for identifying care coordinators. Palliative home care teams enable patients to receive personalized care in the comfort of their own home setting (Labson, Sacco & Weissman, 2013). This service is usually provided as a means of ensuring the continuity of care from hospital to home, with the availability of around the clock, i.e. 24-hour-a-day staff catering (Holley et al, 2009). However, this is often only feasible through interchanging team members with shifting work schedules and hours or supplementing additional members to a team, meaning that teams are commonly made up of changing staff members. Moreover, since home care requires intensive supervision and care, professionals must be readily available to respond to patient needs (Bodenheimer, 2008). This can provide additional challenges for identifying those who play a key role in care coordination as team members keep changing and may adapt their roles in order to meet the demanding and quickly changing needs of palliative patients, fueling further confusion (Luckett et al, 2014)

### **Need for Further Analysis**

Without clearly identified roles, standards of palliative care cannot be granted, and the quality of coordination may be compromised. Yet, to date, little is understood about who plays a key role in care coordination. This is especially true for Swiss palliative home care, where research efforts have focused on specialized palliative care settings rather than home care in Switzerland (Alvarado & Liebig, 2015). Although some previous research in this field has identified GP's as important actors in Swiss palliative home care (Mitchell, 2002), few studies have sought to address who the key coordinators are in palliative home care. The aim of the study, therefore, was to address this gap in the research and thus

explore who plays a key care coordinator role in palliative home care, from the perspectives of palliative home care teams.

## **The Research Questions**

Coming out of the literature in this field, the starting premise of the study was that clearly designated care coordinators are important for ensuring efficient care coordination and high-quality care provision in palliative care. The literature described here and the findings from the previous study that indicated confusion concerning professional roles were provoked for the following research questions:

1. What does care coordination look like in primary home care?
2. Who/ which professionals are responsible for care coordination in primary home care?

These questions were the starting point for the next study, which was developed into the second manuscript, shown below:

## **Manuscript 2: Care coordination in palliative care: Who plays a key role? *International Journal of Integrated Care*, (In press, 2020)**

### **Aims of Research**

The aim of the study was to address the gap in research by identifying which professionals play a key role in coordination in primary home care settings.

### **Link to Subsequent Study**

The link between good care coordination and high-quality palliative care has been strongly evidenced, both through healthy literature and empirical research, as discussed. Moreover, the results from the second study demonstrated that the ambiguity concerning the care coordinator role considerably inhibited coordination. Additionally, given that clearly designated care coordinators are considered a prerequisite for effective coordination and high quality of care, the last study sought to explore perceptions of quality of care in palliative home care. In order to get a clear picture for perceptions of quality in palliative care, the investigation considered the perspective of those closest to palliative patients, i.e. palliative health care professionals and relatives of palliative patients. The evidence supporting the value of investigating perceptions of quality in palliative care is given below, as a means for illustrating the basis for the third study

### **3. Quality in Palliative Care**

High quality of care is of paramount importance for palliative care services (Hanson et al, 2014), not least because the health status of palliative patients is often critical, thus demanding effective care services with respect to both pain and symptom management, as well as good physical and psychosocial support functions (Gemmell, Yousaf & Drone, 2020). Important indicators of quality in palliative care include; care that maintains patients' comfort, dignity, and personhood; timely, effective, and compassionate communication by clinicians with patients and families; alignment of medical decision-making with patients' values, goals, and preferences; support for the family; and support for palliative professionals (Violette, 2020). However, quality of care is a highly complex phenomenon, one that is not necessarily determined by the outcomes of care but may be constituted of multiple components, such as the; effectiveness, acceptability, efficiency, access, equity and relevance of care (Donabedian,

1988). Importantly, quality of care is also evaluated subjectively by the individuals who come into experience with care (Ke et al, 2019) and their personal evaluations of care may therefore be shaped by their experiences, expectations, sociocultural conditions and moral beliefs (Johnson et al, 2004).

## **Evaluating Quality of Care**

With so many aspects to consider, evaluating quality of care often proves difficult across all domains of care (Merwin, Synder & Katz, 2006). In palliative care services, these difficulties are further complicated because the factors that influence service evaluation may not be directly related to treatment or services (Gonella et al, 2019) but may be related to patient outcomes, which are sometimes untreatable (Hultman, Reder & Dahlin, 2008). Many approaches to the evaluation of quality exist in palliative care. On an international level, the UK Gold Standards Framework (Shaw et al, 2010), the National Consensus project on palliative Care (Blouin, Fowler & Dahlin, 2008) or the SENTI-MELC study (Van den Block et al, 2008) are used to assess quality in palliative care. However, such measures have often been shown to be inconsistent (Cook, Render & Woods, 2000) and are not necessarily transferable to all healthcare system since healthcare systems differ substantially regarding many structural and organizational aspects (Hermann et al, 2012). In Switzerland, these differences persist even within the country, as described (e.g. Reeves, Schweighoffer & Liebig, 2020). However, a well-recognized model for the evaluation of palliative care, known as the ‘proposed systems approach’ (Bainbridge, 2010) helps to describe the factors that constitute quality in health care. He proposes that key factors indicative of the quality of care include; the availability of care (i.e. that palliative services are accessible to those who need them, when they need them), the client centeredness of care (i.e. respect for patient wishes and adequate involvement of relatives of patients in care), satisfaction with care (including physical and psychosocial care) and communication and information transfer (i.e. collaboration and transfer of patient information between palliative care providers). Moreover, in order for palliative care services to be evaluated positively, palliative care ought to be readily available, the patient should always be at the center of care (i.e. their needs should be respected and their relatives should be adequately involved in care), patients should feel satisfied with the level of care they receive (including both physical and psychosocial care) and communication and the transfer of information with respect to care should be to a high standard (i.e. patients and relatives should have frequent, clear communication about care).

## **Perspectives of Quality in Palliative Care**

In order to gain an accurate understanding of quality of care in palliative care, perceptions of individuals closest to those in care are highly insightful (Austin et al, 2000). The critical health status of palliative patients often makes it difficult to obtain their feedback for studies investigating quality in palliative care (Hansen et al, 2014), making the insight of relatives crucial, if not a proxy for patients’ perceptions of quality of care (Aasbao et al, 2017). Naturally, the extensive experience that health care professionals and relatives of palliative patients have of palliative care services make their insights invaluable for understanding quality of care. The perspectives of relatives of palliative patients are more relevant than ever, not only because of their closeness to the patient, but also because of their increasing involvement in palliative care services (Burns et al, 2013). A growing body of research supports that relatives are becoming increasingly embedded into palliative care teams, particularly as more aspects of palliative care are provided in a patients’ family home environment (Gomes et al, 2005) and many relatives receive palliative training (Kuchinad et al, 2020). In addition, many relatives assume the role of primary care givers, i.e. individuals who provide support without payment (Cohen et al, 2006). Prior research that has explored perceptions of care in palliative services, on the basis of the perspectives of the

professionals found key aspects of care that have been evaluated poorly such as; the availability of care services, the continuation of care, physical and psychosocial support, satisfaction with care and communication between palliative care providers (De Boer et al, 2017, Gamondi et al, 2015). Importantly, research that has compared the perspectives of different actors with respect to care has often identified considerable discrepancies with respect to perspectives of the quality of care (Oosterveld-Vlug et al, 2019, Ying-Xuan et al, 2019). For example, professionals have been shown to over-estimate the quality of care delivery with respect to patients and relatives (Frey et al, 2020), whilst patient and relatives perspectives have revealed poor evaluation of care with respect to; psychological support, access to care and pain and symptom management (Iyer et al, 2019). Identifying perspectives of quality of care in palliative services facilitates a broader, more accurate understanding of the quality of care and identify areas for improvement. However, the majority of existing literature has investigated perceptions of a specific aspects of quality of care, such as; perceived patient centeredness of care (Brazil et al, 2007) or availability of support services for relatives (Hudson & Payne, 2011, Feldenzer et al, 2020). Similarly, in Switzerland, only a few studies have explored factors which might indicate quality of care in palliative settings, such as the coordination of care (Reeves, Schweighoffer & Liebig, 2020) or interprofessional collaboration within palliative care teams (Alvarado & Liebig, 2016).

### **Need for Further Analysis**

Ensuring high quality of care is not guaranteed, and the standard of palliative care service provision is often deemed unsatisfactory (Wittenberg Lyles et al, 2009). However, there is limited understanding about how the quality of care in palliative care services is perceived. In view of the gap in research, this article explores perceptions of quality of care in palliative services from the perspectives of those closest to care. Importantly, the study compares the perceptions of palliative patients in order to bring to light inconsistencies and synergies in perspectives and to acquire a well- informed understanding of quality of care in palliative services, according to those who are arguably most qualified to give it.

### **The Research Questions**

From the state of the research concerning quality of care in palliative care, the following questions emerged:

1. How is quality of care perceived in palliative home care?
2. What synergies or inconsistencies in perspectives exist between professionals and relatives of palliative patients?
3. What are the areas for improvement for quality of care?

These research questions were sought to be addressed through the study featured in manuscript 3, below:

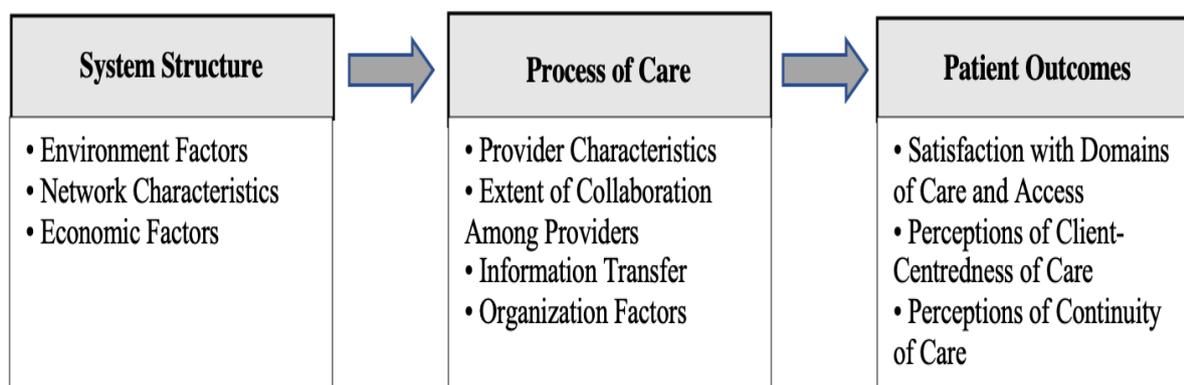
**Manuscript 3: Comparing professional and relatives' perspectives of quality of care in palliative care: A qualitative interview study *Journal of Integrated Care*, (In press, 2020)**

## Aims of the Study

The aims of the study were to explore perceptions about the quality of care in palliative care from the perspectives of palliative professionals and relatives of palliative patients. Specifically, to identify synergies and divergences in perceptions of quality of care, as well as to highlight the complexity of quality of care in palliative care settings and indicate areas for improvement for quality of palliative services.

### c) Theoretical Framework

Out of the basis of the literature described, the starting point for addressing the research questions relate to fundamental key concepts in health service research. Specifically, a well- recognized conceptual framework provides an outline for analyzing and evaluating regional palliative care services. It's foundations are based on the Donabedian's (1988) 'S-P-O model' of assessing health services and evaluating the quality of health care outcomes (Donabedian, 1988) but are more expanded to include more factors of care (Bainbridge et al, 2010). The S-P-O-model describes that the context in which care is delivered, (i.e. the system structure) as an important determinant of the activities and interactions throughout the delivery of healthcare (i.e. processes of care). Importantly, these structures and processes help to explain quality of health care, as reflected by patient outcomes. Based on this perspective, as well as previous concepts and empirical studies Bainbridge et al. (2010) propose to refer to these three tiers of health care systems in order to evaluate palliative care. This is illustrated in figure 1 below. This theoretical framework informed the underpinnings of the research, including the development of the interview guidelines that were used to investigate important aspects of care. In this way, deeper insight into these important factors for the evaluation of quality in palliative care, as well as their relationships to one another could be explored.



**Figure 1.** Conceptual framework for the evaluation of integrated palliative care networks (adapted from Bainbridge et al. 2010)

## Summary of the Chapter

As outlined in this introductory chapter, three interrelated studies were carried out to explore aspects of coordination and quality of care in both primary and specialized palliative care settings. As demonstrated, the studies were informed by literature and sought to build on knowledge of the state of research in palliative care, especially in Switzerland. Specifically, the studies were not only carried out to address existing gaps in literature but were also in response to the empirical findings of each study.

This was done in order to ensure that real, contemporary issues that were indicated in the data were focused on to ensure that the areas that were most in need of research could be addressed. Furthermore, to investigate these topics, the research was founded on strong theoretical constructs, coming from the theoretical framework for the evaluation of palliative care (Bainbridge, 2010). The methodology, research findings of the studies are provided in the next chapter.

## **Chapter 2. Empirical Research**

This chapter is dedicated to the description of the empirical research that is the basis of the articles that comprise this cumulative thesis. This section will therefore begin by describing the overall study design and outlining the general research conditions that are common to all three of the studies. Following this, a synopsis of the manuscripts will be provided. Each manuscript will therefore be summarized individually so that the overall description of the research methods and results of each study are given.

### **1. Research Design**

Since little is known about the field, a qualitative study design was adopted for each study in order to adequately address the research questions at hand. The strength of qualitative research is its ability to provide complex textual descriptions of how people experience a given research issue. Notably, it can provide valuable information about the “human” side of an issue – that is, the behaviors, beliefs, opinions, emotions, and relationships of individuals and is highly effective for identifying intangible factors, such as psychosocial issues and interpersonal issues that may not be readily apparent otherwise. Given that in all research fields of interest, investigating the research concepts, from the perspectives of relevant informants, i.e. palliative professionals and/ or relatives of palliative patients was essential, qualitative methods were deemed most appropriate. An alternative research approach, such as quantitative methods would not have been able to investigate these exploratory research questions in the same way as qualitative methods allow for since they are concerned with objective data. To maximize the exploratory nature of my research, I chose to utilize in-depth interviews to investigate the research questions as they are optimal for collecting data on individuals’ personal histories, perspectives, and experiences, particularly when sensitive topics, such as palliative care experiences are being explored. Similarly, when developing the interview guideline, a semi structured interview style was adopted since this style is typically more flexible – that is, it allows for greater spontaneity and adaptation of the interaction between the researcher and the study participant. From this, responses of interviewees are encouraged to provide rich data for analysis. In view of the benefits of qualitative research methods described here, I considered a qualitative research approach ideal for the studies presented in this work.

### **2. General Research Conditions**

This section will present the key conditions and aspects of research that are common to all the studies that comprise of this dissertation. The purpose of this is to provide sufficient detail and justification for the conditions of the study, as well as to avoid repetition, where the same conditions, sample or methods were adopted across studies. Specifically, the; study setting, recruitment methods and study materials, and interviews that are common to all three manuscripts are detailed as followed. Since this information is described here, it will not be unnecessarily be repeated during the further description of the methods for each study described in the methods sections that follow.

## Study Setting

As described in the introduction, the study setting for the research in the case of all three manuscripts were based on data from palliative care services in four Swiss Cantons. These cantons were; Ticino, Vaud, Basel- city and Luzern. Importantly, these cantons were intentionally selected to adequately reflect rural and urban regions of Switzerland as well as diversly developed policy contexts for palliative care in Switzerland. This was done in order to ensure a representative basis for study of palliative care in Switzerland, as the starting point for the research.

## Recruitment Methods and Study Materials

The participants for all studies were identified in each canton via internet searches and personal referral. This was mostly done through word of mouth, i.e. via recommendations or suggestions from other professionals known personally to the research team. Participants for each study were recruited via e-mail invitation or telephone call. However, in the case of manuscript 3, flyers for recruiting relatives of palliative patients to the study were additionally utilized. These were distributed in hospitals and in private practices across the four cantons, written in the language corresponding to the canton. Research materials common to all three studies include; informed consent forms, satisfaction with care surveys and interview guidelines. These forms and interview guidelines were provided in German, Italian and French so that they could be understood by the participants of any of the four different language speaking regions of Switzerland. Informed consent was obtained from participants at the outset of each study. Please see appendix C for excerpts of study materials.

## Interviews

*Interview guidelines* were informed by concepts derived from a conceptual framework for the evaluation of integrated palliative care (Bainbridge, 2010), as discussed in the theoretical framework section of the previous chapter. Importantly, the interview questions featured different concepts that related to the specific focus of each study. Please see appendix C for interview guidelines for professionals and relatives.

*In- depth qualitative interviews* were used as carried out in person in a semi-structured format and delivered in the language corresponding to the official language of three different language regions, i.e. German, French or Italian. Interviews typically lasted between 45-60 minutes and were conducted in a location determined by the participant (e.g. clinic, personal office, in a home setting or a public place). Interviews were carried out by the researchers who formed part of the SNF NRP 74 project research team. All interviews conducted in Ticino were carried out by myself, whilst interviews conducted in Vaud and in the German speaking cantons of Switzerland (Luzern and Basel city) were divided between key associates of the NRP 74 project, as well as four psychology master's students from the Fachhochschule Nordwestschweiz, Olten, who assisted with the recruitment and data collection period of the project as part of their master's degree training. All interviews were audio-recorded and transcribed verbatim in their original language, with all personal identifiers removed.

*Transcription and translation of interviews* processes were as followed. Some interviews that were conducted in French and German were transcribed by a professional transcriber, hired for this function in the project. Other French and German audio files of interviews were transcribed by the master's students or the core researchers of the NRP 74 project. All Italian audio files were transcribed by me personally. The decision to divide the task of transcribing the study interviewers were two fold, one to

be time efficient, due to the sheer volume of data that there was and secondly, to ensure accuracy and validity of the data as the data was transcribed in the language corresponding to the native or second language the researchers. In the same way, interview transcriptions were also translated by the researchers into English, where necessary, to facilitate the data analysis process of myself as the key qualitative researcher. Moreover, where needed, parts of transcripts were translated with the assistance of online translation applications (e.g. deeppl.com) and double checked by one of the research team, in order to ensure that the meaning of the sentence correctly corresponded with the translation. This process was done to ensure that the data was reliable and that the true meaning of the data could be extracted to accurately inform the findings of the study.

### **3. Synopsis of Manuscripts**

A synopsis of the manuscripts that comprise of this thesis will now be presented in this section below, indicated by the three manuscript titles. Specifically, an overview of the methods and a summary of the study results will be provided. Since this section essentially summarizes the studies that have already been either successfully published or are in press for publication in peer reviewed, scientific journals, partial results of the presented work have already been published.

**Manuscript 1: Reeves, E., Schweighoffer, R., & Liebig, B. (2020). An investigation of the challenges to coordination at the interface of primary and specialized palliative care services in Switzerland: A qualitative interview study. *Journal of Interprofessional Care*, 1-7.**

#### **Methods**

The aim of the study was to identify challenges to coordination between primary and specialized palliative care services. The study involved 24 interviews with 11 general practitioners (GPs) and 12 nurses working in primary palliative care services, in addition to an additional 15 interviews with 9 specialized medical doctors (e.g., oncologists) and 6 specialized palliative care nurses working in hospitals, hospices, mobile palliative care teams (MPCTs), and specialist private practice.

#### **Explanation of Chosen Research Methods**

The data were analyzed using “structural content analysis” (Kuckartz, 2012). This was deemed a suitable approach for the study as it is generally used where knowledge of the field is limited, as was the case here. Whilst my analysis was guided by concepts of Bainbridges’ (2010) evaluation of health care to guide my analysis, I also allowed for the categories and names for categories to flow from the data. This process is commonly referred to as inductive category development (Kondracki & Wellman, 2002). This approach was useful for ensuring that the knowledge generated from the analysis was based on participants’ unique perspectives and grounded in the actual data. This was important given the limited existing knowledge about challenges to coordination at the interface of primary and specialized services of palliative care.

#### **Data Analysis**

The data analysis began by reading all data repeatedly to achieve immersion in the data and obtain a sense of the data as a whole. Then, the data were read word by word to derive codes by first highlighting the exact words from the text that appeared to capture key thoughts or concepts. Next, I made notes of

my first impressions, thoughts, and initial analysis. As this process continued, labels for codes emerged that were reflective of more than one key thought. These often came directly from the text and subsequently become the initial coding scheme. Codes were eventually sorted into categories based on how different codes were related and linked. These emergent categories were used to organize and group codes into meaningful clusters. For example, to facilitate clarity in the analysis of the data, a distinction was made between concepts, which differentiated between challenges to explicit forms of coordination, which relies on instruments (e.g., electronic tools, schedules, plans) and verbal and written communication (instructions, meetings, feedback), and challenges to implicit forms of coordination (i.e., the processes involving non-verbal aspects of communication or actions), including the synchronization of members' actions based on unspoken norms and assumptions (Espinosa et al, 1994). Next, definitions for each category, subcategory, and code were developed. To prepare for reporting the findings, some exemplars for each code and category were identified from the data. Importantly, I consulted with my project supervisor and colleagues about the codes that I applied to the initial transcripts and with their approval, agreed on a set of codes to apply to all subsequent transcripts. This was done in order to ensure consensus regarding the codes and analysis. Similarly, codes and themes in the data were discussed and reflected upon among the research team to ensure rigor in the analysis. On the basis of this, the codes were then grouped together into clusters of challenges which were then clearly defined. The data in the subsequent transcripts were then coded according to these clusters of challenges. After coding manually, I then re-coded the data using a qualitative data analysis software package (MAX QDA) to organize the data efficiently and in a systematic manner.

## Results

The findings of the study identified three clusters of challenges to coordination between primary and specialized palliative care services. These clusters included; organizational challenges to coordination, which relate to explicit forms of coordination, relational (i.e. interpersonal) challenges to coordination and structural challenges to coordination, which relate to implicit forms of coordination. An overview of the findings are displayed in the next table and their key components are then summarized.

<b>Structural Challenges</b>	<b>Organizational Challenges</b>	<b>Relational Challenges</b>
Lack of time for coordination with other services	Non-standardized use of electronic patient records (ERP)	Conflicting understandings of professional roles
Lack of financial remuneration for coordination with other services	Lack of pre-planned/ regular meetings between PPC/SPC	Conflicting team understanding
Lack of knowledge and awareness of available services	Non-direct communication between providers	Distrust for professional competencies

Table 2. Overview of challenges to coordination at the interface of primary and specialized care

### *1. Organizational challenges to coordination*

Organizational challenges related to explicit forms of coordination. The challenges to coordination that were categorized under ‘organizational challenges’ included; (a) non- standardized use of electronic patient records (EPR), (b) lack of preplanned/regular meetings between primary/specialized palliative care providers, and (c) indirect communication between providers.

### *2. Relational challenges to coordination*

Relational challenges to coordination related to implicit forms of coordination. The categories of this theme are (a) conflicting understanding of professional roles, (b) conflicting team understandings, and (c) distrust for professional competencies.

### *3. Structural challenges to coordination*

Structural challenges to coordination related to implicit forms of coordination. The categories related to this final theme included; (a) lack of time for coordination with other services, (b) a lack of financial remuneration for coordination with other services, and (c) lack of awareness of available services.

## **Manuscript 2: “Care coordination in palliative care: Who plays a key role?” International Journal of Integrated Care, (In press)**

### **Methods**

The aim of the study was to identify who plays a key role in care coordination in palliative home care. The study involved 24 interviews with 12 general practitioners (GPs) and 12 nurses in palliative home care setting, as well as 29 family members of palliative patients from the four Swiss Cantons of study.

### **Explanation of Chosen Research Methods**

The data were initially analyzed using thematic analysis. This allowed for the themes in the data to be effectively explored in detail. However, after this, grounded theory (Corbin and Strauss, 1990) was used to visibly demonstrate the relationships that were found between the themes in the data. This was done in order to make sense of how the various themes that were identified in the data were related and contributed to the main phenomenon that was pointed to by the study findings (i.e. ambiguity of the key coordinator role). Importantly, it also was useful to demonstrate, not only how these themes are related, but what the consequences of these findings are for palliative care services. In this way, grounded theory helped elucidate the ‘story’ of the data, which provided contextual understanding of the themes and their implications of the findings for palliative care services.

### **Data Analysis**

Initially, all of the interview material was well reviewed. This included re-listening to all of the audio recordings and reading the interview transcripts. The first few transcripts were firstly coded manually. Thereafter, the subsequent codes were grouped into themes of similar and interrelated concepts. A second researcher of the team cross-checked to compare the codes that were applied to the initial transcripts and agreed on a set of codes to apply to all subsequent transcripts. This was done in order to ensure inter-coder reliability. Codes were then discussed with the project lead and agreed upon between us. Following this, the codes were clearly defined. The data in the subsequent transcripts were coded accordingly. Next, the remaining transcripts were organized and electronically coded, supported by qualitative data analysis software (MAX QDA), for efficiency purposes. Later however, the method

of Corbin and Strauss, who champion the development of ‘core categories’ (i.e. overarching concepts that tie the other categories together) was adopted. This made it possible to illustrate the relationship between the categories found in the data. The paradigm scheme of Corbin and Strauss was instrumental to visibly demonstrating the relationships between categories in a clear and understandable manner. This included; the core phenomenon, causal conditions, context, consequences and strategies.

## Results

Findings of the study revealed that there was considerable ambiguity concerning who plays the key coordinator role in palliative home care (i.e. confusion and/ uncertainty relating to who plays the key coordinator role in palliative home care). The causal conditions of this phenomenon included the informality of professional roles (i.e. that professional roles are more flexible rather than clearly defined) and lack of communication between team members. Moreover, the consequences of this included; conflicting understandings of key coordinator role and family members feeling overburdened. Lastly, strategies adopted by interviewees included; clear communication of the key coordinator role (e.g. telling the team who is responsible for care coordination) and maintaining a stable palliative home care team (i.e. minimizing changes to the palliative care team by keeping the team members the same, as much as possible).

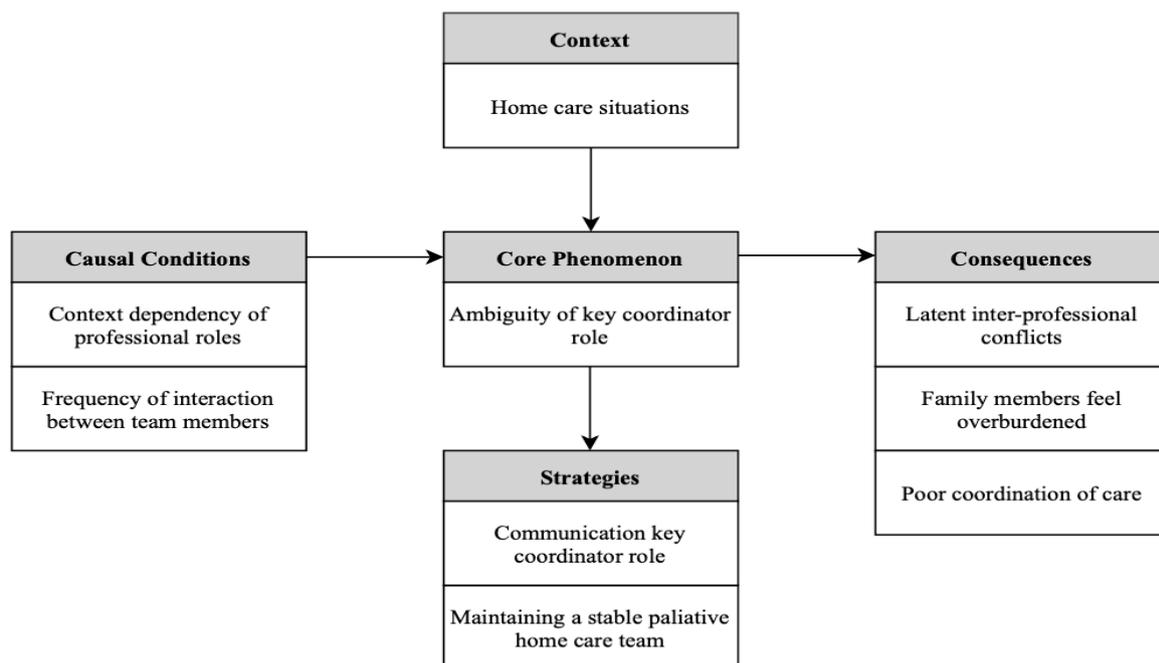


Figure 2. A paradigm model for the ambiguity of the key coordinator role, adapted from “Care coordination in palliative care: Who plays a key role?” *International Journal of Integrated Care*, (*In press*)

### **Manuscript 3: “Comparing professional and relatives’ perspectives of quality of care in palliative care: A qualitative interview study” *Journal of Integrative and Complementary Medicine (in press)***

#### **Methods**

The aim of the study was to identify and compare perspectives of quality of care between palliative professionals and relatives of palliative patients. Interviews were carried out with a total of 40 professionals working in palliative care and 26 relatives of palliative patients across four Swiss cantons. The sample included 40 professionals working in primary palliative care and specialized palliative care. These were; 11 general practitioners (GP's) and 12 nurses working in primary palliative care services, as well as 15 interviews with 9 specialized medical doctors (e.g. oncologists) and 6 specialized palliative care nurses working in hospitals, hospices, mobile palliative care teams (MPCT's) and specialist private practice. Moreover, a total of 26 caregivers participated in 22 interviews and one focus group (with three daughters and one son of a palliative care patient).

#### **Explanation of Chosen Research Methods**

The data were analyzed using thematic analysis (Braun & Clarke, 2009). This method was used because this type of analysis is optimal for identifying and reporting patterns within the data. This technique was therefore particularly useful for later comparing the themes that emerged in the data set so that synergies and discrepancies in perspectives of quality in palliative care could easily be identified.

#### **Data analysis**

The first step in the process entailed reading the interview transcripts and listening to audio recordings from the interviews in order to get familiar with the data. Next, the interview transcripts were divided according to interviews with professionals and interviews or interviews with relatives of palliative patients. Two researchers were involved with initially coding the data. I coded the data for the interviews with professionals and the other researcher coded the majority of data for the relatives, excluding the Italian speaking relatives from Ticino, which I coded for reasons of linguistic ability. A few transcripts were taken from each data set and coded manually. Between us, i.e. one researcher who speaks fluent French and German, and the other who speaks fluent Italian, we coded the data according to our linguistic ability. Moreover, we assisted each other if data was not understandable due to language barriers by translating segments of text in English (our shared spoken language), where helpful. After this, we discussed and compared the perspectives that we found within the data that related to the key topics (i.e. availability of care, the client centeredness of care, satisfaction with care (including physical and psychosocial care and communication and information transfer), (Bainbridge, 2010). The similarities and differences between the perspectives of relatives of palliative patients and professionals were identified and compared. Moreover, the perspectives identified in the data were continuously re-examined and discussed between the researchers before agreeing on them. This was done in order to ensure consensus between the researchers regarding the codes and analysis. The transcripts that followed were then coded according to the prominent perspectives that were identified in the data. As a final step, the data was coded using a qualitative data analysis software package (MAX QDA) to organize the data in an efficient and systematic way. This made it easier to report results later in the form of a written manuscript as the data was stored electronically.

## Results

Results revealed considerable differences between professionals and relatives perspectives with respect to the following aspects of care; 1) the availability of care, 2) client-centeredness of care (including respect for patient wishes and relatives involvement in care, 3) satisfaction with care (including physical and psychosocial) and 4) communication and information transfer. Importantly, the results revealed that family members felt that; care is not always readily available, care is poorly coordinated, patient needs are overlooked because of lack of time, some professionals are perceived to be incompetent, communication is lacking, and psychosocial needs are neglected. On the other hand, professionals indicate that relatives may be too involved in patient care and express concern due to the high risk of burn out caused by the high stress and emotionally taxing circumstances of palliative care. These results are overviewed in the table below:

Aspects of Care	Professional Perspectives	Relative Perspectives
<b>Availability of Care</b>	Care is easily accessible to patients	Care is not always easily accessible or available
<b>Client Centeredness of Care Respect for Patient Wishes Relatives Involvement in Care</b>	Care is patient centred and wishes are respected Relatives are too involved in care	Relatives are highly involved in care but would like to be more involved
<b>Satisfaction with care Physical Psychological</b>	Patients are satisfied with care Physical needs are better addressed than psychological needs	Poor coordination of care Poor continuity of care Lack of Professional competency
<b>Communication and Information Transfer</b>	Perceived lack of time for communication between palliative care team members	Lack of time for coordination between palliative care team members

Table 3. Overview of Perspectives of Quality in Palliative Care

## Chapter 3. General Discussion

This chapter includes the following sub-streams of information; a general discussion of the study findings and their, the added value of the research to knowledge in the field, the limitations of the research and the implications for practice and recommendations for future research. Lastly, my ‘final thoughts’ will conclude this dissertation.

All of the studies pertaining to this work contribute independently and substantially to the current state of knowledge in palliative care today. Each study brought important findings to light that meaningfully addressed both the research questions at hand and the goals of research. The specific findings of each study are discussed in detail in their respective manuscripts. Therefore, this general discussion will

highlight only some of the key contributions of the individual studies. Following this, there will be a discussion of the key collective findings of the studies, on the whole, i.e. the findings of research that are shared across the studies. These findings merit discussion as the strong commonalities to the research findings not only substantiate the study findings in themselves but also vouch for the prevalence of these issues in the field of palliative care.

## **Key Study Findings**

**Manuscript 1.** The aim of the first study was to identify challenges to coordination between primarily and specialized palliative care services. Whilst previous studies in Switzerland have been situated *within* palliative care services, the first manuscript was able to speak to the specific challenges to coordination exist *between* services. On one level, the findings further evidenced the fragmented nature of structural provisions for palliative challenges that exist to coordinating care, in line with what has been demonstrated of palliative care service provisions in Switzerland (Reeves, Schweighoffer & Liebig, 2019). Moreover, it further supports the literature advocating that sufficient resources, good infrastructure, and continuous funding are integral to achieving sustainable, integrated healthcare delivery, especially in palliative care (Groeneveld et al., 2017). Crucially however, the findings went beyond these explicit barriers to coordination and identified many barriers that arise from structural, relational organizational facets of coordination. These indications are important as in Switzerland, the explicit barriers that may come from a lack of provisional structures to coordination may not easily be improved because the infrastructure to coordination simply is not there or is insufficient for the necessary function. However, interpersonal barriers that were shown to play a large role in coordination across teams may be addressed to a certain extent, irrespective of limitations posed by provisional structures. To this end, the findings therefore strongly emphasize the professional formation in palliative care so that professionals are well equipped to manage such interpersonal barriers to care and ultimately can foster practices that are beneficial to ensuring effective coordination between services. Moreover, some structural barriers, like a lack of team meetings can easily be remedied through efforts within palliative care teams to instigate more team meetings in order to foster clear communication of tasks and support good interpersonal relationships respect for professional roles.

**Manuscript 2.** The objective of the study was to identify which professionals play a key role in care coordination in palliative home care. Findings importantly revealed that this is considerable ambiguity concerning who care coordinators are in palliative home care. This was mainly attributed to the fact that the key coordinator role is often context dependent, rather than a fixed position as professionals often adapt their role to meet rapidly changing patient needs or adjust to limited staff availability. This builds on the literature which shows that the increasing strain on the palliative care system can often result in professionals going above their usual professional responsibilities to meet the demands (Pavlish & Ceronsky, 2009). Similarly, the findings affirm previous studies, which highlight that poorly defined professional roles contribute to poor coordination between professionals and poor quality of care. However, importantly, the results also shed light on the negative impact that ambiguity concerning key coordinators has on family members, who consequently take on care coordination roles themselves and are over-burdened and often financially under-supported for what they do. The results therefore ultimately stress the importance of better support for family members of palliative patients, so that they would not be burdened with additional tasks, without recompense, but be empowered in their roles. Moreover, the findings support that clear communication of professional roles to all members of the palliative teams, including relatives is crucial for mediating problems with identifying care coordinators. Moreover, the need for adequately supporting those who are in coordinating positions has been also highlighted. Thus, since professionals often adopt coordination roles informally, the need for

ensuring adequate training for all palliative professionals is especially urgent. In this way, all professionals of the palliative team at least have the skill set and formal education required to manage coordinative functions.

**Manuscript 3.** This study sought to identify perceptions of quality in palliative care from the perspectives of professionals and relatives of professionals, as well as highlight convergences and synergies in perspectives. Findings identified divergent perspectives regarding quality of care including; the availability and access to care, the client centeredness of care, satisfaction with care (including physical and psychosocial care) and communication and information transfer. It could be summarized, that whilst professionals often evaluated quality of care to be “satisfactory”, relatives indicated the opposite to be true. Whether the quality of care is simply overestimated by health care professionals, or that relatives have expectations beyond on the capability of health care professionals and capacity of the health care system is up for debate. Nonetheless, the study highlighted critical differences between professional and relative perspectives that are worth attention. Significantly, family members reported serious concerns about quality in palliative care, including; that palliative care is not always readily available, care is poorly coordinated, patient needs are overlooked because of lack of time, some professionals are perceived to be incompetent, communication is lacking, and psychosocial needs are neglected. Professionals agreed with relatives that psychosocial needs are not as well addressed as physical needs and also reported that communication problems exist. However, professionals also expressed different concerns about aspects of care, including preoccupation for relatives of palliative care who are often extremely involvement in care, due to the high risk of burn out caused by the high stress and emotionally taxing circumstances of palliative care. Both similarities and discrepancies in perspectives represent a demand for addressing the shortcomings of palliative care services. From both relatives and professional perspectives, the high involvement of relatives, without recompense, was evident and is a clear area of need for improvement.

## **General Findings and Implications**

Whilst the individual findings of each study add vital knowledge to their fields of research within palliative care, taken together, the studies also echo similar findings that are important for the development of high-quality services. The common findings included; a lack of financial support for palliative care, poorly defined professional roles in palliative care settings, insufficient palliative care training opportunities and a lack of awareness for palliative care services. These findings are described below, with reference to their implications for palliative care.

### **Inadequate Financial Support for Palliative Care**

The findings collectively reflect a clear lack of financial remuneration available for palliative care services. Notably, the Swiss national tariff system (TARMED) does not subsidize many tasks which fall outside of typical job requirements of professionals, but that in reality, are integral to their daily working lives. As such, the lack of reimbursement makes the continuation of these tasks challenging. Equally, in Switzerland, relatives living in the same household as palliative patients may receive some financial reimbursement, but this does not apply to all cases and to those who care for the patient outside but live separately (Federal Office for Public Health, FOHP, 2016). The findings support prior evidence that that the financial strain of care for relatives of palliative patients contributes to significant distress, financial losses, worry and risk of burn- out (Gardiner, 2014). Moreover, the findings support that financial support is especially important as many family members are also ‘primary caregivers’ in palliative care. This means that they are individuals who provide the most care for the patient, without

payment (Cohen et al, 2006). Literature consistently shows that adequate financial reimbursement for staff services in the context of care is paramount (Groenveld et al, 2017) and is a vital consideration for ensuring good quality care and alleviating stress for carers (Travis & Hunt, 2001)

### **Poorly Defined Professional Roles**

The findings from all studies indicate that professional roles are often poorly defined in palliative care settings. Predominantly, this arises from the complex and quickly evolving palliative situations which can force individuals in palliative care teams to assume roles that are not a usual part of their expected function within the team. This is also true in the case of relatives of palliative patients, who can assume more responsibilities within the palliative care team that only further contribute to psychological distress and financial strain. Since the importance of clearly defined professional roles for ensuring the good functioning of the palliative care team, especially with respect to facilitating coordination, it is crucial that roles are clarified or better established. There may be various approaches to this. The most evident option is to adopt designated care coordinators into palliative care teams, such as; case managers or advance practice nurses. Alternatively, the second is to ensure that professional roles are communicated clearly and frequently within palliative care teams. This means that all professionals can be considered ‘care coordinators’ if they communicate this to the team. This type of team functioning is already practiced in the context of ‘trans-professional teams’, where roles are flexible and self-autonomous (Klarare et al, 2018). This can be effective, provided that both professionals and relatives of palliative patients receive enough support to be able to carry out coordinative tasks effectively. Ideally, they should thus have access to; appropriate financial remuneration for the time taken to engage in coordinating services, adequate training for care coordination and interprofessional collaborative practice and opportunities for psycho- social support (Larson & Tobin, 2000). More research about how palliative care teams can operate in a trans professional way within and between teams is presently being investigated (Reeves, Schweighoffer & Liebig, forthcoming, see appendix D for details).

### **Insufficient Palliative Training Opportunities**

For both palliative professionals and relatives of palliative patients, adequate training in palliative care should be central to their role for ensuring high quality palliative care. Naturally, professionals require the appropriate palliative training for their positions in order to meet the complex demands of palliative patients. However, many challenges in the functioning of the care team can arise from interpersonal or organizational factors that are aside from the professional medical training. The findings across the studies strongly build upon other reports in international literature that professionals often don’t have enough training of palliative care before they embark on their working roles in the context of palliative care teams (Al Qadire, 2014). Specifically, the results stress that professionals in Swiss palliative care teams ought to be equipped with the knowledge and skill set to facilitate interprofessional and coordinative practice in care, building on current arguments that the education for palliative care in Swiss undergraduate medical curricula is far too limited and needs strengthening (Pautex et al, 2008). Such developments are more urgently required than ever as healthcare providers will now need to undergo intense training to acquire new skills in care decision making and effective symptom control for patients who do not receive life-saving measures as a result of corona (Joni et al, 2020). If basic palliative care training cannot be guaranteed then the quality of palliative care is only going to be more challenged in the face of the pandemic, where specialist training is increasingly needed in order to adequately manage comorbid corona and palliative circumstances and symptoms (Borasio et al, 2020).

## **Lack of Awareness for Palliative Services**

Lack of awareness for available services in palliative care is usually discussed with respect to patient awareness for the availability of care as patients are often not aware of the services available to them (e.g., Borgstrom et al, 2019). However, the results from the studies indicate that professionals' and relatives are also often not aware of the services available to themselves or others. Concerningly, professionals were in some cases unaware of the services that were at their disposal for patient use. Moreover, in the last study, family members also supported that professionals did not inform them about the palliative care services available to them. If high quality care provision is to be ensured, it is imperative that all those involved in care are aware of the available services (Baxter et al, 2018). Otherwise, naturally this could result in limited access to patient care and potentially adverse effects for patients who do not receive the appropriate services, when needed. Today, as the corona virus results in many more people needing to access palliative care services, public awareness for palliative care is increasingly imperative.

## **Limitations of Research**

Limitations of the research undertaken are acknowledged. Firstly, although the cantons were strategically selected to be representative of palliative care in Switzerland, the generalizability of study findings may be limited as the studies were based on four cantons. Moreover, it is not clear how representative are the reported experiences, attitudes, and beliefs regarding the investigated topics of the study are. This may be because people who actively contribute to research around palliative care may have a greater interest in the topic or hold more pronounced views in its regard. In the case of the second study, it was not possible to discriminate between different specific palliative home care settings, which are influenced by different patient trajectories and can result in different challenges to identifying care coordinators than the ones identified in the study. Additionally, whilst the studies were able to obtain important insight about aspects of care from those closest to care, they were not able to include patient perspectives. This is because the research ethics committee did not grant the research team access to interviewing palliative patients, due to the sensitive topics of the interviews which could be potentially distressing for palliative patients. Moreover, this may have required more specialized skills and training for interviewing than what my colleagues and I possessed. However, naturally, the inclusion of palliative perspectives might have offered an even deeper understanding of perceptions and experiences of care coordination and quality of care. Yet, despite the given limitations of research, the contribution of the research to knowledge in this field is highly instrumental for understanding the complex phenomenon of care coordination and quality in palliative care.

## **Strengths of Research**

It is worth reiterating the novelty and added value that this research has for the current status of knowledge in this important sphere of healthcare as this is a chief aim for all scientific research, including my own. In the case of each study, there was a clear gap in research which has been partially filled by this work, and that of the NRP 74 research team in the context of the wider project. As clearly demonstrated in the literature, there was an evident lack of knowledge concerning the research questions addressed by the manuscripts, certainly within Switzerland and often internationally, to some degree. This research has been a considerable effort towards shedding light on these poorly understood aspects of palliative patient care and service delivery, specifically with regards to care coordination and quality of care in palliative care. Furthermore, each study built on the findings from the previous study, meaning that the real-life issues that were indicated in the data were explored so that critical areas of research

were not overlooked. Importantly, since the data derives directly from individuals who are well qualified best to speak on these topics, i.e. palliative professionals and relatives of palliative patients, the insights provided are invaluable for; the health care community, for fellow scientific researchers, for health policy makers, and for all those involved in palliative services.

## **Implications for Palliative Practice**

Collectively, the findings of the studies endorse the following steps for palliative practice moving forward. First and foremost, adequate financial remuneration for professionals in palliative care services to be adequately supported for their roles is paramount. This extends to relatives also who strongly need the financial backing in order to support their increasing involvement in the care of their relatives, usually without external recompense and according to the feasibility of their own funding (Berry et al, 2017). Additionally, professionals from all palliative care services should receive standardized interprofessional education as a part of their palliative formation to foster shared team understandings, values, and trust for professional competencies, as well as to increase awareness for available palliative services. Moreover, given the challenges of coordination and the negative impact of role ambiguity on quality of care, it is strongly recommended for palliative services to appoint designated care coordinators within services in order to facilitate care coordination both within and between services or engage in better communication habits. Lastly, in view of the intense involvement of relatives in patient care and the growing tendency for relatives to become primary care givers, adequate psycho-social and financial support should, in no case, continue to go unprovided.

## **Recommendations for Future Research**

In the face of demographic changes, cost discussions and staff shortages, palliative care has the potential to shape future research on chronic, long-term care and other fields of healthcare. Moreover, as we have seen with the rapid spread of the corona virus and its devastating impact on public health, it is important for palliative care services to be well-prepared to deliver high quality of care. However, palliative care research doesn't receive enough support, with public funding and some third-party money from humanitarian funds or charities as the only financial resources for research in palliative care and end of life care (Eychmüller and Pautex, 2019). The increased necessity for palliative care services today should be a loud cry for change in this regard. To this end, future research ought to receive more financial investment from governing bodies in health care and should focus on exploring how high-quality care and effective care coordination within and between palliative services can be best achieved. In support of this aim, strategies to implement palliative education more strongly into practice, as well as initiatives to implement care coordinators in palliative care services should continue to be investigated.

## **Personal Contributions to Future Research**

In response to the challenges to coordination that were identified at the interface of primary and specialized care, the following study sought to expand on understanding the underlying causes of these challenges which may stem from specific contexts of palliative care where different existing modes of teamwork may exist. An overview of the abstract and main findings of this manuscript are presented in the appendices:

**Forthcoming Manuscript:** “Crossing Borders: Teamwork related challenges in Palliative Care”  
Emily Reeves, Reka Schweighoffer, Brigitte Liebig, (forthcoming).

I will also share findings from my research at the upcoming Swiss Public Health Conference, where I hope that the findings of the study will be of interest to health care practitioners, policy makers and fellow researchers:

**Forthcoming Presentation of Research:** Coordination at the Interface of Primary and Specialized Palliative Care Service” – Emily Reeves/Prof. Dr. Brigitte Liebig (Fachhochschule Nordwestschweiz, NRP 74), From Evidence to Public Health Policy and Practice, Swiss Public Health Conference, 2-3 September 2020.

## **Final Thoughts**

Through the eyes of those closest to care, the research was able to bring to light important areas of need in palliative care services, that may otherwise have been overlooked. These contributions are but a small step in the right direction for understanding how quality in palliative care can best be supported. Yet, the research is built on the valuable testimonies to the reality of life with palliative care and thus should be respected as such. When I began this research in 2017, nobody could have predicted the importance of palliative care services in the pandemic era of 2020. However, our new reality brings to the forefront the realization that quality in palliative care cannot afford to be compromised. The status quo in palliative care has been overtly challenged by the severity of the demands of the current pandemic. Thus, the meaningful implications of the research and urgency to implement some of the recommendations for practice in this work should not be ignored.

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## **Appendices**

### **Appendix A: Manuscript Copies**

A1: Manuscript 1

A2: Manuscript 2

A3: Manuscript 3

### **Appendix B: Certificates of Publication Status**

B1: Certificate from International Journal of Integrated Care

B2: Certificate from Journal of Integrative and Complementary Medicine

### **Appendix C: Study Materials**

A1: Recruitment flyer for Relatives of Palliative Patients

A2: Informed consent forms for Professionals and Relatives of Palliative Patients

A3: Questionnaires for Palliative Professionals and Relatives of Palliative Patients

A4: Interview guidelines for Relatives of Palliative Patients

### **Appendix D: Supporting Information**

D1: Information about the Research Project

D2: Scientific Contributions of Research Project

D3: Information about Forthcoming Manuscript

D4: Curriculum Vitae

# An investigation of the challenges to coordination at the interface of primary and specialized palliative care services in Switzerland: A qualitative interview study

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## ABSTRACT

Good coordination of healthcare services is vital for ensuring health cost efficiency and high-quality care for patients. It is especially important in the context of palliative care as services are often highly fragmented due to a combination of diverse professional groups, organizations, and approaches to care. However, the coordination of services in this field is often evaluated as insufficient. Little is known about the challenges to coordination in this sector in Switzerland. The present study addresses this gap in research by investigating the challenges to coordination at the interface of palliative care services in Switzerland. Interviews ( $n = 24$ ) with 38 healthcare practitioners working in palliative care in four cantons (Basel-City, Lucerne, Ticino, and Vaud) form the basis for this investigation. The selected cantons not only represent French, Italian, and German language regions of Switzerland but also represent diverse rural, urban, and historical contexts. Expert interviews are analyzed using structural content analysis. Three clusters of challenges to coordination were identified in the data: (1) organizational challenges to coordination, which relate to explicit forms of coordination; (2) relational challenges to coordination; and (3) structural challenges to coordination, which relate to implicit forms of coordination. The study reveals a need for better financial support for coordination in palliative care and a stronger focus on interprofessional coordination in educating professionals in palliative care. Future research on how to further foster good team coordination practices between primary and specialized palliative services merits further investigation. Since these findings are indicative of areas for improvement for coordination at the interface of Swiss palliative care services, they are of particular interest for healthcare practitioners, policymakers, and researchers involved in the evolution of coordinative practice.

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## KEYWORDS

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## Introduction

Good coordination of healthcare services is essential for ensuring health cost efficiency and high-quality care provision for patients (Albrecht, McKee, Alexe, Coleman, & Martin-Moreno, 2008). In the context of palliative care, good coordination requires the effective marshaling of professionals and other resources required to carry out patient care activities and is usually managed by the exchange of information among providers of different aspects of care (Xyrichis & Lowton, 2008; McDonald & McCallin, 2010). Palliative circumstances especially require well-coordinated responses in the face of quickly changing clinical status or patient preferences for location of care (Agar et al., 2008). Yet, the coordination of services in this field is often evaluated as insufficient (Peikes, Chen, Schore, & Brown, 2009).

Previous literature has indicated factors that challenge coordination within palliative care settings. Notably, many challenges to coordination arise from the specific requirements of patient trajectories, which call for the coordination of different palliative care services and combinations of professional competencies (Murray et al., 2015; Turner-Stoke et al., 2007). Patient populations, regional conditions, network characteristics, and availability of resources can also present barriers to coordinative action (Bainbridge, 2010). In Switzerland, further challenges to

coordination are attributed to cantonal differences regarding palliative care. Specifically, the federalist organization of the Swiss health system does not allow for uniform standards of palliative practice. Crucially, although the “National Strategy for Palliative Care 2013–2015” provides a general guideline for palliative practice for the 26 Swiss cantons (Federal Office of Public Health, FOPH, 2016), they are free to adhere to or ignore the guidelines where they feel appropriate. Consequently, rather than a cohesive approach to palliative care, provisional structures and implementation are extremely fragmented (Radbruch & Payne, 2011), with differences also found between rural and urban contexts (Alvarado & Liebig, 2015). Moreover, understanding of the challenges to coordination in palliative care in Switzerland is rather limited (Wittenberg-Lyles et al., 2009). The majority of the existing literature regarding palliative services in Switzerland focuses on challenges to interprofessional collaboration rather than coordination (Alvarado & Liebig, 2016; Alvarado & Liebig, 2015) and is limited to outpatient or stationary palliative contexts. Certainly, interprofessional collaboration and coordination are strongly related and are both important for effective team functioning (Evert, Laars & Noordegraaf, 2019; Reeves, Xyrichis, & Zwarenstein, 2018). However, interprofessional collaboration refers to when professions work together to achieve common goals and is often used

as a means for solving a variety of problems and complex issues (Green & Johnson, 2015). On the other hand, interprofessional coordination specifically describes the managing of tasks, resources, and people (Malone & Crowston, 1994). This suggests that coordination is not only part of a collaboration but can be understood as a specific activity carried out by group members when managing interdependencies.

Little is known about the challenges to coordination at the interface of primary palliative care and specialized palliative care services. Identifying challenges to coordination at the interface between primary and specialized palliative care is imperative as patients frequently require a transfer from primary to specialized services and the task of navigating through this transition can be demanding (Liebig & Piccini, 2017). The present study aims to explore perceived challenges to coordination at the interface of Swiss primary and specialized palliative services. This insight is needed to inform health policy regarding coordinative practices between palliative services in Switzerland.

## Methods

A qualitative study design was adopted to explore perceived challenges to coordination between primary and specialized palliative care services from the perspectives of healthcare practitioners working in Swiss palliative care services.

## Sample

Results are based on a qualitative study in which semi-structured interviews with a total of 38 professionals working in palliative care in different regions of Switzerland were carried out, namely the following cantons: Basel-City, Lucerne, Ticino, and Vaud. These cantons not only reflect rural and urban regions but also diversely developed policy contexts for palliative care in Switzerland. The sample included 24 interviews with 11 general practitioners (GPs) and 12 nurses working in primary palliative care services, as well as 15 interviews with 9 specialized medical doctors (e.g., oncologists) and 6 specialized palliative care nurses working in hospitals, hospices, mobile palliative care teams (MPCTs), and specialist private practice.

## Data collection

Data were collected between January and June of 2018. The participants were identified in each canton via Internet searches and personal referral. They were recruited via e-mail invitation or telephone call. Those included in the study were interviewed by three researchers in a semi-structured interview format, in the language corresponding to the official language of the canton (Vaud: French, Ticino: Italian, or Lucerne/Basel: German). Interviews lasted between 30 and 45 minutes and were conducted in a location determined by the participant (e.g., clinic or personal office). Interview guidelines were informed by concepts derived from a conceptual framework for the evaluation of integrated palliative care networks (reference 8) and covered key topics to explore challenges to coordination (see Table 1). Demographic data were collected from all participants.

**Table 1.** Excerpt of interview questions.

(1) How are tasks and responsibilities divided in your network/cooperation?
(2) Who, in your opinion, has a key role in your network/cooperation when it comes to coordinating tasks?
(3) Who takes the lead in your network/cooperation?
(4) Who takes the lead in a critical situation?
(5) How does the communication work in your network/with other professionals? (with respect to intensity, quality, means of communication)
(6) Do you feel that everybody is as committed to the network/collaboration, as they should be?
(7) Would you say, you work on the basis of common goals and values?
(8) Do you and your team or collaborators do have a trustful and respectful relationship to each other?
(9) How do you solve problems in your network/together with your collaborators?

Interviews were audio-recorded and transcribed verbatim in their original language, with all personal identifiers removed.

## Data analysis

The data were analyzed using “structural content analysis” (Kuckartz, 2012) to identify and report patterns within the data. The first stage of analysis involved familiarization of the data, i.e., audio recordings and the transcripts. The second stage was coding the data. The first few transcripts were coded by two researchers, and subsequent codes were grouped into clusters around similar and interrelated concepts. To facilitate clarity in the analysis of the data, a distinction was made between concepts, which differentiated between challenges to *explicit forms of coordination*, which relies on instruments (e.g., electronic tools, schedules, plans) and verbal and written communication (instructions, meetings, feedback), and challenges to *implicit forms of coordination* (i.e., the processes involving non-verbal aspects of communication or actions), including the synchronization of members’ actions based on unspoken norms and assumptions (Espinosa, Lerch, & Kraut, 2004; Malone & Crowston, 1994). The researchers cross-checked to compare the codes that were applied to initial transcripts and agreed on a set of codes to apply to all subsequent transcripts. This was done in order to ensure consensus between the researchers regarding the codes and analysis. Codes and themes in the data were constantly discussed and reflected upon among the team of three researchers to ensure rigor in the analysis. On the basis of this, the codes were then grouped together into clusters of challenges which were then clearly defined. The data in the subsequent transcripts were then coded according to these clusters. Data were then re-coded by one of the researchers using a qualitative data analysis software package (MAX QDA) to organize the data efficiently and systematically.

## Ethical considerations

Formal research approval for this study was obtained from the Ethics Committee of Northwestern Switzerland (EKNZ) on 29 August 2018 (Req-2018-00490). At the outset of interviews, participants received and completed an informed consent form for participation in the study and recording of interviews. Before each interview, explanations about objectives, reasons for recording interviews, voluntary participation, and

confidentiality of data were given. The anonymity of participants was guaranteed.

**Results**

The aim of this study was to identify challenges to the coordination at the interface of primary palliative care and specialized palliative care services in Switzerland. Three clusters of challenges were identified in the data (see Table 2). These were (1) Organizational challenges to coordination, which relate to *explicit forms* of coordination; (2) Relational challenges to coordination; and (3) Structural challenges to coordination, which relate to *implicit forms of coordination*. These challenges are discussed with respect to the perspective from which they derive (i.e., primary and/or specialized service provider perspectives) and are explained as follows.

**Organizational challenges to coordination**

The categories of this cluster of challenges include (a) non-standardized use of electronic patient records (EPR), (b) lack of preplanned/regular meetings between primary/specialized palliative care providers, and (c) indirect communication between providers.

**Use of EPR**

As reported by both PPC and SPC service providers, coordination is hampered by non-standardized use of EPR systems. Professionals use systems for the storage and sharing of EPRs that are specific to their own PC institution or practice. However, it is not possible to share patient documents and other relevant patient information across incompatible electronic systems, which is often the case across primary and specialized palliative care services. As one nurse asserted: “We use old fashion methods, because people are not up to date so you can’t just send them a file or link online (...) frustrating really!” (Nurse, Ticino). The majority of the respondents thus express a desire for the use of a standardized information transfer systems across institutions: “It would save so much time and would be so convenient for everyone! I don’t know why we don’t have this already” (Assistant nurse, Ticino).

**Lack of regular meetings**

Interviewees also expressed that the coordination of patient care is harder to achieve, as meetings with members from the other services are mostly “ad-hoc” rather than preplanned or scheduled regularly. Therefore, it is difficult to remain informed about care coordination. To be able to attend meetings, professionals must be extremely flexible when a meeting

is called spontaneously, which is difficult to achieve amidst an already busy schedule. As one interviewee argued: “I cannot be expected to drop things and go, this is simply not realistic for me” (GP, Vaud).

**Indirect communication**

Another problem reported for coordinating tasks is the inability to communicate with other service providers directly (i.e., not face to face or on the telephone). Mainly this was attributed to difficulties in reaching other services via telephone or e-mail: “It’s so difficult to get hold of the GP when you need them. We all have busy working lives” (Specialist, Luzern). Moreover, having to communicate via a second person such as a colleague or secretary when the relevant professional is not available complicates coordination: “If you reach a voicemail or a secretary, you don’t know if the message will really go through. If it’s something urgent then you might be stuck” (Head nurse, Ticino). Problems with indirect communication were reportedly worsened by geographical distances between providers. Providers face complications when they are not able to reach others via telephone or e-mail correspondence, a common problem among GPs whose time is in high demand, as they cannot easily meet up with them personally otherwise. As described by a GP: “Within my own team, I can just talk to them directly and Mendrisio is a small area, but if I need to reach a specialist all the way in Lugano (large town in Ticino), it’s much more complicated as it’s much further away” (GP, Ticino).

**Relational challenges to coordination**

The categories of this theme are (a) conflicting understanding of professional roles, (b) conflicting team understanding, and (c) distrust for professional competencies.

**Professional roles**

Respondents describe conflicting understandings of the professional roles of members of the other service. Specifically, with respect to identifying those responsible for the coordination of tasks and decision-making, ambiguity is apparent. Notably, both members of primary and specialized palliative services felt that they were the sole responsible actor for the coordination of tasks. Moreover, there was a lack of understanding of the role of the members of the other team with respect to the coordination of patient care. As one specialist remarked: “I’m not sure why I would need to talk to primary palliative services once I have the patient under my custody” (Specialist, Lucerne).

**Table 2.** Overview of challenges to coordination at the interface of primary and specialized palliative care services.

Challenges to coordination at the interface of Swiss primary and specialized palliative care services		
Organizational challenges	Relational challenges	Structural challenges
Non-standardized use of electronic patient records (EPRs)	Conflicting understanding of professional roles	Lack of time for coordination with other services
Lack of preplanned/regular meetings between primary/specialized palliative care services	Conflicting team understandings	Lack of financial remuneration for coordination with other services
Indirect communication between providers	Distrust for professional competencies	Lack of awareness of available services

### **Team understanding**

Similarly, interviewees clearly showed conflicting team understandings. Specifically, although some primary palliative care practitioners reported feeling part of a larger palliative team, which includes specialized palliative care members, others did not. Notably, some interviewees did not see themselves as working as part of a team at all so they did not see the need to coordinate with others beyond their immediate team of professionals, within their own field. Markedly, a specialist reported how a GP claimed that it was not necessary to pass on their patient to specialized care as “they did a three-month palliative care course, and therefore didn’t see the need for the patient to be transferred to a specialist” (Specialist, Ticino). Similarly, the disparity in views concerning team understanding was evident. Interestingly, most primary and specialized palliative professionals considered themselves team members: “Of course I am part of a group of people that work together as part of a palliative care team” (assistant nurse, Basel). Yet GP’s responses included remarks that reject the notion of being in a team: “Palliative care team? What palliative care team?” (GP, Vaud) and “no, I am not part of a ‘team’” (GP, Basel).

### **Trust in competencies**

Many interviewees alluded to distrusting the professional competencies of members of the other services. Many attributed this to unfamiliarity of other professionals in the other services. Therefore, where possible, they would rather assign coordinative tasks to members of the same team, rather than another. Moreover, some members reportedly do not trust members of the other services to know how to carry out a task. As one nurse described “I feel a bit embarrassed to explain to a specialist what they should do, but sometimes they don’t know because they haven’t worked as closely with the patient as we have” (Assistant nurse, Ticino). One or two participants also reported that previous interpersonal conflicts with members from other teams about the disagreement of patient care prevented them from wanting to cooperate with them in the future. For example, “I try to avoid working with that doctor, and if I know he will be there, and I would rather ask for someone else to work with me on a task instead” (nurse, Ticino)

### **Structural challenges to coordination**

The categories related to this final theme are (a) lack of time for coordination with other services, (b) lack of financial remuneration for coordination with other services, and (c) lack of awareness of available services.

Unsurprisingly, many professionals reported that a lack of personal time prohibited them to commit to coordinating tasks with other services: “Often I really don’t have time to take a phone call because I am with a patient, never mind meeting personally” (GP, Vaud). Additionally, interviewees explained that most coordination with the other services goes unpaid so although there might be some opportunities to meet more often, it is not often followed through. One nurse in Ticino recalled that: “At the very beginning, our team, the specialist and the patient meet up and this time is

paid, but then after that, that’s it.” It was also apparent from some interviews that some professionals do not actively coordinate with members of other services as they are not always aware of the services that are available to them. When asked about collaboration with professionals from other palliative services, one specialist in Luzern admitted that they “didn’t know that MPCT’s were available in the area.”

### **Discussion**

It is unsurprising that the inability to share patient documents electronically presents challenges to coordination at all interfaces between palliative care-related occupations and institutions. The sharing of relevant, timely information across professional boundaries is fundamental for good care coordination (Nancarrow et al., 2013). Patient documents are essential for providers to understand patient requirements and determine appropriate care (Brunner, 2010). Other countries have developed electronic palliative care coordination systems (Hall, Murchie, Campbell, & Murray, 2012). However, Switzerland is not so far advanced as not all cantons and their pertaining palliative care services use electronic patient documents. Notably, the use of EPRs was only enforced in Switzerland in 2017 in nursing homes and hospitals, although it is not yet obligatory in primary care (Bundesamt für Gesundheit (BAG), 2019). Given that patient documents contain vital information for the treatment plan of patients, delays in acquiring patient documents can delay patient treatment, potentially resulting in poorer quality of care.

Failure to schedule regular meetings and indirect communication between providers presents a clear challenge to coordination since in the complex, demanding working environment of palliative care, time constraints are inevitable (Jünger, Pestinger, Elsner, Krumm, & Radbruch, 2007). Specifically, as meetings are frequently arranged informally, it is plausible that professionals cannot find the time to meet spontaneously amidst a busy working schedule.

While a few meetings between services are predetermined, these are often optional and therefore professionals may not be inclined to prioritize them. Opting out of meetings could be indicative of a lack of motivation for attendance. Since individuals are often driven by personal and professional values (Hoffer, Godfrey, & Thistlethwaite, 2013), it could suggest that the value of these meetings is not apparent to those working in the field. If this is the case, this finding alludes to a need for enforcing the value of coordination between teams within palliative services and implementation of regular meetings. The literature strongly supports that structured meetings where attendance is required are more effective for ensuring the cooperation of services (Garcia, 2009). The finding that indirect communication presents challenges to coordination between service providers reflects previous health literature that miscommunication is common where multiple actors are involved (Lockett et al., 2014). This finding is alarming as indirect communication allows for delays in information transfer and potential miscommunication. Since palliative situations can be very delicate, the miscommunication of information regarding a patient or delay in coordination of care (e.g., transfer from primary to

specialized palliative care) can have detrimental implications for patient outcomes.

On a deeper level, apparent inconsistencies in understanding of professional roles among providers are identified. Specifically, professionals' opinions about who is responsible for coordination or decision-making differ between services. Notably, many professionals see themselves as the person responsible for coordination, while this opinion is not shared by others. On the contrary, while some specialists believe their role to be central to decision-making and coordination, some specialized palliative care members did not see the need for cooperating with them once patients had been transferred into their care. Some ambiguity concerning professional roles may be attributed to the context dependency of those in the coordinative role. This finding may be explained by the literature which supports that the decision of who takes coordination roles is mostly determined in the context of specific conditions, if not in the individual case (Bainbridge et al., 2010). However, a lack of consensus could have a negative impact on coordination since it can be unclear among the healthcare practitioners who are ultimately in charge of coordination. Practically, this might also hinder interprofessional collaboration because those who believe they are solely responsible for coordinating tasks may not be motivated to collaborate with others. The literature supports that clearly identified professionals who are appointed to coordinate, e.g., case managers, are beneficial for ensuring good coordination (Gomes et al., 2012; Sleeman, Davies, Verne, Gao, & Higginson, 2016). Empirical findings also demonstrate that identifying a key coordinator helps mitigate coordinative issues and facilitates integrated care (Lockett et al., 2014). The data also revealed opposing beliefs about team ideology. Essentially, some professionals identified themselves with being part of a palliative care "team" that included the other service, while others did not. While this result does not seem unusual for professionals across healthcare settings (Harrison, Sampson & Devries, 2019), these findings have some considerable implications for coordination. Notably, if an individual does *not* identify with being part of a wider palliative care team, then the motivation to coordinate service provision with others, or a rationale for needing to do so, is somewhat lacking. This could result in members of palliative services not cooperating with others, where it might be beneficial.

The findings also indicate distrust for professional competencies of those working in other palliative care fields. Crucially, it was suggested that primary palliative care members do not wish to pass on their patients to specialists because they do not believe they need to do so, indicating a lack of trust for specialist services. This result reflects previous reports that some physicians consider palliative care as a rather "naturally given" human competence and therefore not an issue of formal learning (Wollin, Yates, & Kristjanson, 2006). This is significant as the appropriate transition of patients from primary to specialized palliative care is fundamental for ensuring optimal treatment outcomes for the patient (Bainbridge et al., 2010). Failure to do so can result in adverse patient outcomes such as discontinuity of care (Bally, Lingenhel, & Tschudi, 2012). However, fostering an environment where there is mutual trust between actors

might help to remedy these negative effects (Hansen, 2009; Wolkowski, 2010)

Finally, many professionals report structural challenges to coordination with other palliative services. Crucially, many respondents reported a lack of time for coordination with others. This is hardly surprising given the extensive literature surrounding healthcare professionals who are overburdened with work (Cassel, Ludden, & Moon, 2000). However, this finding could also be related to the lack of financial remuneration available for coordination between services. The Swiss national tariff system (TARMED) that financially supports these professionals does not extend to crucial tasks such as coordinating further specialized care. Thus, professionals must dedicate time to coordinating tasks across services, with little to no recompense. In view of this, allocating time toward coordination between services is unlikely to take first priority. As the literature shows, adequate financial reimbursement for coordination between services is paramount (Reeves, Schweighoffer & Libeig, 2019). Specifically, financial support has a substantial impact on the time allocated for coordination activities and the quality of care provided (Travis & Hunt, 2001). Sufficient resources, good infrastructure, and continuous funding are integral to achieving sustainable, integrated healthcare delivery, especially in palliative care (Groeneveld et al., 2017). Lack of awareness for available services in palliative care is usually discussed with respect to patient awareness for the availability of care (e.g., Borgstrom et al., 2019). However, the results indicate that professionals' coordination with other services may be restricted as they are not aware of the services available to them. This has potentially adverse effects for patients who might require additional support from other services. Given that awareness of the availability and accessibility of resources is vital for ensuring integrated care (Baxter, Johnson, & Chambers et al., 2018), professionals should be well informed of the range of services available for their use.

### **Limitations of the study**

Limitations of the study are acknowledged. It is unclear how representative are these experiences, attitudes, and beliefs regarding challenges to coordination between primary and specialized services. This may be because people who actively contribute to research around palliative care might have a greater interest in or more pronounced views on the topic. In this study, we did not include palliative patients or their relatives. However, patients and relatives of palliative patients are also key members of palliative care services so their perspectives on challenges to coordination between services may have provided an even richer understanding of these challenges. Other studies that have compared patient perspectives or relatives' perspectives with professional perspectives in this field have highlighted interesting differences in views between professional groups and patient/relative groups with respect to different aspects of care (reference). Future research that could also explore patient and relative perspectives in addition to or in comparison with professional perspectives on this topic would thus provide an interesting insight to inform the development of care coordination between palliative services.

## Conclusions

The aim of this study was to investigate challenges to coordination at the interface of primary and specialized palliative services in Switzerland. The findings not only affirm previous literature that proposes that Switzerland is in need of improving coordination of palliative services but indicate specific challenges to coordination at the interface of these services. Specifically, three key clusters of challenges to coordination at the interface of primary and specialized palliative services were identified. Firstly, organizational challenges included: the non-standardized use of EPRs, a lack of preplanned/regular meetings between primary/specialized palliative services, and indirect communication between providers. These factors were particularly detrimental to the exchange of important patient information necessary for good care coordination. Secondly, relational challenges were conflicting understandings of professional roles and team understandings, as well as distrust for professional competencies. These challenges particularly deterred interprofessional coordination and collaboration. Lastly, structural challenges, including a lack of time for coordination, a lack of financial remuneration for coordination, and a lack of awareness of available services, were identified. These findings clearly indicate barriers to coordination that should be addressed in order to ensure high quality of care provision for palliative patients.

On the basis of these insights, the following recommendations for improvement are proposed. First and foremost, adequate financial remuneration for professionals engaged in coordination at the interface of services must be provided. Additionally, professionals from both primary and specialized services should receive interprofessional education as a part of their palliative formation to foster shared team understandings, values, and trust for professional competencies, as well as to increase awareness for available palliative services. Furthermore, given the difficulty of communication between providers, it would be advisable for palliative services to appoint designated care coordinators at the interface of services in order to facilitate care coordination. Moreover, future initiatives to develop compatible electronic records would be beneficial for mitigating organizational challenges to coordination at the interface of services. The results of this study are of value to healthcare practitioners, policymakers, and researchers involved in the evolution of coordinative practice. Future research to identify further strategies and initiatives for facilitating coordination between primary and specialized palliative services warrants investigation.

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## Declaration of interest

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## Care coordination in palliative home care: Who plays the key role?

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### Abstract

**Background:** Clearly identified professionals who are appointed for care coordination are invaluable for ensuring efficient coordination of health care services. However, challenges to identifying roles in palliative care are well documented in literature. Notably, in order to meet high demands on palliative home care settings, many care practitioners perform tasks that surpass the responsibilities and regulations of their role, including care coordination. Without clearly defined roles, standards of care cannot be guaranteed. Yet, little is understood about who plays the key role in palliative home care.

**Aim:** The present study aims to address the gap in the research by identifying who plays a key role in coordination in palliative home care.

**Methods:** Interviews with general practitioners (GPs), nurses and relatives of palliative patients were carried out in Swiss cantons (Vaud, Ticino, Luzern and Basel) to identify key coordinators of care. Interviews were analyzed using content analysis and presented using grounded theory.

**Results:** Findings indicated that there was considerable ambiguity of the key coordinator role. 1) Causal conditions of this phenomenon were; informality of professional roles and lack of communication between team members, 2) Consequences of this included; conflicting understandings of key coordinator role and family members feeling overburdened, 3) Strategies adopted by interviewees included; adapting or taking control of care coordination. These findings are highly indicative of areas for improvement for care coordination in palliative home care settings. Specifically, they underline a profound need for clear communication between palliative care service providers regarding which professionals assume a key coordinative role, or who are delegated a coordinative role at any given time. Crucially, since the findings reveal that relatives are intimately involved in care coordination, the findings point to a lack of adequate financial and psycho-social support for relatives of palliative patients who are burdened with coordination tasks, without the appropriate recompense.

### Keywords

Palliative care, care coordination, home care, Switzerland, qualitative study

### Introduction

Clearly identified professionals who are appointed for care coordination are invaluable for ensuring efficient coordination of health care services [1, 2]. Care coordination involves “the regulation of diverse elements into an integrated and harmonious operation” [3]. In palliative home care settings, individuals who play a key role in care coordination often include: general practitioners (GPs), nurses, advanced practice nurses and case managers [4]. These individuals are involved in coordination activities such as: outreach to patients by phone or mail; conducting face-to-face patient encounters; providing social support for patients; collecting, managing, and exchanging patient data; supporting physicians; and backing up clinical and administrative staff [5].

Palliative home care teams allow patients to receive high-quality, personalized care in their own home setting [6]. The service is usually provided as a way of continuity of care from hospital to home, with the offer of up to 24-hour-a-day staff availability [7]. This is often only possible through supplementing additional members to a team or interchanging team members with shifting rotas, meaning that teams are commonly made up of changing staff members. Moreover, since home care requires intensive supervision and care, professionals must be readily available to respond to patient needs [8]. This can provide a challenging context for identifying those who play a key role in care coordination. Challenges to identifying roles in health care are well documented in the literature [9,10,11] and are largely attributed to health care practitioners performing tasks that go well beyond the responsibilities and regulations of their role [11]. Notably, in everyday practice healthcare providers are increasingly performing roles that, in addition to clinical practice, concern organizational and managerial aspects, including care coordination [12, 13].

Similarly, in order to meet increasing demands on health services, many care workers experiences “vertical substitution”, i.e. a role which is typically performed by a worker at a higher occupational station is now performed by a worker at a lower occupational station [14]. Crucially, these factors have been shown to contribute to adverse effects for care coordination as they can result in ambiguity concerning role recognition amongst care providers, i.e. “the situation where individuals do not have a clear direction about the expectations of their role” [9] and fuel role conflict, where individuals disagree about what the expectations are for a particular role [15]. Without clearly identified roles, standards of care cannot be granted [16] and the quality of coordination may be compromised [17]. Yet, little is understood about who plays a key role in care coordination. This is especially true for Swiss palliative home care, where research efforts have focused on specialized palliative care settings rather than home care in Switzerland [18]. Although some previous research in this field has identified GP’s as important actors in Swiss palliative home care [19], few studies have sought to address who the key coordinators are in palliative home care. The aim of the present study is, therefore, to address this gap in the research and thus explore who plays a key care coordinator role in palliative home care, from the perspectives of palliative home care teams.

## Methods

### *Sample and context*

Results are based on a qualitative study. The sample included 24 interviews with 12 general practitioners (GPs) and 12 nurses in primary palliative care including the home care setting, and 29 family members of palliative patients in different regions of Switzerland (see table 1). Qualitative data was collected between January 2018 and April 2019. The relevant participants for the study were identified in each canton via internet searches and personal referral and were recruited via email invitation or telephone call. As table 1 shows, the sample includes a larger number of women in the group of nurses and family members, while a slightly higher number of male GPs were interviewed. The mean age of those interviewees was 53 years of age for professionals and 59 years amongst family members.

Participants	Number	Gender		Age (Mean)
		Female	Male	
GP’s	12	5	7	53
Nurses	12	10	2	53
Family members	29	20	9	59

Table 1. Demographic data of participants

### *Ethical considerations*

Formal research approval for this study was obtained from the Ethics Committee of Northwestern Switzerland (EKNZ) on the 29<sup>th</sup> of August 2018 (Req-2018-00490). At the outset of interviews, participants received and completed an informed consent form for participation in the study and recording of interviews. Prior to interviews, explanations about objectives, reasons for recording interviews, voluntary participation, and confidentiality of data were given. The anonymity of participants was guaranteed to them and ensured through the exclusion of all personal identifiers from interviews

### *Interviews*

Interviews were semi-structured and carried out in the language corresponding to the official language of three different language regions, i.e. German, French or Italian. Interviews lasted between 45-60 minutes and were conducted in a location determined by the participant (e.g. clinic, personal office, in a home setting or a public place). Interview guidelines were informed by concepts derived from a conceptual framework for the evaluation of integrated PC networks [20] and covered key topics to explore perceptions of coordination in primary palliative care. Interview questions for professionals included; “who in your opinion

has a key role in your team when it comes to coordinating tasks?” and “how are tasks and responsibilities divided in your team?”. Questions directed at family members included: “who plays a key role in coordination in the palliative care team?” and “do you know how tasks and responsibilities are shared in the team?”.

### Data analysis

The first stage of analysis involved familiarization of the data, i.e. audio recordings and the transcripts. Audio files were either fully or partially transcribed in their original language by a professional transcriber or by one of the researchers, depending on the language of the interview. Two of the researchers are fluent in German, one is fluent in French and another is fluent in Italian. The transcriptions were translated where needed into the corresponding language of the researchers. The second stage was interpreting the data. The data from interviews was originally analyzed using ‘thematic analysis’ [21] to systematically identify and report content related patterns within the data. The first few transcripts were firstly coded manually and subsequent codes were grouped into themes of similar and interrelated concepts. A second researcher cross-checked to compare the codes that were applied to the initial transcripts and agreed on a set of codes to apply to all subsequent transcripts. This was done in order to ensure inter-coder reliability. Codes were agreed upon and were then clearly defined. The data in the subsequent transcripts were coded according to these themes. Lastly, remaining transcripts were organized and electronically coded, supported by qualitative data analysis software (MAX QDA) for efficiency. Later, the method of Corbin and Strauss [22], who espouse the development of ‘core categories’ (i.e. overarching concepts that tie the other categories together) was adopted. The paradigm scheme of Corbin and Strauss was used, which includes; the core phenomenon, causal conditions, context, consequences-and strategies [22]. This was done in order to clearly illustrate the relationship between the categories found in the data.

### Results

The aim of this study was to identify who plays a key role in coordination in a palliative home care setting, according to the perspectives of professionals and family members in the field. Findings indicated considerable ambiguity concerning who is responsible for care coordination in palliative home care contexts. Findings are presented using the conceptual framework proposed by Corbin and Strauss for the development of categories and subcategories [22]. The categories include; the identified core phenomenon (ambiguity of key coordinator role), causal conditions for this ambiguity of the key coordinator role, the context in which ambiguity of key coordinator role is found, the consequences of ambiguity of this key role and strategies adopted by the participants to mitigate this. The relationships between these categories are demonstrated in figure 1.

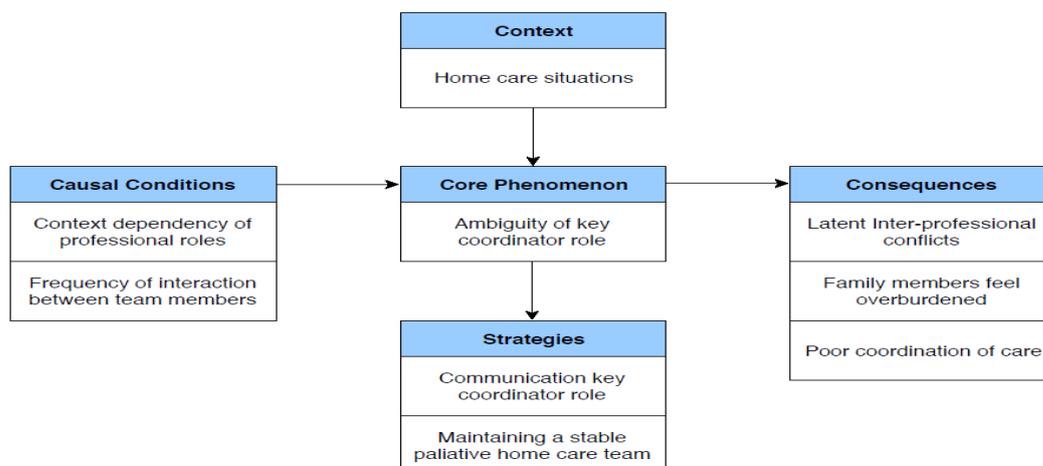


Figure 1. Ambiguity of the key coordinator role in palliative home care

### ***Core Phenomenon: Ambiguity of key role for coordination***

The data revealed considerable ambiguity concerning the key coordinator role in the palliative home care setting. This was apparent in the discrepancy of responses in all three groups of interviewees regarding who is the key worker in primary palliative care teams. For example, whilst it was acknowledged by many participants that GPs are “theoretically” considered key coordinators, it was also argued that the key coordinator role does not fall so strongly on the GP in everyday practice: “In theory, yes, the GP is in charge - but in the end it is the nurse who is looking after all the care and making the decisions” (family member). This view is also supported by a professional in the field: “We see the doctor if we need him for a morphine prescription or something but I am looking out for everything on the ground here since I am with the patient night and day, almost every day” (nurse). Ambiguity is also evident in the lack of consensus regarding who obtains the key role in coordinating tasks. Notably, there are many cases of family members, nurses and GPs who all consider themselves to play a key role in coordination. Whilst a GP argues: “I am responsible for the care plan of patients and that they get the care that they need (GP), a nurse reasons the same: “I see to it that she (the patient) gets what she needs and when she needs it. If she needs something else, I can usually tell, and I can organize for her whatever it is that she needs” (nurse). Interestingly, family members also consider themselves as the key coordinators: “this is my job full time, it’s not a real job but this is what I do day and night. I am the one organizing things for my mum, every step of the way. I have everything here about my mother at my fingertips; I don’t need information from the nurses or anyone. I know exactly what medication she needs and when” (family member). When asked about who is the coordinator, a relative replies that they are as: “I know everyday life with my mum, it’s been years now. If she needs something else or something is wrong, I know what to do by now. I know how to tend to her because I learnt it all” (family member).

### ***Context: palliative care at home***

Palliative home care is designed to provide symptom management while treating holistically (i.e. catering to physical and psycho-social needs) and allowing patients the choice of receiving high-quality, personalized care in their private home setting. The service is often provided as a way of continuity of care from hospital to home, with the offer of up to 24-hour-a-day staff availability. This is commonly only feasible by adopting additional members to a team who have complimentary working hours, meaning that teams are often made up of changing staff members. Moreover, since those in home care require intensive supervision and care, professionals must be readily available to respond to patient needs and changing states of health. This can provide a challenging context for identifying clear coordinators across situations. Some nurses report that care teams frequently change members which often results in ambiguity concerning who is responsible for care coordination or decision making: “It really depends who is around because it’s not always the same people working (...) if somebody new comes in (to the team) and you have to teach them from scratch what to do (...) they don’t really know how we do things or who they should go to in situations” (nurse). This perspective is shared by family members who express the belief that new members to the team can cause confusion because they don’t adhere to the implicit norms that allow coordination: “normally, people know they should contact Maria (nurse) if there is anything, but if the person is new (to the team), then they don’t necessarily get it straight away” (family member).

### ***Causal conditions for the ambiguity of key coordination roles***

The findings indicate two key factors that contribute to the ambiguity of the key role for care coordination in palliative home care settings, including; difficulty of formalized roles and a lack of communication between team members in primary palliative care.

### ***Context dependency of professional roles***

Findings indicate that interviewees experience their roles depending on specific conditions and situations. A ‘formalized’ role, in the sense of standardized, normed behavior is difficult to achieve in the palliative care setting at home. Interviewees described their understandings of their roles in the team to be a result of circumstance. For example, the majority of nurses who considered themselves to have key roles in

coordinating tasks felt this way as they are most often available and in contact with patients: “of course we are aware of everything to do with their care plan because we see them (the patients) every day” (nurse). Moreover, some nurses and family members propose that the GP plays a key role in coordinating tasks in the case of critical situations since they are often not as visible as nurses: “I see the nurses almost every day. On the other hand, I see the GP when there’s bad news.. in the case that my mum really needs something” (family member). However, it is also reported that the GP is not always available in a critical situation. Therefore it is the nurse who makes the decisions in the moment: “my daughter was having a terrible episode, she needed an ambulance but the doctor took two hours to arrive to us, so in the meantime, it was the nurse who did everything for us” (family member).

#### *Frequency of interaction*

Although many participants report the GP as the ideal care coordinator, nurses and family members highlight that they have limited contact with GPs. The frequency of contacts between actors determines to whom central roles are assigned in in the home care setting: “Sure, maybe I should ask the doctor but it’s easier for me to ask the nurse because I see her more often” (family member). Most nurses and family members agreed that they did not have much contact with GP’s compared to nurses. As one nurse states: “I work daily with other nurses and I don’t often see the doctor” (nurse). However, there are some exceptions as individuals living in rural areas report higher visibility of GP’s: “I am lucky because my family doctor lives in this little village. Here, I can even walk to see him if I need to” (family member). However, if GPs are not readily available, the assignment of coordination roles is dependent upon situational requirements, independent from professional roles, as the following quotation shows: “maybe we ring the doctor but he’s not available and then what are we supposed to do, just wait? No, we ask the nurse for the next steps, we can’t wait too long for things or my mother suffers” (family member).

### **Consequences**

#### *Latent inter-professional conflicts*

Findings reveal contradicting beliefs regarding who has the key role in coordinating tasks in palliative home care settings. For instance, while one GP describes that: “I am who has the final say of course, although I delegate tasks to the nurses” (GP), some nurses perceive the GPs role to be far less significant: “at the end of the day, we need them to sign off prescriptions” (nurse). The ambiguity of key coordinator roles also causes the relationships within the care team to suffer and be charged by latent inter-professional conflicts. Since the central task of coordination, if not clearly defined, is often mixed with a leadership function. Notably, in the case of GPs, the lack of frequent interaction with patients in the home care setting can result in information gaps, which in turn hinders decisions from being made, as the following quote illustrates: “I have to fill the doctor in and it’s embarrassing because I respect his rank but I have to find a way to tell him what needs to be done” (nurse). As a head nurse describes, the role that a professional in the team takes is often determined by who appears to be present at the time that coordination of care must take place: “Yes, theoretically, the GP is usually the one who ought to have the say in what should happen to the patient.. but the reality is that he’s not always around and then it falls on me to make choices for the patients care” (head nurse).

#### *Family members feel overburdened*

Many family members report feeling highly responsible for the care coordination of their family member: “we take on decisions for them, and of course they (palliative patient) want to retain their autonomy as long as possible but we have the responsibility” (family member). Moreover, since many family members have been taught how to administer treatment and feel that they know their relative the best, they consider themselves key players for care coordination: “Since I am the one who is with them at all times, I have learned what they need and when they need it” (family member). Further, family members report that frequent contact with the PPC team makes them feel vital to the care process “I have a lot of contact with the nurses and I attend visits to the doctor, so I am heavily involved” (family member). In one case, the family member reports being crucial for decision making since the medical condition of the palliative patient

is such that they are unable to make informed decisions for themselves: "I cannot avoid being involved in this process. My daughter cannot think for herself, so I am obligated to be involved in every step of her care plan and I make the decisions for her" (family member). At the same time, many family members report feeling overwhelmed in their role: "I gave up my job a long time ago and it (care for family member) took over my life, I tried to keep my head above water but it so hard sometimes, I would just burst into tears thinking I couldn't keep at this for much longer" (family member). The following quotation shows in more general terms the extraordinary burden that arises from care situations in which family members assume a central role: "I work more now than I ever did in my entire life.. and that is saying something! I can't leave the house for a coffee with a friend because I know at 4pm I have to give my daughter her treatment".

### **Strategies**

The interviews illustrate several strategies to cope with the ambiguity of coordinating roles. Critically, the clear communication of the coordinative role and maintaining stable palliative home care teams appear to mitigate ambiguity of the coordinator role.

#### *Communication of coordinator role*

Respondents discuss the importance of team members communicating their roles frequently and unambiguously to others, to avoid confusion and to facilitate the coordination of tasks. One of the primary reasons for this seems to be that the situations of patients can be quickly changing and thus require immediate action. As one participant acknowledges: "I also cannot be around 100% of the time, so this is something I have to accept and I leave it to the head nurse to decide on things I would usually have a say on" (GP). In response to this, professionals describe that they clearly communicate when they are in a coordinative role: "I tell family members to contact me if they have any questions or doubts in their minds about anything. They always seem to respond well to this and I think it solves a lot of issues because they don't need to wonder who to contact in case of something; they know I'm here" (head nurse). Moreover, if a professional delegates the coordination role to another professional, this is clearly communicated to other members of the palliative team. One GP explains: "When I know I won't be around, I tell the others to contact the head nurse for everything to do with the patient. Of course, some things only I can be responsible for, like prescriptions, but on the whole, the head nurse can be left in charge" (GP). One family member also describes how when new members join a team they explain to them who is usually responsible for the care coordination of the patient: "Since they're new they don't always know the nurse so I sometimes have explained to new members that this particular nurse is the person to go to in case of anything or see this other person if you don't know how about timings of things!"

#### *Maintaining team stability*

Professionals and family members equally experience the confusion in key coordination roles resulting from frequent changes in the team. In this situation it seems evident to most of the interviewees to keep the team as stable as possible: The familiarity with other members of the team is identified as highly relevant to inform team members of professional roles - roles of coordination especially - since working in a team for a long time creates routines and expectations with respect to inter-professional interaction. As a nurse explains: "Since I have been working with the same team every day, I don't doubt that I have to ask the other nurse about the schedule, I know that she is the person responsible for that" (nurse). The implicit character of coordination facilitates everyday interaction: "you don't need to ask who is doing what, you're already well informed" (GP). In order to maintain this stability, some describe trying to schedule their working hours with the same team members they're used to working with "It's not always possible, but Elizabetta (nurse colleague) and I try to be on the same shifts together when we can, especially when it's the same patient we know well. Then we try to both attend them or be working with them at the same time" (nurse). Family members in particular report that having worked with the same members of a team aids in understanding who is the key coordinator: "Since I know everyone really well, we have our routine going and that means I know who is in charge of what and when!" (family member). schedule, I know that she is the person responsible for that" (nurse)." In order to facilitate this, one family member reports specifically

requesting a nurse to treat their family member: "I request that Maria comes, when I know that things are intense with my mum and that she might need more help because I feel better that way than if it's just someone else who shows up. Usually she's available for us!"

## **Discussion**

Ambiguity of key coordinator roles is a widespread phenomenon in palliative home care settings in Switzerland. This is one of the most important results of this explorative study, which also indicates that the ambiguity is predominantly caused by the context dependency of roles and a lack of communication between palliative care team members. The negative consequences of ambiguity concerning the key coordinator role are manifold and include; conflicts in inter-professional collaboration and family members feeling over-burdened with care coordination. On the other hand, results indicate that clear communication of situated key roles, as well as the maintenance of stable palliative care teams can facilitate care coordination in palliative home care settings.

The ambiguity concerning who plays a key role in care coordination is somewhat surprising, given the strong emphasis placed on designated care coordinators in palliative care settings [22, 23]. Yet, the results overlap meaningfully with other empirical findings, which demonstrate that role ambiguity in health care settings can often arise out of the demanding nature of care, encouraging professionals to take on roles spontaneously [22] despite the demands of the role going beyond what might typically be expected [24, 25]. In line with this, our findings indicate that since the palliative home care team often changes to meet patient needs and cater to full-time care rotas, the coordinator role is mostly determined in the context of specific conditions, if not in the individual case [20]. For instance, nurses reportedly felt they played a key role in care coordination when GP's were not present, reflecting the context-dependency of the coordinator role in this specific setting. This also builds on the growing body of research that raises awareness that healthcare providers are performing roles that, in addition to clinical practice, concern organizational and managerial aspects [12, 13]. Furthermore, it supports empirical findings that demonstrate that nurses shift from dependence on physicians to a new, more responsible and autonomous role [26]. In addition, a lack of communication between care providers adds further confusion and disclarity to understanding roles. For example, whilst responses from GPs, nurses and family members indicate that GP's ideally play a key role for care coordination, it is apparent that a lack of communication diminishes the perceived significance of their role in this regard. This is somewhat to be expected given that contact with others is important for establishing roles [27]. However, the findings also indicated that if professionals communicate clearly when they are in a coordinative role, this could be sufficient to mitigate ambiguity about who is the key coordinator in a given circumstance. This principle is already effectively adopted in trans-professional teams, where member roles are flexible rather than fixed [23]. Crucially, the effective functioning of such teams relies heavily on team members communicating their roles clearly [29], something that the results from this study can only attest to, given the negative consequences associated with the poor communication of roles. Whilst clarifying roles may mitigate issues with identifying key care coordinators, it could be argued that these issues could potentially be easily resolved by hiring a designated care coordinator, i.e. an individual who is clearly appointed for the job of coordination of patient care. This would make sense, given that the results essentially allude to the drawbacks of care coordination being carried out informally by health care professionals, who don't necessarily have the specialized training, nor the time, for coordinating care as official care coordinators do. Firstly, clearly identifying one designated professional could, quite basically, answer the question of who is responsible for coordinating a task, independent of the context or situation. In addition, since care coordinators are solely preoccupied with coordination tasks and do not have to invest their time for other patient demands, as other health care professionals do, they can be fully dedicated to the role, without other commitments. Moreover, the data suggests that since health care professionals take on care coordination tasks, in addition to their already busy agendas catering to patients, a care coordinator could be beneficial for relieving some of the extra workload and pressure surrounding care coordination. Unsurprisingly, many countries have sought to implement care coordinators in palliative care teams to address these considerations and reaped the benefits with respect to coordination and quality of care, as well documented in literature [22, 23]. Different health care systems may of course adopt care coordinators

to varying degrees and capacities, depending on the demands from the care services. In the United Kingdom (UK), the United States (US) and Canada, care coordinators are a long standing, fundamental pillar of palliative care services [30]. However, whilst adopting official coordinators into palliative care services is a crucial development, it is still not standard practice in Switzerland. Initiatives to encourage the implementation of advance practice nurses and case managers in Swiss palliative care services are only recently gaining attention in the field of palliative care [31]. However, as the data suggests that Switzerland is still behind in this regard, since care coordination is seemingly adopted informally by health care professionals, rather than by an official care coordinator. Moreover, as already discussed, Swiss cantons implement practices independently from one another, which means that there is no standardized approach to how the coordination of services is managed in Swiss palliative care.

### *Implications of role ambiguity*

Effective role recognition is considered an important element of high-quality care coordination [20]. Conversely, as previously demonstrated in health care settings [32, 33] and echoed by the present findings, role ambiguity contributes to conflicts in role understanding and poor coordination of care in home care settings. Importantly, the data reveal the negative impact that this has on family members of palliative patients. Essentially, the lack of clarity with respect to care coordinator roles contributed to family members feeling responsible for and overburdened with care coordination. This finding is in line with prior research that demonstrates that family members of palliative patients feel highly involved in the care of their loved ones [34]. It is reasonable to assume that families of palliative patients desire a specific role in the home care situation for several reasons; notably, the private character of the care at home, assigns additional responsibility to family members, which may only partially be shared by 'visiting' professions [34]. Moreover, palliative education is increasingly accessible for family members, encouraging their involvement in care coordination and its related tasks [31]. This reflects that care coordination demands the appropriate formation and competencies [2]. Importantly, it is a role that requires the appropriate recognition and support [5]. Yet, whilst responses from professionals imply that they see either their own role or that of another professional as significant for care coordination, they did not share the same belief about the involvement of family members in coordination. This might allude to the role of family members either being overestimated by the relatives themselves or underestimated by the professionals in the study. Critically, if it is the case that family members play a key role in coordination but that professionals fail to recognize it, it could mean that family members are not receiving the emotional or practical support they may require for this role. Unfortunately, the evidence suggests that family members of palliative patients in Switzerland are already under-supported. Whilst there is financial support available for family carers in some other European countries, the UK and the US [35], Switzerland does not yet have regulations which allows for this [36]. This in itself may contribute to the experiences of the burden that many family members report since they must finance themselves whilst caring for their relative. This is not only costly but particularly challenging, if not impossible, for individuals who are no longer in employment because of their obligations to their family member, as is the case for many [37]. Adequate reimbursement in health care is of upmost importance for ensuring good quality care and alleviating stress for carers [34, 36, 38, 29]. Beyond that, appropriate training and emotional support should be readily available to them in order to match their involvement in care coordination. Finally, in order to diminish role ambiguity in palliative home care teams, team members should experience similar training; this would also serve to consolidate team understanding and functioning of care coordination roles.

### **Conclusions**

This study reveals that there exists considerable ambiguity concerning who plays a key role in care coordination amongst professionals and family members of palliative patients in palliative home care settings. Moreover, the findings reveal that this ambiguity can be attributed to the fact that the key coordinator role is often context dependent, rather than a fixed position. Moreover, the findings affirm previous studies, which highlight that poorly defined professional roles contribute to poor coordination between professionals and poor quality of care. Importantly, the results shed light on the negative impact

that ambiguity concerning key coordinators has on family members, who consequently take on care coordination roles themselves and are over-burdened and financially under-supported. The results ultimately stress the importance of clearly communicating key roles to all members of the palliative teams, including relatives, as well as highlighting the need for adequately supporting those who are in coordinating positions. The outcomes of this study are of interest to health care practitioners, policymakers and researchers involved in the support of care coordination in palliative home care settings. Crucially, future initiatives to encourage the effective communication of roles and to consolidate standardized palliative care team understandings regarding care coordination roles ought to be invested in. Likewise, ensuring that family members of palliative patients are ensured the appropriate education, psycho- social and financial support that reflects their involvement in care coordination warrants special attention.

### **Limitations**

The explorative design of this study does not allow for generalizing the experiences, attitudes and beliefs found here with regard to who plays a key role in care coordination in palliative home care settings. Further, the results are based on the findings from interviews in only four Swiss cantons. Whilst the cantons provide a good representation of Swiss rural, urban areas and language regions, the results may not be generalizable to all Switzerland. A further limitation is that it is not possible to discriminate between different palliative home care settings, which are influenced by different patient trajectories and can result in different challenges than the ones identified here.

### **Conflict of interest**

The authors declare no conflicts of interest with respect to the research, authorship or publication of this article.

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## **Comparing professional and relatives' perspectives of quality of care in palliative care: A qualitative interview study**

### **Abstract**

#### **Background**

High quality of care is an important aim for palliative care services. However, quality of care is a complex phenomenon that is subjectively perceived by those closest to the services and that is often evaluated poorly. Prior research has highlighted difficulties in evaluating quality of care and has highlighted different perspectives. Yet, still little is understood about how the quality of care in palliative care services is perceived. Investigating the perspectives of key individuals involved in palliative care, i.e. palliative professionals and relatives of palliative patients can provide invaluable insight for understanding quality of care.

#### **Aims**

To identify perceptions about the quality of care in palliative care from the perspectives of palliative professionals and relatives of palliative patients and to identify synergies and divergences in perceptions of quality of care, as well as to highlight the complexity of quality of care in palliative care settings and indicate areas for improvement for palliative services.

#### **Methods**

This was a qualitative study involving semi-structured interviews that were guided by the proposed system approach model for the evaluation of palliative care (Bainbridge, 2010). Interviews were carried out with a total of 40 professionals working in palliative care and 26 relatives of palliative patients across four Swiss cantons (Ticino, Basel, Vaud and Lucerne). The sample included 40 professionals working in primary palliative care (PPC) and specialized palliative care (SPC), including; 11 general practitioners (GP's) and 12 nurses working in primary palliative care services, as well as 15 interviews with 9 specialized medical doctors (e.g. oncologists) and 6 specialized palliative care nurses working in hospitals, hospices, mobile palliative care teams (MPCT's) and specialist private practice.

#### **Results**

Results revealed considerable differences between professionals and relatives perspectives with respect to the following aspects of care; 1) the availability of care, 2) client-centeredness of care (including respect for patient wishes and relatives involvement in care, 3) satisfaction with care (including physical and psychosocial) and 4) communication and information transfer. Importantly, the results revealed that family members feel that care is not always readily available, care is poorly coordinated, patient needs are overlooked because of lack of time, some professionals are perceived to be incompetent, communication is lacking, and psychosocial needs are neglected. On the other hand, professionals indicate that relatives may be too involved in patient care and express concern due to the high risk of burn out caused by the high stress and emotionally taxing circumstances of palliative care.

#### **Conclusions**

The different perspectives uncovered, including both their similarities and discrepancies represent a demand for addressing the shortcomings of palliative care services. Specifically, findings indicated that professionals may overestimate the quality of care in palliative care. The findings indicate that future initiatives to ensure that family members of palliative patients are adequately supported, both psycho-socially and financially warrant investment. These findings are in view of informing health policy with respect to aspects of care that require specific attention to improve overall quality of care and urge future research in this field in to explore how these aspects of care can be best supported.

## Introduction

High quality of care is a vital goal for palliative care services (Hanson et al, 2014), not least because the health status of palliative patients is often critical, thus demanding effective care services with respect to both pain and symptom management, as well as good physical and psychosocial support functions (Darzi et al, 2008). However, quality of care is a complex phenomenon, one that is not necessarily determined by the outcomes of care but may be constituted of multiple factors and evaluated subjectively by the individuals closest to care, i.e. palliative professionals and relatives of palliative patients (Ministry of Health Services, 2012). Moreover, ensuring the efficient delivery of care is not always guaranteed, and the standard of palliative care service provision is often deemed unsatisfactory (Wittenberg Lyles et al, 2009). Yet, little is understood about how the quality of care of palliative services is perceived. Thus, the aim of the present study is to explore perceptions of quality of care in palliative care, as well as highlight the complexity of the phenomenon. Specifically, the objectives are to identify convergences and divergences in perspectives with respect to key elements of quality of palliative care and to identify avenues for refining existing indicators of quality of palliative care. These are important aims as ensuring clinicians in palliative care settings are well informed about the experience and perspectives of palliative relatives allows them to potentially adapt and implement interventions accordingly so that they better serve patients and those who care for them (WHO, 2006, Ministry of health and care services, 2012). To this end, this qualitative study is based on data concerning perceptions of quality of palliative care, derived from health care professionals working in primary and specialized palliative care settings, as well as relatives of palliative patients. The insights of these actors are crucial for informing policy-makers, healthcare managers and healthcare personnel in the sphere of palliative care, to identify potential areas for improvement and promote high quality of care provision. The following chapter will provide some background to quality of care specific to the context of palliative care services. This also includes some description of the ‘proposed systems approach model for the evaluation of quality of palliative care’ (Bainbridge, 2010) that is the basis for this investigation, as well as some description about the value of exploring perceptions of palliative professionals and relatives of palliative patients for understanding the quality of palliative care services. Thereafter, the methodology of this qualitative study and its findings will be described. The paper will conclude with a discussion of the findings, followed by conclusions, recommendations for future research and limitations of the study.

### *Quality of care in palliative care*

Founded on several descriptions in literature, the World Health Organization (WHO) defines the quality of care as “the extent to which health care services provided to individuals and patient populations improve desired health outcomes” and proposes that, in order to achieve this, health care must be safe, effective, timely, efficient, equitable and people-centred (WHO, 2016). Specifically, the quality of care is considered to be provided to a high standard when the preferences of patients and relatives are taken into account and that their perceptions of care constitute dimensions of quality of care (WHO, 2006). A highly recognized model for the evaluation of palliative care was developed by Bainbridge and colleagues, (2010). According to this ‘proposed systems approach for the evaluation of palliative care’, the following factors are indicative of the quality of care; the availability of care (i.e. that palliative services are accessible to those who need them, when they need them), the client centeredness of care (i.e. respect for patient wishes and adequate involvement of relatives of patients in care), satisfaction with care (including physical and psychosocial care) and communication and information transfer (i.e. collaboration and transfer of patient information between palliative care providers). Moreover, in order for palliative care services to be evaluated positively, palliative care ought to be readily available, the patient should always be at the center of care (i.e. their needs should be respected and their relatives should be adequately involved in care), patients should feel satisfied with the level of care they receive (including both physical and psychosocial care) and communication and the transfer of information with respect to care should

be to a high standard (i.e. patients and relatives should have frequent, clear communication about care). In palliative settings, important domains of palliative care quality include; care that maintains patients' comfort, dignity, and personhood; timely, effective, and compassionate communication by clinicians with patients and families; alignment of medical decision-making with patients' values, goals, and preferences; support for the family; and support for palliative professionals (Nelson et al, 2011).

### *Perceptions of quality of care*

The perspectives of individuals close to palliative patients are imperative for understanding the quality of care in palliative care services (Austin et al, 2000). Naturally, the perspectives of health care professionals (e.g. general practitioners (GP's), nurses, specialized doctors, such as oncologists and specialized nurses), as well as palliative patients and their relatives, have therefore been investigated with interest to understand quality of care, given that their extensive experience of palliative care makes their insights invaluable. The perspectives of relatives of palliative patients are more relevant than ever, not only because of their closeness to the patient, but also because of their increasing involvement in palliative care services (Burns et al, 2013). A growing body of research supports that relatives are becoming increasingly embedded into palliative care teams, particularly as more aspects of palliative care are provided in a patients' family home environment (Gomes et al, 2005) and many relatives receive palliative training (Kenneth et al 2001) and assume the role of primary care givers, i.e. individuals who provide support without payment (Cohen et al, 2006). Moreover, since the critical health status of palliative patients has proven challenging for recruiting patients and obtaining their feedback for studies investigating quality in palliative care (Hanson et al, 2014), the insight of those closest to patients are crucial, if not a proxy to patients perceptions of quality of care (Aasbao et al, 2017). Prior research that has explored perceptions of care in palliative services, on the basis of the perspectives of the professionals, patients and relatives involved in care have identified key aspects of care that have been evaluated poorly such as; the availability of care services, the continuation of care, physical and psychosocial support, satisfaction with care and communication between palliative care providers (De Boer et al, 2017). Moreover, research that has compared the perspectives of different actors with respect to care has often identified discrepancies with respect to perspectives of the quality of care (Austin et al, 2000, Oosterveld-Vlug et al, 2019, Ying-Xuan et al, 2019). For example, professionals have been shown to over-estimate the quality of care delivery with respect to patients and relatives (Brimmer, 2012). Identifying perspectives of quality of care in palliative services allows to gain a broader, more accurate picture of the quality of care and identify areas for improvement. However, the majority of existing literature has investigated perceptions of a specific aspects of quality of care such as perceived patient centeredness of care (Brazil et al, 2007) or availability of support services for relatives (Hudson & Payne, 2011). Similarly, in Switzerland, some studies have explored factors which might indicate quality of care in palliative settings, such as the coordination of care (Reeves et al, 2020) or interprofessional collaboration within palliative care teams (Alvarado & Liebig, 2016). However, there is limited understanding about how the quality of care in palliative care services is perceived. In view of the gap in research, this article explores perceptions of quality of care in palliative services from the perspectives of those closest to this field, i.e. palliative professionals and relatives of palliative patients. Importantly, the study compares the perceptions of palliative patients in order to bring to light inconsistencies and synergies in perspectives and to acquire a well- informed understanding of quality of care in palliative services, according to those closest to this field.

## Methods

A qualitative study design was adopted to explore the perspectives of quality of care from the perspectives of palliative professionals and relatives of palliative patients in Switzerland. Results are based on semi-structured interviews with a total of 40 professionals working in palliative care and 22 relatives of palliative patients were carried out. The sample included 40 professionals working in primary palliative care (PPC) and specialized palliative care (SPC), including; 11 general practitioners (GP's) and 12 nurses working in primary palliative care services, as well as 15 interviews with 9 specialized medical doctors (e.g. oncologists) and 6 specialized palliative care nurses working in hospitals, hospices, mobile palliative care teams (MPCT's) and specialist private practice. Moreover, a total of 26 caregivers participated in 22 interviews and one focus group (with three daughters and one son of a palliative care patient), of which 19 (73.1%) were female. The age of respondents ranged from 46 to 76 years, with a mean of age 60. In most cases, caregivers were daughter or son (46%) or spouse/ partner (35%). Two mothers and one father cared for their children and in two cases, the sister cared for her sibling. The interviews were carried out in different regions of Switzerland, namely the following cantons: Basel-City, Lucerne, Ticino and Vaud. These cantons were selected to accurately reflect rural and urban regions and differently developed policy contexts for palliative care in Switzerland.

Participants	Number	Gender		Age (Mean)	Age (Mean) overall
		Female	Male		
GP's (PPC)	12	4	8	56.67	52.375
Nurses (PPC)	12	12	0	48.1	
GP's (SPC)	12	8	4	48	50.6
Nurses (SPC)	4	3	1	57.75	
Family members	26	19	7		60 (59.7)

Table 1. Demographic data of interviewees

### *Data collection*

The data for the study was collected between January 2018 and October of 2018. The participants were identified in each canton via personal referral. They were recruited via email invitation or telephone call. Those included in the study were interviewed by three researchers in a semi-structured interview format, in the language corresponding to the official language of the canton (Vaud: French, Ticino: Italian or Lucerne/Basel: German). Interviews lasted between 60 minutes on average and were conducted in a location determined by the participant (e.g. clinic, personal office or in the home of the family member of a palliative patient). Interview guidelines were informed by concepts derived from a conceptual framework for the evaluation of integrated palliative care networks (Bainbridge, 2010) and covered key topics to explore perceptions of quality of care. Interview questions for professionals included questions about aspects of quality of care such as perceptions regarding satisfaction with care, access to palliative care and perceptions of client centeredness. Questions about perceptions of satisfaction/ access with care included: "Would you say that the services of your palliative care network are available/ accessible to all patients?" and "Are patients satisfied with the care they receive in your network?". On the other hand, questions about perceptions of client centeredness included the following: "How satisfied are the patients with the communication and information transfer within the framework of palliative

care?” “Do you have the impression that family/ friends of patients are appropriately involved in the palliative care, which your network provides?” and “Do you think that your network can adequately consider the needs of patients? (medical, non-medical, spiritual)” (see table 2). The questions proposed to family members covered a range of questions that gauged perceptions about the following aspects of care: the availability/ access to care, client centeredness of care, satisfaction with physical care (including pain and symptom management) and psychological care, as well as communication and information transfer. These questions included: “were the palliative care services (previously) easily accessible for you and your relatives?”, “how satisfied is your relative with the physical care that he / she has received?”, “how satisfied is your family member with the psychological or psychological care that he / she receives?”, “do you feel that your family member is at the center of all decisions, activities and efforts of the palliative care team?”, “when you think about the wishes, needs and preferences of your relatives, do you think that they are respected by the palliative team?” and “do you know your family member's future treatment plan and are you satisfied with this plan?” (see table 3). Participants were encouraged to elaborate on answers and provide relevant examples from their experience, where appropriate. Demographic data was collected from all participants. Interviews were audio recorded and transcribed verbatim in their original language, with all personal identifiers removed.

1. Would you say that the services of your palliative care network are available/ accessible to all patients?
2. Are patients satisfied with the care they receive in your network?
3. How satisfied are the patients with the communication and information transfer within the framework of palliative care?
4. Do you have the impression that family/ friends of patients are appropriately involved in the palliative care, which your network provides?
5. Do you think that your network can adequately consider the needs of patients? (medical, non medical, spiritual)

Table 2. Interview questions for palliative professionals

1. Were the palliative care services (previously) easily accessible for you and your relatives?
2. In your opinion, how satisfied is your relative with the physical care that he / she has received?
3. In your opinion, how satisfied is your family member with the psychological or psychological care that he / she receives?
4. Do you feel that your family member is at the center of all decisions, activities and efforts of the Palliative Care team?
5. When you think about the wishes, needs and preferences of your relatives, do you think that they are respected by the PC team?
6. Do you know your family member's future treatment plan and are you satisfied with this plan?

Table 3. Interview questions for relatives of palliative patients

### *Data analysis*

The data were analyzed using thematic analysis (Braun & Clarke, 2009) to identify and report patterns within the data. The first stage of the analysis involved familiarization of the data, i.e. listening to the audio recordings and reading through the transcripts. The second stage was coding the interview data. Firstly, the data was divided between the transcripts relating to interviews with professionals and those relating to interviews with relatives. Two researchers were involved with initially coding the data. One researcher coded the data for the interviews with professionals and the other researcher coded the data for the relatives. The first few transcripts from each data set were originally manually coded by the researchers. Between one researcher who speaks fluent French and German, and the other who speaks fluent Italian, the researchers were able to code the data according to their linguistic ability. Importantly, the researchers explained important segments of the data to one another if it

was not understandable due to language barriers in their commonly spoken language, English. After this, the researchers consulted with one another to compare the perspectives that they had discovered within the data relating to the key topics (i.e. availability of care, the client centeredness of care, satisfaction with care (including physical and psychosocial care and communication and information transfer). The converging respectively diverging perspectives between the two interview groups were identified, continuously re-examined and agreed upon between the researchers. This was done in order to ensure consensus between the researchers regarding the codes and analysis. The data in the subsequent transcripts were then coded according to these prominent perspectives. Following this, the data was coded using a qualitative data analysis software package (MAX QDA) to organize the data in an efficient and systematic way.

### *Ethical considerations*

The study received formal research approval for this study from the Ethics Committee of Northwestern Switzerland (EKNZ) on the 29th of August 2018, (Req-2018-00490). Prior to commencing interviews, participants received and completed an informed consent form for participation in the study and recording of interviews. Before each interview began, the researchers provided information about the objectives of the study, as well as the reasons for recording interviews. Moreover, the concepts of voluntary participation and confidentiality of data was explained to the participants to ensure that they were in agreement with participation in the study.

## **Results**

The comparison of perceptions of professionals working in palliative care and relatives of palliative patients resulted in considerable differences with respect to the following aspects of care; 1) the availability of care, 2) client-centeredness of care (including respect for patient wishes and relatives involvement in care, 3) satisfaction with care (including physical and psychosocial) and 4) communication and information transfer. These perceptions are compared and described in detail below.

### *1. Availability of care*

The availability of care refers to the perception that services are accessible to those who need them, when they need them (Schaller, 2007). Results indicated considerable divergences with respect to this crucial element of the quality of care. Namely, professionals perceive that they provide palliative services highly available to patients/ relatives, whilst relatives perceive that they are a) poorly informed about availability of care, b) access to care is a result of independent initiative rather than direction from professionals and c) despite professionals insisting that they provide all the relevant information about available palliative services to patients/ family members, relatives felt under prepared for palliative care and had a limited awareness of palliative care services. These findings are explained in more detail below.

#### *Professionals perspectives*

Professionals did not report problems with the availability of care. Instead, they believed palliative services to be easily accessible to patients. According to GP's, patients are well informed of the services available to them, as one GP explains: "they know which services are around and they're given all the information they need. We tell them everything there is to know". Another GP supports this notion, adding that there is also plenty of additional information for patients regarding care treatments online and in hospitals or clinics: "we have leaflets about services here and all you have to do is type in "palliative.ch" and offers will come up".

#### *Relatives perspectives*

By contrast to professionals, relatives of palliative patients reported the following issues concerning the availability of care. Firstly, they perceive that they are provided with limited information about services. Closely related to this, they report that they must seek information about services themselves

### *a. Limited provision of information about palliative services*

A high number of family members disagree with having been informed by professionals about services but report only accessing palliative care services informally, i.e. by hearing about palliative care through friends or family: “It was more mouth-to-mouth, i.e. through people who also had their relatives in palliative care, who actually told us and enlightened us (about palliative care)”. Moreover, relatives suggest that the degree of information and support may be overestimated by GP’s, as relatives explain that patients are not always made aware of the services available to them. As one daughter of a palliative care patient explains: “They (doctor) say your mother needs this and that but then it’s like where? I don’t know who to go to. Maybe a week goes by and nobody got in touch with me. In the meantime, I don’t know where I’m supposed to go with her (mother)”. Relatives also describe that they were not prepared for palliative care services because it had not been explained to them by the professionals, as one mother recalls: “I thought when they found a lump there that she (daughter) was being referred to a gynecologist. I didn’t know that she needed an oncologist, no one explained that to me. it was just suddenly.. oh, here’s the oncologist.. then I realized it must be cancer”.

### *b. A ‘Laissez-faire’ attitude to providing palliative services*

Many relatives indicated that patients and relatives must use their own initiative to find out information about palliative services on their own. For instance, one relative says: “It is accessible and if you type in "Palliative Care Luzern", then you just come to this palliative community via Google. I think it's very clear if you're a little interested and look it up yourself”, whilst another respondent remarks: “So you have to inquire and know where to inquire.” Further, the responsibility of organizing palliative services for family members is perceived to fall often in the hands of family members and is not facilitated enough by professional support. As one relative explains that the health care professionals did not provide enough practical support for accessing palliative care services: “hospital didn’t really help much. I had to have a bed and a wheelchair and everything. And I organized it all myself. She (nurse) just gave me the phone numbers.” Likewise, another family carer argues that without professional help, it may not be so easy for the average person to find out about palliative care services because if you are not already familiar with medical services then you might struggle to be informed about palliative care services and have access to it: “because I work at the hospital, it's easier for me so for me it's accessible...but I just don't know what it's like for someone who isn't that smart.”

### *c. Limited awareness of palliative care*

In a few cases, it was also evident that relatives had a limited awareness, not only of the services, but of palliative care in general. For instance, one family member describes how they were not informed about palliative services and were left to find out for themselves. As one relative describes: “ I thought to myself, "But what is palliative care for? What the hell are they doing? " and they just said to me, "make contact, you’ll see”. Similarly, a partner of a palliative patient describes that despite her partner being treated in palliative care, her partner was not explained what palliative care services were for and thought that they were only relevant in the case of terminal illness: “my partner had the feeling that palliative care only comes into play when there is nothing left to do when it comes to dying”. Similarly, another relative explained that she was not made aware of palliative care services until a much later stage of her family member being in care and she didn’t expect it to be relevant because she had only ever heard of it in the context of a HIV AIDS: “it was only later that the doctor drew my attention to the possibility of palliative care.. Palliative medicine is too little known in my eyes. Except for in the case of AIDS.”

## **2. Client centeredness of care**

Key aspects of client centeredness of care include perceived respect for patient needs and preferences relating to care and the perceptions concerning the involvement of family members in care. Data concerning these perspectives are discussed below.

### ***Respect for patient wishes***

Results indicated that there was generally shared consensus between professionals and family members of palliative patients that the needs and wishes of the patients are respected and taken into consideration during care. Notably, many professionals expressed their opinion that the patient is “at the center” of all care decisions. As one specialist doctor describes: “Of course, it all depends on the client. We try to take into account all their desires and see them as a person, on the whole, absolutely”. In general, family members agreed that professionals respected the patients’ wishes when treating them. One family member gave the example that their son who was in care requested that he be accompanied to all meetings with the GP by his father and that this was ensured: “he didn’t feel confident being in meetings on his own because it was often overwhelming.. but when he asked that I attend and take notes for him, the team did everything to accommodate us. We worked around a schedule that suited all of us then”. However, there were also some notable complaints from family members who didn’t feel that the patient is truly at the “centre” of care because they felt that the health care practitioners working with them were too busy to dedicate time to the patient, so they didn’t feel like their family member was a priority. Although, one mother acknowledges the inevitability of this, she also admits her frustration: “I of course accept that the world doesn’t revolve around us and the nurses are busy... but it’s not nice to feel that your daughter is just one of many patients.. but you feel this because they just don’t have time to talk to us about what she wants.. they have too many other people’s needs to think of”. Similarly, another relative supports the notion that patients are not given the full attention of health care professionals but must instead fight for it, otherwise, they risk being forgotten: “he (the patient) doesn’t draw attention to himself or is very reserved.. he doesn’t get attention at all. So they just leave him alone. Someone who’s always shouting gets a lot more attention”.

### ***Relatives’ Involvement in care***

#### *Relatives perspectives*

With respect to the involvement in care, the vast majority of relatives reported feeling intensely involved in care. Many of them describe that they play a crucial role in the care of their loved one with respect to treatment plan and decision making. As one relative explains, they play a fundamental role in the decision making process with respect to the patients care: "There was no decision that was not made without her and my consent.. we were completely in agreement and involved in the decision-making and reflection process." Similarly, many others give the example that they know the treatment plan and schedule of their relatives care to support their involvement in care and often describe themselves as part of the care team. As one daughter explains: “I have a black file here filled with every detail about when she should take her medications, which ones. I know everything at this point. The nurses leave me to tend to her bandages and so on because they know I am no different to them, I am also one of her carers”. However, in two cases, family members reported that they don’t feel involved enough in care, not because of a failing on the part of the professional to keep them involved, but because of resistance from the patient. As explained by a mother: “He (son) refuses to let me in to meetings. He wants his treatment to be between him and his doctors.. and I can’t override that.. unfortunately.. I am just on the side lines”.

#### *Professional perspectives*

Also, most professionals agree that family members are fully involved in care. As described by one nurse: “I know mothers and daughters who could tell you more about pain medications for their relative than the nurse on the same team who’s been there for years. They’re absolutely involved!”. However, in some cases, professionals felt that relatives can be too involved. For instance, one GP feared that the relative risked ‘burn out’ from the extent of his involvement with care: “I saw the husband doing everything he could, everything he invested at the cost of his career, his training... it's incredible, and there's little compensation... there's no tax allowance to support this...I have to be very careful about the burn-out of the spouse who can't take it anymore. The spouse can sometimes get out of control and then psychologically it's difficult.”. This is in line with a specialist doctor who admitted to not wanting to include a family member too much because they are too emotionally invested so the specialist feels wary to involve relatives too intensely in the decision making process: “when it comes to

making decisions, unfortunately, they can't be trusted to make the 'best' decisions let's say, because their emotions are too in it". Consequently, despite family members feeling extremely involved in the care process, responses from some GP's suggest that the family members may not be as involved as they might think. Another doctor admits that he with-holds information from relatives in some cases: "I don't want to gloss over this, of course, conversations are also taking place behind the patient's back.. or it is expressed that one should not communicate certain things with the patient, which is quite difficult for me, it's a legally gray area..". Similarly, a few GP's mentioned difficulties in involving families for practical reasons such as not all family members agreeing on a course of action with respect to care. As one doctor describes: "families are always involved but it's not always easy with families, because you have the son from Geneva who doesn't agree with the son from Lausanne. The son of Lausanne thinks that you shouldn't put her in a palliative care centre, that she should die at home and the one in Geneva who thinks it's better to have care."

### 3. *Satisfaction with care*

Satisfaction with care describes how satisfied professionals and family members perceive the patient to be with respect to their overall care, including both the physical and psychosocial care that they receive. Perspectives with respect to these domains of satisfaction with care are described below.

#### *Professionals perspectives*

Results demonstrated that overall, professionals and family members perceived patients to be satisfied with care. However, professionals often acknowledged their limited capacity to estimate the satisfaction of patients. As demonstrated by one family doctor when asked if he believed that his patients are satisfied with the care they receive: "I don't know. How do we evaluate that? Was it all right? How are you doing? Most of the people I sent to a mobile unit to or hospitalized felt satisfied. But it's only an impression". Yet, on the whole, professionals generally reported that they believe patients to be satisfied. One nurse even goes as far as to say: "I don't think I have ever known a patient to be truly unhappy with the care that they get here".

#### *Relatives perspectives*

Whilst the majority of family members seemed to be happy with the care and feel that their family member is or was content with the palliative care received, many family members also raised some specific issues which negatively impacted their perception of the satisfaction with care. Notably, relatives often contributed dissatisfaction with overall care to a) poor coordination of care, b) a perceived lack of professional competency and c) poor continuity of care. Moreover, family members had some complaints about the physical and psychosocial care their patient received and especially felt that psychosocial support was lacking. These aspects of care that relate to perceptions of perceived satisfaction with care are expanded below.

##### *a. Poor coordination of care*

It was commonly expressed by relatives that the care provided by palliative care teams was poorly coordinated. For instance, a relative describes that the care of her mother was compromised due to poor coordination of care and time : "It was bad organization. The nurses never came on time. They also had no plan when they would come. It was agreed for about 8 o'clock, but it could be 10 o'clock by the time they came. In the meantime, my mother was lying in bed in the wet diapers and couldn't cope anymore". Similarly, one person explains a situation where the care was badly coordinated because professionals were not sure what medications had already been received by the patient: "they were not well informed and didn't appear to know what was going on they didn't even know if they'd given him any medication. When we saw that they weren't sure, I was really not happy". In addition, some relatives mentioned that they were unhappy with care because they found the coordination of care unreliable. One relative describes their frustration: "depending on the time, there were very quick changes and every time you came someone else was there again, so any consistency was often missing.. actually continuously". Similarly, another made the point that they couldn't answer if they were satisfied with care

because the level of care was so unpredictable: “one day, you might get the best team ever with you and it’s all great.. but just as quickly, you find yourself with strangers for a team.. and it’s just the opposite of great!”.

*b. Poor continuity of care*

Continuity of care is an important aspect of care that can refer to the relational continuity (patient continuing to seeing usual practitioner); informational continuity (continued communication and knowledge where patient information flows easily between involved care providers); and management continuity (coordination of care so that transition between care providers is clear and seamless for the patient) (Reid et al, 2002). Some family members describe their frustration when it appeared that: “I can't do anything for you anymore. So that's another shock you can finally imagine". Understandably, family members also report suffering because of the sudden drop in communication with professionals once their relative no longer needs their care or is transferred to another care facility. As one relative describes, there was no form of continuity of care once the treatment for the patient ended: “from one day to the next, I went from seeing their (nurses) faces any time I needed them, to suddenly being all alone again.. I think that’s a terrible part of care because my life goes on but the care just stops”. Yet another person explains a situation where the continuity of care was not there as in their case where their partner died, they were left without or knowledge about what the next steps should be: “So my partner died and the only thing I thought was: Now I have to call somebody and I don't know who...so I don't know what to do now.”

*c. Lack of professional competency*

Alarmingly, quite a few family members reported that they were dissatisfied with the quality of care because they felt that the professionals were not competent: As one person puts it bluntly: “I wasn't happy with the home care service because they may be nice people but they are not competent”. Similarly, another relative was so unhappy with the care that she wanted to have the professional who was working with her family member removed because she felt that she wasn't competent: “Let's just say I had to deal with a nurse who wasn't up to the task. I talked to the head nurse about it, I said, "This one (nurse) has to get out of here. It's not okay at all". Another relative speculates that the standard of care could be lower now because of a lack of sufficient training: “It's just the level of care that's gone down. I have the impression that it has dropped because of this because I think that some foreign doctors do not have the level of Swiss studies”. In another situation, the relative implies that the competency was so poor that they would have liked to have stepped in themselves to carry out the treatments: “I would have liked there to have been a volunteer for a while because I noticed that there were some treatments that were sometimes so poorly done”. She goes on to explain that the nurses failed to meet the needs of the patient and they were not attended to in times of need: “So for example they didn't give her anything to drink for a very long time, she was dying of thirst, after she was cold and then she was hot because of her changing temperature but no one passed to help”

***Physical and psychosocial care***

Physical care involves medical and practical aspects of care, but also pain and symptom management (Ferris et al, 2002), whilst psychosocial care involves meeting the emotional; psychological, and existential needs of palliative patients and their families, in helping to alleviate grief, fear, and other psychological and social problems (Bainbridge, 2010). Results indicated the following key perspectives with respect to physiological and psychosocial care emerged: a) psychosocial care is lacking b) physical care is prioritized over psychosocial care and c) relatives feel conflicted about approaches to pain and symptom management. The data pertaining these perspectives are discussed below.

*a. Psychosocial care is lacking*

Professionals support that many services are available with respect to treating both physical and psychological needs and doctors and nurses consider themselves to be attentive to the physical and psychosocial demands of patients and their relatives. As one adamantly puts it: “It isn’t just a job but it’s my duty to make sure that they (patients) are looked after in every way imaginable. This is palliative care, it’s about giving them the best possible life at this time of their life”. Despite this, both family members and professionals seemed to be in agreement that psychosocial care is considerably lacking compared to physical care. One GP expresses that they’re not as comfortable with providing psychological support as they are with providing physical support and admit to not being as concerned with ‘spiritual’ needs: “Every day, medical needs I can do.. spiritual needs I think clearly not. We’re not very good at this. I’m rarely interested in knowing what the patient’s spiritual position is, I am rather involved in all kinds of things about pain but no, I’m not very good at this psychological thing”. Moreover, another GP implies that although psychological issues should be addressed, psychological support is difficult to provide because psychosocial problems are expected and are considered ‘normal’ in palliative care: “Spiritual needs shouldn’t be neglected, nor depression, but when you realize, “Oh yes, she has cancer”- it’s normal that she is sad”.. What should we do about her depression?” This may account for why professionals also report that they don’t necessarily advertise the options for psychosocial support available but rather only provide this type of information if it is requested. As one GP explains: “there are psychologists and support groups available, especially for bereaved widows or so but I give this information out only if I am asked.. I don’t usually ask them (patients) about their spiritual needs”.

*b. Physical care is prioritized over psychosocial care*

Perhaps such thinking might account for why many family members also reported that they felt that their relatives’ psychological needs were not taken as seriously as their physical ones. One concerning example was provided by one relative who describes that they felt that only when their relative started threatening to take her own life, did she receive proper care: “She wanted to get it over with and she said, "I'm going to get a knife and kill myself" and then I went to the doctor and I said, "Now you listen to what she said to me and you do something" and then they said, "OK, we heard her despair". Oh yes, because then it was more physical, that’s what they really meant by ‘despair’. We had to wait a long time because I felt the despair long before that”. Also, with respect to receiving psychological help, family members admit that they have limited knowledge about where they can receive this, as one father describes: “I have heard of churches that send people out to come and talk with you.. but I am not sure that this is something that people like us would have the chance to have”.

*c. Relatives feel conflicted about pain and symptom management*

On the other hand, with respect to physical care, some family members reported feeling conflicted regarding pain and symptom management (i.e. commonly pain killers or sedatives, e.g. morphine). Whilst the majority of relatives desired their family member in care to be in as little pain as possible, they also struggled with the perceived negative impact on the patients’ quality of life. As one relative describes the adverse effects of pain killers: “So here we are, well, we try to relieve the symptoms, we calm the pain, but the more we calm the pain, the more the person’s personality goes away and that I find difficult to bear.. she (family member) had been concerned that she would “end up like a vegetable" and that decisions would be made in her place.” Another mother describes a similar concern: “If we say, yes, up the dosage then the doctor will do so, but at what cost? Perhaps her life will be spared, but what kind of a life are you saving.. she’s totally out of it on medications”.

**4. Communication and information transfer**

Communication and information transfer refers to all aspects of provider collaboration and patient-centered interactions (Bainbridge, 2010). The sharing of information that is relevant, accurate, transparent, concise, and timely is an essential element for ensuring high quality palliative care (Oandasan. 2006). Responses from professionals and relatives echoed similar concerns with respect to communication between relatives, patients

and professionals and the transfer of important care information. Crucially, the majority of professionals reported issues with finding time to talk with patients or their relatives. As one assistant nurse explains: “it goes without saying that we’re all busy around here. I do my best but I am limited to quick pop ins” (assistant nurse). Another GP admitted that despite trying to reassure patients that he is available for them, he often misses phone calls and cannot make meetings: “I tell them I am reachable 24/7 which is technically true but practically not - my days are so full, one visit runs over and then I can’t make the next one”. Also, some family members reported that information about patient care was poorly explained or lacking, as one relative describes that: “They (nurses) explained it badly to us because they should have said when she is unconscious and she sleeps then you shouldn't try to give her anything to drink, but they didn't tell us that.” In other cases, relatives describe miscommunications because information is not passed on to them directly. One family member describes that they waited a long time for nothing because a message was relayed to them: “She (nurse) should have come but had an emergency and couldn't come. She reported it to the central office, but then they forgot to pass the message on to us and we had waited two hours after all that.”

## **Discussion**

The findings of this study highlighted important aspects with respect to the quality of palliative care. Specifically, it indicated valuable perspectives and experiences from the professionals and relatives of palliative patients with respect to the availability, client centeredness of care, the satisfaction with care and communication and information transfer.

Firstly, the data reveal a high level of disagreement between professionals and relatives’ opinions with respect to the availability of care. Crucially, whilst professionals perceived that they make palliative services highly available to patients and their relatives, relatives expressed that they were poorly informed about the availability of care services. Instead, relatives described feeling ‘left alone’ to discover palliative services for themselves, or in the case where they were encouraged to seek palliative services, the responsibility to take the initiative to get in touch with palliative services fell on them. It also became apparent that professionals mainly understood care to be available to patients because the infrastructures for services are present. However, relatives described that since professionals did not inform patients about these services, care was not perceived to be easily available or accessible. The experiences of relatives which describe situations in which professionals do not adequately inform patients about the availability of care is highly concerning given that failing to provide patients with information about care can result in missing out on the appropriate treatment which, at the palliative level may well contribute to further deteriorating health outcomes to already fragile patients. A vast body of literature supports that misinformation can also negatively impact the quality of patient care because the coordination of care is prohibited by inaccurate or untimely information (Luckett et al, 2014). In the case of palliative care, patients who may require specialized care but who not made aware of or are not connected to these services risk neglecting their health in a potentially critical point of their illness trajectory (Bainbridge, 2010). If it is the case, as the relatives imply, that patients and relatives are not sufficiently informed about the services available to them and/ or that they must rely on themselves to reach out to services, this indicates that not only is there a considerable failing on the behalf of professionals to meet patient needs but points to a clear demand for professionals to re-evaluate their approaches to the provision of service information.

Another important finding relates to divergent perceptions of the client centeredness of care, especially with respect to the involvement of relatives in care. Adequate involvement of relatives in care is a vital aspect of the quality of care (Burns et al, 2013). Yet, the responses indicated that whilst relatives and professionals agreed that relatives were highly involved in care, they differed in opinions with respect to the appropriateness of their involvement. Specifically, health care professionals often expressed concern with the extent of involvement of relatives in the process of care. Many explained that they were worried that family members may have taken on too much responsibility in the care of their relative and risked psychological distress, including ‘burn-out’. Consequently, a few GP’s alluded to concealing information from family members regarding the patient out of fear of causing too much stress, particularly with respect to decision- making concerning care. The concerns

expressed by the GP's here are legitimate, especially given the extensive literature supporting the association between care givers and high risk for a whole host of adverse psychological effects including, but not limited to; depression, anxiety, burn-out, stress, fatigue and insomnia (Sand et al, 2008, Totman et al, 2015). However, the conflict expressed by the GP's here raise questions of what it means for relatives to be adequately involved in care but also begs the question, to what extent should they be in care, or, in what capacity? There is a growing body of evidence to support that relatives are not only involved in care, but are becoming increasingly fundamental actors of the palliative care team (Woodman, 2016). In many cases, family members have been described as 'primary caregivers' in palliative care literature. This means that they are individuals who provide the most care for the patient, without payment (Cohen et al, 2006). Whilst numerous European countries, the United Kingdom and the United States have adopted strategies to financial support such primary caregivers (Gardiner et al, 2014), Switzerland does not yet support health regulations which enable such initiatives to such an extent. Relatives living in the same household may receive some financial reimbursement, but this does not apply to all cases and to those who care for the patient outside but live separately (FOHP, 2012). This in itself may well contribute to the burden resulting from involvement in care that the health care professionals describe in the data. Adequate reimbursement in health care is of upmost importance for ensuring good quality care and alleviating stress for carers (Travis & Hunt, 2001). Beyond that, appropriate training and emotional support to equip relatives to manage their high level of involvement in the care of their loved one should be provided.

The concerns raised by relatives of palliative patients with respect to the satisfaction with care are an important discovery of this study. Where health care professionals in the field often felt that they could not necessarily comment on the satisfaction of patients, relatives were able to shed light on the specific issues that negatively impact their evaluation of care. Relatives pointed to a number of factors that attributed to a negative evaluation of the satisfaction with care, these were; poor coordination of care, poor continuity of care, as well as neglect of psychosocial needs and a perceived lack of professional competency. Poor care coordination has been consistently identified as a problematic facet of care in the context of palliative services (Reeves & Zwarenstein, 2018). These results echo recent literature concerning coordination of palliative care services in Switzerland that highlight some of the problems described here such as; poor organization of care resulting from frequent changes within the care team, miscommunication between palliative care team members and a lack of time for care coordination (Reeves et al, 2020), and they further advocate the need for improvement in this regard. With respect to the perceivably poor continuity of care, which relates to the reported problems with communication and information transfer, these findings indicate a need for strengthened communication between patients, relatives and providers. One way that this has been suggested is through allocated care coordinators who facilitate the care coordination and communication between actors in the palliative team (Reeves et al, 2020). Notably, in palliative care settings where such methods have been adopted, such as via the employment of case managers who manage the smooth transitioning of patient care continuity, this has been shown to be well received by patients and relatives (Ozelick et al, 2014).

## **Conclusions**

The findings of this study brought to light different perspectives with respect to the quality of palliative care. Significantly, professionals working in the field and relatives of palliative patients held different beliefs with respect to key aspects of care including; the availability and access to care, the client centeredness of care, satisfaction with care (including physical and psychosocial care) and communication and information transfer. Whilst there was consensus between professionals and family members with respect to various dimensions of care, the study highlighted important apparent divergences between professional and relative perspectives. Significantly, family members interviews showed that whilst health care professionals strive to provide the highest quality care provision, there are some aspects of care lacking. Their primary concerns were that care is not always readily available, care is poorly coordinated, patient needs are overlooked because of lack of time, some professionals are perceived to be incompetent, communication is lacking and psychosocial needs are neglected. Professionals agreed that psychosocial needs are not as well addressed as physical needs and also

reported that communication problems exist. However, professionals raised other concerns with aspects of care, notably that, whilst it is good that relatives are involved in care, they are wary of their over involvement due to the high risk of burn out caused by the high stress and emotionally taxing circumstances of palliative care. These different perspectives, including both their similarities and discrepancies represent a demand for addressing the shortcomings of palliative care services. These findings are thus in view of informing health policy with respect to aspects of care that require specific attention to improve overall quality of care and urge future research in this field in to explore how these aspects of care can best be supported.

### **Recommendations**

In response to the findings of the study, the following propositions for the consideration of health policy with respect to palliative care in Switzerland are proposed. Firstly, in view of the significant involvement of family members of palliative patients in the process of care, adequate psychosocial and financial support should not only be available but mandatorily provided in the case that family members are primary care givers. This measure is proposed in order to alleviate psychological and financial burden from relatives to reduce the risk of adverse health and financial outcomes often caused by involvement in palliative care. In addition, professionals in the field are urged to ensure that they provide the relevant information about the availability of not only basic palliative care but the psychosocial support available to patients and relatives. The formation of palliative professionals should ensure that they are equally equipped to cater to psychological issues as they are to physical ones to avoid the neglect of psychosocial needs. With respect to the coordination issues faced in palliative care teams, designated care coordinators should be employed to mitigate the miscommunication and untimely delivery of information.

### **Limitations**

This study relies on the perspectives of professionals and family members. However, palliative patients' insight and perceptions would have been invaluable for understanding patient experience of the quality of care in palliative services. Importantly, this information could have served important knowledge to inform policy and recommendations concerning quality of care in palliative services with patient wishes in mind. Another drawback of the study, as acknowledged by some of the health care professionals that were interviewed, is that it is difficult to accurately assess the quality of care without measured scales, and it is uncertain to what extent professionals and relatives of palliative patients can evaluate the standard of care since they are not the patient themselves. Specifically, much literature supports that health care professionals tend to over-estimate patients' satisfaction and overall quality of care provision (Hoffman & Del Mar, 2016). Whilst it is recognized that health care professionals and the relatives of patients may have an excellent insight to the patients' experience of care, inevitably, the most accurate understanding of the quality of a patients care would be one that comes directly from the patient.

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10 August 2020

Dear Ms Reeves

This letter is to confirm that your paper - **Care coordination in palliative home care: Who plays the key role?** - was accepted for publication in the International Journal of Integrated Care on 8 July 2020. It is currently undergoing proof reading and typesetting before it is published.

Sincerely

Susan Royer

**Managing Editor**

**International Journal of Integrated Care**

# **OBM Integrative and Complementary Medicine**

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## **Certificate of Acceptance**

This is to certify that the following paper now is officially accepted for publication in the journal *OBM Integrative and Complementary Medicine*:

**Manuscript ID:** obm-icm-0959  
**Type:** Original Research  
**Title:** Comparing professional and relatives perspectives of quality of care in palliative care: A qualitative interview study  
**Author:** Emily Reeves \*, Brigitte Liebig, Eveline Degen  
**Special Issue:** Integrative Therapies in Palliative Care  
**Date of Submission:** July 14, 2020

It is now in press and will be published online soon. Congratulations to the author!

A handwritten signature in black ink, appearing to read 'G. Litscher'.

Gerhard Litscher

Editor-in-Chief, *Medical University of Graz*

A handwritten signature in black ink, appearing to read 'Kelley Zhang'.

Kelley Zhang

Managing Editor, *ICM Editorial Office*

Wir suchen für ein vertrauliches Gespräch

# Familienangehörige

von Patienten und Patientinnen, welche **palliativ begleitet** werden.

Die Gespräche sind Teil eines vom Schweizerischen Nationalfonds geförderten Projekts, in dem es um die **Verbesserung der Palliativversorgung** in der Schweiz geht.

**Ziel der Studie** ist es, zentrale Aspekte der Palliativversorgung zu erkennen und deren Auswirkungen auf die Patientinnen und Patienten zu ermitteln.

**Dabei geht es um Ihre Erfahrungen mit der ambulanten und/oder stationären palliativen Betreuung vor Ort.**

Die **Gespräche dauern 1h** und werden **an einem Ort Ihrer Wahl geführt**. Alle Themen werden streng **vertraulich** behandelt und nicht an Dritte weitergegeben. Auch können Sie das Interview jederzeit abbrechen, falls Sie sich dabei nicht wohl fühlen.

Für Ihre **Anmeldung zu einem Gespräch** bitten wir Sie, sich bei **Eveline Degen** ([eveline.degen@students.fhnw.ch](mailto:eveline.degen@students.fhnw.ch) / Tel. 077 412 99 08) oder per e-mail bei **Prof. Brigitte Liebig** ([brigitte.liebig@fhnw.ch](mailto:brigitte.liebig@fhnw.ch)) zu melden. Wir stehen Ihnen auch gerne für Fragen zur Verfügung!

Geleitet wird das Projekt von **Frau Prof. Dr. Brigitte Liebig** (Hochschule für Angewandte Psychologie, Fachhochschule Nordwestschweiz) im Rahmen des **Nationalen Forschungsprogramms „Gesundheitsversorgung“ (NFP 74)**. Das Programm dient dazu die komplexen Herausforderungen in der Versorgung von chronisch kranken Patienten und Patientinnen in der Schweiz zu bewältigen.

## Formale Zustimmung für Angehörige

“ Kooperation und Koordination in Palliative Care Netzwerken. Palliative Care Netzwerke in der Schweiz.”

### Hintergrund der Studie

In der Schweiz gibt es wenig gesichertes Wissen zum Funktionieren und den Wirkungsweisen von palliativen Versorgungsnetzwerken. Diese Studie will Richtlinien für die Zusammenarbeit und die Koordination von Leistungserbringern im Bereich Palliative Care generieren und erfolgreiche Modelle der palliativen Grundversorgung aufzeigen.

### Ziel der Studie

Ziel der Studie ist es, die Zusammenarbeit und Koordination von Leistungserbringern sowohl innerhalb der palliativen Grundversorgung als auch zwischen diesem Feld und der spezialisierten Palliativversorgung zu analysieren. Zudem sollen erfolgreiche Formen der lokalen/regionalen Versorgung und deren Voraussetzungen identifiziert werden.

### Anonymität

Die Interviewdaten werden mithilfe von Codes verschlüsselt und so aufbewahrt, dass Dritte keinen Zugang zu den Daten haben. Ihre Anonymität ist zu jeder Zeit gewährleistet.

### Einwilligung

Ich verstehe, dass meine Teilnahme freiwillig ist und dass es mir jederzeit freigestellt ist, meine Teilnahme ohne Angabe von Gründen zurückzuziehen.

Ich verstehe, dass relevante Daten, die während der Studie gesammelt wurden, von MitarbeiterInnen der oben genannten Studie eingesehen werden können. Ich habe die Erlaubnis, jederzeit Zugang zu meinen Unterlagen zu erhalten.

Ich stimme zu, an der oben genannten Studie teilzunehmen.

\_\_\_\_\_  
Name TeilnehmerIn

\_\_\_\_\_  
Datum

\_\_\_\_\_  
Unterschrift

\_\_\_\_\_  
Name InterviewerIn

\_\_\_\_\_  
Datum

\_\_\_\_\_  
Unterschrift

## Approbation formelle

*“Collaboration et coordination dans les réseaux de soins palliatifs. Les réseaux de soins palliatifs en Suisse.”*

### Contexte de l'étude

En Suisse, on sait peu de choses sur le fonctionnement et l'efficacité des réseaux de soins palliatifs. Cette étude vise à générer des lignes directrices pour la coopération et la coordination des prestataires de services dans le domaine des soins palliatifs et à identifier des modèles de soins palliatifs de base efficaces.

### But de l'étude

L'objectif de l'étude est d'analyser la coopération et la coordination des prestataires de services tant au sein du secteur des soins palliatifs primaires qu'entre ce domaine et les soins palliatifs spécialisés. En outre, il convient d'identifier les formes réussies de soins locaux/régionaux et leurs conditions préalables.

### Anonymat

Les données d'entretien sont cryptées au moyen de codes et stockées de manière à ce que les tiers n'aient pas accès aux données. Votre anonymat est garanti en tout temps.

### Consentement

Je comprends que ma participation est volontaire et que je suis libre de me retirer à tout moment sans donner de raisons.

Je comprends que les données pertinentes recueillies au cours de l'étude peuvent être consultées par les collaborateurs de l'étude susmentionnée. J'ai la permission d'accéder à mes dossiers en tout temps.

"J'accepte de participer à l'étude ci-dessus.

nom du participant

sortir

signature

---

---

---

nom de l'intervieweur

sortir

signature

---

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## BREF QUESTIONNAIRE

**Coopération et coordination dans le domaine des soins palliatifs. Réseaux de soins palliatifs en Suisse.**

Enfin, nous aimerions vous demander de répondre aux questions suivantes

1. Prénom, Nom :

---

2. Sexe :  homme  femme

3. Groupe d'âge: \_\_\_\_\_

4. Veuillez indiquer votre plus haut niveau d'éducation et, le cas échéant, votre diplôme universitaire.

---

5. Combien d'années d'expérience professionnelle avez-vous ? Années : \_\_\_\_\_

6. Combien d'années d'expérience en soins palliatifs avez-vous ? Années: \_\_\_\_\_

7. Quel est le nom de votre poste actuel ?

---

8. Avez-vous une formation supplémentaire dans le domaine des soins palliatifs ?

Oui

Non

9. Êtes-vous membre d'un réseau officiel de soins palliatifs ?

Oui

Non

Dans quelle mesure êtes-vous satisfait de la coopération et de la coordination au sein de votre équipe/réseau ?

1

2

3

4

5

6

7

## Kurz-Fragebogen

### Kooperation und Koordination in Bereich Palliative Care.

Wir möchten Sie zum Abschluss bitten, noch folgende Fragen zu beantworten.

1. Bitte geben Sie hier Ihren Vornamen und Namen an:

---

2. Geschlecht: männlich  weiblich

3. Jahrgang: \_\_\_\_\_

4. Wie lange wird Ihr/e Angehörige bzw. Freund/in schon in der Palliative Care betreut?

Anzahl Jahre: \_\_\_\_\_

5. Wo und von wem wird Ihr Familienmitglied behandelt? (Institutionen/Fachleute)

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6. Hat Ihr/e Angehörige bzw. Freund/in aus Ihrer Sicht ausreichend Zugang zu Palliative Care?

ja  nein

7. Wie zufrieden sind Sie mit der Kooperation unter den Fachleuten im Bereich Palliative Care?

	0	1	2	3	4	5	6	7	8	9	10	
gar nicht zufrieden	<input type="checkbox"/>	vollumfänglich zufrieden										

8. Wie zufrieden sind Sie mit der Palliativpflege, die Ihr Familienmitglied erhält?

	0	1	2	3	4	5	6	7	8	9	10	
gar nicht zufrieden	<input type="checkbox"/>	vollumfänglich zufrieden										

## INTERVIEWLEITFADEN

### für palliativmedizinische Grundversorger und spezialisierte Versorger

#### I. VERSORGUNGSSTRUKTUREN

##### A. ARBEITEN IN DER PALLIATIVVERSORGUNG

1. Sind Sie Teil eines größeren 'Palliative Care Teams' oder 'Netzwerks' in Ihrer Stadt oder Region?

##### Falls ja:

- Welche Leistungserbringer gehören alle zu diesem Netzwerk? (*im Bereich der Grundversorgung//die Zusammenarbeit mit spezialisierter Versorgung (Hospitäler/Spezialisten/Hospize) und mit unterstützenden Diensten (Ambulatorien, Mobile Palliative Care Teams)*)
- Wie ist der Name und in welcher Region ist Netzwerk situiert?

##### Falls nein:

- Mit wem arbeiten Sie hauptsächlich auf dem Gebiet der Palliativmedizin zusammen? (*in der Grundversorgung// in der spezialisierten Versorgung (in Krankenhäusern/Spezialisten/Hospize)// mit unterstützenden Diensten (Ambulatorien, MPCTs?)*)

##### B. NETZWERKEIGENSCHAFTEN und WIRTSCHAFTLICHE FAKTOREN

2. Können Sie uns etwas über die **Geschichte** dieses Netzwerks/dieser Zusammenarbeit erzählen? Wie ist es/ist sie entstanden?
3. Wie sind **Arbeiten und Verantwortlichkeiten** in ihrem Netzwerk/ in Ihrer Zusammenarbeit aufgeteilt?
4. Auf welche **Richtlinien oder Standards** beziehen Sie sich in Ihrem Netzwerk/in der Zusammenarbeit?
5. Haben sie in Ihrem Netzwerk/in der Zusammenarbeit **gemeinsame Ideale** oder eine bestimmte **Vision**, die Ihre Arbeit und Zusammenarbeit anleiten? Wenn ja welche?
6. **Über welche finanziellen Ressourcen verfügen sie** in Ihrem Netzwerk/in der Zusammenarbeit?
7. Gibt es weitere **Anreize/unterstützende Faktoren**, welche die Zusammenarbeit in Ihrem Netzwerk bzw. zwischen Professionellen/Institutionen fördern?

##### Zur Prüfung:

- Werden Probleme/Herausforderungen genannt?
- Werden für PPC/SPC/unterstützende Dienste spezifische Aspekte und Herausforderungen genannt?

## II. PFLEGEPROZESS

### **B. ORGANISATIONALE FAKTOREN/KOORDINATION**

**Im Folgenden möchten wir Ihnen einige Fragen zum Betreuungsprozess stellen. Wenn Sie einmal an einen Ihrer letzten Patienten und dessen bzw. deren Betreuung denken**

8. Wer besitzt aus Ihrer Sicht eine **Schlüsselrolle** in Ihrem Netzwerk/ in der Zusammenarbeit, wenn es um die Koordination von Aufgaben geht?
9. Wer übernimmt die **Führung** in Ihrem Netzwerk/ in der Zusammenarbeit?
10. Gibt es Möglichkeiten, die Arbeit in Ihrem Netzwerk/ in der Zusammenarbeit zu **reflektieren und zu evaluieren**?

**Zur Prüfung:**

- Werden **Probleme/Herausforderungen** genannt?
- Werden für **PPC/SPC/unterstützende Dienste** spezifische Aspekte und Herausforderungen genannt?

### **D. ZUSAMMENARBEIT ZWISCHEN PROFESSIONELLEN**

*(Bitte beantworten Sie diese Fragen immer mit Blick auf Ihre Erfahrungen im Bereich der Grundversorgung// der Zusammenarbeit mit spezialisierter Versorgung (Hospitäler/Spezialisten/Hospize) und mit unterstützenden Diensten (Ambulatorien, Mobile Palliative Care Teams)*

11. Würden Sie sagen, dass Sie auf der Grundlage **gemeinsamer Ziele und Werte** arbeiten?
12. Haben Sie und die anderen Professionellen eine **vertrauensvolle und respektvolle Beziehung** zueinander? (Ja/Nein? Warum?)
13. **Wie lösen Sie Probleme** in Ihrem Netzwerk/gemeinsam mit den anderen Professionellen?
14. Wie teilen Sie **Risiken und Verantwortlichkeiten** in Ihrem Netzwerk/gemeinsam mit anderen Professionellen?

**Zur Prüfung:**

- Werden **Probleme/Herausforderungen** genannt?
- Werden für **PPC/SPC/unterstützende Dienste** spezifische Aspekte und Herausforderungen genannt?

### **E. INFORMATION/KOMMUNIKATION**

*(Bitte beantworten Sie diese Fragen immer mit Blick auf Ihre Erfahrungen im Bereich der Grundversorgung// der Zusammenarbeit mit spezialisierter Versorgung (Hospitäler/Spezialisten/Hospize) und mit unterstützenden Diensten (Ambulatorien, Mobile Palliative Care Teams)*

15. Wie verläuft die **Kommunikation** in Ihrem Netzwerk / mit anderen Professionellen? (mit Blick auf **Intensität, Qualität, Instrumente** der Kommunikation)

**Zur Prüfung:**

- Werden **Probleme/Herausforderungen** genannt?
- Werden für **PPC/SPC/unterstützende Dienste** spezifische Aspekte und Herausforderungen genannt?

### III. PATIENTENZUFRIEDENHEIT

#### F. ZUGANG ZU PALLIATIVE CARE UND BETREUUNGSQUALITÄT

16. Würden Sie Ihrer Erfahrung nach sagen, dass die Dienstleistungen Ihres Netzwerks/Ihrer Zusammenarbeit **für alle Patienten verfügbar** sind?
17. Sind aus Ihrer Sicht die Patienten **zufrieden mit der körperlichen und psychosozialen Betreuung**, die sie in Ihrem Netzwerk/Zusammenarbeit erhalten? (ja, nein, warum?)
18. Und wie zufrieden sind aus Ihrer Sicht die Patienten/Patientinnen mit der **Kommunikation und Informationsweitergabe** im Rahmen der Betreuung?

##### Zur Prüfung:

- Werden **Probleme/Herausforderungen** genannt?
- Werden für **PPC/SPC/unterstützende Dienste** spezifische Aspekte und Herausforderungen genannt?

#### G. WAHRNEHMUNG VON PATIENTENZENTRIERTHEIT

19. Haben Sie den Eindruck, dass **Familie/Freunde von Patienten** angemessen in die Palliativmedizin involviert sind, die Ihr Netzwerk/die Zusammenarbeit von Professionellen zur Verfügung stellt?
20. Denken Sie, dass Ihr Netzwerk bzw. Ihre Zusammenarbeit **die Bedürfnisse der Patienten angemessen** berücksichtigen kann? (medizinische, nicht-medizinische, spirituelle Bedürfnisse)

##### Zur Prüfung:

- Werden **Probleme/Herausforderungen** genannt?
- Werden für **PPC/SPC/unterstützende Dienste** spezifische Aspekte und Herausforderungen genannt?

#### H. MASSNAHME-EMPFEHLUNGEN

21. Wo sehen Sie heute **Ansatzpunkte für eine Verbesserung der Zusammenarbeit** in Ihrem Netzwerk/zwischen Professionellen im Bereich der Palliative Care?

##### Zur Prüfung:

- Werden für **PPC/SPC/unterstützende Dienste** Ansatzpunkte genannt?

#### SCHLUSS

22. Gibt es weitere Dinge, die Sie gerne im Zusammenhang mit unserem Thema ansprechen möchten?

**HERZLICHEN DANK!**

## INTERVIEW-GUIDELINE für Angehörige von Palliativpatienten

### I. ERFAHRUNGEN MIT DER PALLIATIVMEDIZIN

1. Können Sie uns Ihre bisherigen Erfahrungen mit der Palliativmedizin schildern?

**Überprüfung:**

- Sie haben einen Familienangehörigen, der palliativmedizinisch betreut wurde oder wird. In welchem Verhältnis stehen Sie zu diesem Angehörigen (Familie, Freund etc.)?
- Wo wird der/die Angehörige behandelt? (Hospiz/Krankenhaus/Zuhause..)
- Wie lange ist Ihr/e Angehörige schon in Palliativpflege?
- Weshalb wird der/die Angehörige palliativ betreut? (Diagnose?)

### II. VERSORGUNGSPROZESS

*(Wir möchten Ihnen einige Fragen über Ihre Erfahrung mit der Palliativpflege stellen. Bitte antworten Sie einfach aus der Erfahrung heraus, welche Sie und Ihr/e Angehörige/r mit der Palliativpflege gemacht haben.)*

#### A. ORGANISATORISCHE FAKTOREN

2. Können Sie mir etwas über das Palliativteam erzählen, von welchem Ihre/r Angehörige/r betreut wird/wurde?

**Überprüfung:**

- Wie viele Personen arbeiten im betreuenden PC-Team zusammen?
  - Wer ist/sind der/die signifikante(n) Mitglied(er) des PC-Teams?
  - Gibt es eine Teamleiterin oder einen Teamleiter im Sinne der Führung?
  - Wie oft hat der/die Angehörige Kontakt mit dem PC-Team in einem Monat?
3. Wer hat Ihrer Meinung nach die Schlüsselrolle im Team inne, wenn es um die Koordination von Aufgaben geht?
  4. Wie würden Sie Ihre Rolle in der Palliativpflege Ihrer/ Ihres Angehörigen beschreiben?
  5. Mit welcher Person aus dem Palliativ Care -Team haben/hatten Sie am meisten Kontakt?
  6. Wer ist/war Ihre Ansprechperson in einer Notfallsituation?

## **B. ERFAHRUNGEN BEZÜGLICH DER ZUSAMMENARBEIT ZWISCHEN ANBIETERN**

7. Würden Sie sagen, dass das PC-Team auf der Basis gemeinsamer Ziele und Werte arbeitet/e? (Bitte erläutern Sie Ihre Antwort)

### **Überprüfung:**

- Was sind diese gemeinsamen Ziele/Werte?
- Würden Sie sagen, dass diese gemeinsamen Ziele/Werte mit Ihren eigenen übereinstimmen? (Ja, nein, warum?)

8. Würden Sie die Beziehung zwischen Ihnen resp. Ihrer/ Ihrem Angehörigen und dem PC-Team als vertrauensvoll und respektvoll beschreiben? (Ja/Nein? Warum?)

9. Haben Sie, ausgehend von Ihren Erfahrungen, Probleme oder Herausforderungen in der Zusammenarbeit von Palliativversorgern erlebt?

- a. Zusammenarbeit von PPC mit SPC
- b. Zusammenarbeit von PPC mit unterstützenden Diensten (MPCT`S)
- c. Zusammenarbeit PPC untereinander (Hausärzte und Pflegefachpersonen)

### **Überprüfung:**

Wenn ja: «Haben Sie aufgrund von Problemen negative Auswirkungen der Zusammenarbeit zwischen Palliativversorgern beobachtet?»

## **III. PATIENTENOUTCOME**

*(Bitte greifen Sie auf Ihre Erfahrungen, sowie die Erfahrungen der/ des Angehörigen zurück, um diese Fragen zu beantworten)*

### **A. ZUFRIEDENHEIT MIT PALLIATIVE CARE UND ZUGANG ZU PALLIATIVE CARE**

10. Waren die Dienstleistungen der Palliativmedizin (bislang) für Sie und Ihre/n Angehörige/n leicht zugänglich? (ja, nein, warum?)

### **Überprüfung:**

- z.B.: Haben Sie das Gefühl, dass Sie Informationen über Palliativ Care und deren Dienste einfach erhalten (z.B. online, durch einen Spezialisten oder durch Informationsbroschüren)?

11. Wie zufrieden ist Ihr/e Angehörige/r Ihrer Meinung nach mit der körperlichen Betreuung, die er/sie erhält/erhalten hat? (bitte erläutern Sie Ihre Antwort)

- ....mit der körperliche Betreuung? (ja, nein wieso?)
- ...mit dem Symptom- und Schmerzmanagement? (bitte ausführen)

12. Wie zufrieden ist Ihr/e Angehörige/r Ihrer Meinung nach mit der psychischen bzw. mit der seelischen Betreuung, die er/sie erhält/erhalten hat? (bitte erläutern Sie Ihre Antwort)

## **B. INFORMATIONSTRANSFER**

*(Bitte greifen Sie auf Ihre Erfahrungen, sowie die Erfahrungen der/ des Angehörigen zurück, um diese Fragen zu beantworten)*

13. Sind/Waren Sie und Ihr/e Angehörige/r zufrieden mit der Kommunikation und dem Informationstransfer zwischen den Gesundheitsversorgern (Institutionen/Personen)?

14. Und sind/waren Sie zufrieden mit dem Informationstransfer zwischen Versorgern und Ihnen bzw. Ihrer/m Angehörigen? (ja, nein, warum?)

### **ÜBERPRÜFUNG:**

- Werden Probleme oder Herausforderungen genannt. (ja, nein, welche?)

## **C. WAHRNEHMUNG DER KLIENTENZENTRIERTHEIT DER BETREUUNG**

15. Haben Sie das Gefühl, dass Ihr/e Angehörige/r im Zentrum aller Entscheidungen, Aktivitäten und Bemühungen des Palliativ Care-Teams steht/stand? (ja/nein, warum?) (können Sie ein Beispiel nennen?)

16. Wenn Sie über die Wünsche, Bedürfnisse und Vorlieben Ihrer/s Angehörigen nachdenken, denken Sie, dass diese vom PC-Team respektiert werden/wurden? (Ja, nein, warum?) (Können Sie ein Beispiel nennen?)

17. Welche Beziehung hat bzw. hatte Ihre/ Ihr Angehörige/r zu seinen Betreuern hat von der Qualität her? (gute oder schlechte Beziehung? warum?)

## **D. WAHRNEHMUNG DER VERSORGUNGSKONTINUITÄT**

18. Haben Sie das Gefühl, dass Ihr/e Angehörige/r bisher gegeben und angemessen kontinuierliche betreut wurde? (ja, nein, weshalb?)

### **Überprüfung:**

- Auch hinsichtlich der Informationsweitergabe

19. Kennen Sie den zukünftigen Behandlungsplan Ihres Familienmitglieds und sind Sie mit diesem Plan zufrieden? (ja, nein, warum?)

#### **E. EMPFEHLUNGEN**

20. Wo sehen Sie Möglichkeiten zur Verbesserung der Pflegequalität, die Ihr/e Angehörige/r erhält/erhalten hat?

21. Gibt es noch etwas, was Sie anmerken möchten?

**Vielen Dank für Ihre Teilnahme!**

## **Appendix C1 : Information about the Research Team**

**Project Lead: Dr. Prof. Brigitte Liebig** studied psychology, sociology and anthropology at Goeth University, Frankfurt and completed her Habilitation at the faculty of Philosophy and History at the University of Basel, Switzerland. She is a professor at the School of Applied Psychology at the Fachhochschule Nordwestschweiz (FHNW), Switzerland and teaches privately at the University of Basel's Department of Sociology. She is the lead of the project and she previously lead several other related projects including; “Decision making practices at the end of life. The case of general practice”, Swiss National Science Foundation, NRP67: End of Life (2012-2015), which identified core elements of decision making in community-based palliative care. Currently (2015-2017) she directs together with Maya Shaha a study on inter-professional collaboration at the Inselspital, Bern University Hospital, Switzerland, funded by the Federal Office of Public Health and the Foundation of Nursing Sciences Switzerland.

**Research Associate: Emily Reeves- Poot** holds a Bachelor of Science (BSc) degree in Psychology from Queen's University Belfast and a Master of Science (MSc) degree in Health Psychology from Kings College London. She is a PhD candidate at the University of Basel, Switzerland at the department of Psychology and an associate researcher on the NRP 74 project, primarily responsible for the qualitative research of the project.

**Research Associate: Reka Schweighoffer** holds a Bachelor of Science (BSc) degree in Psychology and a Masters of Science (MSc) degree in Clinical Psychology and Neuroscience from the University of Basel, Switzerland. She is a PhD candidate at the University of Basel at the department of Psychology and an associate researcher on the NRP 74 project, primarily responsible for the quantitative research of the project.

**Research Assistant: Eveline Degen Jermann** holds a Bachelor of Science (BSc) degree and a Master of Science (MSc) degree in Applied Psychology from the University of Applied Sciences and Arts Northwestern Switzerland

## Appendix C2: Scientific Contributions of the Research Project

### Active participation

Title	Type of contribution	Title of article or contribution	Date	Place	Persons involved
<a href="#">From Evidence to Public Health Policy and Practice, Swiss Public Health Conference 2020</a>	Talk given at a conference	Coordination at the Interface of Primary and Specialized Palliative Care Service	01.07.2020	Online, Switzerland	Reeves Emily; Liebig Brigitte;
Hochschulkolloquium, Hochschule für Angewandte Psychologie	Individual talk	Kooperation und Koordination im Bereich der Palliativversorgung	12.02.2020	Olten, Switzerland	Liebig Brigitte;
Hochschulkolloquium, Hochschule für Angewandte Psychologie	Individual talk	Teamwork across the Interface in Palliative Care. Options and Limits	12.02.2020	Olten, Switzerland	Reeves Emily;
6. World Conference on Advanced Nursing and HealthCare 2019:Exploring Latest Innovations in Nursing and Healthcare	Talk given at a conference	Crossing borders: Teamwork Related Challenges in Palliative Care	13.06.2019	Brussels, Belgium	Schweighoffer Reka; Liebig Brigitte; Reeves Emily;
16. World Congress of the EAPC Palliative Care 2019: Global palliative care – shaping the future	Poster	Poster: Coordination and collaboration in Palliative Care. Palliative Care Networks in Switzerland	23.05.2019	Berlin, Germany	Liebig Brigitte; Schweighoffer Reka; Reeves Emily;
• 5. Forumsveranstaltung der Nationalen Plattform für Palliative Care (Frühlingsforum): Palliativversorgung in der Schweiz.	Talk given at a conference	Voraussetzungen erfolgreicher Kooperation in der Palliative Care: Die Sicht der Fachpersonen	26.04.2019	Bern, Switzerland	Degen Jermann Eveline; Reeves Emily; Liebig Brigitte;
<a href="#">21. International Conference on Palliative Care and Pain Syndromes, Nursing (ICPCPSN 2019)</a>	Talk given at a conference	Primary and Specialized Palliative Care in Switzerland: A Nationwide Survey on Prerequisites and Best Practices of Collaboration and Coordination	21.01.2019	London, Great Britain and Northern Ireland	Reeves Emily; Liebig Brigitte; Schweighoffer Reka; Nagy Noemi;
National Palliative Care Congress: Gemeinsam Sorge tragen/Prendre soins ensemble	Talk given at a conference	Coordination and Leadership in Palliative Care Teams	14.11.2018	Biel, Switzerland	Degen Jermann Eveline; Reeves Emily; Schweighoffer Reka; Liebig Brigitte;
12. Kongress der Deutschen Gesellschaft für Palliativmedizin: Auf breiten Wegen. Integration, Innovation, Intuition	Talk given at a conference	Barriers and facilitators of coordination between primary palliative care and specialized palliative care	05.09.2018	Bremen , Germany	Reeves Emily; Schweighoffer Reka; Liebig Brigitte;
Wennberg International Collaborative Spring Policy Meeting	Talk given at a conference	Community Readiness for Palliative Care - a Comparison of four Swiss Cantons	12.04.2018	Zurich, Switzerland	Liebig Brigitte; Schweighoffer Reka; Reeves Emily;
Public Health 3: Vorarlberger Gesellschaft für Public Health: „High noon“ für die Primärversorgung – Versorgungsmodelle für die Zukunft	Poster	Coordination and Collaboration in Palliative Care Networks in Switzerland	19.01.2018	Schloss Hofen, Vorarlberg, Austria	Liebig Brigitte; Schweighoffer Reka; Reeves Emily;
Smarter Health Care, NRP 74 Conference	Talk given at a conference	Collaboration and Coordination in Primary Palliative Care. Palliative Care Networks in Switzerland	05.09.2017	Lucerne, Switzerland	Schweighoffer Reka; Liebig Brigitte; Reeves Emily;
Studententag des CAS «Interprofessionelle spezialisierte Palliative Care	Talk		19.06.2020	Bern, Switzerland	Degen Jermann Eveline;
Frühlingsforum Plattform Palliative Care und BAG	Talk		26.04.2019	Bern, Switzerland	Degen Jermann Eveline; Reeves Emily;

## Appendix C3: Information about Forthcoming Manuscript

**Manuscript Title:** “Crossing Borders: Teamwork related challenges in Palliative Care”

Emily Reeves, Reka Schweighoffer, Brigitte Liebig, (*forthcoming publication*).

**Background:** Palliative situations are not only demanding for patients and families, but also for palliative care providers. Literature has highlighted that for professionals, challenges can arise from various factors, such as the critical status of patients, rapidly changing patient trajectories and dealing with death and dying. However, little is understood about the specific teamwork related challenges to palliative care provision, which often is highly inter-professional, and spatially and temporally separated.

**Aims:** This contribution aims to highlight some of the most important factors related to challenges of teamwork in palliative care.

**Methods:** The analysis starts from Bainbridge’s et al. (2010) conceptual framework of health service evaluation, as well as concepts of inter-professional teamwork. It is based on the content analysis of semi-structured interviews with health care practitioners working in palliative care in different regions of Switzerland. The sample includes 24 interviews with general practitioners and nurses in primary palliative care, as well as 16 interviews with specialist in hospitals, hospices, mobile palliative care teams and private practice gathered in 2018/19.

**Results:** The results indicate several challenges, such as; frequent changes of staff and the need for the adoption of new team members, a lack of role recognition and leadership and conflicting team attitudes and beliefs, particularly when inter-professional work, and work *across* primary and specialized palliative care domains is concerned.

**Conclusions:** Most of these challenges result from the particular character of palliative care teams, which often do not allow for the continuity of relationships and the development of common standards and norms. In order to alleviate these challenges, we suggest a more ‘agile’ approach to the management of tasks and responsibilities. Further, time resources for team development across professional and institutional borders seem especially necessary to ensure team cohesion, trust and common understanding in palliative care.

Context	Modes of teamwork	Key challenges to teamwork	Challenges to teamwork at the interface
Mostly Specialized palliative care	Multi-professional	<ul style="list-style-type: none"> <li>Limited collaboration with other staff members</li> </ul>	<ul style="list-style-type: none"> <li>Conflicting team understanding in primary and specialized palliative care</li> <li>Lack of designated coordinators at the interface</li> </ul>
Mostly Primary Palliative Care	Inter-professional	<ul style="list-style-type: none"> <li>Ambiguity of professional roles</li> <li>Leadership is context dependent                             <ul style="list-style-type: none"> <li>Team instability</li> </ul> </li> </ul>	
Mostly Primary Palliative Care	Trans-professional	<ul style="list-style-type: none"> <li>Ambiguity of professional roles</li> <li>Leadership is context dependent                             <ul style="list-style-type: none"> <li>Team instability</li> </ul> </li> </ul>	

Table 1. Overview of the challenges to teamwork within and between primary and specialized care.

## CURRICULUM VITAE

### Emily Reeves- Poot

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8610-CH  
Uster  
Tel: +41 76 246 22 42  
Email: emily.reeves@unibas.ch



### PERSONAL DATA

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**Date of birth** 28.06.1992  
**Nationality** Italian/British  
**Civil Status** Single  
**Gender** Female  
**Permit** B Permit

### EDUCATION

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**Jun 2017 - University of Basel**  
Department of Psychology, PhD Candidate  
PhD Dissertation: "Coordination and Collaboration in Palliative Care Networks in Switzerland"; Funded by NRP74  
Supervisor: Prof. Dr. Brigitte Liebig, PhD  
Co-supervisor: Prof. Dr. Rolf Stieglitz, PhD

**DEC 2016 Kings College London**  
Health Psychology, Master of Science, Graduated with Merit

**DEC 2014 Queen's University Belfast**  
Psychology, Bachelor of Science; Graduated with Honours

**JUN 2013 University of Masaryk, Czech Republic**  
Erasmus Scholarship

### PROFFESIONAL EXPERIENCE

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**APR 2020- PRESENT SWISS SCHOOL OF PUBLIC HEALTH (SSPH+)**  
Project Manager

**JUN 2017 – MAR 2020 Fachhochschule Nordwestschweiz (FHNW)**  
Department of Psychology  
Olten, Switzerland  
Research Associate

**MAY –Nov 2016 JBR Morgan Solicitors**  
London, United Kingdom  
Executive Assistant

**Responsibilities:** Organizing business meetings of senior partners at the London office, coordinating movements of staff around the city, establishing new business through networking events, developing professional letters, documents and emails.

**JAN – APR 2016**

**Kings College London**

London, United Kingdom  
Research Assistant

**Responsibilities:** Data collection and systematic review of literature. Assistance in development of medical intervention booklet for breast cancer patients.

**JUN 2012**

**Blumenrain Pflegeheim**

Therwil, Switzerland  
Internship: Health Care Assistant

**Responsibilities:** Caring for patient comfort (e.g. assistance with doing daily activities) and monitoring patient conditions (e.g. blood pressure, adherence to medication)

**MAY 2008**

**Kilpeacon Residential Home**

Altrincham, United Kingdom  
Internship: Health Care Assistant

**ADDITIONAL EXPERIENCE**

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**FEB – SEPT 2018**

**University of Zurich**

Department of Psychology  
Guest Lecturer

**Responsibilities:** Developing and teaching a series of workshops on qualitative research methods for PhD and masters level students.

**JUN 2018**

**University of Neuchatel**

Department of Psychology  
Guest Lecturer

**Responsibilities:** As part of my lecture series at the University of Zurich, I provided a workshop on qualitative studies held at the University of Neuchatel within their “Mediating Minds” event for masters, PhD and post-doctoral students.

**AUG 2018**

**Project Denkge**

Tibet, Asia  
Community Service Worker

**Responsibilities:** Provision of shelter for locals. Community Services included restoration of a town building and outreach with local community in Dengke and Tibetan areas

**MAR – SEPT 2010**

**Latin Link Organization**

Chile, South America  
English- Spanish Translator

**Responsibilities:** Translating for a team of 10 native English speakers. Teaching English in a local primary school and provision of free psychological counselling of women and children in abusive circumstances.

**JAN – MAR 2010**

**Swiss International School**

Basel, Switzerland  
Teaching Assistant

**Responsibilities:** Assistant teaching for primary school classes and additional support for child with autism.

## EXTRA CURRICULAR ACTIVITIES

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- Member of the Advisory Body for the Emerging Health Care Leaders Program (EHCL) through the National Research Programme (NRP) 74
- Active member of the EHCL program, attendance in numerous workshops on a variety of topics (e.g., Project Management, Presentation Skills, Early Career Funding, Knowledge Transfer, Expert Grant Visitor Program)
- Extensive experience in preparation and delivery of professional presentations to wide, academic and scientific audiences.
- Ongoing training: ‘Diploma in Coaching and Mentoring’: Institute of Counselling

## SOFTWARE COMPETENCIES

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**Microsoft Office** Excel, Access, Word, PowerPoint

**Other** Nvivo, MAXQDA, SPSS

## LANGUAGES

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**English** Native Speaker

**Italian** Native Speaker

**Spanish** Fluent Proficiency

**German** B1 Proficiency

**French** Basic Proficiency

## PERSONAL INTERESTS

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Teaching, counselling, coaching, public speaking, networking, connecting with people of different backgrounds and cultures, event organization and planning

## PROFESSIONAL REFERENCES

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