Aspects of inter-professional collaboration and perceptions of caregiving in palliative care

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List of abbreviations

CN	community nurse
CAS	complex adaptive system
GP	general practitioner
PHCT	palliative home care team
PCU	palliative care unit
PST	palliative support team
WPL	workplace learning

Chapters 2-7 are based on the following publications

Chapter 2: Inter-professional collaboration within fluid teams

Paper 1: Mertens F, De Gendt A, Deveugele M, Van Hecke A, Pype P. Interprofessional collaboration within fluid teams: Community nurses' experiences with palliative home care. Journal of Clinical Nursing 2019; 28(19-20): 3680-3690.

Chapter 3: Healthcare professionals' experiences of inter-professional collaboration during patients' transfers between care settings in palliative care

Paper 2: Mertens F, Debrulle Z, Lindskog E, Deliens L, Deveugele M, Pype P. Healthcare professionals' experiences of inter-professional collaboration during patient's transfers between care settings in palliative care: a focus group study. Palliative Medicine 2021; 35(2):355-366.

Chapter 4: Patients' experiences of transfers between care settings in palliative care

Paper 3: Mertens F, Sercu M, Derycke A, Naert L, Deliens L, Deveugele M, Pype P. Patients' experiences of transfers between care settings in palliative care. Submitted

Chapter 5: Family carers' experiences regarding patient transfers between care setting in palliative care

Paper 4: Mertens F, Vanderstichelen S, Goeminne E, Tesch T, Deveugele M, Deliens L, Pype P. Family carers' experiences regarding patient transfers between care settings in palliative care: an interview study. Submitted

Chapter 6: Healthcare teams as complex adaptive systems: understanding team behavior through team members' perception of interpersonal interaction

Paper 5: Pype P, Mertens F, Helewaut F, Krystallidou D. Healthcare teams as complex adaptive systems: understanding team behavior through team members' perception of interpersonal interaction. BMC Health Services Research 2018; 18(1):570.

Chapter 7: Workplace learning through collaboration in primary healthcare

Paper 6: Mertens F, de Groot E, Meijer L, Wens J, Cherry MG, Deveugele M, Damoiseaux R, Stes A, Pype P. Workplace learning through collaboration in primary healthcare: A BEME realist review of what works, for whom and in what circumstances: BEME Guide No 46. Medical Teacher 2018; 40(2): 117-134.

GENERAL INTRODUCTION

Chapter 1:

Background, research questions and outline of this dissertation

PREFACE: CHALLENGES IN PALLIATIVE CARE DELIVERY

The global need for palliative care is increasing due to population ageing and rises in cancer incidence and other non-communicable diseases, but also because medical developments have turned deadly diseases into more chronic conditions. The number of people worldwide requiring palliative care is estimated at 56.8 million, 25.7 million of which have a life expectancy of less than a year (1, 2). Furthermore, people with advanced progressive illness have a range of complex needs and symptoms, and the received care is increasingly multifaceted (3). Both demographic changes and evolutions in biomedical science have thus resulted in a growing complexity of the needs of patients with advanced progressive illness. Furthermore, family carers play a pivotal role in providing physical and emotional support and companionship for their loved ones. As the global need for palliative care is increasing, resultantly the burden of care for family carers is expected to grow (4, 5).

Palliative care is, by the nature of its practice, collaborative. Collaborative practice between involved healthcare professionals is an established standard of care to address the needs of patients affected by a life-threatening illness as well as the needs of their families (6). Inter-professional collaboration has been identified as an effective means to adequately organize health services because the complexity of healthcare requires the integration of knowledge and practices of different professional groups. Inter-professional collaborative practice is "When multiple health workers from different professional backgrounds work together with patients, families and communities to deliver the highest quality of care" (7). Even so, the involvement of multiple caregivers, each with a specific professional background, providing palliative care across settings, can cause a fragmentation of care and hence poses a challenge on the coordination and continuity of care (8-10). Involved healthcare professionals thus face the difficulty of collaborating effectively in order to meet the care needs of patients, within and across palliative care settings.

With respect to care organization, palliative care services have in recent decennia increased in both number and type under the impulse of the World Health Organization (11, 12). In Belgium, the first palliative care initiatives originated in 1980. In light of the complexity of today's palliative care, it is unclear how palliative care services currently collaborate to provide high-quality care.

Against this backdrop, this dissertation aims to gain insight into inter-professional collaboration in palliative care delivery. A better understanding of this topic can help identify areas of improvement as well as provide suggestions towards practice, education and policy.

This general introduction positions the dissertation within a wider societal and scientific context and pinpoints the existing gaps in research and knowledge.

BACKGROUND

Healthcare professionals involved in palliative care delivery today are expected to be competent and keep pace with ongoing changes within healthcare, to collaborate inter-professionally, within and across palliative care settings and to adapt to rapidly changing and uncertain conditions, in order to provide care that is tailored to the patient's and patient's family's palliative care needs. The significance of the terms marked in bold, will be clarified in the subsections below.

The following subsections will be discussed: 1) Inter-professional collaboration in palliative care – which competencies are required?, 2) Palliative care organization in Belgium, 3) Inter-professional collaboration and team membership fluidity, 4) Patient transfers across care settings, 5) Adaptation, uncertainty and the complexity science perspective

1.1. Inter-professional collaboration in palliative care – which competencies are required?

This dissertation does not elaborate on the topic of education in palliative care, nor on the process of acquiring competencies through education. Nonetheless, it is contextually appropriate to call attention to the competencies required within inter-professional collaboration in palliative care.

In order to deliver the highest quality of care and to meet patients' complex palliative needs, professionals involved must have acquired necessary competencies. The European Association of Palliative Care (EAPC) has described ten core competencies for all healthcare professionals, all of which are considered fundamental for the delivery of high-quality clinical palliative care practice (see box 1) (13, 14).

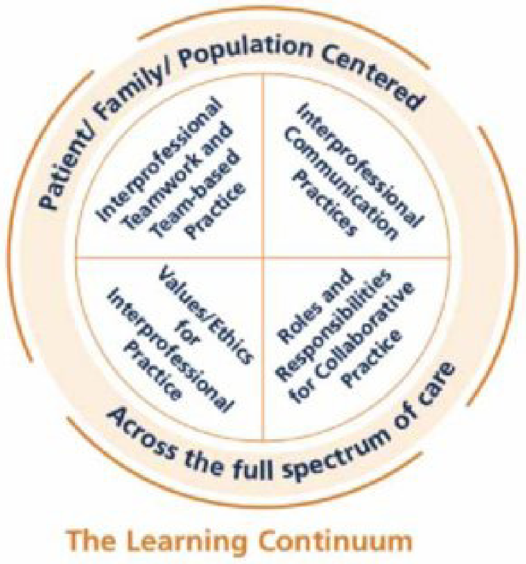
Box 1: Ten core competencies in palliative care (13, 14)

1. Apply the core constituents of palliative care in the setting where patients and families are based
2. Enhance physical comfort throughout patients' disease trajectories
3. Meet patients' psychological needs
4. Meet patients' social needs
5. Meet patients' spiritual needs
6. Respond to the needs of family carers in relation to short-, medium- and long-term patient care goals
7. Respond to the challenges of clinical and ethical decision-making in palliative care
8. Practise comprehensive care co-ordination and interdisciplinary teamwork across all settings where palliative care is offered
9. Develop interpersonal and communication skills appropriate to palliative care
10. Practise self-awareness and undergo continuing professional development

This thesis focuses on core competency 8: 'Practise comprehensive care co-ordination and interdisciplinary teamwork across all settings where palliative care is offered' . This competency is essential in order to meet the needs of patients and family carers.

To learn how to collaborate inter-professionally, inter-professional education curricula have been developed to move beyond profession-specific education efforts and engage students of a range of professional backgrounds to interactively learn from one another (16, 17). The Inter-professional Education Collaborative (IPEC) has therefore formulated ***inter-professional collaborative competencies*** within the Inter-professional Collaboration Competency Domain (figure 1) (18).

Figure 1: Inter-professional Collaboration Competency Domain



Four core competencies, displayed within the inner circle in figure 1, are rooted within the following desired principles (18):

- patient- and family-centered
- community- and population-oriented
- relationship-focused
- process-oriented
- linked to learning activities, educational strategies, and behavioral assessments that are developmentally appropriate for the learner
- able to be integrated across the learning continuum
- sensitive to the systems context and applicable across practice settings
- applicable across professions
- stated in language common and meaningful across the professions
- outcome driven

An overview of these four core competencies for inter-professional collaborative practice is shown in box 2.

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1) Interdisciplinary teamwork relates to the collaborative efforts undertaken by individuals from different disciplines such as psychology, anthropology, economics, geography, political science and computer science. Inter-professional collaboration is a type of inter-professional work which involves different health and social care professions who regularly come together to solve problems or provide services (15. Reeves S, Lewin S, Espin S, Zwarenstein M. Interprofessional teamwork for health and social care: John Wiley & Sons; 2011.). For the sake of clarity, in this thesis we use the term 'inter-professional collaboration' instead of 'interdisciplinary teamwork'.

Box 2: Core competencies for inter-professional collaborative practice (18).

Competency 1: Work with individuals of other professions to maintain a climate of mutual respect and shared values. (Values/ethics for Interprofessional Practice)

Competency 2: Use the knowledge of one's own role and those of other professions to appropriately assess and address the health care needs of patients and to promote and advance the health of populations. (Roles/Responsibilities)

Competency 3: Communicate with patients, families, communities, and professionals in health and other fields in a responsive and responsible manner that supports a team approach to the promotion and maintenance of health and the prevention and treatment of disease. (Inter-professional Communication)

Competency 4: Apply relationship-building values and principles of team dynamics to perform effectively in different team roles to plan, deliver, and evaluate patient/population-centered care and population health programs and policies that are safe, timely, efficient, effective, and equitable. (Teams and Teamwork)

Aside from acquiring the necessary competencies during undergraduate education, professionals are also expected to keep pace with ongoing changes in healthcare. This occurs by means of lifelong learning and continual professional development, either through formal or informal learning opportunities. Professionals learn during formal medical education sessions, but also through clinical practice by collaborating with others in the workplace (19).

Workplace learning during inter-professional collaboration

Learning through collaboration in the workplace, also called workplace learning (WPL), arises from interactions between professionals of the same educational background (intra-professional) as well as between professionals with different disciplines who work together to care for a patient (inter-professional) (20, 21). Workplace learning has broadly been defined as "learning taking place at work, through work and for work" (22). Evidence has shown that learning in inter-professional teams is an effective means of enabling healthcare professionals to better understand each other, to work more collaboratively and thus to enhance patient care and service delivery (20, 23, 24). Workplace learning has been studied extensively during undergraduate medical education, where it is accepted as the way students learn (25, 26). However, within the context of healthcare professionals working and learning after graduation, a knowledge gap exists with respect to the mechanisms by which WPL through collaboration takes place as well as the contextual factors that facilitate or inhibit such learning. One of the studies in this dissertation seeks to fill this gap.

1.2. Palliative care organization in Belgium (27, 28)

Competent professionals collaborate inter-professionally to meet the patients' complex palliative needs, whether they be physical, psychological, social, or spiritual. They provide palliative care at home, in the hospital, in residential and nursing homes. Generalist palliative care is provided by all health and social care professionals, while specialist palliative care is provided by healthcare professionals with specialist or accredited training in palliative care (29).

In Belgium, ***Palliative care network***s have been created to sensitize health care providers and coordinate the provision of palliative care locally. In total, 25 palliative care networks cover the entire Belgian territory (15 networks in Flanders, 1 bilingual network in Brussels, 8 networks in Wallonia and 1 network in the German-speaking community). These networks have a number of responsibilities:

- Informing the population about the available services and palliative care offering in the region
- Promoting and supporting collaboration among all palliative care providers in the region (in primary care, nursing homes, hospitals, palliative care units, residential homes, volunteer organizations, families and informal caregivers)
- Providing training to and education for healthcare professionals and volunteers
- Supporting and organizing volunteer capacity in palliative care
- Keeping records of palliative care offered in the region

In addition, three ***Federations of Palliative Care*** have been established in Belgium: one in Flanders, one in Wallonia and one in Brussels. They represent the institutions and organizations working within the sector of palliative care. Furthermore, they have been founded to provide support and expertise to all healthcare providers, to be an intermediary between healthcare settings and palliative care professionals and to negotiate with the government.

1.2.1. Organization of palliative care at home

In palliative home care, the family physician or general practitioner (GP) and the community nurse (CN) are the key healthcare professionals to provide general palliative care (30-33). Often, they rely on the support and expertise provided by palliative home care teams (PHCTs) for specialist palliative care. Each regional palliative care network consists of a multidisciplinary palliative home care team. The team is composed of nurses (trained or experienced in palliative care), a (family)physician (trained or experienced in palliative care and available at least 4 hours per week), administrative personnel and a psychologist. As defined with the RIZIV-INAMI, the PHCT has the following missions (27):

- To discuss problems with caregivers and advise them about all aspects of palliative care (e.g. pain and symptom management, psychological and spiritual support)
- To inform the patient and the patient's family about diagnosis, treatment and prognosis
- To coordinate palliative care by making arrangements with family physicians, other caregivers and volunteers
- To ensure that the necessary care material is available at the patient's home
- To provide psychological and spiritual support to primary healthcare professionals

The two first missions justify that PHCTs are available 24/7.

Furthermore, ***palliative day care centres*** have been created complementary to palliative home care teams. They provide specialized palliative care for patients with more complex palliative needs, that would not be possible at home. They also offer important support and respite care for family and informal carers. Belgium has 6 recognized palliative day care centres.

1.2.2. Organization of palliative care in the hospital

Two palliative care structures have been set up for the provision of palliative care in the hospitals: palliative care units and palliative support teams.

First, ***palliative care units*** (PCU) consist of 6 to maximum 12 beds. The number of PCUs per hospital is restricted to one. A total number of 379 beds is recognized in Belgium. The PCU is meant for those patients who cannot be cared for at home and for whom a hospital admission is considered unnecessary. The unit provides pain and symptom control, psychological guidance and bereavement counselling in a domestic atmosphere and is accessible 24/7 for family and friends. The PCU is coordinated by a physician, with special experience in palliative care, and has 1.5 FTE nurse per bed. Furthermore, the PCU should be able to rely on an oncologist, anesthetist, geriatrician, physiotherapist, social worker, chaplain, psychologist and psychiatrist.

Secondly, the palliative function in the hospital has been developed for hospitalized patients in need of palliative care, who are not staying in a PCU. This function is compulsory in every hospital and comprises all activities for the treatment, care and support of terminal patients:

- Introduce palliative culture in order to make the caregivers aware of its necessity
- Advise hospital staff and hospital management with regard to palliative care and palliative care policy
- Organize palliative care training
- Provide continuity of care when a patient in the terminal phase of illness is discharged
- Register and evaluate the palliative mission within the hospital

This palliative function is carried out by a multi-disciplinary team whose members belong to medical, nursing and paramedical services and is assisted by a mobile ***palliative support team*** (PST), composed of at least three halftime members: a physician-specialist, a nurse and a psychologist.

1.2.3. Organization of palliative care in residential and nursing homes

A palliative care function is created in each residential and nursing home. The coordinating physician and head nurse are responsible for introducing a culture of palliative care within the institution, dispensing advice and organizing training sessions in palliative care. As in the home care setting, the provision of palliative care relies on the regular nursing home caregivers, but they can fall back on advice from a specialized ***palliative reference nurse*** within the institution.

1.3. Inter-professional collaboration and team membership fluidity

Generalist and specialist palliative care providers, whether within the home, nursing home or hospital context, usually collaborate in teams. A team approach is a principal element of the WHO definition of palliative care, which is commonly accepted as the gold standard across Europe (6). Xyrichis et al. (34) defined teamwork in healthcare as "A dynamic process involving two or more health professionals with complementary backgrounds and skills, sharing common health goals and exercising concerted physical and mental effort in assessing, planning, or evaluating patient care. This is accomplished through interdependent collaboration, open communication and shared-decision making. This in turn generates value-added patient, organizational and staff outcomes" (34). For inter-professional teams to work effectively, multiple factors have been found important. Effective team functioning depends on attention being given to communication, interpersonal relations, team composition and team structure and organizational factors (35). However, medical teams today do not always have a stable composition, but are often characterized by changes in team composition. They can consist of a stable core group, complemented by continually changing team members (i.e. team member replacements, additions or withdrawals), referred to as team membership fluidity (36). Such teams change and adapt more frequently and operate within looser boundaries. The literature describes both advantages and disadvantages of team membership changes (36-39). An advantage may be an increased availability of knowledge and skills within the team. Changes can also fuel reflection on team processes. These benefits may result in an increased team flexibility and a more effective team performance. A disadvantage of team membership change may be the loss of tacit and explicit knowledge when a team member leaves. Furthermore, attention may be temporarily diverted from a task as the team is in a state of flux (36, 37). To maintain performance, adaptation is a critical skill in ad hoc teams, experiencing regular membership changes as well as altering conditions (36, 39). Team membership fluidity is characteristic for palliative care delivery, both within palliative home care as well as during the interface of patients being transferred between care settings. Gaining insight into the dynamics between collaborating members of fluid teams may aid in directing future strategies toward improved inter-professional collaboration and education.

1.4. Patient transfers across care settings

Inter-professional collaboration includes collaboration between professionals across care settings. In palliative care, patient transfers across care settings are common due to the patient's fluctuating burden of serious illness (40-42). Inter-professional collaboration across settings is therefore key for high-quality care. Transfers can take place from hospital-based care to community-based care, or vice versa. They have previously been termed as "transitions of care" or "transitions" and defined by Coleman and Boult (43) as "coordinated and continuous movements of patients between health care locations, providers or different levels of care as their medical condition and care needs change" (43). However, because multiple caregivers with various professional backgrounds are involved in providing end-of-life care across settings, these transitions pose a challenge on the coordination and continuity of care. Barriers to effective care transitions have been described and categorized at three levels: 1) the delivery system level (i.e. the organization of the current healthcare system into distinct, independent institutions), 2) the clinician level (e.g. disease-specific care managers assigned to specific care settings without formal mechanisms for communication with the primary care team) and 3) the patient level (e.g. patients not well enough prepared or equipped to optimize the care they will receive in the next setting) (44). Accordingly, patient transfers across palliative care settings are often associated with new or worsening symptoms, delays in discharge and follow-up, miscommunication about follow-up and disruption in the continuity of care (43, 45). Consequently, this may compromise patients' safety and may result in high rates of health service use and health care spending (45, 46). Improvement of inter-professional collaboration at the interface between primary and secondary care can thus ameliorate the quality of the palliative care delivery (47-49). It is therefore recommended to gain a deeper insight into how palliative care services and professionals currently collaborate to ensure continuity of patient care across settings and how patients and family members are involved.

1.5. Adaptation, uncertainty and the complexity science perspective

Healthcare, including palliative care, is rapidly changing and complex. In this complex environment, healthcare professionals in daily practice, have to make decisions and adapt to ever-changing and to uncertain conditions (50, 51). These complex situations in palliative care delivery can be examined through the lens of complexity science, one of the latest generation of systems thinking that study complex systems or ‘Complex Adaptive Systems’ (CAS) (52). A complex adaptive system is defined as a collection of individual agents, with the freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent’s action changes the context of other agents (53). Examples of CAS have been studied and identified in many areas, including biology, meteorology, the financial market and in healthcare. Specifically, healthcare teams have been described as CAS (54).

An overview of the core principles of CAS, each illustrated with an example of healthcare team functioning, is displayed in table 1 (55).

Table 1: Core principles of CAS, illustrated with examples of healthcare team functioning (55).

CAS principles	Examples of healthcare teams functioning according to the CAS principles
Complex systems consist of multiple components. Such systems are understood by observing the rich interaction of these components, not simply through the understanding of the system’s structure.	In primary palliative care, specialised palliative care nurses are collaborating with general practitioners (GPs), community nurses, palliative care physicians, hospital-based specialists, patients and their families. Understanding the structure and composition of this multi-setting collaboration is not enough to understand how patient care is actually being delivered. Therefore, we need to take the interprofessional relationships into account, based on mutual understanding and respect for each other’s expertise.
The interaction between components can produce unpredictable behaviour.	A nurse reporting to a general practitioner the status of a patient who is still in pain after raising the pain medication three times may cause different reactions by different GPs. One GP may send the patient to the hospital for advice while another GP may arrange for a joint home visit with the nurse to re-evaluate the patient and jointly deliberate a change in therapy and keeping the patient at home. This all depends on the self-confidence of the GP, the relationship with the patient, the goals and preferences of the patient, the GP’s current workload, the way the nurse reported on the pain etc. As such, the same action can produce different and unpredictable reactions.
Complex systems have a history and are sensitive to initial conditions.	A physiotherapist who makes therapy suggestions, based on his expertise, to a physician about a patient and who is being overruled by the physician will take this experience into account during a next collaboration. He might present his next therapy suggestions in another way than the first time or he might execute his therapy without notifying the physician. The way the next collaboration is being initiated, e.g. with clear agreements on tasks and responsibilities, might influence the interactional behaviour.
Complex systems interact with, and are influenced by, their environment.	A primary healthcare team is an open system, acting within the environment of the wider healthcare system with its rules and practice realities. Changing conditions, e.g. legal restrictions in nurses’ tasks, availability of drugs, the installation of a new healthcare service in the neighbourhood may alter the team behaviour. This new behaviour can in turn influence the team’s environment e.g. communication with the new healthcare service can lead to collaborative agreements.

CAS principles	Examples of healthcare teams functioning according to the CAS principles
The interactions between elements of the system are non-linear, that is to say that the results of any action depend on the state of the elements at the time, as well as the size of the input. Small inputs may have large effects, and vice versa.	A team member who forgets to make a note in the patient's chart about changing the pain therapy (input) may receive a simple instruction from his colleagues to adjust his error (small effect). On the other hand, if no one notices the error, the patient may receive the wrong dose and suffer major side effects followed by a major team dispute (large effect).
The interactions generate new properties, called 'emergent behaviours' of the system, which cannot be explained through studying the elements of the system, however much detail is known. In complex systems, such emergent behaviour cannot be entirely predicted.	A psychologist of a multidisciplinary team noticing burnout signs in one team member's behaviour may address the latter and urge him to respect his personal boundaries. This may cause a change in interaction with other team members ultimately leading to the reviewing of the team tasks and changing the way the team addresses patient care needs.
Complex systems are open systems: when observed, the observer becomes part of the system.	An external team coach, hired to optimise the team functioning and observing the team activities during a week may, by his mere presence, influence the team behaviour before he even has written his report and presented his views to the team.

In regarding healthcare teams as CAS, complexity science sheds a new light on how to consider inter-professional collaboration in palliative care. By focusing on patterns of interactions and relationships among systems it can provide new insight on how to better manage the unpredictable nature of palliative care situations (50).

2. RESEARCH AIMS

The general aim of this dissertation is to gain a deeper understanding in aspects of inter-professional collaboration as well as in aspects of caregiving in palliative care, which can help identify areas of improvement. With respect to aspects of inter-professional collaboration, this thesis draws attention to collaboration from the perspective of inter-personal interaction in palliative home care, from the perspective of collaborating professionals at the interface between primary and secondary care and from the perspective of complexity science. With respect to caregiving aspects, these are investigated by examining the viewpoints of patients and family carers.

The thesis is divided into three parts, each addressing two research aims.

In the first part, the focus lies on inter-professional collaboration in palliative home care on the one hand, and across palliative care settings on the other, by exploring the experiences of healthcare professionals.

The second part focuses on aspects of caregiving, by examining the experiences of patients and family carers with respect to transfers between care settings in palliative care as well as how these settings respond to patients' needs.

The third part investigates inter-professional collaboration in palliative home care from a complexity science perspective and workplace learning as emergent behavior of inter-professional collaboration.

A further clarification about the respective parts and research aims can be found below.

Inter-professional collaboration in palliative home care and across care settings

In palliative home care, the general practitioner (GP) and the community nurse (CN), both key formal care providers (30-32), often appeal for the support and advice of a palliative home care team's expert nurse (PHCT nurse). Although the GP, the CN and the PHCT nurse may, individually, be part of a fixed team, a new temporary team – also labeled an ad hoc team (56) – is often formed around each new palliative patient. These team membership changes, referred to as team membership fluidity, challenges professionals to work effectively to provide high-quality care. The ***first research aim*** is therefore to gain insight into team dynamics of collaborating healthcare professionals in palliative home care, concentrating on the following triad of healthcare providers: the GP, the CN and the PHCT nurse. This is done from the viewpoint of CNs. Earlier studies already reported on views and experiences of GPs and CNs regarding their role in palliative care (30, 32, 57-61), on the GPs' perceptions and preferences regarding their collaboration with PHCTs (62) and the evaluation of PHCTs by GPs and CNs (63). However, studies reporting on CNs' experiences with respect to inter-professional collaboration within the triad of collaborating healthcare providers (CN-GP-PHCT nurse) are scarce. The research questions formulated are: How do CNs experience the collaboration with the GP and the PHCT nurse in palliative home care and what are the perceived factors influencing this collaboration?

Apart from home care professionals, multiple other professionals are involved in the care trajectory of patients with a life-limiting illness. Furthermore, patient transfers between care settings are common. The background section of this general introduction touched on the challenges in inter-professional collaboration associated with patient transfers. The ***second research aim*** is therefore to gain insight in inter-professional collaboration at the interface between primary and secondary care, by investigating patients transfers between care settings in palliative care. Research questions formulated are: What are the perceptions of different healthcare professionals regarding inter-professional collaboration during a patient's transfer between palliative care settings? What are the perceptions of the different healthcare professionals regarding the involvement of the patient and the patient's family members during a transfer between palliative care settings?

Patients' transfers between care settings in palliative care: caregiving experiences of patients and family carers

Part two of this dissertation complements the perceptions of healthcare professionals regarding inter-professional collaboration during a patient's transfer between palliative care settings, as described in part one. With the objective to optimize caregiving and collaboration during the patients' palliative care trajectory, it is not only important to investigate experiences of healthcare professionals, but it is equally important to listen to the voice of patients and family carers. In the second part of this thesis we therefore broaden the scope of patient transfer processes, approaching it from a different angle by exploring the caregiving experiences of patients (Research aim 3) and their family carers (Research aim 4) regarding transfers between care settings in palliative care.

With respect to ***research aim 3***, research questions formulated are: What factors are perceived to influence the decision to move to another care setting? How do patients perceive the way care settings respond to their needs? What are the expectations of patients towards the treating family physician in guiding the transfer?

With respect to ***research aim 4***, the research questions are: How do family carers experience the illness trajectory of their next of kin related to transfers taken place? What are their experiences and attitude regarding the transfer decision? What are family carers' experiences regarding the patient's transfers across settings?

Inter-professional collaboration in palliative home care from a complexity science perspective and workplace learning as emergent behavior of inter-professional collaboration

Previously, in part one of the thesis, we focused on inter-professional collaboration from the perspective of inter-personal interaction in palliative home care and from the perspective of collaborating professionals at the interface between primary and secondary care. In part three we investigate inter-professional collaboration from a another perspective, namely the perspective of complexity science. While the first research aim explores inter-professional collaboration within an ad-hoc home care team, the ***5th research aim*** is to gain deeper insight in the functioning of a team that takes care of a palliative patient at home (the CN, the GP and the PHCT nurse) by using the principles of complex adaptive systems (CAS). Furthermore, we aim to explore factors influencing workplace learning (WPL) as emergent behavior of inter-professional collaboration. Complexity science has been introduced in healthcare as a theoretical framework to better understand complex situations (52), such as those found in palliative care delivery. It focuses on the relations and interconnections of the system components rather than the individual components and has been suggested as an appropriate conceptual framework to understand team processes and support team development (50). Furthermore, by using the CAS lens to explore how learning occurs as emergent behavior of inter-professional collaboration, insights may be gained on how to optimize the learning network feature of the collaboration. The research questions formulated are: How can the functioning of a healthcare team be described, as it originates from the members' interactions, using the CAS principles as a framework? What factors influence WPL as emergent behavior of a CAS?

The ***6th research aim***, complements the 5th research aim in that it seeks to better understand the process of WPL through collaboration in primary healthcare and the conditions influencing WPL. Insights in the process of WPL during collaboration in primary healthcare may identify implications for practice and research that may contribute to the optimization of healthcare professionals' lifelong learning and continuing professional development, one of the core competencies in palliative care. The following research questions are addressed: Who learns during WPL through collaboration in primary healthcare? When does the learning take place? How does the learning occur? What is being learned?

3. METHODS

Qualitative research: interviews and focus groups

Qualitative research was considered the best approach to address research aims 1-5.

To address ***research aim 1***, we performed semi-structured interviews with 20 community nurses (CN). Participants were recruited through regional palliative care networks (PHCT) in Belgium. Nurses of the PHCT networks selected all CNs with whom they had recently collaborated (shortly after the palliative patient's death).

To address research aim 2-4, we focused on palliative care provided within one of the fifteen palliative care regions in Flanders. The region, with a population of 264,000 has one regional PHCT, 34 nursing homes, and 4 hospitals. All four hospitals have a palliative support team (PST) and the largest hospital also has a palliative care unit (PCU) with 9 beds. All care settings within the palliative care network of the covered region were included: the regional PHCT, two nursing homes and two hospitals participated in the research project. In addition to the home care setting, a palliative day-care centre from an adjacent region was included. Participant recruitment happened with the assistance of the coordinators of each of the care settings. To address ***research aim 2***, we performed 9 focus group discussions with 53 healthcare professionals (physicians, nurses, psychologists, social workers, dieticians, spiritual workers), all involved in palliative care and/or palliative patients' transfers. To address ***research aim 3***, semi-structured interviews with 20 patients were conducted. Criteria for participant inclusion were being admitted to one of the participating palliative care services, being physically and mentally capable to participate in the interview and to be recently involved in a transfer between care settings. To address ***research aim 4***, semi-structured interviews were carried out with 21 family members. The criterium for participant inclusion was being a close family member of one of the patients recently admitted to one of the participating palliative care services and involved in a transfer between care settings.

To address ***research aim 5***, an interview study was done with 21 PHCT nurses, 20 CN and 18 general practitioners (GPs) in Flanders. A two-step analysis was used, consisting of a deductive approach and using the principles of a complex adaptive system (CAS) as coding framework for the interview transcripts. Next, an inductive approach was used to identify patterns in the codes for each CAS principle.

Realist review

To address ***research aim 6***, we performed a realist review. A realist review is an interpretative, theory-driven evidence synthesis that uses cross-case comparison to understand and explain how and why different outcomes have been observed in a sample of primary studies (64). This methodology was chosen because workplace learning results from complex interactions during practice, during which contextual factors trigger mechanisms to generate different outcomes (65). To understand the process of workplace learning through collaboration in primary healthcare, the links between context, mechanisms and outcomes needed to be explored. These links could be best explored by using realist methodology.

For details on the individual research methods of each study, please refer to the corresponding papers in this thesis.

An overview of studies and used methods in this thesis is provided in the table below.

Table: Overview of studies and used methods

Research aims	Research questions	Paper	Methods
PART I Aim 1: to gain insight into team dynamics during inter-professional collaboration in palliative home care	How do CNs experience the collaboration with the GP and the PHCT nurse in palliative home care and what are the perceived factors influencing this collaboration?	Paper 1	Qualitative study Interview study with CNs (n=20)
Aim 2: to gain insight in inter-professional collaboration across palliative care settings	What are the perceptions of different healthcare professionals regarding inter-professional collaboration during a patient's transfer between palliative care settings? What are the perceptions of the different healthcare professionals regarding the involvement of the patient and the patient's family members during a transfer between palliative care settings?	Paper 2	Qualitative study Focus groups with diverse professionals (n=53) from different palliative care settings
PART II Aim 3: To explore experiences of patients regarding transfers between care settings in palliative care	What factors are perceived to influence the decision to move to another care settings? How do patients perceive the way care settings respond to their needs? What are the expectations of patients towards the treating family physician in guiding the transfer?	Paper 3	Qualitative study Interview study with patients (n=20)
Aim 4: To explore experiences of family carers regarding patient transfers between care settings in palliative care	How do family carers experience the illness trajectory of their next of kin related to transfers taken place? What are their experiences and attitude regarding the transfer decision? Wat are family carers' experiences regarding the patient's transfers across settings?	Paper 4	Qualitative study Interview study with family carers (n=21)
PART III Aim 5: to gain deeper insight in the functioning of the team taking care of the palliative patient at home by using the principles of complex adaptive systems (CAS) and to explore factors influencing workplace learning (WPL) as emergent behavior of inter-professional collaboration	How can the functioning of a healthcare team be described, as it originates from the members' interactions, using the CAS principles as a framework? What are factors influencing WPL as emergent behavior of a CAS?	Paper 5	Qualitative study Interview study with PHCT nurses, CNs and GPs (n=59)
Aim 6: to understand the process of WPL through collaboration in primary healthcare and the conditions influencing WPL	Who learns during WPL through collaboration in primary healthcare? When does the learning take place? How does the learning occur? What is being learned?	Paper 6	Literature review – Realist review

4. OUTLINE OF THE DISSERTATION

Following the general introduction, PART I addresses inter-professional collaboration in palliative home care and across care settings. Chapter 2 explores inter-professional collaboration in palliative home care. Chapter 3 describes the perceptions of healthcare professionals with respect to inter-professional collaboration during a patient's transfer between palliative care settings.

PART II focuses on patients' transfers between care settings in palliative care and describes the caregiving experiences of patients (Chapter 4) and family carers (Chapter 5) regarding these transfers.

PART III is devoted to inter-professional collaboration from a complexity science perspective and workplace learning as emergent behavior of inter-professional collaboration. Chapter 6 describes insights in the functioning of the team taking care of the palliative patient at home by using the principles of complex adaptive systems and the factors influencing workplace learning as emergent behavior of inter-professional collaboration. Chapter 7 focuses on the process of workplace learning through inter-professional collaboration in primary healthcare and the conditions influencing this workplace learning.

Finally, the general discussion consists of a summary and discussion of the main findings, methodological reflections and recommendations for clinical practice, education, policy makers and future research.

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PART I:
INTER-PROFESSIONAL COLLABORATION IN PALLIATIVE HOME CARE AND ACROSS PALLIATIVE CARE SETTINGS

Chapter 2:

Inter-professional collaboration within fluid teams in palliative home care

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Interprofessional collaboration within fluid teams:

community nurses' experiences with palliative home care

Abstract

Aims and objectives. To explore how community nurses (CNs) experience the collaboration with general practitioners (GPs) and specialist palliative home care team (PHCT) nurses in palliative home care and the perceived factors influencing this collaboration.

Background. The complexity of, and the demand for palliative home care is increasing. Primary palliative care is provided by CNs and GPs, often in collaboration with PHCT nurses. Although these professionals may each individually be part of a fixed team, a new temporary team is often composed for every new palliative patient. These membership changes, referred to as team membership fluidity, challenge professionals to work effectively.

Design and methods. A qualitative research design, using semi-structured interviews with CNs. Participant selection happened through regional palliative care networks in Belgium. The network's PHCT nurses selected CNs with whom they recently collaborated. Twenty interviews were conducted. A constant comparative analysis approach was used. COREQ guidelines were followed.

Results. Formal interprofessional team meetings were not common practice. The other's approachability and knowing each other positively influenced the collaboration. Time constraints, the GPs' lack of expertise, communication style, hierarchy perception and income dependency negatively influenced the collaboration with GPs and determined PHCT nurses' involvement. The coping strategies of CNs balanced between a behaviour focused to the patient and to the professional relationship. Specialist PHCT nurses were relied upon for their expertise but also to mediate when CNs disagreed with GPs.

Conclusion. Community nurses showed to be highly adaptable within the fluid team. Strikingly, dynamics described in the doctor-nurse game 50 years ago are still present today and affect the interprofessional communication. Interprofessional education interventions can contribute to improved interprofessional collaboration.

Relevance to clinical practice. The study findings uncovered critical knowledge gaps in interprofessional collaboration in palliative home care. Insights are relevant for and related to professional wellbeing and workplace learning.

Impact statement:

What does this paper contribute to the wider global clinical community?

- Community nurses showed to be highly adaptable within the fluid team. Noteworthy however, communication dynamics described in the doctor-nurse game 50 years ago – when doctors were regarded as being superior to nurses and nurses' recommendations had to appear to be initiated by the physician - are still present today.
- In addition to relying on specialist palliative home care team nurses for their expertise, they were relied upon as coalition partners against general practitioners when disagreements arose.
- The study findings shed light on the dynamics between the collaborating ad hoc team members and uncovered critical knowledge gaps in interprofessional collaboration in palliative home care. To improve collaboration and healthcare outcomes, interprofessional education interventions should be further developed in the healthcare professionals' curriculum, with the era of team fluidity taken into account. Findings highlight the need for further research on interventions, aimed at improving the interprofessional communication in daily practice.

1. Introduction

An ageing population and medical developments, which turn deadly diseases into chronic conditions, have contributed to an increasing number of palliative patients (United Nations, 2017). Most palliative patients prefer to remain and die at home whilst surrounded by their relatives (Gomes et al., 2012). Palliative home care is complex and requires a multidisciplinary approach that is delivered by general practitioners (GPs) and registered nurses working in the community [hereinafter referred to as 'community nurses' (CNs)] (Beernaert et al., 2015; Borgsteede et al., 2006; Burt, Shipman, Addington-Hall, & White, 2008). Additional assistance from a specialist palliative care nurse from the palliative home care team (PHCT) may be required. The trio of collaborating professionals, namely the CN, the GP and the PHCT nurse, form an ad hoc team, which means that the team composition may change with every patient. Therefore within this context, and considering the complexity of palliative care, it is a challenge to ensure that these different professionals work effectively together to deliver high-quality care. Understanding the dynamics between the collaborating ad hoc team members may help to direct future collaborations and interprofessional education strategies.

2. Background

In recent years, the focus of care in Europe and North America has shifted from predominantly hospital-based to home-based care, with emphasis on a patient-centered and team-driven approach. These shifts require interprofessional collaboration and specific collaborative skills from the professionals involved (Chen et al., 2006). As the elderly population increases, so does the prevalence of multi-morbidity, therefore the demand for home health care increases and becomes more complex. This increasing healthcare demand and more intensive and individualised patient treatments mean that the role of the CN has evolved, including as a collaborator (for example case management which requires collaborative skills) (Bodenheimer & Bauer, 2016; Dickson, Gough, & Bain, 2011; Niezen & Mathijssen, 2014).

In palliative home care, the GP and the CN are the key formal care providers (Beernaert et al., 2015; Michiels et al., 2007; Offen, 2015; Van den Block et al., 2008). Community nurses play a central role in primary palliative home care and thus deliver physical, psychosocial, emotional, informational and organisational care (Offen, 2015). Due to its specificity and complexity, palliative care requires a team-based approach (Organization, 2002; Sepúlveda, Marlin, Yoshida, & Ullrich, 2002), therefore CNs and GPs often collaborate with specialist palliative care nurses from the PHCTs to adequately respond to the patient's symptoms and needs (Beernaert et al., 2015; Dahlhaus, Vanneman, Siebenhofer, Brosche, & Guethlin, 2013; Organization, 2010; Pype et al., 2013). Within Europe, PHCTs – similar to the ones in our study - are available in 37 out of 46 countries and the number of PHCTs are expanding (Centeno-Cortes et al., 2013). Palliative home care teams are multiprofessional teams, providing specialised support and advice on all aspects of palliative care (symptom control, psychological and spiritual support) to patients and their families, as well as to GPs and other healthcare providers (such as CNs). Their mode of action depends on the local model of care delivery and the level of involvement of the primary caregivers (Centeno-Cortes et al., 2013; Centeno et al., 2016).

Xyrichis et al. (2008) defined teamwork as 'a dynamic process involving two or more health professionals with complementary backgrounds and skills, sharing common goals and exercising concerted physical and mental effort in assessing, planning or evaluating patient care. This is accomplished through interdependent collaboration, open communication and shared decision making'.

Palliative home care in Belgium

Primary palliative home care is provided by CNs and GPs. Belgian CNs either work alone or in group practices, which can either be mono-disciplinary or multidisciplinary following the recent integration of home nursing into multidisciplinary primary care practices. The organisation of home nursing is twofold, CNs can either be self-employed or work as employees. Community nurses are mainly employed by private not-for-profit organisations with a specific focus on home nursing. A physician's prescription is required for the reimbursement of nursing interventions (Sermeus et al., 2010; Sermeus W, 2010).

General practitioners and CNs often appeal to the support and advice of specialist palliative care nurses, being members of specialised palliative home care teams (PHCT). Regional palliative care networks were created in the late 1990s, with 15 located in Flanders (the Dutch-speaking part of Belgium). Palliative home care teams, providing specialised palliative care, are organised within the regional palliative care networks and consists of palliative care physicians, psychologists and specialist PHCT nurses. Most PHCT home visits are performed by the PHCT nurses with consent of the GP. The palliative care physicians and psychologists advise and support the PHCT nurses during weekly team meetings where patient cases are discussed (Keirse et al., 2009).

Although the GP, the CN and the PHCT nurse may each individually be part of a fixed team, a new temporary team - also defined as an ad hoc team (Roberts et al., 2014) - is often composed for every new palliative patient. These team composition changes may challenge professionals to work effectively together and provide high-quality care. Existing research described the views and experiences of GPs and CNs regarding their role in palliative care (Beernaert et al., 2015; Burt et al., 2008; Dahlhaus et al., 2013; Groot, Vernooij-Dassen, Crul, & Grol, 2005; Mitchell, Loew, Millington-Sanders, & Dale, 2016; Offen, 2015; Walshe & Luker, 2010), the GPs' perceptions and preferences regarding their collaboration with PHCTs (Pype et al., 2013) and the evaluation of PHCTs by GPs and CNs (Goldschmidt et al., 2005). Although the ultimate goal of interprofessional collaboration is providing high-quality care, this paper focuses on the experiences of collaboration. To the author's knowledge, no studies have reported on the experiences of CNs with regard to interprofessional collaboration within the triad of collaborating healthcare providers (CN-GP-PHCT nurse). Gaining insight into these experiences and understanding the dynamics between the collaborating ad hoc team members may help to direct future strategies to improve interprofessional collaboration and education.

3. Study aim

The study aims were twofold: (1) to explore how CNs experience the collaboration with the GP and the PHCT nurse in palliative home care and (2) to explore the perceived factors influencing this collaboration.

4. Methods

4.1. Design

A qualitative research design was adopted, using semi-structured interviews. The study was conducted according to the COREQ: consolidated criteria for reporting qualitative research (See COREQ checklist in Supplementary File 1) (Tong, Sainsbury, & Craig, 2007).

4.2. Setting and participants

In the palliative home care setting, the daily interactions between CNs, GPs and PHCT nurses vary in frequency and type and are defined by the respective responsibilities, e.g. doctors provide CNs with prescriptions, a written report is available at the patient's house, PHCT nurses have phone call interactions with GPs and CNs for reporting and discussing. Meetings can be scheduled when needed.

Participants were recruited through the regional palliative care networks in Flanders. Four networks in different areas were purposefully selected on a geographical basis. The PHCT in each selected network was contacted and, after informed consent, asked to cooperate. Nurses of the PHCT subsequently selected all CNs with whom they had recently collaborated (shortly after the palliative patient's death). Of the group CNs that were informed and willing to participate, the researchers selected five per network, paying attention to the diversity of gender, age, years of experience and type of employment. Additional sampling was scheduled if data saturation was not reached after the analysis.

4.3. Data collection

Twenty semi-structured one-to-one interviews were conducted by the authors FM and ADG, and were approximately one hour in length. The participant's age, number of years in practice and employment type was recorded. FM and ADG reviewed the transcripts of the first three interviews to adapt and refine the interview guide. The interview guide (Box 1) was comprised of topics on interprofessional collaboration and interprofessional communication. Follow-up questions were asked based on the responses of the CNs. All interviews took place between May 2013 and February 2014 and were audio recorded and transcribed verbatim.

Box 1: Interview guide

Interprofessional collaboration

- How do you perceive the collaboration with both the GP and PHCT nurse?
- What changes in the interprofessional collaboration with the GP occur when the PHCT nurse joins the team?
- Who takes responsibility in the multidisciplinary team?
- What kind of responsibilities are there?
- What are the influencing factors for sharing tasks and responsibilities?

Interprofessional communication

- How do members of the interprofessional team communicate?
- How are you involved in decision-making processes?

4.4. Ethical considerations

Ethical approval was obtained (ethical approval number B670201317239).

Participants were provided with oral and written information explaining the objectives of the study. Written informed consent was requested. The information emphasised the preservation of the confidentiality, voluntary participation and the opportunity to opt out at any time. Participants were interviewed at a location of their choice. Interview transcripts were provided with a number.

4.5. Data analysis

A constant comparative method was used to analyse data (Fram, 2013; Hewitt-Taylor, 2001). Transcripts were read and re-read so the researchers could familiarise themselves with the data. To validate the analysis process, FM and ADG independently coded seven interviews. Subsequently, the codes were discussed and compared for similarities and differences hereby constructing an initial coding frame. This coding frame was adapted after each discussion. The remaining 13 interviews were coded by FM. All codes were again compared with regards to their similarities and differences and categories and subcategories were created. An inductive and iterative approach was used during the analysis process, hereby comparing interviews and codings. Author group discussions (FM, ADG, PP and MDV) were held to identify concepts and to discuss the relationships between the concepts using visual representations. Finally, a researcher familiar with qualitative research (AVH) but not previously involved in the researcher triangulation process read two interviews and the analysis text to verify and enhance trustworthiness. NVivo 10 software was used to support data analysis.

4.6. Rigour

This study is part of the principal author's PhD project. All but one of the other authors work within academia, previously gained their PhD and were familiar with qualitative research methods. Lincoln and Guba's criteria (i.e. credibility, transferability, confirmability and dependability) was used to assure the trustworthiness and rigour of the qualitative data (Lincoln & Guba, 1985). Peer review of the interview style was performed to ensure data credibility. Interview records, transcripts and analysis documents were meticulously maintained. As three of the authors have experience in the delivery of primary palliative care, we continuously reflected upon the interview and analysis process to ensure the analysis was a true reflection of the data. By introspection and mutual collaboration, reflexivity aspects were thus considered. Independent initial coding was compared and discussed to enhance reliability. Researcher triangulation was used at all stages of the review process to enhance data credibility, dependability and confirmability.

5.Results

5.1. Participants

Twenty CNs were interviewed. As the last interview did not reveal new themes, researchers did not perform additional interviews. Out of 20 participants, 16 were female. Their mean age was 46 years (range 35-57 years) and their professional experience in community nursing ranged from 5 months to 35 years. Four CNs worked solo and 16 worked in monodisciplinary group practices (five were employees).

Sample characteristics are shown in Table 1.

Table 1: Sample characteristics.

Community nurse (CN)	M/F	Age	Experience as a CN (years)	Practice organisation
CN 1	F	47	25	Solo
CN 2	F	40	Missing	Solo
CN 3	F	49	27	Group (employee)
CN 4	F	57	4	Group (employee)
CN 5	F	35	14	Group
CN 6	M	44	16	Group
CN 7	F	55	35	Group
CN 8	F	46	5 months	Group (employee)
CN 9	F	40	9	Group (employee)
CN 10	F	56	34	Group
CN 11	M	36	8	Group
CN 12	F	40	17	Group
CN 13	F	42	16	Solo
CN 14	M	54	21	Group
CN 15	F	50	24	Group

Community nurse (CN)	M/F	Age	Experience as a CN (years)	Practice organisation
CN 16	F	44	24	Group (employee)
CN 17	M	49	24	Group
CN 18	F	44	22	Group
CN 19	F	51	21	Group
CN 20	F	40	2	Solo

Results are presented according to the research aims. In addition, the different concepts with respect to the interprofessional collaboration are described. The following results are illustrated with quotes from participants. Each quote is identified with participant number, gender and age.

5.2. Experiences of collaboration

Within the triad of collaborating healthcare providers, the experiences of CNs were diverse with regards to interprofessional contact. In addition to the written observations and messages in the patient's file at their home, most CNs had ad hoc telephone contact on a one to one basis with both the GP and the PHCT nurse to update each other on the patient's situation. For some CNs, meeting other involved healthcare providers occurred in an unplanned manner, and formal interprofessional team meetings rarely took place. However, for others, interprofessional team meetings were common practice and were perceived as a necessity to streamline patient care.

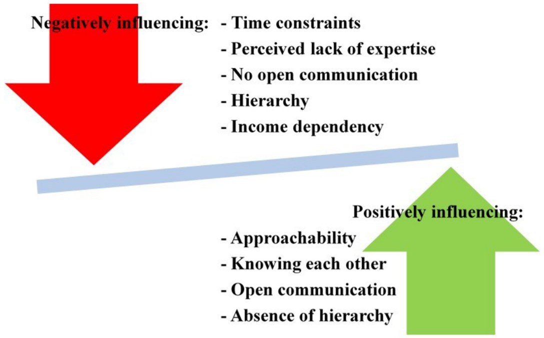
> *'It happens sometimes that we are there at the same moment by accident, and of course, then you have a chat. But we don't really arrange a team meeting, not really… Moreover, if you have a good handover by phone… After all, the GP is busy and so are we, so if things go well… If somehow something goes wrong, of course then we will inform each other … We are not the organizing kind...' (CN 20; F: 40 years).*
>
> *'With every new patient case - and in chronic care most of the time many people are involved - we take everybody on board in our practice… It doesn't work if you forget to invite one of the involved caregivers for the meeting' (CN 6; M: 44 years).*

Some interviewees reported that a PHCT nurse joining the team meant that extra attention was paid to task agreements and updating each other on the patient's case. The interprofessional collaboration as such was said not to be influenced or changed; however, the results of this study show the significance of PHCT nurses and their influence on the collaboration dynamics.

5.3. Factors influencing collaboration

Collaboration with the GP and the PHCT nurse was perceived to be influenced by specific factors (Figure 1). Approachability and knowing each other positively influenced the collaboration.

Figure 1: Perceived factors influencing the collaboration



Approachability

Community nurses felt respected and acknowledged when GPs were approachable to discuss a patient's case, when they answered the CNs' questions or when they responded to their observations quickly. Furthermore, GPs jointly deliberating with CNs on treatment decisions was strongly appreciated.

> *'… For instance last week, I'm visiting a patient with a lot of problems: a high blood pressure, irregular pulse, an uncontrollable headache, well I just need to send him an SMS: "Doctor, these are my observations", on the spot I get his answer: "I'll go and see him tonight". After his visit I get a message again: "This and that has been done, please do follow-up". That's really superb you know, you really feel respected and acknowledged' (CN 2; F: 40 years).*

> *'Several GPs around here attended the palliative care course with the PHCT, and they know all about it. When I enter the patient's house those GPs tell me: "Come and take a look, I did the calculation like this, what do you think about it". "Well doctor, that's ok, I always do it like this as well", or something alike. In mutual deliberation, that's just superb, to be consulted like this' (CN 16; F: 44 years).*

Concerning PHCT nurses, all CNs perceived them to be highly approachable and willing to help. Several CNs frequently relied on the experience of PHCT nurses. Some CNs regarded PHCT nurses as their back-up to seek confirmation from after changing a patient's medication dose. Although a GP's permission was given, they asked for additional confirmation as they preferred not to take sole responsibility for administering medication. Furthermore, the ability of PHCT nurses to demonstrate technical procedures resulted in CNs' learning and feeling more confident.

> *'Yes, the PHCT has always been my back-up. Some GPs tell us, "Yes, you can increase the dose of the plaster, go ahead". As one GP told us: "Yes, you know better than us", and it is true indeed but I don't want to do this on my own responsibility. So I'll check with the PHCT to see if it's okay that I raised the dose… then also they know about it. I don't like to do this on my own. Because you never know…' (CN 12; F: 40 years).*

Knowing each other

A history of working together and knowing each other resulted in feelings of trust and knowing what to expect from each other. Furthermore, CNs stated that working together improved the interprofessional relationship, which in turn positively influenced interprofessional collaboration.

> *'…with those others, I regularly share palliative patients, which makes me know where we stand with one another, and that we can trust each other blindly and that I also know how they're working' (CN 10; F:56 years).*
>
> *'Because the closer the collaboration, the better the relationship . The more you understand one another, the better you'll collaborate' (CN 11; M: 36 years).*

Factors that put the collaboration with the GP under stress included time constraints, the GPs' lack of expertise, their communication style, the perception of hierarchy and income dependency. These factors also determined the involvement of the PHCT nurses in the collaboration process. The coping strategies of CNs balanced between a behaviour focused to the patient and to the professional relationship. For example, some CNs would not hesitate to initiate a discussion on collaborative problems with the GP, as their 'primum movens' was the dedication to optimal patient care; however, others did not dare to question the GP's acts as they did not want to harm the professional relationship. In contrast, CNs felt more comfortable expressing themselves to PHCT nurses as they were regarded as equals.

> *'When I feel something's wrong, I'll always make a phone call or I'll go to the GP and I talk with him. On the spot I mean, I won't let it simmer for days because this we can't do. I'm quite straightforward actually. Most of the times it's just some fine-tuning, or getting a better understanding, nothing more. Because actually we all want the same, you know. We all want the patient to die comfortably' (CN 11; M: 36 years).*
>
> *'With the PHCT nurse I can express myself better. She's a nurse too you know, that's actually the same level as me. I don't dare to say to the doctor "Why do you still put him on a drip?" I'm scared of doing something wrong by this' (CN 9; F: 40 years).*

Time constraints

The collaboration between the CN and GP was put under stress when the nurse could not rely on the GP to deliberate on the treatment decision due to time constraints. When the GP was not able to be reached or had restricted the CN's phone calls, the CN turned to the PHCT nurse for advice. On the one hand they were worried about keeping the patient waiting in discomfort, but on the other hand, they did not want to take decisions on their own. In contrast to the GP, the PHCT nurse was always perceived as willing to listen and responding immediately.

> *'They (PHCT nurses) do listen to your problem and they give you an answer on the spot. Whereas when you're calling a GP he never has time or you can't even reach him. You may leave him a message but he doesn't call you back. Then you feel uncomfortable, because you know that the patient is suffering, or is being agitated and you don't want to decide on*

> *what to do yourself. So, in the end, you call the PHCT, as they communicate better compared to the GPs' (CN 12; F: 40 years).*

GPs expertise

Collaboration with the GP was also negatively influenced when he was perceived to be less experienced in palliative care. Accordingly, when the GP and CNs judged the patient's situation differently, tensions occurred when CNs did not feel that their concerns were being recognised (for example the anticipation of possible urgent complications). Hence to prepare for potential emergencies, the PHCT nurse was asked for additional information as she was regarded as an expert in the field.

> *'I called this GP and I told him "Doctor, this patient suffers from the vena cava superior syndrome, and I'm not experienced in this." "Oh but you don't have to worry about that…" was the answer! He didn't know it either, I guess, otherwise you don't say such a thing. That wasn't helping me at all. And then I'm glad the PHCT was there because these people are more knowledgeable and experienced. I was afraid the patient would suffocate, and then what? So I consulted the GP and asked him "What can we do if this happens?" "Well, then you just call me", he said. But you know, if something like this is happening, you don't have time to make phone calls, you know, you need to be able to do something. But they (GPs) don't always understand…' (CN 16; F: 44 years).*

Communication style

Some CNs felt inhibited to ask questions to the GPs because of their communication style. When open communication with the GP was absent, some CNs preferred to rely on the PHCT nurse. In contrast, other CNs would ask their questions to the GP nevertheless. They did not want to risk the GPs feeling bypassed and them disagreeing to future collaborations with PHCT nurses.

> *'Who to call first? Not easy you know! Because we want to keep the GPs approving the PHCT's involvement for future patients. The younger GPs rarely refuse this, but if it's an older one, and he feels mistreated, we don't want him to say, "Next time, I don't want them to get involved" ' (CN 1; F: 47 years).*

Through experience, CNs learned how to approach and communicate with GPs so as not to affront them. One communication strategy sometimes used was to make the GPs feel like they had solved the problem, while the CNs had really prompted it. Some CNs reported not entering into a discussion with the GP, even if the quality of patient care suffered. Despite knowing that the GP's prescribed medication dose was insufficient, they preferred to wait for the results and report this to the GP. As such, they created an opportunity for the GP to make treatment conclusions and propose adaptations. However, other CNs found it easier to express their objections, especially when the patient's comfort was at risk. The PHCT nurses were perceived to be important mediators in disagreements when GPs were not open to discussing the patient's treatment options.

> *'GPs… you have to learn how to work with them, that's not always easy. But sometimes you can turn the whole thing around, to make it seem as if it's coming out of their mouth. You have to make some suggestions' (CN 16; F: 44 years).*
>
> *'When they say "We can talk about it but it should be like this" then you know already. "I will prescribe this, what do you think about it?", then I know to some of them I can say "Yes, or maybe it's too much or not enough". But with others, I know I won't discuss, let's wait and see. Then I say "Yes, we can start like this, but is it ok for you if I call you tomorrow to report on the effect?" And then they are glad to be able to adapt if necessary' (CN 10; F: 56 years).*
>
> *'…we're having less conflicts with doctors who are open for discussion and deliberation. Often, we have the feeling that mostly solo working GPs don't see enough palliative patients. They lack experience and feel some fear to start certain drugs or they do not master certain techniques, which makes them not use them. And so you get conflicts when the nurse wants to start up a syringe driver and the GP doesn't agree. There the PHCT plays a major role, as a mediator, listening to both sides, and making sure that they reach a certain level of agreement' (CN 6; M: 44 years).*

Hierarchy

The GP was regarded as the professional who was ultimately responsible. Depending on the GP's style, hierarchy was perceived to be an influencing factor in the collaboration. When confronted with GP's hierarchical style, some CNs felt obliged to use a cautious approach and choose their words carefully. Conversely, other CNs reported a perceived change in the interprofessional relationship with GPs in general compared to recent years, which was less affected by hierarchy. This resulted in CNs feeling more relaxed towards GPs who treated them as equals. Accordingly, they felt more comfortable discussing the patient's care policy. In contrast to GPs, PHCT nurses were perceived as equals (as described above).

> *'Some GPs we're calling to say, "Doctor we think this or that", respond to us by saying "I am the doctor and I am making the decisions". They simply do not accept suggestions, as a nurse you actually have to be so very careful and pay attention… you really have to be so careful to what you're saying. Not all doctors are open for this kind of collaboration, no, absolutely not' (CN 2; F: 40 years).*
>
> *'A PHCT nurse, that's the same level, so different comparing to contacting a GP. Well yes, some GPs act in a normal way, there are some doctors who say, "You don't need to call me doctor, just call me Jan", this makes me feel more at ease. On the other hand, some doctors don't have this attitude and they really treat us like "You are the nurse and I am the doctor"' (CN 9; F: 40 years).*

Income dependency

In addition to hierarchy, income dependency was also perceived to be an influencing factor in interprofessional collaboration, in particular by self-employed CNs. They indicated that they did not wish to risk disrupting the interprofessional relationship with GPs, as their income depended on the GPs' patient referral. As such, they restrained themselves from open communication with regards to suggestions about diagnosis or treatment decisions.

> *'And you really have to be careful about what you're saying… because nurses are only allowed to describe the symptoms, we are certainly not allowed to make a diagnosis. So yes, I'm a little scared for this! And we also need his patient referrals. If he turns against you, then you are in trouble' (CN 18; F: 44 years).*
>
> *'I know the GPs and they are easily offended. I am a nurse eh. If I say to a colleague "Look here, you are not doing it the right way actually", or let me put it differently, "I think there are better solutions for this situation", she will accept, we are equals. And you know, I am not an equal to the GP. The GP is also my employer. So I have to take care not to upset him' (CN 10; F: 56 years).*

6. Discussion

This study aimed to provide insight into the experiences of CNs with regards to interprofessional collaboration during palliative home care, within the CN-GP-PHCT nurse triad. Furthermore, it also aimed to explore the perceived factors that influenced this collaboration. To the best of the author's knowledge, this is the first study to describe the dynamics within the CN-GP-PHCT nurse triad, through the eyes of the CNs.

Within the aforementioned triad, all respondents were members of an ad hoc team that changed composition for every new palliative patient. These team changes are referred to as team membership fluidity (Bedwell, Ramsay, & Salas, 2012; Tannenbaum, Mathieu, Salas, & Cohen, 2012). As such, participants provided care according to the needs of the patient and within a temporary team. Moreover, some aspects of the GP-CN relationship (for example when the GP was perceived to not be open to discussing treatment options) influenced the position of the PHCT nurse (for example as a mediator) within the triad.

In answer to how CNs experience the collaboration with the GP and the PHCT nurse, good aspects of the collaboration arose when healthcare professionals were contactable, when asking questions was possible, when there was sufficient opportunity to discuss the patient's case and when CNs were involved in the deliberation processes. These results are aligned with research results which showed that repeated opportunity for effective, frequent and reciprocal informal communication was the most important tangible element of interprofessional collaboration (Morgan, Pullon, & McKinlay, 2015). Furthermore, participants reported that meetings with other care providers were unplanned and that formal team meetings were not common practice. Literature described ad-hoc interactions to be positive and effective for the informational continuity of patient care (O'Reilly et al., 2017). Nevertheless, prior research also stressed the importance of regular formal team meetings for effective team working (Xyrichis & Lowton, 2008).

This study showed that collaboration with PHCT nurses was particularly highly valued and that most CNs reported often relying on their expertise. These findings support those from previous studies where CNs emphasised the benefits of teamwork and appreciated specialised palliative care nurses as a source of advice (Goldschmidt et al., 2005; Offen, 2015; Tomison & McDowell, 2011). In contrast, other studies found PHCT nurses to be regarded as having a higher hierarchy. This led to CNs fearing that they would be edged out of their established role and thus leading to a defensive response (Burt et al., 2008; King, Melvin, Ashby, & Firth, 2010; Offen, 2015); however, this was not confirmed in this study.

In answer to the perceived factors influencing the collaboration, several notable factors influenced the collaboration with the GP and put stress on interprofessional collaboration. First, hierarchy and income-dependency negatively influenced collaboration with GPs. To deal with the GPs' hierarchical style and safeguard future patient referrals, respondents stated that they used a cautious approach so as to not harm the interprofessional relationship. Conversely, PHCT nurses were regarded as equals. Other research results showed that a hierarchical culture impacts on effective team functioning (Hall, 2005; McInnes, Peters, Bonney, & Halcomb, 2015; O'Reilly et al., 2017; Youngwerth & Twaddle, 2011). When considering income, funding structures that support patient-team encounters rather than patient-doctor encounters and where doctors and nurses are employed alongside each other are some of the factors that enhance efficiency and promote teamwork (McInnes et al., 2015; Pullon, McKinlay, & Dew, 2009).

Second, collaboration was negatively influenced when open communication with GPs was perceived to be absent. Several participants reported that they held back from expressing their doubts or objections on treatment decisions. Alternatively, another strategy was to make GPs feel as though they had solved the problem, whilst it was actually the CN prompting it. Existing evidence endorses the nature of communication as a key factor in teamwork (O'Reilly et al., 2017). In 1967, Stein described 'The Doctor-Nurse Game', where open disagreement between the players (the doctor and the nurse) was to be avoided at all costs. The relationship between doctors and nurses was hierarchical, with doctors being superior to nurses, and the nurse had to make her recommendation appear to be initiated by the physician (Stein, 1967). Price et al. (2014) reported that the historical social positioning of nursing and medicine still influences interprofessional collaboration, despite the fact that the nurse-physician relationship has positively evolved. This is confirmed by the results of this study. Moreover, it is striking that the dynamics described by Stein in 1967 still exist today, as CNs in this study still found it necessary to use this communication strategy towards GPs, even at the expense of the patient's comfort. In contrast, all study respondents experienced communication with PHCT nurses to be open. In addition to relying on PHCT nurses for their expertise when the GP was not available or was perceived to be less experienced, CNs also reported that they acted as important mediators when disagreements with the GP arose. As such, the PHCT nurse was relied upon as a coalition partner. Therefore this study shows that CNs are dedicated to providing quality patient care; however, they often feel hindered to act accordingly for fear of harming the relationship with GPs.

Leever et al. (2010) investigated the ways hospital nurses and physicians cope with frictions. Strategies to overcome these frictions included discussing it with a person other than the one concerned (namely another physician or a staff nurse). Similarly, the results from this study revealed the significance of PHCT nurses in cases of CN-GP disagreements, not only as someone to discuss the situation with but also to lean on as a mediator.

This study highlights the adaptability of CNs within the GP-CN-PHCT nurse triad. The first aspect of this adaptability is related to the temporary team structure, to be considered a fluid team. Today, teams operate in a rapidly changing, dynamic and complex environment. They change and adapt more frequently and operate with looser boundaries than in the past (Tannenbaum et al., 2012). Therefore professionals adapt to the fact that clinical teams are constituted on an ad-hoc basis. Contemporary clinical teamwork then inhabits a place between established routines and improvisation under uncertain conditions (Bleakley, 2013). The second aspect of this adaptability is related to the behavioural style of CNs which, depending on the workplace context and attitude of the GPs, ranges from a more professional relationship-focused style to a more patient-focused approach. This is aligned with the results of a previous study which used PHCT nurses as the target study population (Pype et al., 2014). Although this study demonstrates the adaptability of CNs, the question raised is to what extent hierarchy and lack of open communication affects the provision of quality patient care. Future research, investigating in depth the entire interactions between collaborating professionals, may gain insight into how CNs' perceptions influence their behaviour during the next interaction and ultimately how it influences the quality of patient care.

7. Limitations

It is acknowledged that none of the participants worked in multidisciplinary practices, which therefore influences the generalisability of the results. Furthermore, the Belgian healthcare context and its regulations regarding remuneration may be a limitation. However we expect our findings to be transferable to CNs in other countries, as the Belgian context is exemplary. It hereby transcends the domestic practice due to similarities to healthcare systems within other developed countries.

8. Conclusion

This study demonstrated the adaptability of CNs during interprofessional collaboration in palliative home care. However, the dynamics described in the doctor-nurse game 50 years ago, are still present today and affect the interprofessional communication. Early interprofessional socialisation can ensure that professionals understand their roles in relation to each other. Recognising one's own role and those of other professionals, interprofessional communication and effective team development are core competencies described by the Inter-professional Education Collaborative (Collaborative, 2016). Interprofessional education (IPE) interventions that enable health professionals to learn about, from and with one another may improve collaborations and healthcare outcomes (Reeves, Pelone, Harrison, Goldman, & Zwarenstein, 2017; Reeves, Perrier, Goldman, Freeth, & Zwarenstein, 2013). Further research on interventions that aim to improve interprofessional communication in daily practice is recommended. In addition, these study results confirm the need for further IPE development in the curriculum of healthcare professionals with team fluidity being taken into account.

9. Relevance to clinical practice

The study findings shed light on the dynamics between the collaborating ad hoc team members and uncovered critical knowledge gaps in interprofessional collaboration in palliative home care. These insights are relevant for, and relate to, two essential aspects of clinical nursing practice. First, poor interprofessional collaboration is associated with moral distress (Lamiani, Borghi, & Argentero, 2017); conversely positive interprofessional collaboration may enhance nurses' professional wellbeing (Kaiser, Patras, & Martinussen, 2018). Therefore, insights into collaborative experiences are very relevant. A second aspect, being crucial for nurses' lifelong learning, is workplace learning as an important side-effect of interprofessional collaboration (Mertens et al., 2018).

10. Conflict of interest

No conflict of interest has been declared by the authors

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Chapter 3:

Healthcare professionals' experiences of interprofessional collaboration during patients' transfers between care settings in palliative care

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Healthcare professionals' experiences of inter-professional collaboration during patient's transfers between care settings in palliative care:

a focus group study

Abstract

Background: Continuity of care is challenging when transferring patients across palliative care settings. These transfers are common due to the complexity of palliative care, which has increased significantly since the advent of palliative care services. It is unclear how palliative care services and professionals currently collaborate and communicate to ensure the continuity of care across settings, and how patient and family members are involved.

Aim: To explore healthcare professionals' experiences regarding the communicative aspects of inter-professional collaboration and the involvement of patient and family members.

Design: Qualitative design, including focus group discussions.

Setting/participants: The study focused on one palliative care network in Belgium and involved all palliative care settings: hospital, hospital's palliative care unit, home care, nursing home. Nine group discussions were conducted, with diverse professionals (n = 53) from different care settings.

Results: Timely and effective inter-professional information exchange was considered fundamental. A perceived barrier for interprofessional collaboration was the lack of a shared electronic health record. Efficiency regarding multidisciplinary team meetings and inter-professional communication were subject to improvement.

A striking study finding was the perceived insufficient open communication of specialists towards patients and the lack of shared decision making. This not only hampered advance care planning discussions and early integration of palliative home care, but also the functioning of other professionals.

Conclusion: From the perspective of the integrated care framework, several areas of improvement on different levels of care and collaboration are identified. Support from policymakers and researchers is required to achieve integrated palliative care in regional networks.

What is already known about the topic?

- The involvement of multiple caregivers with various professional backgrounds, providing end-of-life care across settings, can cause a fragmentation of care, which poses a challenge on the coordination and continuity of care.
- Insufficient provider-patient and inter-professional communication, and ineffective team-based care are deficiencies associated with poorly executed patient transfers.
- Literature describes models to improve the quality of care during patient transfers. However, the extent to which studies describe outcomes that reflect on the continuity of care and communication in particular are limited.

What this paper adds?

- The current electronic health record does not allow for timely, efficient and effective information exchange between professionals within and across settings, to guarantee care continuity and high-quality care.
- Multi-disciplinary team meetings are subject to improvement, with respect to team meeting attendance, inter-professional communication and the willingness to discuss shared care goals.
- Open communication of specialists towards patients and shared decision making were perceived insufficient, which not only hampered the timely communication of advance care planning and the early integration of palliative home care. Other professionals expressed as a result limitations in their functioning towards the patient, influencing professional wellbeing.

Implications for practice, theory or policy

- To achieve integrated palliative care in regional palliative care networks, support from policymakers and researchers is required. To allow the exchange of information between involved professionals within and across settings, policy makers should support the further development and implementation of an electronic health record.
- Future research should objectify the impact of the professional actions of doctors (e.g. provider-patient communication) on the professional wellbeing of other team members and the quality of patient care.

Introduction

Palliative care complexity has increased significantly since the advent of palliative care services in western Europe, due to evolutions in biomedical science, demographic changes (e.g. the ageing population) and social changes (e.g. more people living alone) (1). Accordingly, transfers of patients between care settings in palliative care are common and may be unavoidable due to the fluctuating burden of serious illness (2-4). These transfers can take place between hospital based care and community based care in both directions. The involvement of multiple caregivers with various professional backgrounds providing end-of-life care across settings, can cause a fragmentation of care, thus posing a challenge on the coordination and the continuity of care. Delayed transfer of critical information, ineffective delivery of team-based care, insufficient communication about the follow-up, both inter-professionally as well as communication with patients and their family members, are some of the identified deficiencies associated with poorly executed transfers (5-10). Also, insufficient communication with palliative patients being discharged can result in patients not knowing how to manage symptoms, an increased symptom burden and not knowing who to contact. Consequently, these deficiencies may compromise patients' safety and may result in high rates of health service use and health care spending (7, 11). In response to the challenges associated with palliative patient transfers, interventions have been developed and models have been described to improve the quality of care during patient transfers (6, 12-16). Common themes of these models include, among others, inter-professional teamwork and collaboration, and effective communication between healthcare professionals and with patients and their family members (6, 12-16). A recent review of Saunders S. et al. on palliative care transitions from acute care to community-based care concluded however a lack of studies examining outcomes that reflect on care coordination and continuity and communication in particular (7).

With respect to palliative care organization, palliative care services have in recent years increased in number and type under the impulse of the World Health Organization (17, 18). In Flanders, Belgium, palliative care originated in 1995. An overview of palliative care organization and services in Belgium is described in box 1. Similar services and organization of palliative care can be found within Europe (19).

Box 1: Palliative care in Flanders, Belgium (20, 21).

Palliative care in Flanders is organized in 15 regional networks, each coordinating the palliative care of the region covered. Palliative home care teams are autonomous entities, functioning within these regional networks. They provide support and consultation about all aspects of palliative care to patients, their family members and primary healthcare providers (e.g. the general practitioner, community nurses, nursing home nurses). The majority of the home visits by the palliative home care team is carried out by specialized palliative home care team nurses, whereas palliative home care team physicians and psychologists support and advise palliative home care team nurses during weekly team meetings. Within nursing homes, the coordinating physician, together with a head nurse and a palliative reference person (mostly a nurse) are responsible for guaranteeing a culture of palliative care and for offering advice to the nursing home personnel. Within the hospital setting, two palliative care services are present. The first is a palliative care unit, consisting of 6-12 beds. The second is a palliative support team, a multidisciplinary mobile team that provides second-line consultation to hospital staff with regard to palliative care management for patients not staying at the palliative care unit . To optimize the continuity of care and the care coordination for palliative patients during transfers within a palliative care network, we explored healthcare professionals' experiences regarding the communicative aspects of inter-professional collaboration and the involvement of patient and family members.

In the light of today's palliative care complexity, it is unclear how palliative care services and professionals currently collaborate and communicate to ensure the continuity of patient care across settings and how patient and family members are involved.

This study will address the following research questions within that context:

- What are the perceptions of different healthcare professionals regarding the inter-professional collaboration during a patient's transfer between palliative care settings?
- What are the perceptions of different healthcare professionals regarding the involvement of the patient and the patient's family members during a transfer between palliative care settings?

Method

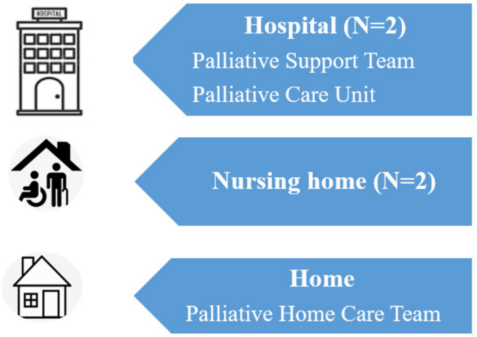
Design

From a phenomenological research perspective, a qualitative research design, using focus group discussions, was considered to be most suitable to answer the research questions as the interactions between the participating healthcare professionals were expected to obtain a broad range of views and experiences (22, 23). This article adheres to the criteria for reporting qualitative research from the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (24).

Settings and participants

This study is part of a larger research project, focusing on palliative care provided within one of the fifteen palliative care regions in Flanders, from the viewpoint of healthcare professionals, patients and informal caregivers. The research project involves all care settings: the home and nursing home care settings, as well as the hospital setting, which includes the hospital's palliative support team and the palliative care unit. The region, with a population of 264,000, has 1 regional palliative home care team, 34 nursing homes and 4 hospitals, all of which have palliative support teams and the largest of which has a palliative care unit (consisting of 9 beds). The regional palliative home care team, two hospitals and two nursing homes were selected to participate in the study. The largest hospital was selected because of its palliative care unit; the selection of the second hospital was based on the highest number of patients receiving support of the palliative support team. Nursing home selection was based on size (the largest).

Figure 1: Participating settings



To obtain a broad range of views and experiences, we included healthcare professionals with a diverse professional background (physicians, nurses, psychologists, social workers, dieticians, spiritual workers), all involved in palliative care and/or palliative patients' transfers. Participant recruitment happened purposefully with the assistance of the region's palliative home care team coordinator, the nursing home directors, the hospitals' palliative support team coordinators and the head nurse of the palliative care unit. The focus groups were organized per participating setting.

Data collection

Nine focus group discussions were held between March and May 2016, at meeting facilities within each care setting. With respect to the focus group composition we opted for heterogeneity regarding the professional background of participants. However, we aimed for homogeneity with respect to the settings, to maximize the different perspectives of the participants out of their specific setting. Two focus group discussions were organized at each care setting, except for the nursing homes, where three were held for organizational reasons. All discussions, lasting about one and a half hours each, were moderated by the principal researcher (FM), GP and experienced in qualitative research, and observed by two master students (ZD or EL). All group discussions were audio recorded and field notes were taken. To initiate and facilitate the discussion, the moderator used a vignette as 'ice-breaker' (Appendix 1). Vignettes are concrete case stories, upon which participants can easily comment (25). Three case stories were developed, describing the transfer of a palliative patient from the perspective of the home care setting, the nursing home setting and the hospital setting, for reasons of recognizability. They were based on the results of a patient chart review study, which took place at the same care settings of the region. Depending the composition of the focus group (home care, nursing home care, hospital setting), we used the vignette related to the care setting in the focus group. Furthermore, a topic guide was used, developed and reviewed within a multidisciplinary team – general practitioner (FM), palliative care physician (PP), nurse (EL), occupational therapist (ZD). For each phase of the patient transfer (at hospital admission, during the course of the transfer, at hospital discharge), the guide consisted of open questions and associated prompts and focused on the following key topics: experiences regarding information exchange, inter-professional communication and provider-patient communication (Table 1).

Table 1: Topic guide of the focus groups

Hospital admission	- Referral letter: What are your experiences regarding the use of a referral letter? What is its importance according to you? - Information gathering: How do you experience the information exchange when patients are admitted? Do you perceive it sufficient to guarantee the continuity of care? What could be improved?
During the course of transfer	- Provider-patient communication: What are your experiences and beliefs regarding informing patients about their condition, prior and during transfer? Which factors influence this communication? - What are your experiences with patient and family involvement during the course of transfer? - How do you perceive the inter-professional communication during the course of transfer, both within and between the care settings?
Hospital discharge	- How do you experience the patients' preparation of discharge? - How do you experience the inter-professional communication and information exchange when discharging patients? What could be improved?

Data analysis

All focus group recordings were transcribed verbatim. A constant comparative approach was used to analyze the data (26, 27). First, transcripts were read thoroughly by FM, ZD and EL to familiarize themselves with the data. Then, all transcripts were independently open coded by FM and divided for coding between ZD and EL. To enhance reliability, researchers subsequently discussed their preliminary codings one by one and compared them for similarities and differences. An initial coding framework was hereby constructed and was modified after each discussion and reaching a consensus. Next, all codes were again compared with regard to their similarities and differences and categories and subcategories were created. An inductive and iterative approach was used throughout the analysis process, hereby comparing focus group transcripts and codings. Finally, the interpretation of the results was discussed with senior researchers (PP, MD, LD) and a final thematic framework was agreed upon. To ensure that the analysis was a true reflection of the data, we continuously reflected upon the focus group transcripts and analysis process, thus taking the reflexivity aspects into account. Illustrative quotes were selected, approved by the research team and translated. NVivo 10 software was used to store the transcripts and to assist with coding of the data and searching of the quotes.

Ethical considerations

Ethical approval was obtained by the ethical committee of the University Hospital in Ghent, AZ Delta Hospital in Roeselare and Sint Jozef Hospital in Izegem (B670201525069, B670201525303, B670201525492). Participants were provided with oral and written information explaining the objectives of the study and were informed about the anonymity of the data. Written informed consent was obtained for the audio-recording of the discussion.

Results

A total of 53 professionals participated in the nine focus groups (Table 2). Professions represented were: physicians (general practitioner , oncologist, haematologist, anaesthetist), nurses (community nurse, specialized palliative home care team nurse, nursing home nurse, nursing assistant nursing home, palliative reference nurse, clinical nurse specialist, head nurse), psychologists, social workers, dieticians, spiritual workers. Participants' characteristics are displayed in Table 2. Functions of participating physicians and nurses are displayed in Table 3.

Table 2: Characteristics of focus group participants

Characteristics	**Number of participants**									
Focus group	1 (N 5)	2 (N 5)	3 (N 5)	4 (N 5)	5 (N 4)	6 (N 8)	7 (N 10)	8 (N 6)	9 (N 5)	Total (N 53)
Care setting	Home		Nursing home			Hospital		Palliative Care Unit		
Sex										
Male	5		6			3		2		16
Female	5		8			15		9		37

Age (years)					
20-29	0	2	0	1	3
30-39	4	2	6	2	14
40-49	4	7	7	4	22
50-59	2	2	4	4	12
60-69	0	1	1	0	2
Profession					
Physician	2	3	4	1	10
Nurse	7	11	6	7	31
Psychologist	0	0	4	0	4
Social worker	1	0	2	1	4
Other *	0	0	2	2	4

* Other: Dietician, spiritual worker

Table 3: Functions of participating physicians and nurses

Profession	Function	Number
Physician (N 10)	General practitioner	5
	Oncologist	1
	Haematologist	1
	Anaesthetist	3
Nurse (N 31)	Community nurse	4
	Specialized palliative home care team nurse	2
	Nursing home nurse	2
	Nursing home head nurse	6
	Nursing assistant nursing home	1
	Palliative reference nurse	3
	Hospital nurse	2
	Clinical nurse specialist	5
	Hospital head nurse	6

Related to research question one, three main themes were derived from the focus group interviews: information exchange, multi-disciplinary team meetings, preparing palliative home care.

Information exchange

Participants indicated they usually receive a written or electronic letter or report, for both hospital admission and discharge. They commented however on the timing, the content and the method of the information exchange.

Regarding the timing, especially GPs reported a large temporal disparity in receiving the discharge report, depending on the hospital, the hospital's ward and the specialist. Receiving the discharge report late hereby entailed the risk of negatively affecting the quality of care.

With respect to the content, both hospital staff and home care professionals stated that this often did not meet the informational needs. In particular, in case of hospital admission, clinical nurse specialists experienced a lack of home context information in the GP's referral letter. Consequently, this information had to be obtained additionally from the patient, the family or home care professionals, e.g. the GP or the community nurse. Similarly, upon hospital discharge, GPs reported a lack of psychosocial information, and it was unclear what information had been given to the patient during hospitalization. Community nurses received the discharge medication overview but also indicated a shortage of additional information regarding hospitalization. Nursing home staff sometimes experienced a lack of discharge information, especially in complex cases or patients requiring a short stay. Being informed about what happened during hospitalization was deemed important in order to understand the origin of patients' symptoms and to be able to answer their questions. Hospital healthcare professionals acknowledged that discharge reports were too concise, containing especially medical information, but containing only to a limited extent psychological information, as illustrated by the following quote:

> *'… a referral letter mentioning besides diarrhea: that's how it goes at home, for instance there's one daughter, ehm who is having a cancer problem herself and she can't guarantee the caregiving any longer. You won't learn this through the referral letter easily. That's something I personally regret very much. Conversely, sometimes the discharge report is too concise and too medical and there often is a lack of information passing through to the GP.' (FG6 Hospital, M, clinical nurse specialist)*

Regarding the method, the absence of a shared electronic health record to exchange information between professionals within or across care settings was a perceived barrier. Both within hospital and home care settings, professionals used a separate medical, nursing and psychosocial record. Moreover, nursing home professionals reported incidents of information loss when patients were transferred from one hospital to another or between the hospital's ward and the palliative care unit (e.g. a hospitalized nursing home resident mistakenly being referred to the palliative care unit instead of referring the patient back to the nursing home after hospitalization).

Overall, the availability of an efficient, digital platform, allowing for information sharing between professionals within and between settings, was deemed essential to overcome barriers of timely, relevant and complete information exchange:

> *'What I find would be a huge support is that communication in homecare and in the hospital would be centralized on one digital platform.' (FG6 Hospital, M, clinical nurse specialist)*

Multi-disciplinary team meetings

Multi-disciplinary team meetings were considered valuable to keep all professionals updated on a patient's case and to discuss shared care goals. However, all participants agreed that the implementation of multi-disciplinary team meetings remained a challenge.

Hospital professionals reported mixed experiences regarding both the meeting attendance and the inter-professional communication during these meetings, depending on the hospital and the hospital ward. General practitioners were often absent, although other hospital professionals understood that this was due to time constraints. Expressed suggestions for improvement were multi-disciplinary team meetings organized through video-conferencing:

> *'To my opinion we should focus more on video conferencing. This means organizing meetings through well yes, video conferencing.' (FG 1 Home, M, GP)*

In addition, some hospital professionals indicated that, depending on the ward, the specialist final responsible did not attend the multi-disciplinary team meetings. This resulted in a perceived risk of information and decision delay and implications towards the quality of patient care:

> *'He (the resident) passes it on to the chief resident (oncologist), ehm the resident is there and we, the dietician, …, the physiotherapist… He is taking this information and consults the chief resident and that's very difficult for us because we don't know when will this information be passed on? Shall it really be done or not? (FG 9 Palliative Care Unit, F, Clinical nurse specialist)*

Concerns were voiced regarding the quality of the meetings. Questions were raised with respect to their efficiency, whether opinions could be expressed openly or whether hierarchy influenced this. However, ever since the participation of other specialists at the multi-disciplinary team meetings, improvements of discussing shared care goals and a more open communication were perceived. To be regarded an equal partner in the discussion was considered pivotal:

> *'it is improving now thanks to our team meetings with the physicians, but it's only since December that we are having team meetings with the physicians. Ehm, and now it is improving: we can have a more open communication and we are moving on, but… those are very tiny steps you know.' (FG8 Palliative Care Unit, F, Clinical nurse specialist)*
>
> *'I think it is very important that everybody sees the other as an equal partner and I think that makes the difference… and if you are at an equal level and you look at things together, then you can move on.' (FG8 Palliative Care Unit, F, Clinical nurse specialist)*

Preparing palliative home care

Both the practical organization and the timing of a patient's discharge towards palliative home care were often perceived inadequate. A timely announcement of a patient's discharge was regarded essential to guarantee the continuity of care. To help prepare home care professionals, the GP and the community nurse were sometimes invited to the hospital prior to the patient's discharge. Nevertheless, home care professionals indicated that discharge was sometimes insufficiently organized, e.g. it took place on a Friday afternoon while medication reports, prescriptions, and essential material were lacking, for example:

> *'I still find the communication between the hospital and us very difficult sometimes. We already had some patients being discharged back home,*

> *they call you, you arrive at their home and there isn't any medication present and those people are completely confused. We went to Brugge (hospital) the other day, 3 days before that lady was being discharged… we discussed everything with the speech therapist, the specialist nurse, we discussed everything we would need, the head nurse, the social assistant was there… That lady gets home, no medication report, she really didn't know anything about it at all… It was Friday night and that's the situation eh.' (FG1 Home, M, Community nurse)*

Home care professionals indicated they were involved too late in the patient's care trajectory, e.g. for oncology patients who undergo a long-lasting treatment process in the hospital setting. Hospital professionals admitted this to be a problem. Both hospital and home care professionals experienced that starting palliative home care in a timely fashion provided the possibility for family caregivers to prepare themselves for the patient's dying process, both practically and emotionally. Conversely, when palliative home care was not initiated early enough and family caregivers were insufficiently supported, the goal of dying at home was hindered:

> *'I observe that if palliative care has been initiated in a timely manner that the patient's dying process is more peaceful… Ehm but if only initiated after the patients received the bad news… then it's always chaos and well then… The family is not prepared for that day to come…Moreover they have been unaware of that process of gradual decline.' (FG9 Palliative Care Unit, F, clinical nurse specialist)*

The following results relate to research question two: the perceptions of different healthcare professionals regarding the involvement of the patient and the patient's family during the transfer between palliative care settings. Related to this, two themes were derived from the focus groups: provider-patient communication and advance care planning.

Provider-patient communication

In the hospital, patients were perceived to be informed late about the status of their illness and hence only then given the option for transferring to the home care setting or the palliative care unit. Non-physician hospital professionals considered informing patients about their diagnosis and prognosis to be the physicians' role and regarded their own role to be supportive. Non-physician healthcare professionals at one hospital expressed problems regarding open communication of some physicians towards their patients. Some nurses took the initiative to discuss the need for open communication with the specialist. Physicians' openness about the patients' condition and prognosis directly affected the organization of appropriate patient care and influenced inter-professional collaboration, e.g. a hospital's social assistants perceived difficulties in organizing additional support when patients were unaware of their prognosis. Also, hospital nurses felt hampered to fully fulfill their job due to a specialists' lack of open communication. For example when the patient was not informed of being palliative, hospital nurses were not able to involve specialized palliative care nurses:

> *'There has to be an open communication towards the patient, which is not always the case until now ehm. Sometimes we are too late, you know. Patients are being informed too late, which restricts us in our communication too because we still have to be careful as to what we tell the patient. When the doctors don't tell the patients about the deterioration or that it's heading the wrong direction then we can't do our job. Ehm… there is some improvement, but there still is a long way to go especially because so far there isn't any open communication from the doctors. As long as there is no open communication from the doctors, we can't communicate openly and we cannot involve the palliative care team if the word 'palliative' is still unspoken.' (FG8 Palliative Care Unit, F, clinical nurse specialist)*

Furthermore, nurses and social workers at one hospital indicated patients were insufficiently involved in a shared decision making process. Rather than the discussion of appropriate treatment options, a therapeutic obstinacy was perceived. This fact was confirmed by the participating anaesthetist.

> *'… when they arrive at the unit, it is often too late and because of that everything has to be arranged in very short time. What I also experience on the hospital ward when people themselves are asking to stop therapy, that they actually still continue a little you know, and well yes, therapeutic obstinacy – I surely can't deny…' (FG8 Palliative Care Unit, M, social worker)*
>
> *'Sometimes of course – it's always easier to just continue the treatment, continue treating, rather than taking the time to have a talk and ac-*

> *tually stop treatment. That's a much bigger effort.' (FG8 Palliative Care Unit, M, Anaesthetist)*

Advance care planning

In general, participating professionals regarded advance care planning important for the delivery of high-quality care. Advance care planning was perceived hampered when patients were informed late about their prognosis and condition. Home care professionals believed that by introducing advance care planning discussions earlier on in the disease trajectory, future problems could be better anticipated.

Nursing home professionals and GPs expressed positive experiences when being called by emergency doctors to deliberate on treatment decisions - thus taking the information of the advance care planning into account – in case of a patient's hospital admission:

> *'On our transfer document everything is being clearly explained and in the hospital, I do think they take this into account, they read it and they are contacting family members more easily to ask them: "what is still being expected , because we see that advance care planning has been discussed"… And then I do believe it is of substantial added value – knowing that we have been contacted because of the advance care planning. I do find that goes well.' (FG5 Nursing home, F, nursing home nurse)*
>
> *'It's been taken into account more and more, you know... Especially emergency doctors, they call us regularly.' (FG 4 Nursing home, M, GP)*

To initiate advance care planning discussions, nursing home professionals expressed difficulties when patients were transferred to the nursing home for a short stay. The large turnover of short term patients negatively influenced advance care planning discussions as they required a good rapport with the patient and family, which was difficult to establish within a short time frame.

Within the hospital context, initiating advance care planning discussions was perceived hindered due to patient-related factors (e.g. patients refusing to talk about end-of-life care), context-related factors (e.g. high workload) or professional-related factors (e.g. not knowing how to handle patient's cues). Furthermore, hospital nurses indicated having a different view on when to initiate advance care planning discussions compared to specialists:

> *'Head nurse oncology: during the ward round with the doctor, I indicate very often: "look, do we have to talk about that yet? Do we already arrange specific things?" But then the doctor says: "but no, it's still too early"… And sometimes I got the feeling that every time while doing the round - again and again - well yes palliative DNR code – that in the end they will say "there she goes again".*
>
> *Social worker: 'Yes, yes, yes, their stance is "we are here to treat, you know. We are not meant to…" It's always like that.'*
>
> *Head nurse oncology: 'The doctor is seeing the patient only one minute, as a nurse, you know, you go all along with the patient.' (FG 8 Palliative Care Unit)*

Discussion and conclusion

Main findings

This study examined the experiences of healthcare professionals involved in transfers across care settings in palliative care, and their perceptions regarding the inter-professional collaboration and the involvement of patient and family members. Five themes were identified: 1) *information exchange*, 2) *multi-disciplinary team meetings* 3) *preparing palliative home care*, 4) *provider-patient communication* and 5) *advance care planning.*

Overall, timely and effective inter-professional information exchange was considered essential. However, participants in all care settings indicated they received a shortage of psychosocial information. Furthermore, the current electronic health record system did not provide enough opportunities for interprofessional information exchange. With respect to multi-disciplinary team meetings, the efficiency regarding attendance, inter-professional communication and the willingness to discuss shared care goals were open for improvement. A striking study finding was the perceived insufficient open communication of specialists towards patients and the lack of shared decision making, which hampered advance care planning discussions and early integration of palliative home care.

Discussion

Previous literature results endorse the necessity of timely, efficient and effective information exchange to guarantee continuity of care and the delivery of high-quality care. Nevertheless, delayed or insufficient information exchange remains common (10, 28, 29), a fact corroborated by our study findings. The electronic health record provides promising opportunities to exchange patient information across settings and improve care coordination. However, it requires changes at both the user level (e.g. participants and type of data exchanged) and the broader level (e.g. legal regulations and technical infrastructure) (30-32). Our study results confirm this information.

Regarding multi-disciplinary team meetings, our study findings are aligned with previous research results stating that both the team composition and the team processes are associated with the effectiveness of multi-disciplinary team meetings. Absence of key professionals and insufficient teamwork are some of the barriers to achieving joint recommendations in multi-disciplinary team meetings (33-35). Furthermore, a climate of respect between team members and good communication contribute to successful multi-disciplinary team meetings (34-37). Reported benefits of such meetings include an increased team competence and strengthening of teamwork and interprofessional collaborative relationships, ultimately influencing patient care (33, 36).

Effective communication and discussing care goals with the patient are key elements in high-quality palliative care. Best practices in these discussions include the sharing of prognostic information and eliciting decision-making preferences. Our study findings revealed serious shortcomings in this field. Literature results confirm patient, physician and system factors to contribute to deficiencies in this communication process (38-40). Physician factors consist of the attitude towards initiating end-of-life discussions, not feeling prepared to conduct these conversations and initiating end-of-life discussions late in the illness course (38-43). A possible explanation for this may be the specialist's lack of communicative skills and/or his persistence in a life-prolonging treatment pathway. However this was not further investigated in our study.

Our data showed that the lack of effective team functioning and open and effective provider-patient communication hampers the timely communication of advance care planning and the early integration of palliative home care. Existing evidence corroborates the timely communication of advance care planning and involvement of palliative home care to be essential to minimize crises and achieve concordance between patient's preferences and the received end-of-life care (44-46). Our findings confirm the latter, however are adding results related professional wellbeing. Namely, as a result of the professional actions of doctors (e.g. provider-patient communication), other professionals experienced limitations in their own professional functioning towards the patient. They described this as a barrier towards their own professional wellbeing.

To overcome barriers of ineffective communication, an interprofessional team-based approach to palliative care, end-of-life communication and decision making across care settings is essential. Its importance has been stressed in previous studies (40, 46-48). A team-based approach, involving shared responsibilities, can result in the burden of end-of-life communication resting not only on the shoulders of a single physician. To enhance interprofessional collaboration in these communication issues, promotion of an interprofessional collaborative culture during early socialization within educational and practice environments is fundamental (47, 49-51). Furthermore, the team-based approach requires all involved health professionals to work together cohesively, to support the palliative patient's care goals through coordinated communication (46). Our study results have uncovered a substantive gap to be filled in in that area, in order to provide qualitative patient care across settings.

The extent to which professionals coordinate services across disciplines and settings are key elements of integrated care. Integrated palliative care aims at improving coordination of palliative care around patients' anticipated needs and involves bringing together administrative, organizational, clinical and service aspects to realize continuity of care between all actors involved in palliative patients' care network (52). The integrated care framework, constructed to better understand the complex interactions of integrated care, describes different integration processes playing inter-connected roles on the macro- (system integration), meso- (organizational and professional integration) and micro-level (clinical, service and personal integration). Functional integration (e.g. communication and IT), and normative integration (e.g. shared values) ensure the connectivity between the various levels (53, 54).

Strengths and limitations of the study

All Belgian care settings that provide palliative care, comparable to other developed countries, were involved in this study. The study specifically focused on one palliative care network and included participants from various professional backgrounds out of the different settings. Together with the choice for focus group discussions, this resulted in a broad perspective on the topic. Getting insight into the viewpoints of professionals working in the different settings within the same region provided a deeper understanding of the mechanisms and the barriers of inter-professional collaboration during palliative patients' transfers. Although this insight may inspire other palliative care settings in Belgium and abroad, we should be cautious to generalize the results, as we were not able to compare this insight to the experiences of collaborating professionals in other networks.

With respect to the focus group composition, the choice for homogeneity regarding setting but a heterogeneity regarding professions can maximize the exploration and understanding of setting-specific experiences. By contrast, too much heterogeneity may inhibit discussion. Heterogeneity regarding professions however, may influence the group discussion too due to status difference of the professionals or sensitive topics being discussed and individuals feeling uncomfortable to respond (55). This may have happened in our study. The use of vignettes to initiate the focus group discussion not only works as 'ice-breaker' but provides the possibility to open the group discussions in a similar way and broaden the focus of the discussions. A limitation could be the distance between the vignette and the social reality (25). However, we have tried to anticipate this by using concrete patient cases aligned with the care settings of the participants. Another limitation may be that participants initially provide socially desirable responses (25). This was avoided through the use of probing questions.

Conclusion and implications

From the perspective of the integrated care framework, our study highlighted several areas of improvement on different levels of care and collaboration, such as ineffective information flow across settings and professionals due to the absence of a shared electronic health record, ineffective inter-professional and provider-patient communication and a lack of shared care goals. Among others, support from policymakers and researchers is required to achieve integrated palliative care in regional networks. Policymakers should support the further development and implementation of an electronic health record, which allows for both the exchange of patient information between involved professionals and across settings. Moreover, future research should objectify the impact of the professional actions of doctors (e.g. provider-patient communication) on the professional wellbeing of other team members and the quality of patient care.

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Appendix 1: Vignettes used during focus group discussions

Case 1 (FG 1-2)	Ms Van Hove, 71 years, living at home, together with her husband, suffers from an oncologic disease. She receives daily care by the community nurse (CN) and regular visits of the palliative home care team (PHCT) nurse. Together with her GP, she discussed advance care planning. Suddenly she develops severe pain in the abdomen, after which she is referred to the hospital by her GP. After 10 days of hospitalization, discharge is planned. Prior to this, the hospital's social assistant discusses the home care needs with her husband. A discharge report is given, containing medication changes and contact information in case of complications. The GP, as well as the CN and PHCT nurse, are informed about the patient's discharge in order to continue home care delivery.
Case 2 (FG 3-5)	Ms Dobbels, an 80 years old widow, lives in a nursing home. She suffers from chronic bronchitis. Besides nursing home care, she receives regular visits of her GP and physiotherapist. Together with her two sons, advance care planning discussions are done. When she develops a severe cough, her GP decides for a hospital referral. During hospitalization, the nursing home is regularly kept updated. After two weeks, the nursing home and the GP are informed about her planned discharge. A hospitalization report with medication changes is provided. The day after discharge, she receives a GP visit in the nursing home.
Case 3 (FG 6-9)	Ms Dubois, 84 years old and living together at home with her husband, suffers from an oncologic disease. Hospital referral is decided by the GP when she suddenly develops a severe diarrhea. During hospitalization it becomes clear that it is getting hard for the husband to provide the homecare all by himself. During a conversation with the hospital's PST nurse, Ms Dubois expresses her wish to stay at home, as long as possible. Advance care planning is discussed and she agrees for starting additional nursing care at home and support of the PHCT nurse. The specialist in charge calls the GP regarding discharge planning, medication changes, the advance care planning discussion and agreements made on starting nursing care at home and regular visits of the PHCT nurse.

PART II:

PATIENTS' TRANSFERS BETWEEN CARE SETTINGS IN PALLIATIVE CARE: CAREGIVING EXPERIENCES OF PATIENTS AND FAMILY CARERS

Chapter 4:

Patients' experiences of transfers between care settings in palliative care

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Submitted

Patients’ experiences of transfers between care settings in palliative care

Abstract

Patients with palliative care needs commonly move between care settings due to serious illness. The involvement of multiple caregivers causes fragmentation of care, thus challenging the coordination and continuity of care. We purposefully conducted 20 interviews with palliative care patients, exploring both their experiences regarding transfers between care settings and the perceived role of the treating family physician. Although home was considered the preferred residence, perceptions of unsafety arose in cases of increased symptom burden and when the organization of home care was insufficiently geared to patients’ needs. Upon hospital admission, experiences did not always meet expectations, varying significantly depending on the hospital, type of ward and reason for hospitalization. Perceived issues regarding hospital discharge were premature release, lack of seamless care and home care insufficiently tailored to patients’ needs. The family physician’s role assignment ranged from pivotal to minimal. Patients especially expected family physicians to guarantee continuity of care.

Introduction

The number of patients with complex palliative care needs is increasing in developed countries due to population ageing, a higher number of people living with chronic conditions and comorbidities and the improvement of disease treatment (3). Patients with palliative care needs also often suffer from serious illness and commonly move between care settings due to the fluctuating burden of illness (4-6). Such transfers can take place between hospital-based care and community-based care. Some of these transfers can be considered necessary or justified (e.g. due to certain medical conditions that can be managed at the hospital only, or in situations of inadequate caring capacity) (7), while others – especially between the home and the hospital - can be inappropriate or potentially avoidable (e.g. due to the ‘rescue culture’ of modern medicine or the inadequate availability of community services) (8, 9). As a consequence of these transfers across settings, multiple caregivers with various professional backgrounds are involved, resulting in a fragmentation of care. This fragmentation poses a challenge on the coordination and the continuity of care (10-13). Lack of continuity of care may result in undesired experiences with palliative care provision (e.g. feeling unsafe during a sudden progression of disease burden or perceived suboptimal support for problems and needs) (11, 14). By contrast, strong continuity of care for patients with palliative care needs is associated with lower rates of emergency department visits, decreased hospital deaths and supportive needs being met (11).

A majority of the patients with palliative care needs prefers to remain and die at home, in familiar surroundings and being cared for by the family physician (16) with whom they often have long-standing relationships. Family physicians have a coordinating role in patient care, providing high-quality responsive care across the lifecycle as well as assuring continuity and collaboration with other health care providers (17). As such, they play a key role in palliative care (18, 19). Many family physicians consider palliative care to be part of their job responsibilities and get satisfaction out of the task (20-22).

Regarding the organization of palliative care, services have, in recent years, increased in number and type under the impulse of the World Health Organization (23, 24). An overview of the definition of palliative care and the recent trends in palliative care organization within the WHO region of Europe is provided in Box 1. In Flanders, Belgium, palliative care services exist since 1995. An overview of palliative care organization and services in Belgium is described in box 2. Similar services and organizations of palliative care can be found within Europe (25).

This study is part of a research project that concentrates on palliative care provided within one of the fifteen palliative care networks in Flanders. To optimize continuity of care and the care coordination for palliative patients during transfers within a palliative care network, we explored experiences of healthcare professionals (26), patients and informal caregivers. This article reports on the experiences of the patients regarding their transfers between care settings and the role of the treating family physician.

From the perspective of the palliative patient, the research questions addressed within this context were:

- What factors are perceived to influence the decision to move to another care setting?
- How do patients perceive the way care settings respond to their needs?

- What are the expectations of patients towards the treating family physician in guiding the transfer?

Considering the importance of continuity of care and care coordination across settings during palliative patient's transfers, various studies have already been carried out. Hurley et al. (27) explored perceptions about care in the home and inpatient hospice, however from the perspective of inter-disciplinary team members. Care provided and care setting transitions in the last three months of life of cancer patients have been studied by Ko et al. (5). The results were based on reports of family physicians. A systematic review of Saunders et al. (13) reported on palliative care transitions from acute care to community-based care and concluded that studies' outcomes suggest that palliative care involvement during transitions might increase the likelihood of being discharged with support services and decrease hospital readmission rates. They however did not include other palliative care services. Likewise the study of Morey et al. (12), describing patient and caregiver perceptions of continuity of care, where it was found that the valuation of continuity of care depended on where a patient was in his transition. Flierman et al. reported on health care providers' views regarding transfers from hospital to palliative care at home. They concluded that efforts should be made to enhance knowledge and skills around identification of palliative needs and communication with patients about end of life. This study too focused only on transfers between hospital and home (28). Patients' perceptions of palliative care quality in hospice inpatient care, hospice day care, palliative units in nursing homes and home care have been investigated in the cross-sectional study of Sandsdalen et al. They concluded that perceptions of the care received scored higher in more care areas for hospice inpatient care, than in other settings and that further research is needed to investigate why perceptions of care differ across settings (29). This paper provides important insights into the patients' perceptions of care quality within and across settings, however this study was based on quantitative research data. Despite the above-mentioned literature, studies that not only examine transfers between multiple settings in palliative care but also use a qualitative research approach and focus on the patient's perspective, are scarce. We aimed to fill this gap, in order to fully understand the perspectives of patients regarding their transfers between care settings in palliative care.

Box 1: Overview of the definition of palliative care and the recent trends in palliative care organization within the WHO region of Europe.

According to the definition of the WHO (1), palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (1).

In Europe, it has been promoted that health care systems should differentiate palliative care into generalist palliative care and specialized palliative care. General palliative care should be provided by all health and social care professionals, while specialist palliative care should be limited to more complex challenges in symptom control and promotion of quality of life and should be provided by healthcare professionals with specialist or accredited training in palliative care (2). According to the European Association for Palliative Care (EAPC), the estimated number of specialized services required to cover the basic needs of palliative care patients are: at least one hospital palliative support team and one inpatient palliative care service per 200,000 inhabitants, and one home care team per 100,000 inhabitants (15). A recent analysis of trends in the organization of specialized palliative care services in the WHO European region showed an increasing ratio of specialized service provision in the last 14 years (15). However, inequalities were reported, with high-income countries achieving a major increase (in all types of services) compared to a little increase (only for inpatient services) for low-to-middle-income countries. Central–Eastern European countries showed significant improvement in home care teams and inpatient services, while Western countries showed significant improvement in hospital support and home care teams. Home care was the most prominent service in Western Europe (15).

Box 2: Palliative care in Flanders, Belgium (30, 31).

Palliative care in Flanders is organized in 15 regional networks, each coordinating the palliative care of the region covered. Palliative home care teams are autonomous entities, functioning within these regional networks. They provide support and consultation about all aspects of palliative care to patients, their family members and primary healthcare providers (e.g. the family physician, community nurses, nursing home nurses). The majority of the home visits by the palliative home care team is carried out by specialized palliative home care team nurses, whereas palliative home care team physicians and psychologists support and advise palliative home care team nurses during weekly team meetings. Palliative day care centres are complementary to primary home care; a multidisciplinary team gives patient support and can offer support to a patient's family. Only patients with an incurable, progressive and terminal disease with a maximum remaining life expectancy of one year that are not residents of a nursing home may come to these centres. Belgium has 6 recognized palliative day care centres, of which 5 are situated in Flanders. Within nursing homes, the coordinating physician, together with a head nurse and a palliative reference person (mostly a nurse) are responsible for guaranteeing a culture of palliative care and for offering advice to the nursing home personnel. Within the hospital setting, two palliative care services are present. The first is a palliative care unit, consisting of 6-12 beds. The second is a palliative support team, a multidisciplinary mobile team that provides second-line consultation to hospital staff with regard to palliative care management for patients not staying at the palliative care unit.

Method

A qualitative design was chosen, using semi-structured interviews.

Settings and participants

All care settings within the palliative care network of the covered region were included in the research project: the patients' home, nursing homes and hospital setting.

The region, with a population of 264,000 has one regional palliative home care team (PHCT), 34 nursing homes and 4 hospitals. All four hospitals have a palliative support team (PST) and the largest hospital also has a palliative care unit (PCU) with 9 beds. The regional PHCT, two nursing homes and two hospitals were selected to participate in this research project. The largest hospital was selected because of its PCU; the selection of the second hospital was based on the largest number of patients receiving PST support. The nursing homes selection was based on its size (largest). In addition to the home care setting, a palliative day-care centre from an adjacent region was also included.

Criteria for participant inclusion were:

- Patients being admitted to one of the participating palliative care services
- Physically and mentally capable to participate in the interview
- Recently involved in a transfer between care settings.

Data collection process

Participant recruitment happened with the assistance of the coordinators of each of the care settings (the PST and PCU coordinators for the hospitals, the nursing home coordinator, the PHCT coordinator for the home setting and the coordinator of the palliative day-care centre). They were asked to anterogradely inform the next four patients (who arrived at the setting and met the inclusion criteria) about the study and to question them about their willingness to participate. To capture patient experiences within each care setting, we aimed to select 4 participants out of each setting, respectively.

Twenty semi-structured interviews took place between December 2015 and February 2016, at a location of the participants' choosing. Interviews were conducted by two master students, lasting approximately one hour. Each interview was audio-recorded and field notes were taken. Prior to data collection, an interview training was given by the principal author, an experienced qualitative researcher. Feedback on the interview style was given after the first interviews.

Interview guide

A topic guide was used, developed and reviewed by the research group. The guide consisted of open questions and prompts, focusing on the experiences pertaining to the decision to transfer to another care setting and the actual course of the transfer as well as the expectations about a future care setting and the role of the family physician.

Data analysis

All interview recordings were transcribed verbatim. We performed a constant comparative approach to analyze data (32-34), using NVivo 12 software to support the analysis procedure. After reading the transcripts thoroughly, all interviews were coded by the principal and second author, both experienced in qualitative research. To validate the analysis process, they independently coded the same three interviews, subsequently discussing and comparing preliminary codings for similarities and differences. An initial coding frame was constructed and modified after each discussion and upon reaching a consensus. This procedure was repeated for the remaining interviews, resulting in the further construction of the coding frame. Next, all codes were once again compared with regard to similarities and differences in order to create categories and subcategories. Throughout the analysis process, an inductive and iterative approach was used, in which interview transcripts and codings were compared. Finally, the interpretation of the results was discussed with the other research team members and a final thematic framework was agreed upon. Since three of the authors have experience in palliative care delivery, we continuously reflected upon the interview transcripts and the analysis process to ensure the analysis was a true reflection of the data. Illustrative quotes were selected by the principal author, approved by the research team and translated.

Ethical considerations

Ethical approval was obtained by the committee of the University Hospital in Ghent and AZ Delta Hospital in Roeselare (B670201524155, B670201524162, B117201523255, B8117201523254). Participants were informed both orally and in writing about the study's objectives and about data anonymity. Written informed consent was requested and obtained.

Results

Twenty patients participated in this study. The recruitment process was a difficult one, influenced not only by the patients' condition but also by the fear of upsetting participants due to the connotation attributed to the word 'palliative'.

Patient characteristics

Of the 20 patients, 11 were female. Their mean age was 65 years, ranging between 41 and 97 years. Fifteen patients had cancer as the main pathology. The remaining five patients suffered from chronic bronchitis, chronic kidney insufficiency, cardiac failure or frailty. Four patients resided at the palliative care unit, four others in the nursing home, while the remaining twelve lived at home. In total, eleven patients were single. Six out of the 12 home-residing patients had a co-habiting partner. Eight patients had children. The family status of two patients was unknown.

Main findings

In general, participants underwent multiple transfers across settings throughout their illness trajectory. Both the nursing home and the palliative care unit were considered the final residence at the end of life, whereas back-and-forth transfers to the hospital were considered temporary. Interviewees accepted a transfer as a necessity, speaking in significantly less detail about it than their illness experiences and how settings had responded to their needs and expectations.

Participants' answers to the research questions resulted in three main themes: 1) Experiencing the home situation: between preference and pragmatism, 2) Perceived setting responses to patients' needs and 3) Expectations towards the treating family physician in guiding the transfer. Theme 1 relates to the first research question (What factors are perceived to influence the decision to move to another setting?), and describes home's meaning to the patient, their preferences regarding residence and the factors influencing the decision for a transfer. Theme 2 and 3 respectively answer research question 2 (How do patients perceive the way care settings respond to their needs?) and 3 (What are the expectations of patients towards the treating family physician in guiding the transfer?).

1) Experiencing the home situation: between preference and pragmatism

Home was considered a familiar place. Although illness caused limitations in the functioning of day-to-day life, patients expressed their preference to stay at home, with or without the support of informal or professional caregivers.

Despite home being the preferred residence, perceptions of feeling unsafe or insecure arose in following situations: increased symptom burden, decreased activity of daily living (ADL), care organization insufficiently aligned to patients' needs or the absence or insufficient capacity of informal caregivers. Participants described how feelings of discomfort gradually arose: e.g. being alone at night with fear of sudden symptom crises; the fear, during the day, that something might happen after the nurse had left; the inability to fetch a glass of water when feeling thirsty, etc.:

> *'We asked for the nurse to come. However, in the end you experience that it's not sufficient, you know. Because in the afternoon, when you're not seeing anybody, and something happens, what do you need to do then? You can't just ring a bell… And also the fact that they [the nurses] didn't find the house a couple of times, then you ask yourself "what are we just trying to do here"… [silence]' (M; Cancer patient; single)*
>
> *'I was dying of thirst and over there, just around the corner, is the water – however, the distance was much too large, you know – although it was not far at all' (F; Cancer patient; single with children)*

For people residing at home, the possibility of regularly visiting the palliative daycare centre was considered an added value, allowing them to forget their troubles temporarily and filling in lonely gaps by providing company, distraction and protection:

> *'At home, well yes, you're alone a lot of time, right? And over there you aren't alone, you see. Over there, there's always somebody, you know… Yes, you can chat about all sorts of things, you can play board games or cards or do craft work or just relax and do nothing or…' (F; Non-cancer patient; single)*

In the event of an acute increase of symptoms, a temporary transfer to the hospital was perceived to guarantee safety as well as immediate and continuous aid:

> *'P: I am pretty realistic. You can say, yes, I don't want to go to the hospital. But that is just a pointless thought. Obviously, everybody prefers to stay at home…, but the perspective of redemption was then a great relief to me… the sudden inability to breathe…*
>
> *I: So you somehow consider the hospital representing better care?*
>
> *P: Maybe, I don't know. How should I say it: 'Immediate care.' I mean, if you're at home, lying in bed, tossing and turning due to the damn pain… I can't ring a bell here, and have a nurse around the corner saying 'I'll call the doctor and we can give you this or that product' and then the pain goes away. If that happens at home, it all takes a lot longer. That's what worries me.' (F; Cancer patient; single with children)*

When patients' care needs became too extensive and informal caregivers could no longer address these needs, a more permanent transfer to the palliative care unit for terminally ill patients or to the nursing home for the elderly participants was the logical next step:

> *'I: Who decided you were to come here then (nursing home)?*
>
> *P: Myself… I was scared… to be alone… I couldn't go to the toilet on my own. I couldn't do anything.*
>
> *I: Were you already bound to your wheelchair then?*
>
> *P: At home, yes, yes. If I had to go to the toilet, then by wheelchair up to the toilet seat. They had to pull me onto it.*
>
> *I: It was your husband who helped you at the time?*
>
> *P: Yes. It was tough for him also, you know.' (F; non-cancer patient; widow with children)*

Although home was the preferred residence, for some patients it was not necessarily considered the preferred place to die. Determining factors in this regard were: the perceived added value of staying at home, the patient's sense of dignity and the informal caregivers' capacities:

> *'So, I think that I, as long as I am OK – well in the sense that I am not a burden to my family – and that, psychologically, I am still myself. Let me tell you: they can put me in a wheelchair, but don't take away my dignity, my personality. As long as I can keep my personality I will stay at home as long as possible – if it's feasible. You know, I am not the only person here at home.' (M; Cancer patient; cohabiting partner)*

2) Perceived setting responses to patients' needs

Patients reported mixed experiences of how settings responded to their needs.

Within the home context, a number of facilities were available to support patients and family members: nursing care, domestic services and family assistance. The way these were implemented however, did not always fully meet patients' needs, e.g. the number or hours of the domestic services. One participant complained about the organization of the domestic services, and perceived to need more help than the two hours provided. Another example concerned the timing of the nursing care:

> *'What happens is that you have to wait for the nurse to come – they don't have fixed hours you know. They have to squeeze you in. Nurses normally come in the mornings. But a quarter to 12 or 5 to 12 is still considered morning, isn't it?' (M; Cancer patient; cohabiting partner)*

Those patients receiving additional support from the palliative home care team (PHCT) appreciated having regular contact with the specialized PHCT nurse and reported being relieved to have his/her phone number, knowing that this person could be reached 24/7 in case of needs, questions, or in case the family physician was unavailable:

> *'… I've got their number, I know I can reach them. Also, when you have a question regarding the pain killers, or for the nurse, you know you can call them if the family physician can't be reached. It's a relief knowing that you have a back-up if you're home and something happens.' (F; Cancer patient; single with little children)*

With respect to the nursing home and the palliative care unit, both were regarded as the final residence at the end of life, even though death was not imminent for nursing home patients. The latter regarded the nursing home as a home substitute

with additional safety and good care. Those patients being transferred to the palliative care unit reported to perceive a maximum feeling of safety and comfort, being treated by pro-active personnel who took ample time for care and a good talk:

> *'It is super here, really, there is nothing to comment upon… You know, here, they've got time. You don't have to ask anything yourself, they themselves come to you asking if they can do something for you. Really, I feel at home here… And you know, they are such warm people. And somehow, they make you to start talking. I already had many good conversations here.' (F; Cancer patient; family status unknown)*

These setting experiences contrasted sharply against those of the hospital, in the event of a temporary hospital admission. Patients spoke about acute symptoms (e.g. acute pain, bleeding, shortage of breath, fever, …) or progressive deterioration (loss of appetite, loss of weight, mobility problems, …) provoking the hospital admission. Whereas certain patients were positive about how they were treated, others explained that their experiences did not match their expectations. Firstly, interviewees reported health personnel to sometimes be insufficiently informed about their medical history, even though they were certain this was registered in their electronic health record. Some patients experienced shortcomings in the inter-professional communication, resulting in the wrong medication being given and thus insufficient symptom control:

> *'I was racked with pain... And in the end it seemed that they [the nurses] had misunderstood… and I asked the doctor: "how come that I am still in pain?" "But yes, they did the opposite of what I told them to do." (M; Cancer patient; cohabiting partner)*

Secondly, patients reported to receive conflicting information regarding treatment options, such as whether or not to perform surgery. Thirdly, patients' experiences varied depending on the hospital or the hospital ward. For example, cancer patients admitted to the oncology ward felt being treated more humanely (personnel took time for the patient, was perceived to be informed about the patient's condition and delivered tailored care) than when admitted to other, non-oncology wards for non-cancer related problems:

> *'I've always been satisfied with hospital X: if you were in pain and you called for a nurse, they would always come and look for a solution. By*

> *contrast hospital Y, but well yeah – that was the ward of abdominal surgery – over there, it was very busy for the nurses – I needed to be given a painkiller at a certain hour – I had quite a lot of pain at that moment – and when I called the nurse, they said: "we're doing patient rounds now. We've started in the other corridor – we'll visit room per room until we reach yours." It took them more than an hour. So, yes, that makes you feel like a number. They don't think per patient, they're just acting room per room…' (F; Cancer patient; single with little children)*

Fourthly, patients' experiences differed depending the cancer type. For example, support for breast cancer patients, consisting of a care coordinating breast cancer nurse and various supportive facilities, differed significantly compared to limited support for pancreas cancer patients.

> *'We were in a group of 12 people, of which 8 with breast cancer. And that's when we saw daylight, because we were really unaware. Like, "Didn't you get this?" and "Didn't they tell you?" And you know, week after week there seemed to be all sorts of initiatives we weren't informed about. Really. You had to figure it all out yourself. Everything. And they themselves had the feeling to be overloaded at certain moments; like "Please leave us in peace for a while – with all those services that aren't beneficial to us at the moment". This was a real eye opener. So, yes, you ask yourself: how can this be? That's two-speed medicine, isn't it?' (F; Cancer patient; single with children)*

With respect to the timing of hospital discharge, patients sometimes felt too weak and therefore unfit to return home. Furthermore, discharge experiences ranged from "well-organized" to "inadequate" and "inefficiently organized with a lack of seamless care". As a result, some patients were obliged to organize themselves, depending their needs:

> *'On Wednesday they told me that I would be discharged the next day. I didn't feel at all ready, but hey, they probably needed the bed…And then, on Thursday morning… the doctor walks in and says: "We will do some more investigations this afternoon." And I say: "Hold on. They told me yesterday that I can go home today." "Well, that's not correct." So, I wasn't allowed to go home after all… And yes, on Tuesday, the week after, I finally went home. The discharge papers weren't entirely in order either. The speech therapist had to come, but the voice test hadn't been performed yet. The physiotherapist had to come, but something else hadn't been done yet. The nurse had to come, but some other things still needed to be taken care of first. The paperwork about my next appointment with the doctor was missing too. Anyway, all such things… And when you called: "Ah, we don't know anything about that." In the end, we organized all these things ourselves… But I have to admit that was the first time we experienced this.' (M; Cancer patient; cohabiting partner)*

3) Expectations towards the treating family physician in guiding the transfer

Patients expressed mixed views on role assignment, expectations and experiences with respect to their family physician.

The role assigned to the family physician varied greatly among patients. For some, the family physician took on a pivotal role - a counsellor, fully involved; to others a rather background role - available on demand; while to a few patients a minimal role – an insignificant position:

> *'I: who did you talk to about coming home?*
>
> *P: well eh, to the doctors involved, but also to the family physician of course, who played a central role at the time.' (M; Cancer patient; Cohabiting partner)*
>
> *'I: I heard you say that your family physician was not involved… Did she play any role at all during the process?*
>
> *P: Actually not. I took all the decisions myself. That's just the way I am. I want to do everything on my own.*
>
> *I: And at the moment of the diagnosis, years ago, was she involved then?*
>
> *P: No, actually not. I did what I wanted and also knew exactly what I wanted… I did go there a few times. And she told me then that I could always drop by for a chat – but, you know, I wouldn't know what to tell her. I don't feel the need to do so. I don't have a bond with her.' (F; Cancer patient; family status unknown)*

The majority of the patients expected to be involved in the decision for a hospital referral and to be sufficiently informed about the reason for hospitalization.

Furthermore, they expected their family physician to be informed about the changes in patient's medical record and to guarantee care continuation after discharge. Patients were grateful towards their family physicians' hospital visit, although they especially expected them to be there for advice and assistance after hospital discharge.

> *'When you're in the hospital, you expect the specialist to be assisting you and when you're home the family physician…' (M; Cancer patient; single)*

Patients hereby appreciated a regular home visit or the physician's initiative to inquire about their condition. These expectations were fully met for some patients, whereas others expressed to be disappointed because the family physician did not take any initiative, despite their long-standing physician-patient relationship:

> *'I: And when you came home, did you call him to let him know that you were back home?*
>
> *P: Well yes, I had to call him for the prescriptions, you know…*
>
> *I: And did he then drop by regularly, or only when you asked him to...*
>
> *P: When I called him, yes. Aside from that, I didn't see him.*
>
> *I: You didn't see him. And during your time at home, did he (family physician) play any role at all?*
>
> *P: No, well no. I didn't see him.*
>
> *I: Not even when you were at home?*
>
> *P: No, no. That's what I was surprised about. (silence) I don't know if he has something against me or what it could be. I don't know.*
>
> *I: But you seem to find that difficult, no?*
>
> *P: Yes. That he didn't visit me is not the only thing - it's just not nice – someone you've known for 20 – 30 years… but I really could have a good chat with him. But hey… (silence) Yes, that was really tough for me.' (M; Cancer patient; single)*

Notwithstanding the long-standing relationship with the family physician, some cancer patients indicated they would rather contact the oncologist for advice and assistance directly when something went wrong, thereby bypassing the family physician, assuming to get a referral anyhow.

Discussion

Main findings

This study examined the experiences of 20 patients with palliative care needs regarding their transfers between care settings. In answer to the research questions, three themes emerged: 'Experiencing the home situation: between preference and pragmatism', 'Setting responses to patients' needs' and 'Expectations towards the treating family physician in guiding the transfer'.

In answer to research question one, participants reported that home was considered the preferred residence. However, perceptions of feeling unsafe or insecure at home arose in cases of increased symptom burden or decreased ADL and when the organization of home care was insufficiently geared to the patient's needs. In addition, home was not necessarily regarded the preferred place to die. In answer to the second research question, some interviewees also regarded both the nursing home and the palliative care unit as a possible final residence, offering safety and good care when home residence became unfeasible. In case of temporary hospital admission, notable experiences were reported on how settings responded to patients' needs, sometimes not meeting their expectations, but varying significantly depending on the hospital, the type of ward and the reason for hospitalization. Perceived issues regarding hospital discharge were: premature release, lack of seamless care and home care insufficiently tailored to the patients' needs. Answering the third research question, the family physician's role assignment were wide-ranging: from a pivotal role to one in the background or even a minimal one. Patients especially expected their family physician to ensure the continuity of care.

Comparison with existing literature

Previous research showed that most patients with an advanced illness prefer dying at home (16, 35, 36). Other studies reporting on preferences for place of death suggest that the perceived burden to others is one of the reasons for not choosing home as the preferred place to die (36, 37). Cai et al. described variables determining the preference for home death for cancer patients (37). Apart from the perceived burden to caregivers, other variables determining this preference were the intensity of visits by a home-based physician and personal support worker, marital status, educational status and the palliative performance scale scores of patients

(37). Reyniers et al. described the preference of dying in the hospital due to the lack of other options and the perception of the hospital as a safe haven at the end of life (38). Some patients in our study made a clear distinction between their preference for home residence and dying at home. Their expressed reasons for wishing not to die at home concerned existential factors (the loss of one's sense of dignity and the loss of the significance of being at home) and psychosocial factors (the feeling of burdening caregivers, being alone or having insufficient caregiver support, the general lack of feeling safe). An important finding of this study is that although the majority of patients with an advanced illness prefer to die at home, patients sometimes change preferences depending on the feasibility of their context situation. These findings underline the importance for involved professionals to carry out a timely evaluation patients' preferences and needs, in order to adapt the care organization and delivery accordingly (e.g. a temporary transfer to the palliative care unit to diminish the caregivers' burden, increase the frequency of visits by family physicians and/or the palliative home care team to positively influence symptom control etc.).

Experiencing feeling safe (or not) was a recurring topic throughout our study results, associated with the changing care needs of the patients on the one hand and a possible transfer between care settings on the other. Previous literature reported on perceptions of safety and good care of patients when transferred to the palliative care unit or to a nursing home (27, 29, 39), which corresponded to our study results. Also, the feeling of safety and familiarity with the hospital setting have been described, being influential factors for seeking emergency department or acute hospital care in case of increased symptom burden in advanced cancer (40, 41). Authors argued that this may be the result of patients being more familiar with hospital services after having extensive hospital contact during the illness trajectory and being less familiar with palliative care services in cases of late referral to palliative home care (40). Interviewees in our study too reported on the safety of the hospital environment, that guarantees immediate and continuous aid in situations of acute illness. However, those interviewees receiving support of the palliative home care team described a feeling of relief to have the phone number of the team, knowing a back-up is always available in case of need.

With respect to the family physicians' role in palliative home care, Beernaert et al. (42) described the broad range of roles of the family physician: a medical expert, a

communicator, a collaborator and a life-long learner. Some of these tasks changed depending on the phases of the illness (e.g. at the time of diagnosis, during treatment or during follow-up), while others were applicable throughout the complete illness course (42). According to patients and relatives, in addition to these roles, essential characteristics of the family physician involved in high-quality palliative care at home include his/her medical proficiency; availability; a person-centered approach; collaborative, informative and communicative nature (including with other professionals); and proactivity (43). Patients in our study generally appreciated the family physician's involvement. However, some interviewees expected more involvement than others. Our study results confirm that the roles attributed to the family physician change throughout the illness trajectory. Noteworthy is that some participants indicated to be disappointed when the family physician lacked a pro-active attitude. The above-mentioned findings highlight the importance of an early involvement of both palliative home care and the family physician during a patient's illness trajectory. Furthermore, family physicians should be aware that patients' expectations towards their involvement (both in subject and in degree of involvement) can change throughout the illness course. It is therefore recommended that these expectations be openly evaluated and agreed upon during physician-patient meetings.

Although a feeling of safety and familiarity with the hospital have been reported, patients with palliative care needs are vulnerable to experiencing problems of care fragmentation and poor care quality during transfers between care settings (10). Poorly executed patient transfers between palliative care settings are often associated with miscommunication (both inter-professional and provider-patient communication), insufficient information exchange, insufficient collaboration between care professionals and a disruption in the continuity of care (10, 13, 26, 28, 44). Our study results corroborate these findings and moreover illustrate that the delivered care, especially within and between hospital and home care settings, was not always tailored to the needs of the patients (e.g. symptom management during hospitalization, timing of hospital discharge, organization of home care).

A last topic to discuss concerns the difficulty of patient recruitment in palliative care research. In our study, the recruitment process was hindered due to patients' bad condition (patients being too weak and ill to be interviewed), particularly those patients residing at the PCU. Furthermore, the fear of upsetting patients due to the connotation ascribed to the word 'palliative', hampered the participant recruitment. This happened especially in the hospital, with respect to patients recruited through the PST. Earlier research reported on the challenges of patient and family carers' recruitment in palliative care research due to professionals' concerns about the vulnerability of the patient or the fear of provoking possible anxiety or upsetting patients and families, being a reason for not approaching eligible patients (45-47). Aoun S et al. furthermore conclude that strategies that facilitate health professionals' understanding of the research and risk and benefits may help reduce gatekeeping in palliative care research (46).

Implications for practice and policy

Although patients in our study reported home to be the preferred residence, the safety issue determined the feasibility of staying at home. Given the rapidly changing nature of life limiting conditions, caregivers and community services are challenged to respond in a timely manner to meet the needs of the patient and to ensure patient's safety. Considering the complexity of palliative patients' needs, more attention should be paid to organize care in a manner tailored to the specific needs of patients. The question hereby is not only if the current spectrum and quantity of available palliative care services are able to meet the actual needs of patients but also how palliative care services and healthcare professionals involved can collaborate efficiently and effectively to provide high quality care across settings. Integrated palliative care focuses on coordinating care around the needs of patients with advanced illnesses and has been increasingly put forward to achieve continuity of care for patients with life limiting conditions (11, 48).

Strengths and limitations

All palliative care settings of the region were represented in this study. Together with the choice of a qualitative research approach, this resulted in a broad perspective on patients' viewpoints on the topic. However, a limitation may be attributed to participant recruitment in the hospital. The concern of upsetting patients because of the connotation of the word 'palliative' may have resulted in a greater participation of patients that approached the end-of-life stage of their illness trajectory. We do not know to what extent these viewpoints differ from patients of an earlier palliative phase.

Insights of this study may inspire other palliative care clinicians and researchers. However, we should be careful not to generalize the results, as the Belgian healthcare context and its palliative care organization may be too specific, even though similar organization of palliative care exist throughout other European countries.

Conclusion

Our study results confirmed that home is the preferred residence, as long as it is perceived a safe environment. Next, patients sometimes change preferences depending on the feasibility of their context situation. Furthermore, a person-centered approach that focuses on the complex needs of the patient rather than somatic aspects of care, has not yet been implemented throughout care settings involved in palliative care. Study findings illustrated shortcomings in inter-professional communication, care fragmentation and care coordination. As such, barriers in inter-professional collaboration need to be tackled to provide high quality care across settings, tailored to the needs of patients. Study findings highlight the importance of early involvement of palliative homecare and the involvement of the family physician in the illness trajectory. In addition, family physicians should be aware that patients' expectations towards their involvement can change throughout the illness course. Accordingly, it is recommended that physicians take the initiative to openly evaluate these expectations with their patients.

Interventions aiming at improving inter-professional collaboration and continuity of care for patients being transferred between settings should be further investigated. Clinicians and policy makers could use these insights to enhance tailored palliative care.

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Chapter 5:

Family carers' experiences regarding patient transfers between care settings in palliative care

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SUBMITTED

Family carers' experiences regarding patient transfers between care settings in palliative care: an interview study

Abstract

Objectives

To understand how family carers experienced the illness trajectory of their next of kin related to transfers taken place between care settings in palliative care, their experiences and attitude regarding the transfer decision and their experiences regarding patient transfers across settings.

Methods

Semi-structured interviews were held with 21 family carers. A constant comparative approach was used to analyze data.

Results

Three themes were identified after data analysis: (1) patient transfer dynamics, (2) experiences regarding the changed care environment and (3) impact of the transfer on the family carer. The dynamics of the patient's transfer were affected by the balance between the care provision (professional and informal care) and the changes in the patient's needs. Experiences regarding patient transfers strongly varied depending on the setting and were based on the personnel's conduct and the quality of receiving information. Study results revealed shortcomings in perceived inter-professional communication and continuity of information during a patient's hospitalization. Concomitant feelings of relief, anxiety or feeling insecure could arise in situations of a patient's transfer.

Conclusion

This study highlighted the adaptability of family carers when caring for their next of kin with palliative care needs. To support carers in coping with their role as caregivers and to share the responsibility of caregiving, involved healthcare professionals should timely evaluate family carers' preferences and needs and adapt the care organization accordingly. A pro-active attitude, which anticipates on the possibility of an impending decompensation of the family carer, is recommended.

When the decision for a patient's transfer is taken, multiple factors influenced the choice of the care setting. Healthcare professionals need to take these factors into account when discussing, with patients and carers, the need for a transfer.

Continuity of information can be improved. Further development and evaluation of interventions, aimed at improving informational continuity can be recommended.

Introduction

Family carers (definition: see box 1) play a major role in caring for patients with palliative care needs (2). They provide emotional support, assist with practical tasks, help to relieve pain or other symptoms and aid in guiding patients through the healthcare and social services systems (3-5). In future, their role is becoming even more important given the fact that the majority of people with a non-curable life-limiting disease prefers to remain at home, as long as possible. Furthermore, the number of patients with complex palliative care needs increases in developed countries due to population ageing, a higher number of people living with chronic conditions and comorbidities, and improvements of disease treatment (6). Although caring for a person with a life-limiting illness can be rewarding, negative effects on the family carer at the physical (e.g. fatigue, older carers having their own health problems), psychosocial (e.g. anxiety, social isolation) and economic levels (medical expenses, working less or giving up work to provide care) have been described (1, 7).

Seriously ill patients with palliative care needs often move between care settings due to a fluctuating burden of illness (8-10). These transfers can take place from hospital-based care to community-based care, or vice versa. Transfers between care settings can be burdensome to patients and their families and pose a challenge on the continuity of patient care (11-14). Poorly executed transfers can be associated with delays in discharge and follow-up, miscommunication about follow-up and disruption of the continuity of care, which may result in higher rates of health care spending and service use (14-16). Importantly, strong continuity of care for patients with palliative care needs results in lower rates of emergency department visits, decreased hospital deaths and supportive needs being met (12).

Past studies have focused either on quantitatively assessing the frequency, types and reasons for transfers (9, 17-19), or target specific patient groups, such as transfers of patients with cancer, heart failure or older patients (9, 20-22). With respect to care settings, previous studies reported on palliative care transitions from acute care [inpatient hospitalization] to community-based care, but did not include other settings that deliver palliative care such as nursing homes and palliative care units (14). Similarly, other studies described patient and caregiver perceptions of continuity of care or health care providers' views on transfers from hospital care to palliative care at home (13, 23). Studies reporting on the experiences of family carers regarding patient transfers across multiple care settings in palliative care, are scarce. We aimed to fill this gap, in order to identify areas of improvement in palliative care delivery and continuity of care during patient transfers.

This study is part of a wider research project, aiming to optimize the continuity of care for patients with palliative care needs during transfers between care settings. The project concentrates on palliative care provided within one of the fifteen palliative care networks in Flanders, Belgium, exploring the experiences of healthcare professionals (24), patients (manuscript in review process) and family carers. This paper reports on the experiences and perceptions of family carers. In this study we aimed to understand how family carers experienced the illness trajectory of their next of kin related to transfers taken place, their experiences and attitude regarding the transfer decision and their perceptions regarding the patient's transfers across settings.

Box 1: Definition of family carer

In literature, the terms 'informal carers' and 'caregivers' are used interchangeably with 'carers'. For this study, we adopted the definition used in the European Association of Palliative Care - Task Force on Family Carers: "Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management" (1). They can live with or separately from the person receiving care and are as such a heterogeneous group.

Method

Design

A qualitative research design was chosen, using semi-structured interviews to deeply explore the experiences of family carers. This paper adheres to the criteria for reporting qualitative research from the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (25).

Settings and participants

An overview of the palliative care organization and services in Belgium is described in box 2. Similar services can be found elsewhere in Europe (26).

Box 2: Palliative care organized in Flanders, Belgium (27, 28)

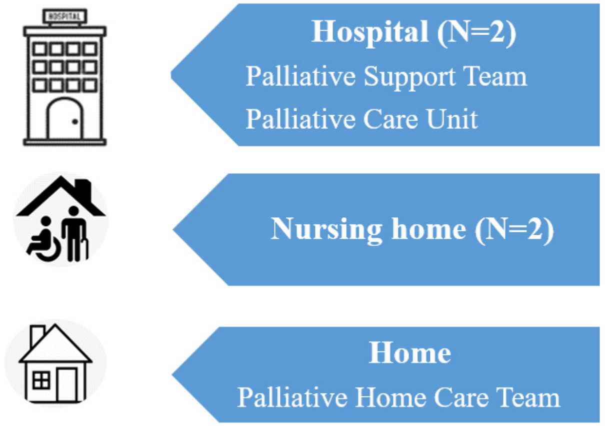
1. Palliative care in Flanders is organized in 15 regional networks, each coordinating and organizing mainly the palliative care training and education of the region covered.
2. Palliative home care teams are autonomous entities, functioning within these regional networks. They provide support and consultation about all aspects of palliative care to patients, their family members and primary healthcare providers (e.g. the family physician, community nurses, nursing home nurses).
3. The majority of the home visits by the palliative home care team is carried out by specialized palliative home care team nurses, whereas palliative home care team physicians and psychologists support and advise palliative home care team nurses during weekly team meetings.
4. Palliative day care centres are complementary to primary home care; a multidisciplinary team gives patient support and can offer support to a patient's family. Only patients with an incurable, progressive and terminal disease with a maximum remaining life expectancy of one year that are not residents of a nursing home may come to these centres. Belgium has 6 recognized palliative day care centres, of which 5 are situated in Flanders.
5. Within nursing homes, the coordinating physician, together with a head nurse and a palliative reference person (mostly a nurse) are responsible

for guaranteeing a culture of palliative care and for offering advice to the nursing home personnel.

6. Within the hospital setting, two palliative care services are present. The first is a palliative care unit, consisting of 6-12 beds. The second is a palliative support team, a multidisciplinary mobile team that provides second-line consultation to hospital staff with regard to palliative care management for patients not staying at the palliative care unit.

The region researched, with a population of 264,000, has one regional palliative home care team (PHCT), 34 nursing homes and 4 hospitals. All four hospitals have a palliative support team (PST) and the largest hospital additionally has a palliative care unit (PCU) with 9 beds. All care settings within the palliative care network of the covered region were taken up in the research project: the home, the nursing home and the hospital, the latter of which included a PST and the PCU. The regional PHCT, two nursing homes and two hospitals were selected to participate in the research project. The largest hospital was chosen, since it was the only one in the region with a PCU while the selection of the second hospital occurred because it had the largest number of patients receiving PST support. The selection of the nursing homes was based on size (largest) (Fig 1: Participating settings).

Fig 1. Participating settings



Recruitment of family carers

Participant recruitment took place with the assistance of the respective coordinators of the PHCT, nursing homes and hospitals' PCU and PST. Inclusion criteria were: being a close family member of patients recently admitted to one of the participating palliative care services, as well as being involved in a transfer between care settings. Attention was paid to recruiting family carers from each of the different care settings providing palliative care, to capture as broad a range of experiences as possible. Additional recruiting was scheduled if data saturation was not reached after the analysis.

Data collection process

Interviews were conducted by the authors TT and EG, two students of Master of Science in Health Care Management and Policy. Prior to data collection, an interview training was given by the principal author (FM), an experienced qualitative researcher. Feedback on the interview style was given by FM after the initial interviews. All interviews took place between April and May 2016, at a location of the participant's choice and lasted about approximately one hour. Each interview was audio-recorded and field notes were taken.

Interview guide

A topic guide was developed, used and reviewed by FM, TT, EG and PP. The guide consisted of open questions and prompts, focusing on the experiences of family carers with respect to the decision for the patient's transfer, the course of the transfer, the communication with healthcare professionals, care changes after transfer and the impact of the transfer on the relationship with the patient (Table 1).

Table 1: Topic guide of the interviews

Illness trajectory	What is the current situation of your next of kin? (if still alive) How did you experience the illness of your next of kin?
Transfer decision	Which problems provoked the transfer? Who took the decision for the transfer? Who was involved? How did you feel about the decision of the transfer?
Course of the transfer	How did you experience the transfer procedure? With whom (healthcare professionals) did you communicate? How did you experience this communication? Did you feel adequately informed regarding your next of kin's condition?
Care after transfer	What has changed after the transfer? How did you experience this?
Relationship with next of kin	Did you experience changes in the relationship with your next of kin?

Data analysis

All interviews were transcribed verbatim. A constant comparative approach was used to analyze the data (29, 30). First, to familiarize themselves with the data, all transcripts were read thoroughly by FM and SV, both experienced in qualitative research. Next, FM and SV independently coded the same three transcripts, to validate the analysis process. Subsequently, preliminary codings were discussed one by one and compared for similarities and differences. An initial coding framework was constructed and modified after each discussion and upon reaching a consensus. Until the 10th interview we followed the identical procedure, first coding independently and then discussing the codings, comparing them for similarities and differences and finally further constructing of the coding frame. For the remaining interviews, only the differences were discussed after independent coding by both FM and SV and after FM compared the codings. Next, all codes in the coding framework were compared again with regard to similarities and differences and grouped into categories and subcategories. An inductive and iterative approach was used throughout the analysis process, hereby comparing interview transcripts and codings. Finally, the interpretation of the results was discussed with the other members of the research team (PP, MD, LD) and a final thematic framework was agreed upon. Reflexivity aspects were taken into account throughout the analysis process. We used NVivo 12 software to store the transcripts, to assist with the analysis process and to search for the quotes.

Ethical considerations

Ethical approval was obtained by the committee of the University Hospital in Ghent and AZ Delta Hospital in Roeselare (B670201525299, B670201525070, B117201525245). Participants were provided with oral and written information about the objectives of the study and informed about the anonymity of the data. Written informed consent was requested and obtained, prior to the interviews.

Results

Twenty-one family carers were interviewed. In two cases, joint interviews were carried out with 2 family carers. Out of 21 participants, 5 were male. Their mean age was 58 (ranging between 26 and 76). Regarding relations: 3 participants were the patients' son, 8 the daughter or 2 the daughter-in-law, 1 the sister, 1 the mother, 2 the husband and 4 the wife or partner. For 7 participants, the patient had died at the moment of the interview. An overview of participant characteristics is given in table 2.

Table 2: characteristics of participating family carers

Interview number	Setting of recruitment	M/F	Age (years)	Relation to the palliative patient	Patient pathology	Patiënt deceased?
1	Nursing home	M	52	Son	Dementia	No
2	Nursing home	F	45	Daughter	Dementia	No
3	Nursing home	F-F	67-71	Daughters	Heart failure	No
4	Nursing home	F	47	Daughter	Chronic bronchitis and mobility impairment	No
5	Nursing home	F	47	Daughter-in-law	Stroke and mobility impairment	No
6	PHCT	F	49	Wife	Cancer (intestinal)	No

Interview number	Setting of recruitment	M/F	Age (years)	Relation to the palliative patient	Patient pathology	Patiënt deceased?
7	PHCT	F	59	Wife	Multiple myeloma	Yes
8	PHCT	M	67	Husband	Cancer (oesophagus)	No
9	PHCT	F	66	Daughter-in-law	Cancer	Yes
10	PCU	M	56	Son	Cancer (prostate)	No
11	PST	M	72	Husband	Cancer	No
12	PCU	M	64	Son	Cancer (prostate)	Yes
13	PCU	F	64	Daughter	Cancer (breast)	No
14	PCU	F-F	26-51	Daughter-sister	Cancer (intestinal)	Yes
15	PCU	F	76	Mother	Cancer (intestinal)	Yes
16	PST	F	68	Partner	Cancer (lung)	No
17	PST	F	64	Wife	Cancer (sinus)	No
18	PST	F	55	Daughter	Cancer (cholangiocarcinoma)	Yes
19	PST	F	43	Daughter	Cancer (bone)	Yes

Although family carers were asked to recall and elaborate on the experiences of the patient's last care setting transfer, all interviews spontaneously brought back memories of the experiences of multiple transfers during the patient's illness trajectory. Data analysis identified three main themes related to the experiences of family carers and care setting transfers: 1) patient transfer dynamics, 2) experiences regarding the changed care environment and 3) impact of the transfer on the family carer. These themes will be addressed one by one.

1) Patient transfer dynamics

Family carers' experiences illustrated the complex dynamics of the events surrounding the patient's transfer. Below, we will elaborate on elements that make up the transfer dynamics: a) care provision, b) changes in patient's needs and influence on professional care, c) transfer process and d) influencing factors regarding the choice of the care setting.

a. Care provision

During the illness trajectory of the patient, carers displayed a high degree of adaptability to provide them practical and emotional support, constantly evaluating and modifying priorities to meet the patients' changing needs. A carer's ability to provide care was influenced by the extent in which daily life could be reorganized in order to better support the patient, and also by the additional external support received. For the sake of the patient, they diminished or cancelled their social activities and hobbies and reorganized their domestic and professional responsibilities. Responsibilities towards the patient's care were often shared among family members (e.g. the spouse, children or siblings), resulting in an entire network of family carers. Non-resident family carers reported that the presence of the patient's spouse and the spouse's condition contributed to the possibility that the patient remained at home:

> *'Actually, we were lucky that our father was still in such good shape, that he took care of so much… Also to help her [mother] get out of her bed… I'm telling you, yes, for the rest, we did as much as we could, but after all, because we also have to go to work, it ended up mainly being dad…' (I19, F, 43y)*

With respect to how caregiving was experienced, family carers declared to take the patient's wishes into account as often as possible, however they sometimes felt walking a fine line between supporting and meddling, being squeezed between respecting the patient's autonomy and taking decisions for the patient's sake. Furthermore, carers often felt having to juggle between care for the patient and for their own family. Some participants reported a 'sandwich-experience' in care provision:

> *'Every morning someone of the domestic service did come by. But still, it's more than that… in the weekend you still had to go. And before we had additional help, I already did a lot… It was a difficult period, also having kids of your own… You have to compromise, you know… I still have an 11 year old little girl, the other one is 16. It was like: the young ones need me, but you always feel the urge to go see your parents, to see if they're OK…' (I2, F, 45y)*

The carer's capacity for caregiving was stretched further if having to deal with his or her own medical problems and/or having to care for multiple family members. Conversely, family carers felt encouraged by the support of friends, neighbors and others with common experiences and concerns. The work context and interaction with colleagues formed a welcome distraction. Employers who showed an understanding for the carer's personal situation and allowed for flexible working hours were highly appreciated and were considered very supportive:

> *'I was lucky to have a good boss – my boss had also lost his wife due to cancer - and he was very understanding. He told me: "Take as many days as you need, I know what it means. We'll fix it…" And also at the time, there was a young couple living next door, they just moved in… And every evening after work, I first went to the hospital. When I got home around nine, the lady next door and also her husband, by the time I had parked my car in the garage, were standing here with some dinner, so I didn't have to cook myself. I mean, a young couple, I hadn't expected that. I told them: "You don't have to do this." She replied: "Whether I cook a potato more or less doesn't make a difference." I really appreciated that… It really felt good, you know. During that whole period, I had a lot of people supporting and helping me.' (IC8, M, 67y)*

Being able to rely on the additional support of professional home care (e.g. a community nurse, a PHCT nurse and domestic care) resulted in a feeling of not being alone in the care process. Regular contacts and home visits by a PHCT nurse were highly valued for pain and symptom management and for mental support towards both the patient and the family carer. PHCT nurses were perceived to anticipate and to follow-up, but also to be very approachable, always at hand and willing to listen:

> *'You get the feeling that you are not on your own… because you can always count on those people if you have questions and they're always available, you can always call them if something is wrong.' (I6, F, 49y)*

Furthermore, carers felt supported when the family physician conducted regular home visits after the patient's hospital discharge, when maintaining contact with the treating specialist, and when being approachable and taking time for queries or in situations of increased symptoms.

b. Changes in patient's needs and influence on professional care

For home residing patients with gradually changing needs, carers arranged for additional professional homecare (e.g. a community nurse, a PHCT nurse, cleaning or domestic services) or modifications to the house (e.g. a stairlift). In addition, the possibility of regularly visiting a (palliative) day-care centre was a solution for care-dependent patients and for those family carers requiring respite care or who were still working:

> *'She actually increasingly needed help … also due the fact that she became afraid of being alone. She had fallen a couple of times and didn't feel confident anymore… In the evening, the nurse came to put her to bed, and she stayed there until the nurse came back in the morning to help her out of her bed. You really felt that she… didn't feel safe anymore, despite having a wheeled walker. She didn't cook anymore either… we went there every evening to make her sandwiches and things like that… And then in October, she was able to go to the nursing home. In the meantime, between June and October, every day, except on Sundays, she went to the day-care centre in order to not be alone all day since we went out to work. She was practically immobile then.' (I5, F, 47y)*

On the other hand, acute changes in the patient's needs (e.g. due to a fever, shortage of breath, vomiting, pain, mobility disorders, complications after surgery, adverse effects of medication) called for a rapid shift in care delivery, which was not always feasible, effective or sufficient within a short time span. It resulted in a patient's transfer to the hospital when patients and family carers regarded home care provision to be insufficient and the hospital to be a better place to receive care. The quote below illustrates, however, that this transfer was not perceived as a matter of convenience, but rather as a necessity:

> *'Then he left [hospital admission], he was vomiting all the time… Well, knowing that he is best off there [in the hospital] … At home, it just wasn't possible anymore. I never did let him go, like "well yes, you can do that at home also…" I let him go the moment that it really…' (I7, F, 59)*

c. Transfer process

The patient transfer process refers to the conditions in which transfers took place, how the decisions for a transfer were taken and how these decisions were perceived by carers.

Transfers took place when an imbalance arose between the patient's care needs and the care that could be provided, either professionally or by the family carer. Both carers and patients expected better care and quality of life in the future setting. Transfers to a nursing home occurred, for example in situations of dementia or frailty. In case of imminent death, a transfer to the hospital or the palliative care unit (either directly or indirectly through hospital admission) was organized. The quote below about a patient in the terminal phase of bone cancer describes a situation in which the care needs became too high and the spouse's and other family carers' capacities were insufficient to guarantee homecare, despite a maximum in professional care and modifications to the house:

> *'In the meantime, we had a stairlift installed, the shower upstairs was completely adjusted… The nurses came three times per day, … she also had a special chair to be able to sit in the shower… but, yeah, the moment you really no longer can stand up on your legs anymore… And always being in that bed to be washed… in the end it is different, also for our father, it's too much extra fuss for him, … also because she [patient] herself said: "this isn't working anymore" and uhm not everything can be left up to our father, despite the fact that we did the laundry and dropped in as often as we could, and I also took care of the cooking…' (I19, F, 43y)*

The family carer's fear to be confronted with the image of the deceased patient at home, was another reason to refer the patient to the PCU or the hospital, instead of remaining and dying at home.

Transfer decisions were taken by patients, family carers or professional caregivers, often in mutual agreement. The voice of the family carer was more prominent regarding transfers from home to the PCU or the nursing home in situations when the carer could not provide sufficient capacity. The following quote illustrates some considerations preceding such a decision, and depicts the decisive position of a spouse after an exhaustive episode of caregiving, her son respecting the decision of his mother:

> *'She said: "Well listen, I don't want to live with that image [deceased husband at home] because I simply won't be able to cope with it. And I can't take care of him. That's one thing." "And secondly, he's been sitting here in his armchair for so long, me having to pull all the weight…"- and she did everything for him, and she became… I certainly felt that she was tired. She said: "Look, I don't want him to come back home. It would be much better if he stays there [PCU]." I said: "Listen mother, it is your decision, I will respect it, but you seriously have to think about this." "But I don't have to think about this anymore"'. (I10, M, 56y)*

Additionally, the family physician, aware of the patient's condition and with whom patients and family carers had a longstanding relationship, was often regarded a confidant, playing a major role in supporting, informing and advising the patient and family carer, for instance whether or not to admit the patient to the PCU or the nursing home. In general, participants appreciated to having a say in the decision process to transfer, but one participant experienced the specialist's advice for a transfer to the PCU as a salvation, knowing that the patient was no longer in a condition that allowed a return home.

> *'That was our salvation, because if she had to come back home, I wouldn't have known how to manage that. She was worn out. And yes, she wanted to, go home… that was her last straw of hope, you know. As long as you're home there is still hope… staying home a little more. She really couldn't anymore. At that moment, she was in such a condition, she was really drained. That's why I consider it was a salvation. It was a salvation by doctor Y who insisted: "Let them take care of you at the palliative care unit"'. (IC15, F, 76y)*

However, transfers did not always happen in harmonious agreement. One participant (son) spoke about transfers as several 'battles' he had to overcome: he had to hold off the specialist's advice to discharge his father from hospital (he was finished with treatment) until a transfer to the nursing home had been arranged; next, in the nursing home, he struggled to have his father's euthanasia request handled with the sense of urgency deserved; finally, he struggled against the nursing home to allow his father to transfer to the PCU in order to fulfill his euthanasia request:

> *'That was another battle won, so to speak, to be able to transfer him from the hospital to the nursing home… In fact, it was again a battle we won the moment he went from the nursing home to the palliative care unit. In a manner of speaking, these are all battles. It isn't a real war, you know – the war we fight is to be able to die.' (I12, M, 64y)*

d. Influencing factors regarding the choice of the care setting

Carers reported to be relieved when their loved one was given the possibility to reside at the place of their preference. In case of a decision taken for a patient's transfer away from home, multiple factors influenced the choice of the care setting: practical aspects, the patient's life expectancy and the perception towards the setting. First, concerns of a practical nature were: the waiting time to bridge before the patient could be transferred (e.g. to the nursing home or to the PCU), costs, accommodation types and facilities at the future setting (e.g. the concern of a well-equipped room and tasty meals in the nursing home). Family carers also attached importance to the travel distance for caring or visiting family and friends to the patient's home, nursing home or the PCU. Secondly, family carers paid attention to the life expectancy of the patient, which influenced the decision for a transfer to either the PCU or the nursing home. A third influencing factor was the perception towards the setting. For example, the perception of being in the familiar surroundings of the oncology ward, resulted in a patient's choice to die at the oncology ward instead of being transferred to the PCU, which was entirely unfamiliar to the patient. There was also the fear of being confronted with dying people at the PCU, whereas the oncology ward was still regarded as a hospital ward. This is exemplified in the following quote of a family carer who expressed a huge relief when her dying mother could remain at the oncology ward instead of being transferred to the palliative care unit:

> *'I: you asked the oncologist: "mother is in familiar surroundings [the oncology ward]. Can't she stay here?" "Yes, I felt relieved", you tell me?*
>
> *I10: Well yes, firstly a relief for our dad, because… he doesn't like to drive and if he needs to take a route that he's not used to … And a sigh of relief for us all, after all, in an environment… in the meantime we were acquainted with the nurses. We could always count on them if anything happened… And also, if some question had to be asked to the oncologists… and we also thought, if you end up in the palliative care unit, will you still see the oncologists? What is the best way to contact them if something happens? And also the idea of "palliative" and a "palliative environment"… they are all people who… are dying… And maybe we were happy that she was in the hospital, ok, even if it was the oncology ward… But everyone there had their own room, and you didn't really see each other. Ok, you saw the family in the corridor, but those people themselves, you didn't really see them. And also, if we would have had to go to the palliative care unit and you are continuously confronted with people who are seriously ill as well, people who can die at any moment or something like that… I really don't know. Maybe a little bit scared too?' (I19, F, 43y)*

2) Experiences regarding the changed care environment

With respect to the changed care environment, both the expectations and experiences of the family carer varied, depending on the setting.

Regarding the carers' setting-specific expectations, the nursing home was considered to be a permanent residence, when home care had become unfeasible. However, it was viewed as a temporary stay after hospital discharge, allowing the patient to regain strength before returning home. The hospital, in turn, was expected to be the setting where patients received temporary help with respect to diagnosis and treatment. In contrast to the hospital ward, where returning home after treatment was still presumed possible, the palliative care unit (PCU) was considered 'the final station' and confronted family carers with the patient's imminent death.

Carers expressed having mixed experiences pertaining to the patient's transfers and new care environment. They were determined by the setting's ambiance, the way they were treated by the staff members and the manner in which information was exchanged. Those participants who became acquainted with the PCU, expressed positive experiences because of the way they and the patient were welcomed and treated, within a domestic atmosphere. Carers appreciated the PCU staff taking time for the patient and the family, the personal care, the sense that 'there are no musts' and 'everything is possible' and all the efforts being taken to please the patient and the family carers:

> *'The humane reception, taking time to speak to us, not treating you like a number… I tell you: it's heaven on earth here… Immediately it became clear that nothing is required and everything is possible… If you are thirsty, you drink. If you aren't, you don't. If you have questions, ask. Whether they are personal, emotional or medical questions, just ask. We will try to answer, but you always get an answer and you don't have to wait a fortnight for one, you understand?' (I12, M, 64y)*

Furthermore, participants appreciated that the patient still had the freedom to make trips or pay external visits. Carers reported that the personnel of the PCU were gifted in grief and bereavement support, making it possible to talk about difficult topics. This included their highly valued approach towards little children and how they helped to prepare them for the patient's imminent death. Although not all participants indicated to need this, they were very grateful that even after the patient's death, they received phone calls from the PCU staff, inquiring about the carer's situation.

Similar positive experiences were reported about the nursing home environment: the way the patient and the family were treated by the nursing home staff, the quality of communication and the way family carers were involved in care plan discussions and decisions. Furthermore, they appreciated the domestic atmosphere:

> *'She's taken well care of here… They come here at least once a week with cheese cubes and salami cubes, a glass of wine… and there's always something to do here. At the moment, she is not moving around, but she says she will as soon as she feels better. With her rollator walker… and then they will go and have a walk with her…' (I3, F-F-, 67-71)*
>
> *'Also, once the transfer has happened [hospital admission from the nursing home], there is sufficient communication to inform about how it is going and to follow up the situation, by e- mail or phone or even by dropping by. If we call the hospital, we inform the nursing home and vice versa. It actually goes really smoothly.' (I5, F, 47y)*

In the hospital context, positive experiences were expressed towards the oncology ward, where personnel was perceived to be more gentle, friendly and took more time compared to other hospital wards:

> *'the oncology ward, treatment there is different. The doctors as well as the personnel are, I might dare say, more compassionate towards the patient… And the doctor's visit is more in depth and calmer. It's not like a quick in and out visit, asking if everything is well and off I go. No, they stay a little and have a chat. The treatment at that oncology ward is actually very, very good.' (I15, F, 76y)*

By contrast, rather negative experiences were reported about other departments, such as at the emergency department, where different caregivers kept continuing to ask questions, and where carers suffered of waiting long before something happened.

Depending on the hospital, mixed experiences were expressed with respect to the comfort and facilities present in the hospital room, flexibility regarding visiting hours, the personnel's conduct and the information exchange. The experiences of how hospital staff treated family carers and patients ranged from very positive (e.g. allowing the patient to leave the hospital to attend a baby shower) to rather negative (e.g. unfriendly; the patient being treated callously). Carers also reported that attention was not always sufficiently paid to the patient (e.g. a vomiting patient who was given medication orally, the medication box left at the table together with the patient and recovered later, without checking whether or not it was empty).

The perceived inter-professional communication within and across hospitals was not always optimal. Examples include: difficulties with information exchange between hospitals regarding the patient's results; the patient not being allowed to eat, yet receiving a tray of food; a presumed failing information flow between professionals about handling the alleviation of pain, resulting in patient discomfort:

> *'they admitted her and put her on a drip… She was strictly prohibited to eat or drink. That's what the specialist told me because I was there at that moment. And then, half an hour later, a tray of food is brought in. So you say to yourself: if it were somebody who didn't know anything about it, they would have eaten it, you know… And also, she was in a lot of pain and the specialist told us that she shouldn't be in pain at all… He said: "If you feel pain, you have to come and tell me, because then we will start a syringe driver". One night, I get there and she was in horrible pain… But the nurse said that she wasn't allowed anything extra. By the time*

> *my brother arrived 3 hours later, they still hadn't give her any painkiller yet… That shouldn't happen, you know…' (I4, F, 47y)*

Family carers attached importance to being informed about the patient's condition. To obtain information during the patient's hospitalization, participants often had to take the initiative, which they sometimes found demanding. Some carers felt hesitant to ask questions, as they did not want to intrude on staff, while others expressed emotions of annoyance at the amount of effort to gain information. Their experiences with respect to acquiring information ranged from very positive with approachable physicians who took time for the patient and the family carer and provided clear and tailored information, to negative, when physicians were difficult to approach. One participant suggested more information would be received from the family physician than from the treating specialist or the hospital nurses:

> *'I: And when you were in the hospital, with whom did you have contact?*
>
> *V: Ah, nobody. If you didn't go to the desk yourself, you wouldn't know anything…*
>
> *S: Nobody said anything… No! We ourselves asked to speak to the doctor when she was ill… They need to have time, you know…*
>
> *V: They should make time for their patients, right?*
>
> *S: You know, the GP would have given more information than them…' (I3, F-F, 67-71y)*

3) Impact of the transfer on the family carer

Although a patient's transfer meant readapting and reorganizing life to combine patient visits with domestic responsibilities, work and even care for the other parent, participants especially expressed an emotional impact following the transfer.

The emotional impact of transfers on family carers was expressed as relief, anxiety, being concerned or feeling insecure. Participants reported being relieved to hand over the responsibility of care, particularly if it was perceived the patient was in good hands, receiving the right care at the right time. There was also a relief of being liberated of the fear that something could suddenly happen to the patient at home and that, in an endeavor to provide help, incorrect or harmful actions could be taken:

> *'Actually, for us it was also a kind of relief. If there's anything, she is never alone anymore… And if something happens - if she falls, the nurses are there… We can help too, but we don't know, if she falls, are we picking her up the right way? …Aren't we causing more harm than good?' (I5, F, 47)*

Despite being confronted with the grief of imminent loss, the carer also felt relieved, knowing that the patient would receive the best possible care at the PCU.

For some participants, the relief of knowing that the patient was in good hands in the new setting resulted in an improved quality of sleep:

> *'I: The periods that he was admitted to the hospital for a longer length of time, how did you experience this?*
>
> *P: Some sort of peace of mind, because I knew they were taking care of him and he had everything he needed there… And also… I'm going to be selfish now… Then I dared to sleep for once… because I knew that he was not here, that nobody could call me… I'm not going to say that I slept well, that isn't it, but differently, a healthier sleep probably. Being able to let go a little. Yes… I've have been very afraid at night… Scared to get up and find him…' (I7, F, 59y)*

Aside from feeling relieved, participants expressed feelings of anxiety as hospital discharge approached while the patient's condition had insufficiently improved. Others were concerned about how long it would be, before facing a next transfer to the hospital. One participant felt insecure, doubting whether she had succeeded in caregiving, as her husband was readmitted to the hospital shortly after discharge:

> *'Well, you're happy that he's going to be discharged and is coming home, but immediately you ask yourself: 'Hopefully it will be a long time before he needs to be admitted again'. It already happened twice, and I tell you: it was a blow that it happened again only after one week. So, you ask yourself, am I not taking care of him well enough? But they told me, the doctor too: "you can't help it, it's G who is in such a weak condition. You really shouldn't feel guilty, there is nothing you can do about it".' (I17, F, 64y)*

Discussion

Main findings

This study aimed to understand how family carers experienced the illness trajectory of their next of kin with palliative care needs related to care setting transfers, their experiences and attitude regarding the transfer decision and their perceptions regarding the patient's transfers across settings. Three themes were identified after data analysis: (1) patient transfer dynamics, (2) experiences regarding the changed care environment and (3) impact of the transfer on the family carer. The dynamics of the patient's transfer were affected by the balance between the care provision (both professional and informal care), on the one hand, and the changes in the patient's needs, on the other. Family carers reported varying experiences regarding the changed care environment, depending on the setting and determined by, among others, how they were treated by the personnel and the quality of receiving information. Concomitant feelings of relief, anxiety or feeling insecure could arise in situations of a patient's transfer.

Comparison with existing literature

Family carers displayed a high degree of versatility, constantly changing priorities to meet the needs of the patient. The carer's capacity, however, needed to be distributed between care for the patient and other responsibilities (e.g. domestic and family duties, work) and was stretched further when having to deal with personal medical problems or having to care for multiple patients. These results correspond to the results of previous studies, that report on the high levels of responsibility taken up by family carers and in which their caregiving is considered a natural, dutiful act (31, 32).

Aside from juggling between all these responsibilities, participants in our study also reported they arranged additional home care as the needs of the patients gradually changed. The additional support of domestic services, community nursing care, palliative home care team nurses and the family physician not only meant the patient's needs were better met, but also resulted in carers not feeling alone in the care process. This finding is consistent with previous research, describing the substantial impact of professional support on the ability of family carers to cope with the role of caregiving and ease the burden of responsibility (32-34). Furthermore, it reveals the dual position of the family carer: providing support and requiring support, as family carers often enter this caregiving role with little or no knowledge or experience (7, 35).

Next to the position of professional support, study results showed that other informal carers can play a considerable role too in supporting patients and family carers (e.g. neighbors, friends, other family members), which is aligned with other study findings (36). This relates to the concept of Compassionate Communities. In the last decade, there has been a growing interest in the development of Compassionate Communities and Compassionate Cities, and their significance towards palliative home care. This public health approach to end-of-life care, promotes the motivation of communities to take more responsibility in their healthcare, improving the care of people at the end of life, in which community support and palliative care work hand in hand (37, 38). This promising evolution may contribute to family carers' better coping with caregiving and to the continuity of palliative home care.

Our study results showed that the decision to transfer a patient occurred as a result of an imbalance between the patient's needs and the professional and informal care. Literature about transfers of patients with palliative care needs, describes some transfers as unavoidable or useful (e.g. in situations of maximum caring capacity or due to certain medical conditions that can only be managed at the hospital) (39). By contrast, other transfers – especially those between the home and the hospital at the end-of-life – can be regarded as potentially avoidable (e.g. due to the inadequate availability of community services) (40, 41). Taking into account that most patients with palliative care needs prefer to remain and die at home in familiar surroundings (42-44), healthcare professionals are thus challenged to use a pro-active approach to prevent avoidable transfers. Five key strategies have been described that can help avoid hospitalizations at the end of life: 1) marking the approach of death and shifting the mindset, 2) being able to provide acute treatment and care at home, 3) holding anticipatory discussions and interventions to deal with expected severe problems, 4) guiding and monitoring the patient and family in a holistic way throughout the illness trajectory and 5) ensuring continuity of treatment and care at home (40). Using this pro-active approach requires, amongst others, an early integration of palliative home care, a timely organization of advance care planning discussions and a healthcare professionals' agreement on shared care goals (45, 46). Previous findings reporting on healthcare professionals experiences within this same research project, showed however a lack of open provider-patient communication, which hampered the timely communication of advance care planning and the early integration of palliative home care (24).

Although end-of-life care literature and health care policies focus on the home setting being the desirable place of terminal care and death (42-44), it is noteworthy that some family carers in our study clearly stated not being able to cope with, or live with, the image of the deceased patient at home. This too was a reason for a patient's transfer, irrespective of the support of additional professional home care. This result raises questions about the topic of 'dying' in the current social context in Belgium. While historically, death and dying were a part of life and occurred within the family home, we can question whether or not people have become alienated from this natural event and may not know how to cope with it, preferring to obscure behind hospital or institutional walls (47).

A next result that merits attention is the factors influencing the choice of the care setting once the decision to transfer the patient had been taken. These were: practical considerations [e.g. the travel distance for visiting family and friends, costs], the life expectancy of the patient and the perceptions towards the new setting. Our study findings showed that some participants, when faced with the imminent death of the patient, were not yet familiar with the PCU. This was a reason to remain and die at the oncology ward instead of the PCU. This finding underlines the major responsibility of healthcare professionals involved, to timely discuss all options in organizing palliative care at the end of life, including a referral to a PCU. At the same time, professionals should be aware of the factors that influence the choice of setting, as described above.

With respect to the changed care environment, family carers in our study were satisfied with personnel conduct and the communication at nursing homes. Highly positive experiences were expressed towards the PCU, because of the personal care, the efforts taken to please the patient and family and to create comfortable circumstances for patients approaching the end of life. These findings are consistent with previous study results (2, 48, 49). This study revealed greatly varying experiences with respect to the hospital, however. The experiences depended on the hospital, the hospital ward and the reason for hospitalization. Although positive experiences have been reported, our findings illustrated a number of shortcomings in tailored patient care and informational continuity of care (the sharing of medical information across care providers and settings) which affected the quality of patient care. This finding is consistent with previous studies in which patients and family carers experienced a lack of informational continuity between providers when receiving care in the hospital (13) Similarly, in a longitudinal qualitative study with patients and family carers in five European countries, this was found to be a weak point in care provision, suggesting the need for interventions to improve communication between teams within the hospital (12).

In case of a patient's transfer, carers in this study expressed feelings of relief, knowing that the patient was in good hands and received good care at the new setting. This relief resulted from a sincere fear of doing wrong during the caregiving trajectory and dying process. Furthermore, the fact that one of the participants spoke in terms of being 'selfish' and feeling relieved when her partner was admitted to the hospital illustrates the burden of caregiving for family carers. Another participant expressed to feel insecure and doubted if she had taken care well enough. This result is consistent with other study findings (7, 32).

Strengths and limitations of the study

All care settings that provide palliative care, comparable to other developed countries, were represented in this study. The study specifically focused on palliative care provided in one regional palliative care network and included family carers who shared their experiences about the different care settings. Together with the choice for a qualitative research approach, this resulted in a broad perspective on family carers' viewpoints on the topic. Although the insights of this study may inspire other clinicians and researchers involved in palliative care, we should be cautious to generalize the results as we were not able to compare these insights to the experiences of family carers in other regions.

Additionally, with respect to participant recruitment, we do not know the total number of family carers approached for participation in this study or the number of persons that did not show interest in it.

Conclusion and implications

This study highlighted the adaptability of family carers in the caregiving process of their next of kin with palliative care needs. To support carers in coping with their role as caregivers and to share the responsibility of caregiving, involved healthcare professionals should timely evaluate family carers' preferences and needs and adapt the care organization accordingly. A pro-active attitude, which anticipates on the possibility of an impending decompensation of the family carer, is therefore recommended.

When the decision for a patient's transfer is taken, multiple factors influenced the choice of the care setting. We suggest that healthcare professionals take these factors into account when discussing, with patients and carers, the need for a transfer.

Experiences regarding patient transfers strongly varied depending on the setting and were based on the personnel's conduct and the quality of receiving information. Study results revealed shortcomings in perceived inter-professional communication and continuity of information during a patient's hospitalization. The development and evaluation of interventions, aimed at improving communication and continuity of information, can be suggested for further research.

Some participants were unfamiliar with the PCU. A topic for future research may be how patients and family carers are informed about the options for organizing palliative care, the way healthcare professionals discuss the different options and the timing of these discussions during the care trajectory of the patient.

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PART III:

INTER-PROFESSIONAL COLLABORATION IN PALLIATIVE HOME CARE FROM A COMPLEXITY SCIENCE PERSPECTIVE AND WORKPLACE LEARNING AS EMERGENT BEHAVIOR OF INTER-PROFESSIONAL COLLABORATION

Chapter 6:

Healthcare teams as complex adaptive systems: understanding team behavior through team members' perception of interpersonal interaction

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Healthcare teams as complex adaptive systems:

Understanding team behaviour through team members' perception of interpersonal interaction

Abstract

Background: Complexity science has been introduced in healthcare as a theoretical framework to better understand complex situations. Interdisciplinary healthcare teams can be viewed as Complex Adaptive Systems (CAS) by focusing more on the team members' interaction with each other than on the characteristics of individual team members. Viewing teams in this way can provide us with insights into the origins of team behaviour. The aim of this study is to describe the functioning of a healthcare team as it originates from the members' interactions using the CAS principles as a framework and to explore factors influencing workplace learning as emergent behaviour.

Methods: An interview study was done with 21 palliative home-care nurses, 20 community nurses and 18 general practitioners in Flanders, Belgium. A two-step analysis consisted of a deductive approach, which uses the CAS principles as coding framework for interview transcripts, followed by an inductive approach, which identifies patterns in the codes for each CAS principle.

Results: All CAS principles were identified in the interview transcripts of the three groups. The most prevalent principles in our study were principles with a structuring effect on team functioning: team members act autonomously guided by internalized basic rules; attractors shape the team functioning; a team has a history and is sensitive to initial conditions; and a team is an open system, interacting with its environment. The other principles, focusing on the result of the structuring principles, were present in the data, albeit to a lesser extent: team members' interactions are non-linear; interactions between team members can produce unpredictable behaviour; and interactions between team members can generate new behaviour. Patterns, reflecting team behaviour, were recognized in the coding of each CAS principle. Patterns of team behaviour, identified in this way, were linked to interprofessional competencies of the Interprofessional Collaboration Collaborative. Factors influencing workplace learning were identified.

Conclusions: This study provides us with insights into the origin of team functioning by explaining how patterns of interactions between team members define team behaviour. Viewing healthcare teams as Complex Adaptive Systems may offer explanations of different aspects of team behaviour with implications for education, practice and research.

Background

Complexity science belongs to the latest generation systems thinking, studying complex systems [1], also called Complex Adaptive Systems (CAS), by focusing on the relations and interconnections of the system components, rather than on the individual components themselves. Applied to the world of termites, for instance, the communication and collaboration between termites is more important than the characteristics of every individual termite. Complexity science has been introduced in healthcare as a theoretical framework to better understand complex situations [2-5]. Using complexity science to study healthcare has provided insights that could not have been reached when only using the traditional explanatory model in medicine based on scientific positivism that describes the linear cause-effect relationship between two isolated events [1]. The way clinicians handle uncertainty during the diagnostic process, the way physiological processes regulate, for instance, blood glucose levels and the way healthcare practices organize themselves according to a number of simple rules are examples of complex system behaviour that cannot be fully understood through linear thinking alone [1, 3]. As such, many healthcare concepts (e.g. diseases) and systems (e.g. hospitals) have subsequently been described as CAS [1, 6, 7]. Also interdisciplinary healthcare teams have been studied through the lens of complexity science [6]. The relationship patterns between individuals resulting in local interaction strategies that affect the quality of care delivery, the rate of information flow and the adaptability during uncertain conditions have been studied in great detail [8-11]. As such, it has been illustrated that the inter-individual interaction is a driving force and a defining factor for the whole system behaviour. So far, most of the studies have focused on a few - usually three or four - selected attributes of complexity theory, with relationships, self-organization and diversity being the most studied ones [6]. Studies do not, however, systematically evaluate all of the CAS characteristics in a team. Additionally, the learning effect of collaboration, the so-called workplace learning, as an emergent behaviour has been described by focusing on collective competence as a distributed capacity of a system or by describing adaptive practices based upon case descriptions [11-13]. Thanks to the quality of the relationships, feedback loops are created and information is shared which, in turn, influences knowledge growth and generates new behaviour in a team [9]. The factors influencing this workplace learning process require further exploration. With some exceptions, another common feature of most studies is that they report on steady healthcare teams working in one institution, such as hospital or nursing home [6, 11, 14]. An example of distributed teams already described in literature as CAS are the palliative home-care teams (PHCTs) [10, 15]. Internationally, palliative home-care teams have been introduced to deliver expert palliative care to patients at home, in collaboration with the regular primary healthcare professionals [16]. These interdisciplinary teams are performing demanding tasks in ever-changing working environments that require high adaptability of the teams [10, 15]. The network structure, where the collaborating team is geographically spread across different organisations, is distinctive for the PHCTs. Previous research has shown that during this collaboration, workplace learning occurs [15]. Exploring through the CAS lens how this learning occurs as emergent behaviour might provide us with additional insights and pave the way for optimizing the learning network feature of this collaboration.

Therefore this study aims to:

1. Systematically identify all CAS principles as expressed in healthcare providers' accounts of collaboration in a network structure.
2. Describe the whole-team functioning according to the CAS principles .
3. Explore factors influencing workplace learning in a distributed team as emergent behaviour of a CAS.

Methods

Setting and Participants

The focus of our study is the healthcare team taking care of the palliative patient at home. We consider the PHCT nurses, the community nurse (CN) and the general practitioner (GP) as the members of this team. The PHCT expert nurses collaborate with GPs and CNs in case complex problems occur involving palliative patients at home. General practitioners carry final responsibility for patient care, PHCT nurses have an advisory role, and CNs are dependent on a GP's prescription to execute their job. As part of a larger study on collaboration in palliative home care in Belgium [15, 17] we interviewed PHCT nurses, community nurses and general practitioners. In that study, all patients (taken care of by the PHCTs) who died during a three-month period were included as index patients in the study but did not participate themselves. Attending GPs, CNs and PHCT nurses of included patients were invited to participate after the patient's death.

Study design and data collection

To study behaviour and interaction, direct observation is the most obvious way of gathering data. However, to understand the ways in which members of healthcare teams operate on a day-to-day basis using the CAS principles as a theoretical framework, insights into the members' perceptions of their daily interaction with each other should be gained. This is because some of the CAS principles cannot be judged through observation of behaviour but require a reflective stance, and are better studied through understanding the individual's perception of the interaction. For instance, whether an individual's behaviour is, following the CAS principle, 'acting according to internalized basic rules' cannot be judged through observation but can only be understood by analyzing accounts of the team members' perception of the basic rules and the way they internalized them. Moreover, the individual's perception of the other's action or of the inter-individual interaction will shape the individual's own behaviour. Therefore, we decided to use individuals' accounts of their perception of team-interaction through interviews. After obtaining informed consent, semi-structured interviews were held focusing on interprofessional collaboration. The interview guide was designed based upon literature on interprofessional collaboration and comprised the following topics: 1. Experiences during the collaboration; 2. Communication with other professionals; 3. Learning from each other during collaboration; 4. Sharing of tasks and responsibility [15, 17]. The interviews lasted between 45 minutes and one hour, were audio-recorded and transcribed verbatim.

Data analysis

Step 1, deductive approach: Two researchers (PP, FM) discussed the CAS principles (see Table 1) and agreed on how to perform the coding using the set of principles as coding framework. After this, one third of the interviews were coded independently by both researchers. The interviews were searched for excerpts where CAS principles could be identified. These excerpts were coded according to the CAS principles. Coding was compared and differences were discussed until agreement on all codes was reached. Next, each researcher coded half of the remaining interviews. This will provide the answer to research question 1.

Table 1 shows the main CAS principles formulated with respect to healthcare teams.

Table 1: Features of Complex Adaptive Systems (CAS) described as team characteristics [1,3]

1. Team members act autonomously guided by **internalized basic rules** *Each team member can act in an autonomous way, guided by basic internalized rules. These rules can be expressed as instincts, constructs*
2. Team members' interactions are **non-linear** *Each team member can act autonomously but the actions have an effect on other team members (and vice versa). This is called the interdependence of the team members. These interactions encompass an exchange of information. An important aspect of the interactions is their non-linearity: small inputs may have large effects and vice versa.*
3. The team has a history and is sensitive to **initial conditions** *The non-linear effects observed in a team result from the modifying influence of initial conditions on the interactions between components. As a result of evolution in the system, the 'initial conditions' for future interactions will be different. As such, a team has a history and a memory, which means that changed conditions are 'remembered' by the system.*
4. Interactions between team members can produce **unpredictable behaviour** *As the interactions can cause non-linear effects, it is impossible to always predict the behaviour resulting from the interactions. Secondly, since the internalized rules are not necessarily equal for all components, the influencing factors for a cause-effect mechanism are not always clear.*
5. Interactions between team members can generate **new behaviour** *A team can display behaviours that cannot be understood by the characteristics of the individual team members.*
6. A team is an open system and interacts with its **environment** *Teams are connected with their environment in different ways. Some of the internalized rules come from the environment; if these rules change, the team changes. As such, the emergent behaviours of teams can be seen as adaptations to the environmental conditions, also called 'self-organisation'. This self-organisation is informed by feedback loops by which the environment feeds the outcomes of the team's actions back into the system. Next, depending on the scale we use, the environment may be part of the team or act as environment. As such, the borders of a team are not fixed but can open or close as a response to interactions with the environment. Finally, the environment consists of teams as well and they all influence each other. A team and its environment co-evolve during this interaction.*
7. **Attractors** shape the team functioning *The actions and interactions of team members are influenced by a set of basic rules as described earlier. Rules push a team member towards a certain action. As a mirror image, attractors attract team members towards a certain action. The trajectory of a team (i.e. the usual pattern of behaviour) is for a great deal determined by its attractors. The precise behaviour of a team on a precise moment is still unpredictable but the 'usual' behaviour will always incline towards the attractors.*

Step 2, inductive approach: For step two, the fragments extracted from the interviews and coded per CAS principle were considered as units of analysis to understand the team functioning according to each principle [18]. Per CAS principle, meaning units were identified by PP, abstracted and labelled with a code. These codes were subsequently sorted into categories. The researchers engaged in a process of reflection and discussion during the analysis and referred back to the original interview transcripts on a regular basis. The underlying patterns within the categories will be presented as aspects of team behaviour in the results section under step 2

[18]. By describing the inductively identified categories in light of the team's daily practice, we will glean the answers to aims 2 and 3.

We used NVivo 10 for the management and analysis of the transcripts.

Reliability, rigour and credibility

Trustworthiness of the data was increased through investigator triangulation. At regular intervals, researchers compared and discussed data and checked analysis by referring back to the data. Three researchers are well-versed in qualitative research. Reflexivity was used throughout the analysis.

Results

Participants

We interviewed 21 PHCT nurses, 20 community nurses and 18 general practitioners. Participants showed a wide variability in terms of age, gender, working experience and practice situation. Details are shown in Table 2.

Table 2: characteristics of study participants

Discipline (N)	Mean age (range)	Gender (male/ female)	Working experience (years)	Practice situation (solo/ duo/group)
General practitioner (18)	46 (33 – 65)	12/6	6- 38	9/4/5
PHCT nurse (21)	46 (34 – 57)	3/18	0,5 – 15	0/0/21
Community nurse (20)	46 (35 – 57)	4/16	2 - 35	4/0/16

Results aim 1

Every CAS principle could be identified in the interview transcripts of the three professional groups. There are differences, however, in the frequency of identifications, per CAS principle and per professional group. Details are shown in Table 3.

Table 3: number of interviews and excerpts per CAS principle with illustration of an interview fragment

CAS principle	Number of interviews where fragments have been found according to the CAS principle (GP/ PHCT/CN)	Number of excerpts according to the CAS principle (GP/ PHCT/CN)	Example of interview fragment coded under the CAS principle.
1. Team members act autonomously guided by **internalized basic rules**	48 (16/14/18)	190 (40/62/88)	I think I might have a talk to him about this, because, you know, I really don't like nurses administering drugs without me knowing it. Or give some extra painkillers just like that. (GP)
2. Team members' interactions are **non-linear**	11 (1/6/4)	11 (1/6/4)	He broke it off quite abruptly. erm, the procedure was what she was, yes, euh, I had the impression that he shot the messenger while he was talking about the procedure. If he doesn't agree with the procedure, then he can question it, but he doesn't have to shoot the messenger, I think. So erm it ended up us having to ignore the syringe driver. That he was going to see to it himself] (PHCT nurse, after an altercation between a GP and the PHCT nurse on medication dose)

3. The team has a history and is sensitive to **initial conditions**	44 (10/17/17)	130 (25/45/60)	That's right, yes yes. Personality, yes, plays a major role in everything. Yes Yes. I see that, if you look at all of our GPs we work with, and those with whom you work occasionally, or those with whom you work very often, then your communication is also very different. (CN) You will be more assertive in the presence of certain general practitioners. How many times have you worked with them? Erm. What are previous experiences with this general practitioner? If you've had a very bad experience, then you will also be much more cautious. Then I think: "Well, the previous experience wasn't good, I have to make sure that this one goes well" (PHCT nurse)
4. Interactions between team members can produce **unpredictable behaviour**	21 (2/11/8)	38 (2/22/14)	It depends on your openness as a doctor. If you have a closed mentality, then you will receive suggestions that you don't really need, whether you like it or not. (GP)
5. Interactions between team members can generate **new behaviour**	25 (5/13/7)	54 (6/31/17)	I go and ask the members of the palliative team. Is there a solution to this problem? And there's also a development in this and those people are more aware of it. If we try to do it well, each from our own expertise and our own training background, you will reach a higher level together] (GP)
6. A team is an open system and interacts with its **environment**	31 (7/12/12)	70 (16/24/30)	But I think it's actually because of us that they can be admitted (PHCT), that's not an obvious a step to take. So often, it's the hospital that takes the first step. The patients are discharged from the hospital and then we have to take care of the aftercare. They are usually aware of the existence of a palliative service, but I still think we take the first step most of the time (CN) And there are those who know it very well, of course. We also have several GPs who have followed the course (on palliative care), who are also well-informed. Sometimes, when I enter the place they approach me and say, 'Have a look, I've done that calculation in such or such a way, what do you think. In consultation, that's great, isn't it? But there are different types of general practitioners. Yes, there is still a lot of work to be done] (PHCT)
7. **Attractors** shape the team functioning	52 (14/18/20)	180 (26/50/104)	In the case of older doctors, it is usually the case that we try to give them the impression that the decision is theirs, but in most cases, we have talked them into it. How can we give them the sense that they made the decision while arriving at a point where it becomes doable for our patient? (CN)

Results aim 2

Below, we present the emergent patterns within the categories for each of the CAS principles.

1. Team members act autonomously, guided by internalized basic rules

Our study results revealed three basic rules shaping the team members' professional attitude and the way they engage in the collaboration.

- Participants in our study clearly stated that their mission in healthcare was to focus on the patient and the quality of care. *'We are here for the patient'* is the most important basic rule for the three professional groups in our study, making it the driving force for team collaboration by sharing complementary expertise. The focus on patient care, along with the willingness to act in the best interests of the patient makes team members acknowledge each other's expertise and allow them to express their opinions on patient problems within their area of expertise or seek advice with other team members in cases of indecision without interference of professional hierarchy. In cases of team members not sharing their expertise or acting on their own, other team members will restore communication without damaging interprofessional relationships.
- The awareness of *GPs carrying final responsibility* is a second basic rule within the context of the healthcare team in our study. As such, nurses cannot initiate or adapt medication or other therapies without seeking the GP's consent. The PHCT nurse confirms the GP's central position by taking the time necessary to deliberate with them the treatment options before meeting the patients and their families.
- A third basic rule in the context of our study is that tasks and *responsibilities need to be clear for everybody*. Having said that, every team member is responsible for their own tasks and duties, although these are not always clearly defined and agreed upon. For instance, monitoring the effect of changes in medication dose on patient's pain level can be done by all professionals involved. Clear agreements are needed in order for therapy adjustments to be followed up efficiently. Even when tasks and roles are being negotiated and agreed upon within a team according to the patient's care needs, some external rules are not to be violated, for instance certain protocols on complex procedures, like palliative sedation.

2. Team members' interactions are non-linear

- *Escalating communication conflicts* were identified as examples of non-linear interactions. One PHCT nurse reported explaining to a GP why they could not assist them in a euthanasia case of a non-terminal patient, because these cases do not belong to the target group of the palliative care team (thereby correctly stating the limits of the team's official mandate). As a response, the GP reacted in an angry manner and subsequently decided to cease collaboration with the nurse involved.

3. The team has a history and is sensitive to initial conditions

History

Several aspects of a team's history influence the current collaboration:

- *Previous positive experiences* of perceiving the complementarity of each other's expertise in providing good quality patient care makes professionals trust one another and share tasks and responsibilities more easily. The resulting mutual respect of each other's knowledge and expertise creates a positive working atmosphere and prevents role conflicts. In case of disagreements on treatment options or differing views on care aims, open and immediate communication is initiated. Positive experiences allow for professionals making a mistake without being blamed by other team members.
- *Previous negative experiences*, however, like nurses acting autonomously without consulting the GP, or GPs neglecting to inform CNs sufficiently on the patient's medical status or ignoring expert palliative care advice, result in an atmosphere of distrust and lead to professionals acting on their own without sharing tasks. This results in a fragmented care delivery, often confusing both professionals and patients about general care aims. In case of disagreements or differing views, there is insufficient communication and professionals act according to their own views on care without consultation or support for their views from other professionals. As such, a history of poor collaboration makes team members judge each other in a harsher way.

- *Knowing each other either* through previous collaboration or on a personal level facilitates communication and establishes a basic sense of trust in each other's competences. You get to know the other's strengths and weaknesses, which results in tailored communication and collaboration.
- *The communication history* also has a major impact. A tradition of systematic and frequent communication facilitates the initiation of a deliberation in case of problems. Previous communication problems, like a GP being repeatedly unavailable for consultation or unwilling to negotiate treatment, cause nurses to find support with other team members, thus excluding the GP from the interaction.

Initial conditions

Alongside the sometimes longstanding and continuous history of a team, the initial starting conditions for every new collaborative episode influence the way team members interact with each other.

- *When a GP is reluctant to share the care for, and the information* about, their patient at the start of the collaboration with the PHCT nurses (e.g. when family members ask for the PHCT nurses' involvement or when hospital services initiate the collaboration when the GP does not feel the need), the interprofessional interaction is less spontaneous throughout the period of collaboration and the PHCT nurses hesitate to make therapy suggestions or discuss care goals. When, however, the GP welcomes the PHCT nurses, or invites them to collaborate, and provides them with insider information about their patient, the PHCT nurses will be more inclined to share all their insights and define shared aims and goals for patient care.
- A team of professionals trusting each other based upon previous collaborations and showing a willingness to collaborate from the start can, therefore, launch *a kick-off meeting* to define care goals and aims before the start of the collaboration. This ultimately leads to more open and constructive communication throughout the collaboration.
- *The composition of the team* at the start of the collaboration influences team members' interactions and the way the team functions. Community nurses having displayed knowledge and expertise on palliative care in previous collaborations receive the GP's trust and are invited by them to discuss treatment options. Similarly, GPs (e.g. younger doctors who received palliative care training as part of their undergraduate studies) who have proved knowledgeable before, encourage more open communication and straightforward deliberation with CNs than GPs without expertise. The same open interaction is facilitated by GPs addressing CNs as peers from the start while GPs stressing professional hierarchy at the beginning of the collaboration hinder open communication.

4. Interactions between team members can produce unpredictable behaviour

- *Crossing task boundaries* or tightening them can be the unexpected result of communication on task and role agreements. A GP telling the PHCT nurses that the former will be in charge of medication decisions often receives unsolicited therapy advice from the PHCT nurses who judge the GP's intentions incorrect, based upon their own expert knowledge. Similarly, PHCT nurses questioning the GP's decision in a professional way, with good care in mind, can be told not to interfere and not to engage in future therapy discussions.
- *Professionals sometimes ignore their own knowledge and expertise* and act in suboptimal ways without apparent reason. PHCT nurses often accept that GPs ignore their advice, without confronting the GP. They prefer to provide suboptimal care to the patient (according to the GP's decision) and to closely monitor the patient and report on suboptimal results, eventually leading to therapy adjustment as was their first choice. The reason to act in this manner is not to damage the collaborative relationship with the GP, which might harm future collaborations for future patients. Similarly, CNs often tend to accept GP's choices that are in contrast with their own views, without commenting upon it. Their reason is that they are dependent on the GP (for prescriptions, for example) for their daily work.

5. Interactions between team members can generate new behaviour

- During interaction and collaboration, professionals learn from each other. *This workplace learning, the acquisition of new skills as an individual or as a team, can lead to a new way of functioning* and is major emergent behaviour resulting from the collaboration. Receiving advice from experts in the team makes team members less dependent in the future and the interaction (advice-seeking behaviour) sometimes diminishes or changes its character. Complex procedures (e.g. palliative sedation or paracentesis) can be executed by a team, even when none of them have ever done it, but combining competences and trust in one another makes the team accomplish the task.

- *New communication strategies* is a second type of emergent team behaviour. Teams with only ad hoc and one-to-one communication may organize whole-team meetings in case of conflicts or as a form of debriefing in the case of complicated collaboration.

6. A team is an open system and interacts with its environment

- *External factors influence the collaboration*. When the GP is less available (e.g. due to workload in general practice in winter time), the PHCT nurse takes over the coordinating role from the GP. As such, the external conditions (e.g. flu epidemic in wintertime causing the GP's reduced availability) pare down the interaction between GP and PHCT nurses and lead to a reshuffling of tasks and responsibilities in the team. The organisation of out-of-hours service (usual care not available during weekend) triggers initiatives within the team, like GPs sharing their private phone numbers with PHCT nurses, leading to a different way of interacting and communicating. Similarly, anticipating potential problems during the weekend, palliative care teams prepare sets of emergency medication and standing orders.
- *The educational system influences the collaboration*. While better education in palliative care for GPs facilitates discussions with PHCT nurses – indeed, the lack of interprofessional training during undergraduate medical training inhibits effective teamwork - learning to use protocols and guidelines results in less flexibility for the team to decide on how to deliver care. Published guidelines, however, are useful for PHCT nurses to prepare a discussion with GPs.
- *Organizing and financing the healthcare system*. Extra fees for care delivery to palliative patients was mentioned by CNs and GPs as stimuli or compensations for the time-consuming interactions and collaboration. Since community nurses are dependent on GPs for their work (they need prescriptions to be allowed to provide care), they are careful when commenting upon GP's decisions or actions.
- *Mass media and ideas of the general public* can influence the team dynamic in complex cases like euthanasia (more requests) or medication use (e.g. morphine is lethal), resulting in discussions and more intense team deliberation.

7. Attractors shape the team functioning

Three main themes emerged as attractors that shape the actual day-to-day team operations and care delivery at operational level: quality of patient care, interprofessional relationships and personal and professional wellbeing are goals that team members try to achieve.

- *The quality of patient care delivery* is the main attractor to initiate a collaboration and to shape the collaboration. In order to reach high-quality and comprehensive patient care, professionals combine their complementary knowledge and skills. Acknowledging and respecting each other's competences often results in deliberation and shared decision-making on treatment plans as peers: professional hierarchy in these cases can be overcome by focusing on expertise instead of on professional background. Some GPs who present themselves as being hierarchically superior in daily practice are willing to make a shift in this behaviour and accept PHCT nurses' advice in case of complex patient problems. In cases where the attractor of patient care is less present and team members experience rivalry between professions with regard to expertise, collaboration is hindered. Communication as a specific kind of interaction is also influenced by this attractor. Scheduled weekly team meetings are complemented by ad hoc phone calls or supplementary team meetings in case of complex patient problems or when team members do not share the same views on care and care aims.
- *Interprofessional relationships* are a second attractor as they are highly valued between team members. Professionals cover up for each other in case of little mistakes or miscommunication, thereby strengthening the professional relationships. GPs and PHCT nurses sometimes meet before jointly visiting the patient to agree on treatment plans. This is to avoid

bedside discussions that might harm the trust of the patient in one or the other and hinder future interprofessional collaboration. In case of conflicting views on treatment options, PHCT nurses often avoid confronting discussions with GPs, and with a view not to endanger the relationship, they prefer to take up the nurses' role and report on their observations of symptoms in great detail so as to guide GPs to treatment adaptations. Community nurses state doing the same, except when the problem in hand is clearly within the nurses' expertise e.g. wound care. In those cases, they have no problems contradicting the GP.

- *Personal and professional wellbeing* is a third attractor, shaping the interaction between team members. Professionals mention seeking support with others for a debriefing after an emotional experience (e.g. death of a patient) or after a conflict with the patient or their family. After a collaboration episode (i.e. after the death of a patient), there is often a palliative care team debriefing to evaluate the care delivery. Some GPs regret not being invited to these, because they sometimes feel the need for a concluding talk. Knowing or feeling that they are doing the right thing, and thus avoiding moral distress, brings PHCT nurses to adhere to protocols for complex situations like palliative sedation. They use the protocol in their communication with the GPs to plan task execution. Most professionals prefer not to carry responsibility on their own but to share the burden and seek support or availability of others, even during out-of-hours service. A distinct aspect of professional wellbeing is the CNs' dependency on GP's prescriptions, resulting in CNs being careful in addressing GPs and being reluctant to contradict them. This might lead to less professional satisfaction in case of CNs feeling pressurized to perform actions they do not agree with.

Results aim 3

The interview analysis revealed factors influencing the information exchange and the sharing of expertise within the team. Both are fundamental prerequisites for workplace learning. These factors are described in Table 4.

Table 4: Facilitating and hindering factors for information exchange and sharing of expertise, according to the CAS principles

Facilitating factors for information exchange and sharing of expertise (CAS principle)	Hindering factors for information exchange and sharing of expertise (CAS principle)
Sharing the same mission of delivering quality care – the willingness to act in the patient's best interests stimulates discussions and shared-decision making (1)	
Professional hierarchy – PHCT nurse spends time deliberating treatment options with GP (1) Creating **horizontal collaborative relationships** from the start facilitates open interaction (3)	**Professional hierarchy** – nurses acting autonomously without deliberation results in atmosphere of distrust (3) Doctors **stressing hierarchy structure** might hinder open communication (3). **Nurses being dependent on doctors** for their daily work and therefore hesitate to comment upon doctor's decisions even when they disagree (4)
	Unresolved **communication conflicts** (2)
Previous positive experiences resulting in mutual respect of each other's knowledge and expertise (3)	**Previous negative experiences** – GPs insufficiently informing CNs on patient's medical status or ignoring expert palliative care advice results in atmosphere of distrust (3)
Knowing each other's strengths and weaknesses results in tailored communication (3) Doctor's **education** in palliative care facilitates discussions with PHCT experts (6) Using **practice guidelines** helps nurses prepare a discussion with doctors (6)	**Lack of interprofessional training** inhibits effective teamwork (6)

Facilitating factors for information exchange and sharing of expertise (CAS principle)	Hindering factors for information exchange and sharing of expertise (CAS principle)
Acknowledging and respecting each other's competences results in deliberation and shared decision-making as peers (7). Valuing **interprofessional relationships** trigger anticipatory interprofessional communication in complex cases to avoid bedside discussions (7)	Nurses sometimes avoid confronting doctors with their differing views not to harm **relationships**. This results in missed learning opportunities (7)
Tradition of systematic and frequent communication facilitates the initiation of a deliberation in case of problems (3)	**Communication problems in the past** like being unavailable for others or unwilling to negotiate treatment excludes professionals from future interaction (3)
	Unwillingness to collaborate or not feeling the need to collaborate at the start (3)
Sharing information prompts the recipients of information to share information as well (3)	
A kick-off meeting at the start of the collaboration leads to better communication throughout the collaboration (3)	
Extra fee compensates for time-consuming interactions (6). **Mass media and general public ideas** trigger more frequent and intense team discussions on complex cases (6)	**Unavailability** due to workload, time restraints diminish interaction (6)
Striving for **personal and professional wellbeing** triggers interprofessional debriefing after emotional experiences or conflicts with patients (7) **Nurses' hesitation to take up responsibility** on their own makes them seek support and deliberate with others, even during out-of-hours service (7)	

Discussion

Our study described the team members' interactions based upon the complexity science framework. We explored the origin of healthcare team behaviour and the factors influencing workplace learning as emergent behaviour. Studying healthcare team members' perception of their interprofessional interaction during day-to-day teamwork through the lens of complexity science helps us to understand how and why healthcare professionals behave in this way as "perceptual information guides our decisions and actions, and shapes our beliefs" [19]. This understanding cannot be derived from studies describing behaviour through observation. Our study allowed us to map internalized views of healthcare providers that define team behaviour. Healthcare teams do not always function as a CAS. In clinical situations where problems and their solutions can be addressed by drawing on procedures and guidelines, teams work in a plan-and-control way, instructions are being given and executed in a straightforward way. Under circumstances where there is uncertainty about how to best deal with the situation, thinking outside the box and trying out different approaches is the most efficient strategy [20]. In these cases, teams work as a CAS. In our study, we found examples of the plan-and-control actions; however, for the purpose of the paper we only focus on accounts of collaborative practice as a CAS [20, 21]. Some of our results are confirmed by literature, both from studies using complexity science as a framework and by studies based upon general learning theories. We will first describe them briefly. Later on, we will focus on the functioning of the team as a learning network and on the understanding of the origin of workplace learning as an emergent behaviour, as we believe that complexity theory can advance our understanding of this theme [5].

Addressing the first study aim, we can state that the CAS principles can be identified in team members' accounts of their perception of the way they interact on a day-to-day basis in the team. We notice that every CAS principle is to be found in the three professional groups' accounts of their perception of team interaction, indicating the relevance of the principles for each professional background. Principle number 1 (team members act autonomously, guided by internalized basic rules) and 7 (attractors shape the team functioning) are illustrated by more fragments from more interviews than the other principles. A reason might be that these principles are most relevant for the daily collaborative practice of the team and, as such, most discussed and most accessible for reflection during the interviews. The shared aim and purpose of teamwork is a major topic to be actively discussed repetitively by team leaders, as is the construction of shared mental models in order to collaborate effectively [22, 23]. These two principles have a structuring quality on the team functioning and behaviour. This structuring quality can also be found in principle 3 (A team has a history and is sensitive to initial conditions) and principle 6 (A team is an open system and interacts with its environment), and both have a large number of fragments and interviews. The other, lesser illustrated principles (e.g. 2. Team members' interactions are non-linear), focus more on the result of the structuring principles and may be less prone to be discussed in daily practice. Equally, team survey instruments do not always capture these dynamic aspects of behavioural processes and emergent states but focus only on the tangible end result [24].

Addressing the second study aim, we can say that healthcare team functioning can indeed be described according to the CAS principles based upon the team members' perception of their day-to-day interaction. Moreover, this way of analyzing the interviews adds an explanatory understanding of the origin of team functioning based upon individual's interactions on top of the descriptive representation in literature [25, 26]. Below, we discuss the different principles according to the frequency they have been identified with within the participants' accounts.

The themes represented under CAS principle 1 (Team members act autonomously guided by internalized basic rules) and 7 (Attractors shape the team functioning) relate to the issue of professional and interprofessional identity. Internalized basic rules and the choice of attractors, to some extent, define people as professionals. During professional identity formation, the characteristics, values and norms of the profession are internalized, which results in an individual acting accordingly [26, 27]. This relates to CAS principle 1. Individuals can, however, develop a dual identity, encompassing both a professional and interprofessional identity [28, 29]. This interprofessional identity builds on the professional identity and helps individuals as they work in teams become part of a collective identity, with agreed goals for the delivery of high-quality patient care [30] . This relates to the attractors of CAS principle 7, which shape the team functioning.

The Interprofessional Education Collaborative (IPEC) has introduced Core Competencies for Interprofessional Collaborative Practice to guide educationalists in designing interprofessional curricula and provides us with an important framework

to look at interprofessional collaboration [31]. Sharing one's personal values with team members and trying to find common ground for a shared aim in teamwork matches competencies 1 (Values/Ethics for Interprofessional Practice) and 4 (Teams and Teamwork) of the Core Competencies for Interprofessional Collaborative Practice of the competency framework. Respect for one another's values in teamwork is also one of the most commonly assessed dimensions of teamwork survey instruments, as described in a recent review [24]. As such, the patterns found in our results match the literature in identifying major foci for collaborative practice and add an extra layer of meaning to the competencies and measurement instruments described above. The insights from our study can thus be used to clarify and illustrate at a practice-based level the competencies and measurement instruments during interprofessional education or evaluation of team functioning. Understanding how team members' interaction influences team behaviour is of importance in designing team training and crew resource management training [32, 33].

Another well represented CAS principle in our study is number 3 (The team has a history and is sensitive to initial conditions). The fact that all professional groups mention previous experiences as a major factor shaping current collaboration illustrates the importance of this principle and has been described before [34]. The team culture and the leadership style influence the way experiences contribute to the functioning of a team [35]. In accordance with the IPEC Core Competency 4 (Team and Teamwork), the results of our study call for due attention to team composition and longitudinal collaborative experiences. This is of importance in fixed teams, like those on hospital wards, but equally and more challenging in teams with ever-changing compositions, the so-called fluid teams, as is often the case in primary-care settings, where team composition is decided upon according to the patient's care needs [21]. Additionally, the initial conditions of a single collaborative episode seem important. Therefore, regular team meetings to discuss the collaboration, and not only the patient care, are of great value. These discussions need to make initial conditions explicit but also serve to regularly evaluate collaboration as building on to the team history and preparing the next initial conditions for a future collaborative episode [22, 35]. Although team design and group cohesion, as part of the team's history, receive attention during team evaluation, the focus on initial conditions modulating a team's behaviour could be addressed more explicitly, especially in larger collaborative groups or fluid teams [24]. A major aspect of teamwork, as mentioned by our participants, is the agreement on tasks and responsibilities (see CAS principle number 1 – results step 2), and reflects IPEC Core Competency 2 (Roles and Responsibilities) [31] and one of the most commonly assessed dimensions of team measurement instruments [24]. Even though this aspect should be a primary topic on team meeting agendas to prevent conflicts on this issue, it does not always seem to receive the attention it deserves [25, 36, 37]. Lack of clarity on roles and responsibilities hampers effective collaboration [38]. Our study shows that the discussions and agreements on tasks and responsibilities are linked to one's internalized basic rules, which may partly explain the sometimes challenging team discussions on this topic.

CAS principle number 6 (A team is an open system and interacts with its environment) stresses the interaction between the team and its environment. Working conditions based upon the organizational culture (e.g. communication strategies) or the broader societal rules (e.g. nurses being dependent on doctors for work prescriptions) are mentioned by participants in our study as moderating the team members' interaction. Context and team culture are known to influence team functioning [35]. Team managers should be aware of this and take the interaction between their team and the broader context into account when discussing team functioning [39].

CAS principle number 5 (Interactions between team members can generate new behaviour) describes the new behaviour a team can show as a result of the interprofessional interaction (e.g. a whole-team meeting can be scheduled instead of relying on the ad hoc, one-to-one communication a team is used to having after a team conflict due to the fact that information on therapy decisions is not communicated adequately). In our study, we also found aspects of workplace learning, meaning the acquisition of new knowledge and skills during collaboration. A recent literature review on workplace learning in primary healthcare describes learning characteristics matching some of the CAS principles, like the influence of hierarchy and of contextual conditions on workplace learning [40]. Creating the conditions to foster workplace learning can shape the emerging team behaviour to optimize functioning and quality of care delivery. This also relates to principle number 6 (A team is an open system and interacts with its environment) as the working conditions are e.g. dependent on the organizational culture and influenced by the culture of educational institutions.

CAS principles number 2 (Team members' interactions are non-linear) and 4 (Interactions between team members can produce unpredictable behaviour) are the least present in the participants' accounts of collaboration. On the one hand, both principles 2 and 4 are described by complexity science as shaping normal CAS behaviour. As such, the general team's behaviour (outside conflict episodes) might also be based upon these. This could not be illustrated, however, with the results of our study. On the other hand, unpredictability and non-linearity may be associated with team conflicts and moral distress. For instance, in order not to harm interprofessional relationships, CNs often hesitate to confront GPs with differing views on care plans, resulting in the perception of suboptimal care delivery by the CNs, ultimately leading to moral distress and professional dysfunctioning [41]. This relates to the overlap and occasional conflict we noticed between CAS principles 1 and 7. The internalized basic rules, influencing healthcare professionals' identity as a healthcare provider, guide their actions and make them behave in a certain preferred way. This personal preference can sometimes be in conflict with team attractors requiring different behaviour or working strategies [41, 42]. Professionals can modify their behaviour according to the context and the needs of the situation. When team attractors diverge too much from a professional's preferred behaviour or personal attractor (intrinsic motivation), tension can arise ultimately, leading to reduced professional well-being or team conflicts [43]. The management of the above-mentioned team conflicts relates to IPEC Core Competency 3, Interprofessional communication, and includes, among others, the subcompetencies of conflict resolution and feedback giving.

When it comes to the third study aim, we found many factors facilitating or hampering the information flow and the sharing of expertise, as fundamental conditions for workplace learning. Many of the factors (e.g. sharing the same values and goals, installing horizontal collaborative relationships) have been described already in literature using complexity theory or other conceptual frameworks [44-48]. Some factors however, such as contextual factors of extra fees or the dependency of nurses on doctors' prescriptions for their job, are less known for influencing information exchange. These factors seem to be specific of the ever-changing team situation in the context of our study and need further exploration. In a similar way, framing the notion of personal wellbeing, acting as a trigger for a debriefing session after emotional or conflict experiences or as a condition for fostering workplace learning, requires further exploration. Finally, some participants stated that good interprofessional relationships, usually seen as the backbone of open communication, resulted at times in hampered communication [49]. While a good and trusting relationship is usually mentioned as being a prerequisite for open and effective communication, our results show that prioritizing this relationship can be done to such an extent that it prevents open communication [50]. This occurred, for instance, when nurses did not want to open a discussion on a doctor's treatment decision in order not to jeopardize their good relationship with them, even when they were convinced that their decision was not correct. The ways in which health caregivers strike a balance between quality of patient care and safeguarding a good interprofessional relationship as attractors for professional behaviour requires further exploration.

A limitation of the study is that we only have data from one specific context. The comparison with literature, however, shows that our results might be generic and transferability to other contexts might be feasible, although this should be done with the necessary caution. Another limitation might be the fact that we performed a secondary analysis of interviews, conducted within another study. However, the focus of the primary study was similar to the current one, namely interprofessional collaboration. Moreover, we reached data saturation for most of the CAS principles (with 'non-linearity' as an exception), which illustrates the wealth of data.

A strength of our study is that we provide an explanatory model of team functioning based upon complexity science while looking at the perceived interaction of team members. Credibility and trustworthiness of the results are guaranteed by the strict analytical procedure on data from three different professions with a wide variety of personal characteristics, and executed by an interdisciplinary team [18, 51].

Implications for practice and research

Some implications for education and practice can be gleaned. First of all, our results can provide educators with an extra dimension of the IPEC Core Competencies. This proves that these should not only be acquired at an individual level but be explained and trained, taking the interactional origin of the competence-related behaviour into account. As such, team training, with due attention for the perception of interaction, might be of value. Looking at team functioning through the lens of complexity theory emphasizes the value of team training, next to that of individual professional training, as has been generally acknowledged in the literature and has been operationalized in training models such as the TeamSTEPPS [52]. Secondly, team leaders and team managers might try to frame team drivers, shared focus and aims within the CAS principles. For instance, making professional behaviour explicit as being the result of internalized basic rules or attractors might facilitate team communication and conflict management. Additionally, our study illustrates how team attractors can modulate behaviour and therefore attractors (existing and new ones) are worth exploring and identifying during team training. While trying to induce change at a systems' level, often emphasis is being placed on overcoming barriers. Complexity theory suggests, as is evident from our data and other studies, that focusing on endorsing existent or installing new attractors might be more efficient [53]. A review of workplace learning during collaborative practice in primary care identified possible attractors (e.g. the willingness to learn from each other triggers open communication and respect for the other's views) that might be used as a source of inspiration in team training [40]. Thirdly, as workplace learning during practice is a substantial part of continuing professional development, creating the conditions to facilitate learning as emergent new behaviour requires attention from team leaders and managers.

Future research needs to confirm these results in other contexts. Also, the overlap and potential conflicts we noticed between CAS principles 1 and 7, where team attractors sometimes overrule individual internalized basic rules, should be further investigated. The motivation to do so needs to be investigated, as well as the effects of these conflicts on the professional well- being of healthcare providers as overruling aspects of one's professional identity might lead to moral distress and professional dysfunction.

Conclusion

This study provides us with insights into the origin of team functioning by explaining how patterns of interactions between team members define team behaviour. Viewing healthcare teams as complex adaptive systems may offer explanations of different aspects of team behaviour with implications for education, practice and research.

List of abbreviations

CAS	Complex Adaptive System
PHCT	Palliative Home Care Team
CN	Community Nurse
GP	General Practitioner
IPEC	Interprofessional Education Collaborative

Declarations

Ethics approval and consent to participate

Ethics approval was obtained from the Ghent University Hospital (B670201213298, B670201317239, B670201317239). All participants signed an informed consent.

Consent to publish

Participants consented to publish the study results.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

PP conceived the study. PP and FM designed the study and analyzed the data. PP, FM and DK interpreted the data. PP wrote the manuscript. DK assisted in writing the manuscript. All authors provided critical feedback on every draft. All authors read and approved the final manuscript.

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Chapter 7:

Workplace learning through collaboration in primary healthcare

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Mertens F, de Groot E, Meijer L, Wens J, Cherry MG, Deveugele M, Damoiseaux R, Stes A, Pype P. Workplace learning through collaboration in primary healthcare: A BEME realist review of what works, for whom and in what circumstances: BEME Guide No 46.
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Workplace Learning through Collaboration in Primary Healthcare:

A BEME Realist Review of What Works, for Whom, and in What Circumstances.

Abstract

Background: Changes in healthcare practice toward more proactive clinical, organisational and interprofessional working require primary healthcare professionals to learn continuously from each other through collaboration. This systematic review uses realist methodology to consolidate knowledge on the characteristics of workplace learning (WPL) through collaboration by primary healthcare professionals.

Methods: Following several scoping searches, five electronic bibliographic databases were searched from January 1990 to December 2015 for relevant grey and published literature written in English, French, German and Dutch. Reviewers worked in pairs to identify relevant articles. A set of statements, based on the findings of our scoping searches, was used as a coding tree to analyse the papers. Interpretation of the results was done in alternating pairs, discussed within the author group, and triangulated with stakeholders' views.

Results: Out of 6930 references, we included 42 publications that elucidated who, when, how and what primary healthcare professionals learn through collaboration. Papers were both qualitative and quantitative in design, and focused largely on WPL of collaborating general practitioners and nurses. No striking differences between different professionals within primary healthcare were noted. Professionals were often unaware of the learning that occurs through collaboration. WPL happened predominantly through informal discussions about patient cases and modelling for other professionals. Any professionals could both learn and facilitate others' learning. Outcomes were diverse, but contextualised knowledge seemed to be important.

Discussion/conclusions: Primary care professionals' WPL is multifaceted. Existing social constructivist and social cognitivist learning theories form a framework from which to interpret these findings. Primary care policy makers and managers should ensure that professionals have access to protected time, earmarked for learning. Time is required for reflection, to learn new ways of interaction and to develop new habits within clinical practice.

Keywords: workplace learning, collaboration, interprofessional collaboration, primary healthcare, realist review

Glossary

Workplace learning (WPL) is 'learning taking place at work, through work and for work' (1), which for medical professionals occurs during clinical practice. This review focuses on WPL occurring as a result of collaboration with healthcare professionals from the same or from different disciplines, at the same location or across organizational boundaries.

Collaboration happens when multiple health workers from different professional backgrounds work together with patients, families, caregivers and communities to deliver the highest quality of care. It allows health workers to involve any individual whose skills can help to achieve health goals (2). WPL may arise as a result of collaboration between professionals with the same educational background (intraprofessional), but, as a consequence of the rise in interprofessional collaborative practice, increasingly arises from the interaction between professionals from several disciplines working together to care for the same patient (interprofessional) (3, 4). In this review, we focus on understanding WPL arising as a result of both interprofessional and intra-professional collaboration.

Primary healthcare is a discipline that has not been defined uniformly in diverse healthcare systems around the world. In Europe, the term is used to refer to community-based settings rather than hospital settings. General practitioners (family physicians), pharmacists, nurse practitioners and physiotherapists are just some members of this discipline (5). In the United States, the term 'primary healthcare' is used to refer to office-based practices (either family medicine, internal medicine or pediatrics) where the focus is on primary care delivery. In this review, in order to be relevant to practice worldwide, we adopted an inclusive view on primary healthcare and included papers describing primary healthcare as defined in the country where the research was undertaken.

Background

Over the last few decades, rapid demographic and epidemiological transitions (i.e. more older people with chronic multi-morbidities), coupled with increased patient proactivity regarding health-seeking behaviors, have resulted in an increase in the number of tasks and responsibilities being placed upon the shoulders of primary healthcare professionals (5-7). Awareness of these changes has led to a change in both the organization of health care services and the ways in which healthcare professionals deliver care. To this end, current models of healthcare delivery now advocate a shift away from reactive clinical work towards proactive clinical and organizational work (8), and from working individually toward interprofessional collaborative practice (ICP) (9-11).

Professionals are expected to keep pace with these changes within healthcare by means of life-long learning. However, this can be challenging, because after graduation and during the career of all healthcare professionals, patient care seems to be the main focus of all activities and learning is often considered a mere side-effect of practice (12). Furthermore, although professionals are expected to engage in formal continuing medical education sessions to promote learning, these have limited value for physicians in terms of facilitating learning (13, 14). Instead, professionals are expected to learn during clinical practice through collaboration with others in the workplace (15), particularly in primary healthcare, where the need to maintain multiple, diverse relationships makes collaboration an essential aspect of professionals' work.

Workplace learning (WPL) has been broadly defined as 'learning taking place at work, through work and for work' (1). The literature on WPL notes that working and learning are inseparable and fundamental (15-17). Learning through work may result from collaboration between professionals with the same educational background (intraprofessional), but as a consequence of the rise in ICP, often arises from the interaction between professionals from several disciplines working together to care for a patient (interprofessional) (3, 4). During undergraduate medical education, where WPL is accepted as the way students learn, WPL has been studied extensively (18, 19). In such an educational context, it is clear that learning is an important goal of participation in practice. However, this is less obvious during clinical practice after graduation. Theories of WPL have been described in the general learning sciences literature (1, 15, 20-23), including, for example, the 'communities of practice' model proposed by Lave and Wenger (24), which is based on the idea of learning through participation (24-26). For healthcare professionals working and learning after graduation, theories that have a clear social dimension, such as sociocultural learning theories and social cognitive learning theories (27, 28), have particular relevance for understanding WPL. However, there is still a lack of clarity regarding the mechanisms by which WPL through collaboration in primary healthcare settings takes place, and the contextual factors that facilitate or inhibit such learning.

We intend to move the field forwards with regards to WPL in primary healthcare by using realist methodology to investigate what works, for whom, in what circumstances and in what respects (29, 30). By developing a better understanding of primary healthcare professionals' WPL through collaboration, we hope to identify implications for practice and research that will ultimately contribute to the optimization of life-long learning for these healthcare professionals.

Review aims and research questions

This review aims to better understand: i) the process of WPL through collaboration in primary healthcare, and ii) the conditions influencing WPL. The following research questions will be addressed:

- Who learns during WPL through collaboration in primary healthcare?
- When does this learning take place?
- How does this learning occur?
- What is being learned?

Method

Rationale for using realist review

A realist review is an interpretative, theory driven evidence synthesis that uses cross-case comparison to understand, and ideally explain, how and why different outcomes have been observed in a sample of primary studies (29). We chose to use this methodology because WPL results from complex interactions during practice, during which contextual factors trigger mechanisms to generate different outcomes such as professionals' behavior (30). We felt that, in order to understand the process of WPL through collaboration in primary healthcare, the links between context (C), mechanisms (M) and outcomes (O), or C-M-O, needed to be explored. These links could be best explored using realist methodology. We used the Realist Synthesis RAMESES Training Materials to provide practical guidance during the review process (31).

Development of an analytical framework

Typically, one of the first steps of a realist synthesis is to make explicit a program theory for interventions (29). However, we did not feel that one overarching program theory of WPL would suffice or be applicable, given the intrinsic complexity of WPL (32). Instead, we followed the approach taken by Walshe and Luker (33), and developed a broad analytical framework, against which we could extract relevant data to address the review questions.

To do so, we first conducted broad scoping searches to examine the breadth and depth of the broad literature base pertaining to WPL. During a stakeholders meeting (with researchers and faculty members of the department of Family Medicine and Primary Healthcare in Ghent University: general practitioners, nurses, psychologists, and sociologists), we discussed the ways in which practicing healthcare professionals are likely to learn in primary healthcare to elicit implicit assumptions and to ensure that our review focused on practice-relevant issues. Informed by the results of our stakeholders' discussion and the explicit theories identified by our scoping searches, we developed statements on WPL (Box 1), which formed an analytical framework.

Some statements align with well-known learning theories such as socio-cognitive theory, which stresses the importance of role-models (27) (e.g. "demonstrating learning behavior affects facilitators' behavior"). Other statements were more experience-based, proposed by the stakeholders, such as "being a facilitator for others can be learned". Models of workplace learning, such as the one proposed by Tynjälä (1) suggest that prerequisites for WPL may be clustered under the headings 'learner factors' and 'learning contexts'. Learner factors were derived from the idea that motivation and experience are important for learning (34, 35). From the work of Illeris (23), it is well known that how the work is organized and the relations at the workplace are important with respect to the affordances for learning a workplace provides. Therefore, we developed statements with respect to the organization of the workplace (for example whether responsibility is shared), and statements about interpersonal aspects of the workplace that may affect learning. Outcomes of learning were not covered extensively in our statements but were derived through axial – and selective coding of the data. Learning processes, clustered under the heading 'how does learning occur?', were informed by learning theories, such as the theory on reflective practice (36, 37). We saw reflection as an interactive and interactional process (36). Overall we adopted a focus on social learning (theories) in our review, even though the wordings of some statements in our framework appear to reflect an individualistic learning approach.

Box 1: Statements which were used as an analytical framework

a. Every professional learns from others during practice
b. Being a facilitator for others can be learned
c. Willingness to learn influences learning
d. Number of years in practice influences learning
e. Professional expertise influences the effectiveness of the facilitator
f. Awareness of learning needs influences learning
g. Workplace artefacts can be used for learning during practice
h. A shared aim or responsibility of a team influences the learning
i. Workload influences learning
j. Learning during practice can be planned or unplanned

k. Difficult clinical situations have learning potential
l. Learning during clinical practice is guided by actual patients' care needs
m. Interprofessional relationships affect learning through collaboration
n. Interprofessional hierarchy affects learning through collaboration
o. The history of a team working together influences learning during practice
p. Learning during practice is partially implicit
q. Reflection on practice is a major process during learning
r. Participating in practice has a better learning outcome than observing practice by others
s. Every professional facilitates others' learning during practice
t. Demonstrating learning behaviour affects facilitators' behaviour
u. Demonstrating facilitative behaviour affects learners' behaviour
v. During collaboration, new knowledge can be created (besides circulating knowledge between professionals)

Search Strategy

Following several scoping searches, five electronic databases (Pubmed, ERIC, ProQuest, Embase and CINAHL) were searched for relevant published and unpublished literature. These databases were chosen to span literature on health sciences and education, and to be as comprehensive as possible when considered together. Search syntaxes were informed by the research questions and not solely by initially derived learning theories, as it was not clear at that stage of the review process whether all WPL aspects would be covered by the learning theories. Search syntaxes were devised in collaboration with a librarian. Syntax was initially developed and piloted in Pubmed before being modified to fit the requirements of the other databases, and combined synonyms of a combination of relevant components: learning, collaboration and primary healthcare. Since the purpose of the review was to consider WPL, we limited the search to papers published after January 1990. This was based on our initial scoping searches, which showed that most of the literature on WPL started from the nineties. To reduce the number of irrelevant references, the additional filters 'human' and 'language' (English, French, German, Dutch) were used for CINAHL and Embase. For the same reason, additional publication filters ('article', 'article in press', 'conference paper', 'conference review' and 'short survey') were used for Embase. ProQuest was used to search grey literature. Appendix 1 contains full details of the search syntaxes used in this review.

Endnote X7 was used to store all identified references.

Screening and Selection

To achieve maximum reliability, a team meeting (PP, FM, EDG and LM) was first held to clarify the in- and exclusion criteria, jointly practice the abstract selection and discuss screening and selection procedures. Screening and selection was then performed in pairs (PP/FM and EDG/LM). Each pair screened the titles and abstracts of half of the identified citations. The two reviewers of each pair independently evaluated the retrieved citations to determine their relevance to the aims of the review. Paper selection was done in two stages: in the first stage, only the titles and/or abstracts were considered. Potentially eligible papers were obtained in full text and re-screened against inclusion and exclusion criteria in the second stage. At each stage, disagreements were discussed in pairs until obtaining agreement, with an additional researcher conducted where consensus could not be found.

Studies were included if they: a) clearly described the learning processes of healthcare professionals in primary care settings; and b) contained sufficient information to determine the content or processes by which learning took place and/or was assessed. With respect to criterion a), data were considered if they were reported either in the method section (e.g. intervention study) or in the results section (e.g. interview study on experiences and beliefs towards WPL).

Studies were excluded if: a) they exclusively described classroom-based education; b) the learning context and processes were insufficiently described; c) the study population consisted solely of undergraduate and graduate students or hospital healthcare professionals; d) they were written in languages other than English, French, German or Dutch; and/or e) they were reported as dissertations or books if they were not electronically available'.

Analytical Procedure[1]

Relevant study data (e.g. study design, publication year, country) were extracted and tabulated using Microsoft Excel. Data were then coded, extracted and analyzed in accordance with their relevance to the review questions. To aid this, a code tree was first created using the initially formulated statements (see Box 1) as nodes. A team meeting (PP, FM, EDG, LM) was held to discuss a pilot coding of four papers and fine-tune the coding procedure, following which data coding and extraction then took place in pairs (PP/LM and FM/EDG). Each member of each pair independently read and re-read half of the included papers, and coded text fragments within the results or discussion section of the paper, provided that they were potentially relevant to one or more of the statements. These were discussed within each pair, and the resulting data were imported into NVivo 11. Next, data pertaining to each statement were examined. This phase was again executed in pairs: PP/FM and EDG/LM. Each pair discussed and analyzed half of the data pertaining to the statements. C-M-O configurations were identified as follows: pairs interpreted which sections of the data functioned as context or a mechanism for a particular outcome within a paper. The duos checked each others' interpretations of the data and discussed differences. Next, comparisons between different contexts and underlying mechanisms were made, and statements were categorized in accordance with the review questions after careful discussion within the research group ('Who': statement a) - f), 'When': statement g) – o), 'How': statement p) – u), 'What': statement v)). Analysis was facilitated through regular team meetings, during which progress was discussed and reflected upon.

Quality Appraisal

Realist reviews seek to explain complex interventions by drawing together evidence from varied sources to illuminate the richer picture (29). This includes various sources of evidence contributing to the underlying theories being explored and does not rank or exclude studies according to their research design (29, 38). Pawson argues that studies should be assessed against the criteria of '*relevance*' (whether the study addressed the theories considered) and '*rigor*' (whether a particular interference drawn by the original researcher has sufficient weight to make a methodologically credible contribution to the test of a particular intervention). As such, both relevance and rigor are not absolute criteria but dimensions of fitness of the data for the purpose of the review (29). In light of this, we did not use conventional approaches to quality appraisal but instead scrutinized the relevance and rigor of papers prior to inclusion in this review.

Results

In total, the search strategy identified 10,858 citations, resulting in 6,930 citations after de-duplication (Table 1 and Figure 1). Of these, 42 papers were selected for inclusion in this review, the details of which are summarized in Supplementary Table.

Table 1. Bibliographic sources of included citations

Database	Citations found (n)	Duplicates (n)	New citations (n)
Initial Pubmed search	3,744		3,744
Adapted Pubmed search based on ERIC search	4,788	3,744	1,044
ERIC and additional ProQuest databases (20)	844	128	716
Embase	879	21	858
CINAHL	603	35	568
	10,858	**3,928**	**6,930**

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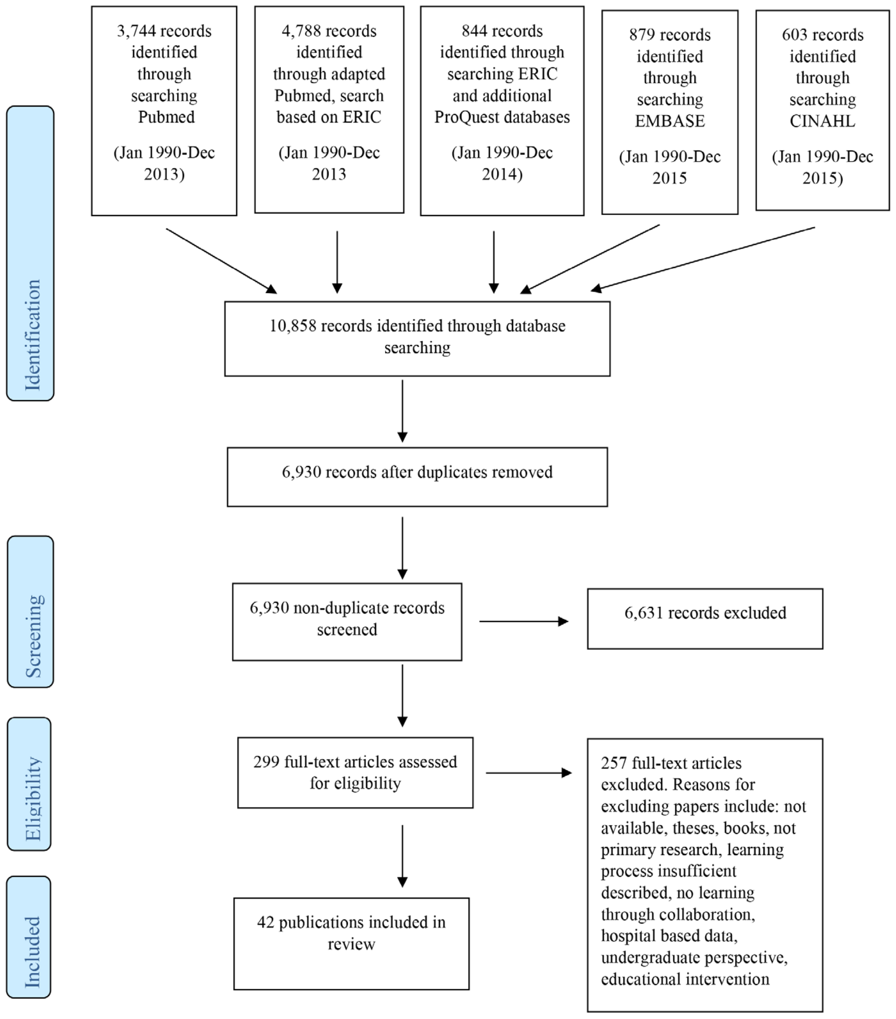
[1] Although the phases of abstract selection and analysis are presented as sequential, they happened overlapping and iterative, as is characteristic for realist reviews29. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review--a new method of systematic review designed for complex policy interventions. Journal of health services research & policy. 2005;10 Suppl 1:21-34.

Figure 1: Flow-chart of included studies



General characteristics of the included studies

Supplementary Table provides a summary of the forty-two included papers. Of these, 23 (55%) came from Europe; nine (21%) from the USA; four from Canada; three from Australia and one each from New Zealand, Mexico and Brazil. The studies varied in design. Twenty-eight studies used a qualitative research design (66%), four studies concerned a project description and qualitative evaluation (9%), four concerned a project description and quantitative evaluation (9%), three studies concerned a project description with both quantitative and qualitative evaluation (7%), one study concerned a project and case exemplar description, one study used action research, one study used both a quantitative and qualitative research design. Thirty-two studies (76%) reported on interprofessional learning, whereas 10 studies (24%) described intra-professional learning through collaboration. Seven papers referred to communities of practices as a learning theory and two papers referred to socio-cognitive learning theories, while the rest of the papers were not explicit about a learning theory but referred to general concepts such as workplace learning (n = 3) or described what activities were performed without mentioning a learning theory.

Main results

Results are presented according to the research questions; throughout, figures are used to illustrate an overview of all C-M-O configurations identified from the included papers.[2] Additional examples of C-M-O configurations from individual papers are presented in Appendix 2.

Who learns during WPL through collaboration in primary healthcare?

Different perspectives were represented in the included studies, and therefore this section presents the perspectives of learners and facilitators[3] separately for clarity.

Perspective of the learners

During WPL in practice, any professional can learn from others, both within the same profession (C) or between different professions (C). This was evident across all forty-two included studies. Ten papers reported on WPL between members of the same profession, of which five (39-43) described the learning of nurses (39) and five (44-48) described learning taking place between specialists and GPs (47). The remaining 32 included papers reported on WPL during interprofessional collaboration, with a broad spectrum of participants: GPs, nurses, midwives, health and social

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[2] In each figure, C-M-O configurations are illustrated using arrows, with references to the relevant included papers in the review. Where no configurations could be made, references pertain to individual C-M-O elements.

[3] Throughout this review, we use the term 'facilitator' to refer to anyone who facilitates another's learning. As such, the facilitator may be a teacher, as well a professional functioning as a role model.

care practitioners, dentists, pharmacists, occupational therapists, physiotherapists, community health workers, receptionists, practice managers and faculty members.

Professionals learn from those who are sufficiently different from themselves (C) to be able to offer additional knowledge and expertise (49-52), yet to whom they are still similar enough (C) to relate (53). Professionals' learning appeared to be influenced by different mechanisms (M), namely: having confidence (54) and recognizing others as experts in their own right (40, 45, 48, 49, 54-57); being open about uncertainties (58, 59); and perceiving partnerships as mutually satisfying (40, 55). Conversely, if others are not seen as experts and there is limited communication or trust in others' expertise (47, 60, 61), learning may be impeded (O). The feeling that some viewpoints supersede others (M) may also impede learning (O) within a traditional hierarchical context (C) (56, 61).

Motivation to learn as an individual or within a group is a necessary mechanism (M) (42, 56, 58, 61-64) to enhance learning (O) (49, 59, 62, 65, 66), which contributes to better service delivery (56, 62, 64, 66). Awareness of practice problems that require solving and belief in the usefulness of certain learning activities contribute to willingness to learn (M) (56, 58, 61, 64). Motivation helps professionals to overcome resistance, build confidence, accept feedback and become more pro-active with respect to asking questions and seeking feedback (58, 61, 64, 67). However, willingness to learn is not sufficient to motivate learners to achieve all of their learning goals; learning goals must also be closely aligned with the context of the learner (C) (45, 48, 61, 63).

People who become aware of their own learning needs (C) (41, 47), others' learning needs or the learning needs of the group (C) (47, 55, 59, 65, 68) are more motivated to learn (46, 56, 59, 61). Awareness of one's learning needs helps professionals to prioritize and to control one's own learning agenda (45, 55, 57, 58). Professionals (e.g. collaborating GPs, nurses, practice managers; pharmacists) learn values, as well as new roles (O), by actually performing tasks (63, 69), particularly those which are closely connected to their daily practice (C) (69). However, the learning process is hampered (O) when professionals are not aware of others' learning needs (C) (45, 47). Learning ends when needs are sufficiently met (47). We found insufficient data about the number of years in practice influencing professionals' WPL **(Figure 2)**.

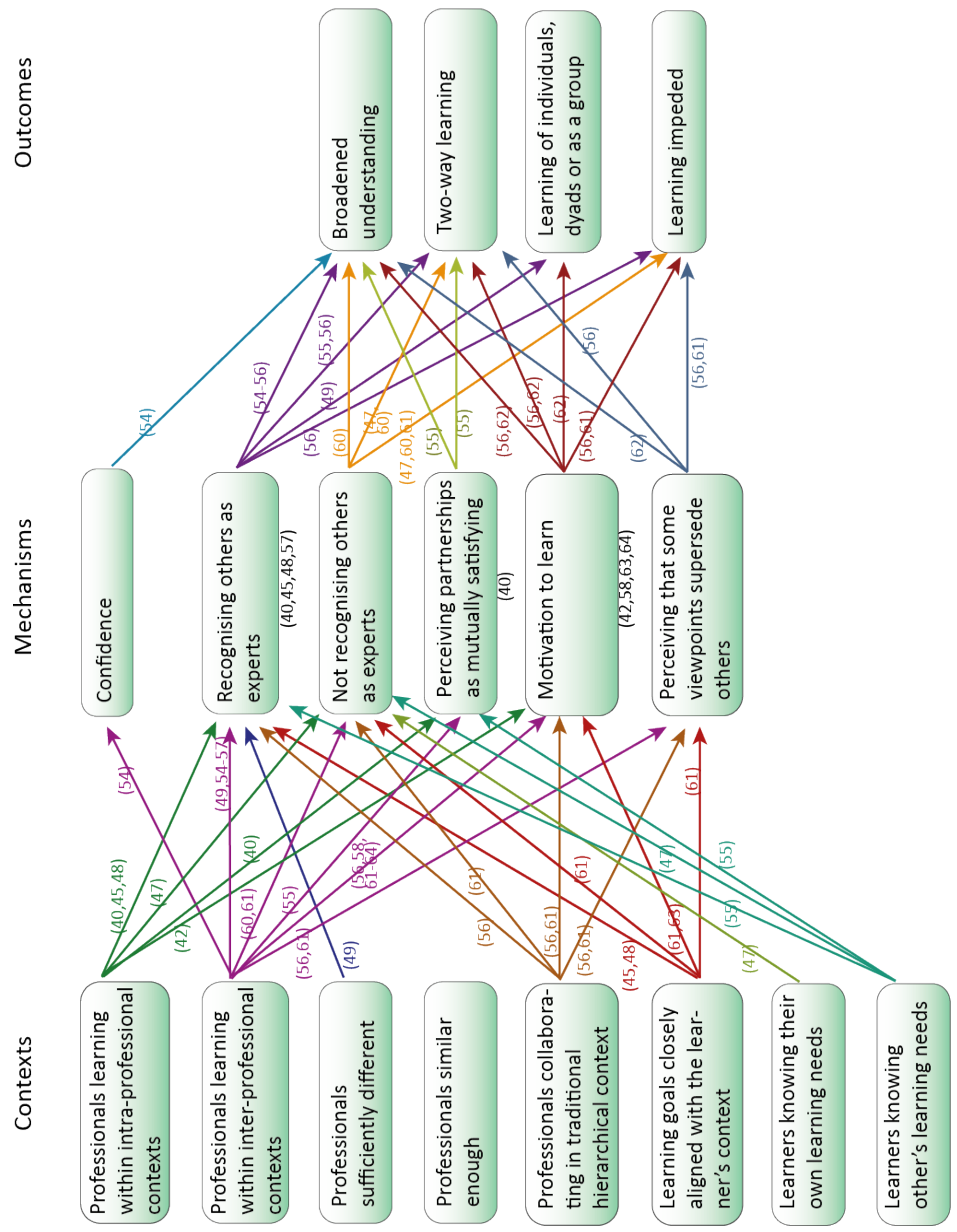

Figure 2. CMO for "Who Learns"- perspective of the learner.

Perspective of the facilitators

Becoming a facilitator for others' learning is, in principle, achievable but does not happen all by itself. Several studies reported on interventions whereby professionals became facilitators for others' learning; namely specialized palliative care nurses facilitating GPs' learning (42), specialists facilitating GPs' and nurses' learning (44, 47), and nurse specialists facilitating each other's learning (65). Facilitating another's learning is a competence which can be learned over time but which requires continuous reflective practice (39, 57, 70), learning by doing (39) and, occasionally, additional formal learning as well (39). Becoming a facilitator can take place: within the context of a learning community (C) with space to exchange ideas and improve skills (67); in an action learning group (C) with other trainee facilitators (65); by observing more experienced colleagues (C), and talking through and deliberating cases with colleagues (C) (49); and/or by being nurtured and guided by supervising leaders (C) (68). Becoming a facilitator changes self-perceptions (O) (70), increases self-confidence (M and O) in the role and stimulates further growth as a facilitator (O) (57, 71, 72). Additionally, becoming more mindful of thought processes can result in long-term changes in one's own clinical practice (O) (70, 71).

Group members' and facilitators' professional expertise or lack thereof, influences the effectiveness of the facilitator, both in a positive and a negative way (54, 62, 70). This influences others' learning in different ways. A novice learner benefits from the support of an experienced clinician and from being exposed to practice under the direction and tutorship of experienced professionals (C) (54, 60, 62, 70). The professional expertise of the facilitator needs to be contextual (48, 70), that is, they must be experienced in treating a specific group of patients (54, 62). In addition, it must be viewed as being relevant to the context of the learner (M) (45). An experienced facilitator is seen as the source for answers to questions and is addressed as such (60). Furthermore, the facilitator needs to be aware of his own expertise (C) (57). However, being seen as too much as an expert, may hinder the learning process because learners might be reluctant to ask questions (M) (42). The support of an experienced facilitator results in continuous learning and the development of clinical and diagnostic skills (O) (54).

The professional role one adopts in a team influences the development and expression of facilitating competencies. A professional who adopts the facilitator role (C) uses their knowledge to advise others (42, 43, 72), sometimes implicitly by vocalizing their own clinical reasoning (42, 43, 70) or by thinking out loud (42, 43, 70). This encourages other team members to get involved in the reflective process, resulting in learning (O). On the contrary, a professional who adopts the role of the 'clinical expert' by contributing expertise in direct patient care to the team may find it more difficult to assimilate knowledge and competencies in facilitation if this is not seen as part of their role (M) (43) **(Figure 3)**.

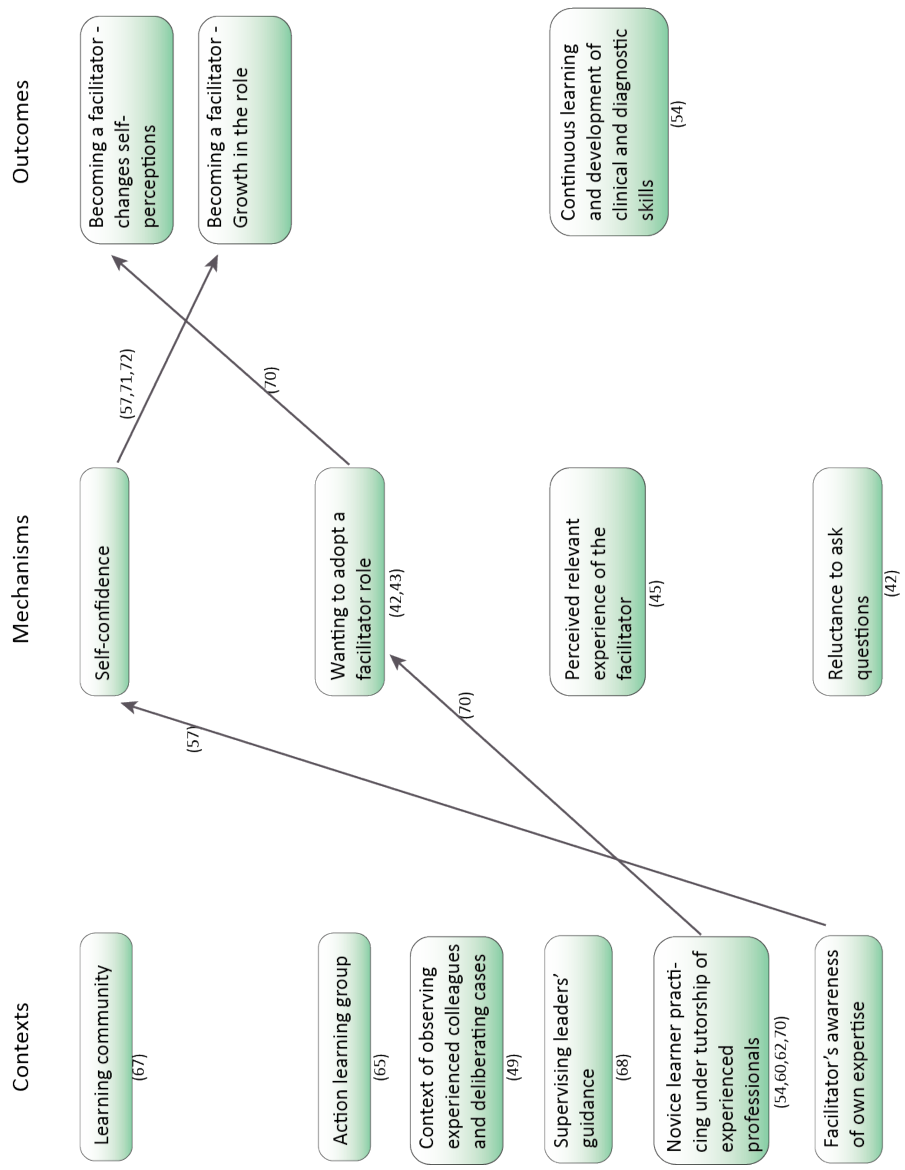

Figure 3. C-M-O for "Who learns" – Perspective of the facilitators.

When does WPL take place?

Broadly, data suggested that both organizational and social factors influence WPL. These are discussed below.

Organizational factors

Learning during practice may be influenced by the way the workplace/work environment is equipped and laid-out (50, 54, 56, 60, 66, 72, 73). For example, workplace artefacts (C), shared aims (C), and marked time (C) all influence WPL (46, 50, 55, 56, 58, 60, 61, 72-75).

Workplace artefacts are diverse tools (for example reflective logs, (flow-) charts, daily care reports, portfolios, protocols, and technological tools) which make learning more shared, contextualized, personalized and patient-centered (O) (46, 50, 54, 56, 60, 73). Artefacts such as protocols (C) can mandate conversations between nurses, GPs and multiple professionals about care (53, 54, 73, 75). The influence of technological tools on learning only occurs in a context where learners have adequate skills (54, 57, 67, 72) and recognize the added value (M) (45, 48, 73). However, even when these conditions are met, change does not occur automatically (although it should be noted that the majority of these studies studied GPs only) (48, 55, 58, 61, 75).

Less tangible aspects of the workplace, such as a shared aim or responsibility (C), also facilitate learning. For example, a feeling of shared responsibility for patient care triggers professionals, whether they are of the same discipline or differing disciplines, to share their knowledge and expertise with others (M) (41, 56). Within the context of a safe learning environment, with shared values and a belief in patient-centered care, recognition of the value of sharing knowledge (M) is an underlying mechanism which facilitates learning (41, 56). Interprofessional learning in itself may also be a shared aim (C) (56) which can enhance the whole team's care quality (48) and can trigger continuous team learning dynamics (O) (65).

In organizations, both planned opportunities (e.g. structured reflection time) and unplanned learning opportunities (C) lead to WPL (47, 54, 61, 62, 64, 68, 73). However, unplanned activities seem to be more motivational (42, 44, 45, 52, 56, 57, 61, 64). For example, seeking out on-the-spot opportunities for peer feedback leads to greater responsiveness to the needs of the moment and facilitates two-way learning (O) (45, 56, 61, 62, 64). Professionals value and appreciate formal opportunities to learn from one another, such as shared visits (48), visits to each other's workplace (45) or comparative feedback (60), but do not prioritize these opportunities over routine clinical activities.

Irrespective of professional discipline, standardizing and regulating learning dynamics is not recommended (56, 61, 64). However, unplanned learning appears to happen less frequently in situations characterized by time constraints and high workloads (C) (56, 73, 76). High workload affects WPL (O) directly (by limiting the time available for time teaching-learning interactions (42), and indirectly (by impacting on professionals' ability and willingness to learn (M) (57, 61, 73, 76)). Reflection on practice experience is time-consuming and even when convinced of the need to learn through reflection, engagement in reflection can be hindered by time constraints (61) and clinical responsibilities (45). Suggested solutions are protected time for team reflection and taking a break from daily practice in order to engage with educational opportunities, such as interprofessional discussions or personal reflection (57, 73, 76).

In the workplace, primary healthcare professionals encounter cases with a high level of complexity at a patient level (such as cultural diversity (64)), a contextual level (practices for which resources are scarce (62, 64)) and/or a professional level (62, 64). All of these complexities provide opportunities for learning. Difficult case management occurs mostly in multidisciplinary and interprofessional collaborations (C), e.g. case discussions in multidisciplinary teams (54, 58, 61, 76), joint patient visits with different professionals (48), joint interprofessional teleconsultations (44). However, intra-professional case discussions, e.g. GP-specialist videoconferencing, also provide opportunities for learning. Besides complex cases, other opportunities for WPL are situations in which patients' care needs lead to consultation. The clinical problems at stake trigger primary healthcare professionals to seek answers as a team (M) (56), through purposeful engagement with other professionals who have the necessary knowledge and expertise (62). This enables them to learn from each other about the specific patient problems at hand. Discussion of patient cases are seen as reciprocal teaching-learning transactions (46, 47, 77). Learning that results from interactions during (difficult) case management is motivated by both professional development outcomes and patient-related outcomes (O) (39, 42, 58, 59, 61, 72, 75). Important driving mechanisms for learning are: the desire to provide high-quality patient care (M) (46, 48, 54, 58, 62); seeking information on professional decisions (M) (59); seeking guidance on professional development (M) (39); and an eagerness to learn (M) (44, 56, 61) or teach (M) (42, 72). Nevertheless, in a study on GPs and specialists, learning was negatively affected (O) by facilitators' reluctance to teach (M) in the presence of patients (C) (44) **(Figure 4)**.

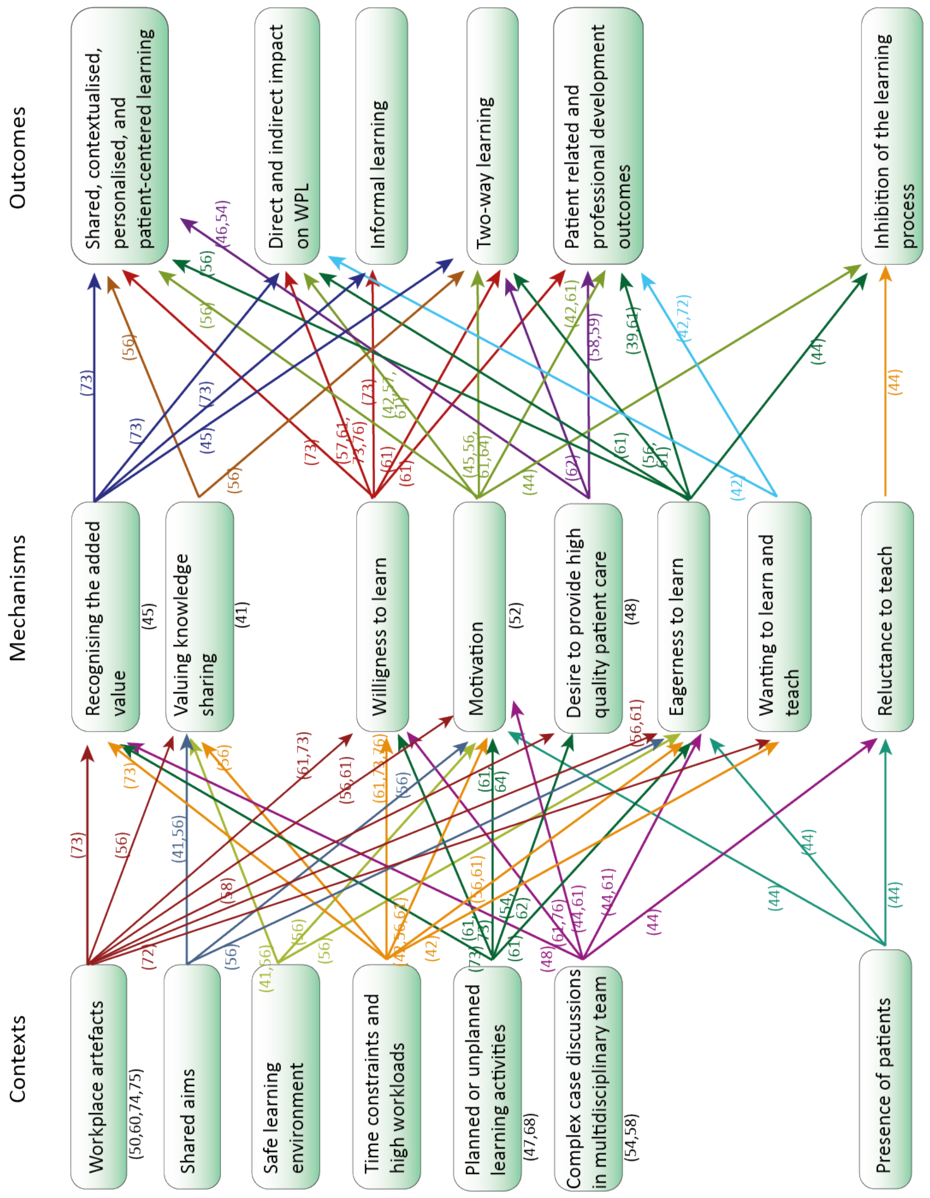

Figure 4. C-M-O for "When" – Organizational factors.

Social factors

The social environment, such as the composion of teams and the nature of relationships at work, influences learning. Strong relationships between healthcare professionals (C) can facilitate learning, because practitioners know one another well (56), feel equivalent (47, 51, 56, 58, 59), trust each other (48, 51, 54, 58, 62, 65), develop relational awareness (in teams) (47, 54, 56, 60), keep lines of (constructive critical) communication open (45, 47, 54, 56, 58, 60) and have a willingness to learn (57). In interprofessional settings, good relationships contribute to a safe environment which supports learning, particularly when collaborating on complex cases (41, 47, 51, 54, 56, 58, 59, 68, 69, 76). Both past positive and past negative experiences of working together in teams (C) or in dyads have an effect on learning during practice. Underlying mechanisms are the intrinsic motivation, anticipation and comfort in knowledge-seeking (M) (47, 55, 56, 58, 61, 73, 75) or the lack of self-direction or considering certain learning approaches to be unsuitable (M) (49, 55, 56, 61). They result in shared (and mostly informal) learning (O) (47, 55, 56, 58, 61, 73, 75), or learning being hindered (O) (47, 55, 56, 58, 61).

Hierarchy between professionals (C) also influences the learning process (45, 58, 60, 78), e.g. in locations where expert palliative care nurses wish to facilitate general practitioners' learning (43). The learning process can be influenced negatively when a physician emphasises or reinforces a perceived hierarchy by adopting a lecture-like style when providing information to advanced practice nurses, resulting in nurses' decreased motivation to learn (M) (60). However, a study about a medical specialist, acting as facilitator for learning in general practice, showed that facilitators could help to overcome barriers to learning (O) associated with hierarchy when the specialist is able to communicate with GPs while "pragmatically relating expert knowledge to clinical experience" (45, 78). Furthermore, getting to know each other in an informal and different context (e.g. a team building weekend) makes it possible to learn from each other afterwards without perceived barriers of authority (O) (56) **(Figure 5)**.

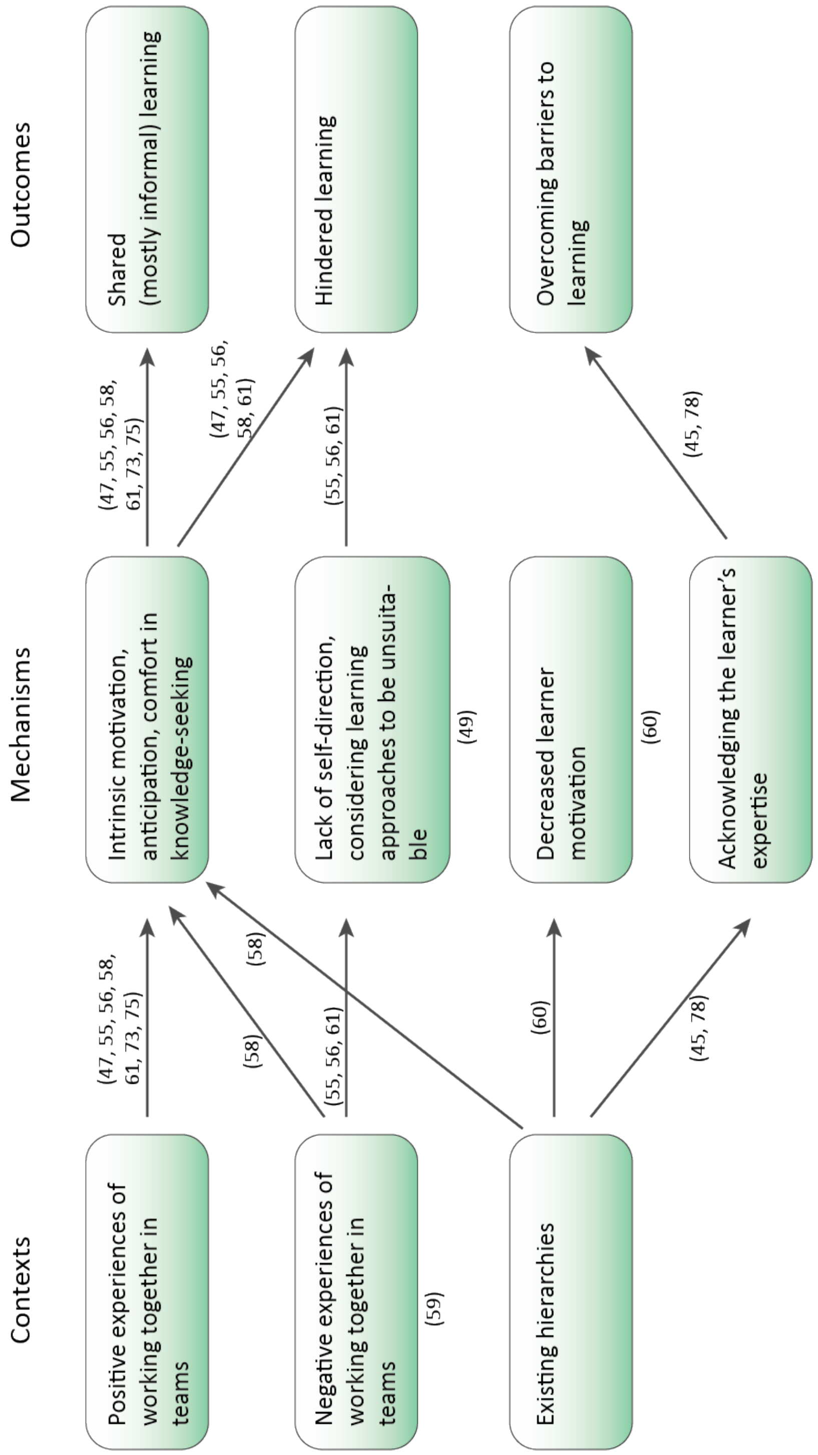

Figure 5. C-M-O for "When" – Social Factors.

How does this learning occur?

Learning takes place via a number of channels, including interactions with other professionals and through others' facilitative behaviours (including discussions, explanations, modelling and facilitating). These are each discussed in turn.

Interactions with other professionals

Learning often occurs without an explicit intention to learn. Sometimes learning occurs but is not explicitly discussed e.g. specialists who explain something to a generalist (C) do not always want their teaching effort noticed (47). Sometimes learning happens unconsciously and implicitly between team members while working together (C) (56). However, even though professionals in primary healthcare engage in implicit learning, not all learning is unintentional. The main driving mechanism for implicit learning is the wish to provide high quality patient care (M) (49, 56, 76, 78) by sharing and discussing tasks (42). Resulting outcomes are collective clinical learning (O) (56) or identification of knowledge gaps through comparing clinical practice and seeking peer data to inform self assessment (O) (58).

A study of interprofessional learning in GP practices, pharmacies and dental practices found that performing an action (C) is very important for the learning outcome; merely observing someone else doing it or getting an explanation on how to do it seems less efficient (56). However, studies carried out in interprofessional settings (GPs and social workers respectively) showed that observation and practice visits of colleagues (C) could be a first step in the learning process (49, 67). The intention and willingness to pass on tacit knowledge (M) is a driving mechanism to allow colleagues to learn by experience (52). Resulting learning outcomes are situated at the level of performing patient care tasks (O) (56), professional development (O) (52) and practice organization (O) (49).

Within the context of experiential learning, reflection on practice (C) is an important part of the learning process. This reflection can be spontaneous or triggered (39, 42, 58), individual or guided or collective (46, 61, 62, 79) and can be related to the task at hand (60) or to one's professional role and identity (61). Driving mechanisms for reflection are the motivation (M) to continue doing it after experiencing the positive effects (61), aiming for quality improvement (M) (79) or explicitly wanting to learn (M) (e.g. primary healthcare professionals learning from local community health workers in a transcultural context) (64) **(Figure 6)**.

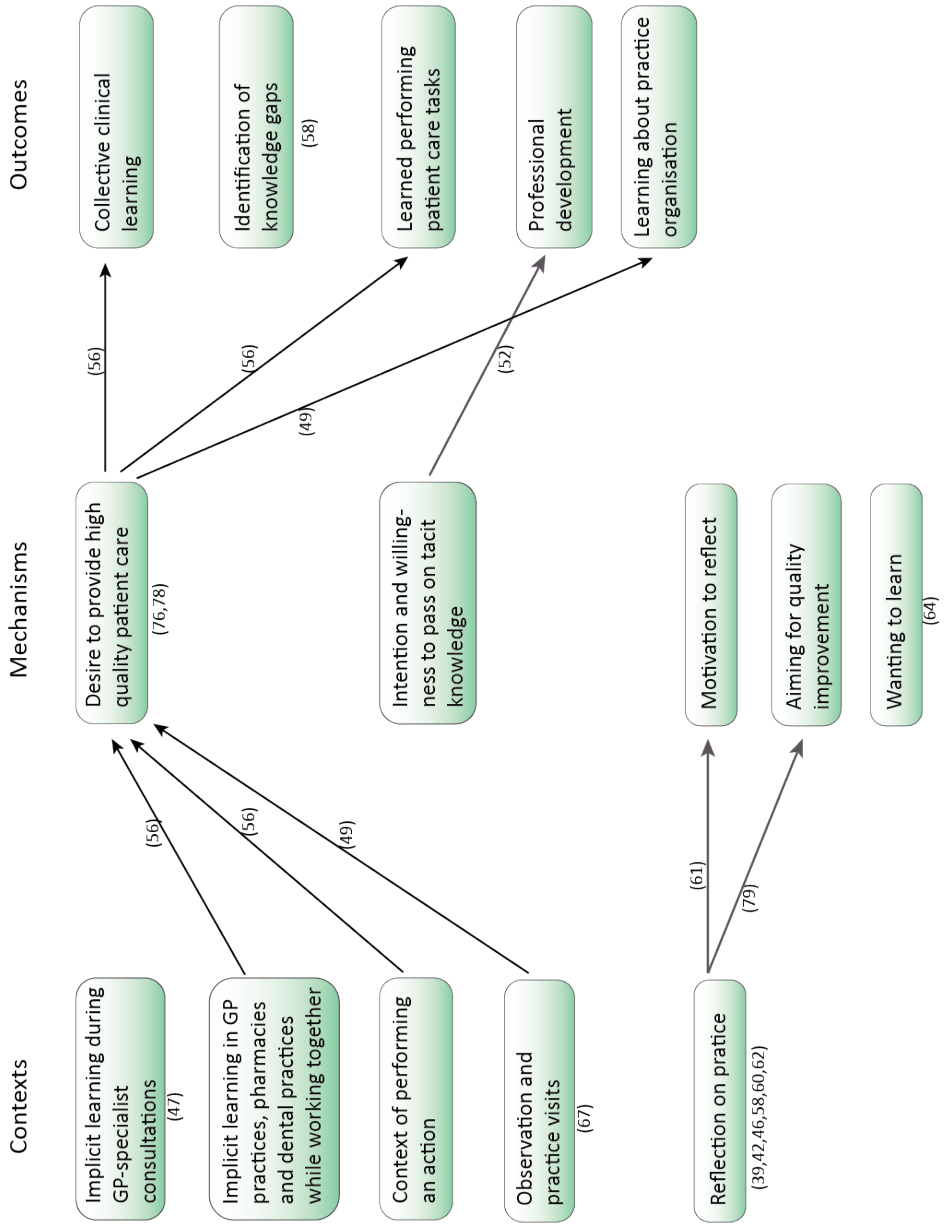

Figure 6. C-M-O for "How" – Interactions with other professionals

Others' facilitative behavior

During daily practice activities, any professional can trigger the learning of another professional. This reciprocal process is also seen in the influence learners have on their facilitators, and vice versa. When learners ask questions in an open and positive manner, request feedback and bring up-to-date knowledge into practice (C) (45, 47, 70, 80), the facilitator learns to recognise opportunities to facilitate others' learning (O) (40, 42), which in turn triggers teaching and facilitative behaviour and challenges them to ensure that their knowledge base is up-to-date (O) (40). The learner's actions motivate the facilitator (M) to continue teaching and facilitating in different ways (42, 57). Regardless of the triggering effect of the learner's learning behavior, some facilitators try to share their knowledge and give advice without being prompted, e.g. in a study with specialized palliative care nurses giving advice to GPs (42, 43). Professionals who exhibit facilitative behavior can also affect the learning behavior of others (39, 61, 75). Facilitators may guide joint reflection, but should do so cautiously and implicitly (C) so as not to harm the interprofessional relationship as learning is secondary to maintaining good collaborative relationships (M) (42).

Reflective learning, implicit learning through participation in practice, modelling and reciprocal learning were all identified in the included studies on primary healthcare professionals. In interprofessional contexts, more studies focused on learning through participation and reciprocal learning, whereas in intraprofessional contexts more studies were done about reflection and modelling through facilitators. Studies examining the context in which GPs learn mostly focused upon learning through participation, compared with studies about the learning of primary healthcare nurses, which focused more on reflection. In both disciplines, modelling through facilitators was seen **(Figure 7)**.

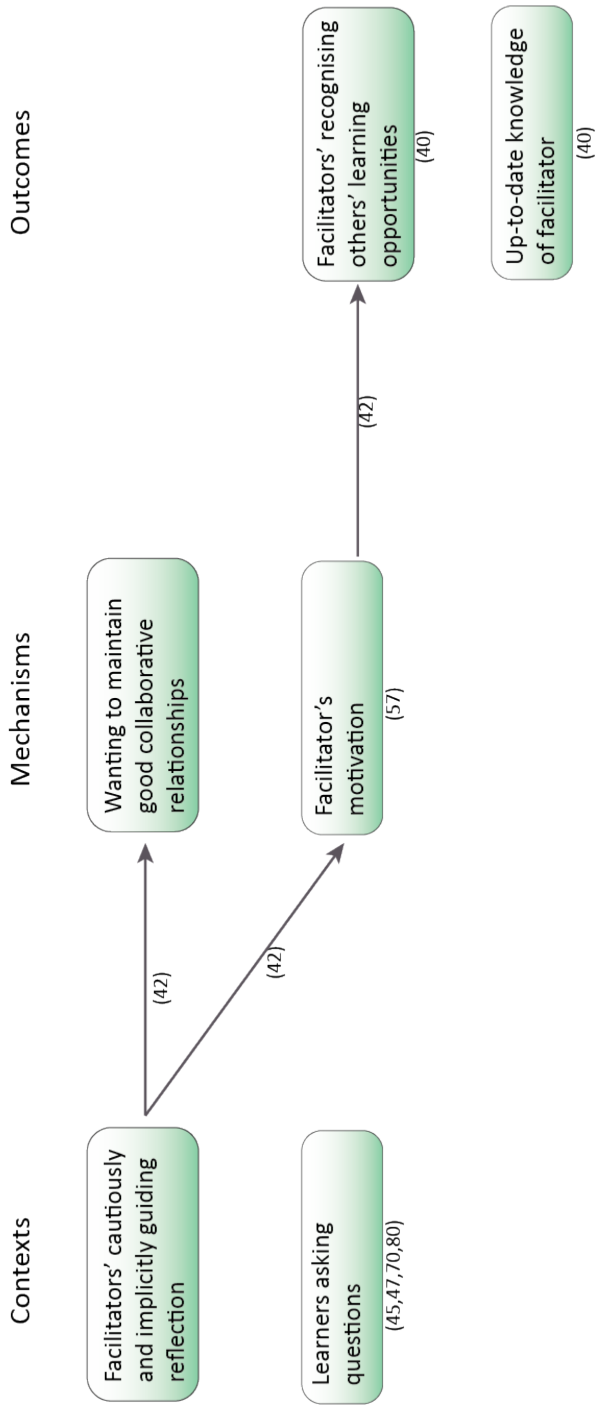

Figure 7. C-M-O for "How": Others' facilitative behavior.

What is being learned?

Outcomes of WPL differed across the 42 included studies, with eight focused specifically on WPL at the team or organization level (48, 53, 56, 66-68, 73, 75). As such, studies primarily reported data pertaining to professionals' individual learning outcomes, with a minority focusing on what was considered relevant for the team.

During collaboration and through interaction with each other, professionals acquire and contextualize knowledge (39, 48, 50, 51, 56, 59, 62, 73, 75). In addition, new attitudes (39, 74), increased self-awareness (41, 56, 61, 63) and new values and roles may develop (69). Professionals develop skills (39, 61, 69) and behavior (61, 74, 75) that they did not previously possess. Learning outcomes are a more realistic and relevant view on medicine (55, 77); growth in clinical care competence (56, 65); refined coping mechanisms (68); evolved interprofessional relationships (48, 55, 76); an impact on the growing learning culture (55); and insight and awareness of one's own and others' professional possibilities (55, 76).

Regular patient care and difficult case management (C) result in diverse learning outcomes, centered on both patient-related and professional development outcomes. They relate to: acquisition of clinical knowledge (47, 54, 56, 72), and a broader understanding of the clinical problem (46, 54, 59); contextualization of generic knowledge (62), acquisition of cultural knowledge and cultural proficiency (64) creativity in problem solving (61, 64); the development of strategies to integrate knowledge into the work setting (62); reciprocal learning of each other's skills (48); development of skills for reflective practice (58, 61); improved patient care (58); individual professional growth (39, 76); enhanced patient-centeredness (77); changed attitudes and beliefs towards diseases (77); and clarification of professional roles.

Learning outcomes are evident not only with respect to independent performance of patient care tasks (56) but also at the level of non-patient related tasks, such as practice organization or chairing a meeting (49). Additional outcomes may include transmission of tacit knowledge and professional skills (e.g. professional flexibility and creativity in unclear situations) (52), and increased insight into one's own and others' personal values and norms (61). Reflective practice can make it easier for professionals to understand the moral dimensions of care, which can benefit both individual practitioners and the team (61).

Facilitating the learning of others also results in enjoyment from being an expert (56); role transition from expert to facilitator (43, 61); acquisition of clinical or cultural-specific knowledge (51, 54, 56, 58, 62) which can also be a reciprocal dynamic (47, 55); and improved self-confidence (62). Other outcomes relevant for the team are professional hierarchy being replaced by knowledge hierarchy (54) and acquisition of team building skills (55). Demonstrating facilitative behavior may lead to group members' passion for work or learning (68) or to the realization that one's own judgment on a case needs to be postponed in order to view the problem from different perspectives (61). This leads to the acquisition, sharing and development of knowledge (75), of ways to communicate guidelines' content (63), of a more exploratory attitude (61) and/or of reflection as a skill (39).

Discussion

This review aimed to better understand the process of WPL through collaboration in primary healthcare and the conditions influencing such WPL. In this discussion, we first discuss the results of the review. We then reflect on whether our findings fit with theories of social (workplace) learning mentioned in the introduction and compare them with other theoretical frameworks. Finally, we then discuss the strengths and limitations of the review itself and outline gaps in the current evidence base, before concluding by summarizing the key findings of this review.

Who learns during WPL through collaboration in primary healthcare?

In our review, we were interested in WPL across a broad range of primary healthcare professionals. Participants in the included studies were mainly GPs and nurses, working in intra-professional or interprofessional settings; studies investigating WPL of pharmacists or dentists were underrepresented. Interestingly, we did not find large differences in what would be considered to be successful learning approaches or beneficial aspects of the learning environment for GPs and nurses. What we did find, however, is that learners who are willing to learn, and who are aware of the importance of finding solutions to practice problems and relevance of the subject matter, are strongly motivated to engage in learning. This finding is not surprising, given the prevalence of motivation theories throughout the WPL literature (1, 23) e.g. self-determination theory (81).

What is surprising, however, is that only three of the included studies reported team-level analyses. Needs and wants, essential for experiential learning from daily practice, are often viewed as something that belongs to an individual learner (35) but seems to be equally relevant for understanding WPL at the group level (34). Unfortunately, given the paucity of team-level data, we were unable to draw conclusions about the influence of motivation of teams; future research is needed to address this gap and shed further light on the process of WPL through collaboration.

In addition to needs and wants, we also identified the importance of being aware of one another's expertise when it comes to WPL through collaboration. This phenomena was mostly observed in papers focused on interprofessional settings, and fits with Transactive Memory Theory, which posits that 'knowing who knows what' is essential for professional practice as it diminishes the need for every professional to have all facts in their own memory (82). As such, communicating each other's expertise in an explicit way may enhance both patient care and interprofessional WPL.

When does this learning take place?

Collectively, data from the included studies indicate that learning takes place when conditions provide opportunities for learning which aligns with the work by Illeris about workplace learning (25). When resources ('artefacts') are available to professionals, they influence WPL. Artefacts include technical resources (such as electronic patient records or technical devices to facilitate video communication between professionals in different locations) and practical resources (such as lay-out of the work environment or days-out). Artefacts act as boundary objects, "that allow connection between different perspectives among communities to achieve a common goal" (83). Consideration of theories of the hybrid or extended mind (84) and other socio-material learning theories (85) may help us to better understand the potential role of artefacts. Interestingly, however, these theories were not referenced in the papers included in our review, even though artefacts were studied frequently.

When practices are very busy, professionals' WPL is influenced by this high workload. We identified 14 studies that explicitly referred to workload; the remaining 28 studies did not mention any influence of workload. However, the relationship between learning and workload is complex, not least because workload is often seen a subjective rather than objective entity (86). When workload is low, with a small number of complex interesting patient cases, WPL through collaboration does not occur. When workload is too high, no room for constructive critical communication remains, thus hindering WPL.

Interprofessional learning is of increasing importance within the medical domain (87, 88). In our review, 32 studies focused on interprofessional learning of primary healthcare professionals, often referring to communities of practice as a relevant learning theory. We expect that, in healthcare, the idea of novices who become experts through participation is appealing because learning through socialization is common. Not mentioned in the included studies was Cultural Historic Activity Theory (89), which might have been a useful framework for understanding learning arising from collaboration between professionals from different professions and different organizations. In Cultural Historic Activity Theory, the wish to reach a specific goal is essential for learning to take place (89), which fits with our finding that a shared aim is important, but realizing shared aims in an interprofessional setting does not always emerge naturally (90). Shared responsibility for patient care reflects the importance of authentic learning environments (28, 91, 92).

Within primary healthcare, the team's history and past experiences was found to influence the quality of team relationships and, as such, their WPL. The history of a team is a concept that might explain successful learning thanks to shared mental models that people have developed in time while working together (93). This might also help to clarify unsuccessful learning, particularly if conflicts have arisen during the team's history that negatively affect learning (94). Conversely, a sense of hierarchy can hinder WPL, as it can impede learners' willingness to ask questions or to seek feedback. Existing (perceived) hierarchy can also form a barrier to providing feedback or to critical questioning. In the included studies, hierarchy was reported upon, yet at the same time measures were proposed to overcome this barrier, such as acknowledgement of others' expertise and awareness of others' specific contexts. Although the literature describes communication approaches to overcome communication difficulties in hierarchical situations (95), the role of acknowledging expertise has –to our knowledge- not been studied in detail.

How does this learning occur?

Practitioners can learn by sharing activities or working in collaboration, or by observing each other. The finding that healthcare professionals learn through participation during every-day working aligns with sociocultural learning theories, in which learning is posited to occur during regular interaction, for example in learning communities (28). An explicit reference to theory about learning communities was found in several studies, while in other studies learning theories were often mentioned much more implicitly by, for example, primarily describing the value of group discussion for learning (44, 46, 48, 54, 58, 61, 76) . In such discussions, it is important to be able to ask questions and seek feedback, and value the importance of being critical in a constructive and reflective manner (96, 97). We also found that planned formal learning seem to contribute to (opportunities for) informal learning. Studies emphasized the importance of 'finding a middle ground between formal and informal learning; that is, not solely relying on informal learning opportunities (98, 99).

Not all of our findings match a conceptualization of learning as an interactional process that occurs while participating in practice. The findings that professionals can learn through observation of others is more in line with Bandura's social cognitive learning theory (100), and with the notion of transformative learning (37). Social cognitive theory (27) stresses the importance of observation, imitation and modelling of other professionals when it comes to learning new skills or behaviors. Transformative learning in this context, emphasizes the role of learning from a formal, structured mentoring arrangement, and conceptualizes mentoring as a two-way learning process (100). Collectively, social cognitive theory and transformative learning put less emphasis on doing things together and discussing with one another; instead, observation of people who are perceived as role models and explicit instruction are seen as more important.

Practitioners can also learn through reflection. In our analytical framework, we drew from contemporary, social conceptualizations of reflection when producing our statement on reflection. The majority of theories of reflection focus on individual learning, often as a result of formal learning activities (36). In recent years the idea of reflection as an individualistic –and mainly mental- activity has been challenged. For example, critically reflective work behavior is now considered to be interactive, and something which is shown in the discourse between professionals (97, 101). In the studies included in our review, the value of reflective conversations next to individual reflection was confirmed.

What is being learned?

Studies reported varied outcomes. Improvements in care provision appeared to be both an important and primary motivator for learning and an intended outcome of learning, thus fitting with recent data from trainee doctors. Indeed, it seems that a major advantage of WPL is that new knowledge is contextualized by adapting it to their local context (102). However, it is important to note that as most studies were qualitative and not longitudinal, evidence about improved care being an actual outcome was missing. Furthermore, the majority of included studies indicated that their interventions were successful, that outcomes were reached, or that conditions were beneficial, leading us to suspect evidence of publication bias (i.e. bias occurring as a result of positive findings being more easily publishable than negative findings (103)).

Reflections

In the previous section, we compared our findings with existing learning theories. Most of our findings could be situated in theories on workplace learning of other (healthcare) professionals. The starting point for this review was that professionals within primary healthcare have to engage in life-long learning and that WPL through collaboration might be an essential part of life-long learning. When reflecting on our findings, we found it remarkable that patient care played such a central role as a motivator for learning, while at the same time learning through collaboration was often not recognized as real learning. In sum, the findings of our review fit with general WPL literature stating that working and learning are inseparable and fundamental. Patient care appears to be a primary motivator for learning, but greater attention ought to be paid to the potential learning opportunities arising from ICP in order to optimize professionals' WPL.

Implications for practice

The stakeholders with a primary interest in this research are primary healthcare professionals, WPL researchers, managers and educators in primary healthcare. The findings of this review have the following implications for these stakeholders.

Primary healthcare professionals

- Professionals are often unaware that they learn through collaboration. As in undergraduate medical education (104), learning during work in professional life should be made explicit and framed as being 'inherent in the practice of patient care' (p.667). As such, developing the competency to learn while caring may diminish the need to organize formal training in situations with a high workload.
- Healthcare professionals do not exclusively identify themselves either as learners or as facilitators. Any professional can both learn and facilitate others' learning. Making this more explicit may help to improve WPL through collaboration.
- Acknowledgement of others' expertise and awareness of others' specific contexts, especially when hierarchy is involved, reduces barriers to learning.
- Unplanned learning activities provide more opportunities for 'just-in-time' learning and for non-hierarchical collaboration than planned learning sessions. The former are perceived as being more motivational.

Professionals who act as managers in primary healthcare

- Policy makers and managers working in primary care should ensure that protected time for learning is available. This time is needed to reflect upon practice, to customize oneself with the new ways of interaction and to develop new habits within clinical practice.
- The layout of the workplace affects learning. Managers need to organize the workplace layout to enhance communication in the workplace. Facilitating casual encounters between different professionals provides opportunities to ask for feedback and to exchange ideas. In addition, workplace layout could promote conversations around artefacts (such as electronic patient records), when they are co-located and accessible to multiple professionals simultaneously. Managers should explicitly state that artefacts such as patient records are not only useful for recording and accounting, but can play a role in learning conversations as well.

Primary healthcare educators

- (Post)-graduate educators should help learners to become aware that all kind of situations provide affordances for learning (i.e. learners do not just learn through lectures delivered outside of the workplace but learn when asking questions, discussing and asking feedback during the work to be done). Curricula should emphasize the importance of informally asking questions and requesting feedback.
- Knowing and valuing the expertise of others is essential for learning, yet this is more difficult in interprofessional settings. Interprofessional modules, focusing on collaboration, should therefore be included in undergraduate education.

WPL researchers

- The studies in our review refer to a limited subset of learning theories. Relying on a wider range of social learning theories as theoretical framework for future studies would improve the knowledge base on WPL through collaboration. Additionally, as most of the selected studies had individuals as their unit of analysis, we recommend that researchers focus on supplementing current research with studies on organizational learning in primary healthcare.
- Although barriers for workplace learning in general have been described, surprisingly, findings of the intervention studies in our review were most often positive. Researchers should build on this observation and focus on clarifying barriers to WPL

Strengths and Limitations

This review has a number of strengths. For example, we included only papers that provided a sufficiently detailed description of WPL, so as to allow for greater theoretical understanding of WPL in primary care. Furthermore, we ensured that all papers were independently screened, selected, assessed and coded by two researchers from different professional backgrounds, thus strengthening the rigour of our review. Also, we used the RAMESES training materials for realist synthesis (31) and the RAMESES Publications Standards (105) to provide practical guidance throughout the review and the writing process. However, it is pertinent to also consider the limitations of this review. First, we started with a broad spectrum of statements. This approach precluded us from presenting a fine-grained overview of CMOs for each and every paper supporting each statement separately. Although this may be seen as a limitation, we believe that our review provides an excellent starting point for studies designed to explore some of the complex (causal) chains of change contained within our statements. Second, we did not refine the focus of our review mid-way, as is common in realist synthesis, because we did not think it appropriate to exclude aspects of our analytical framework at this stage. Instead, we chose to broadly explore each statement, as we felt that a broad overview of all the different learning processes that occur within primary care would provide the most value as present. Third, updating our search during the review was not considered feasible. This limitation is unlikely to have substantively impacted on the findings of this review, but should be borne in mind, particularly given that a number of studies pertaining to interprofessional learning have been published since our search was conducted. Fourth, as is customary in a realist review (29), we focused on the rigour and relevance and did not assess the quality of each and every paper included in our review. Furthermore, most studies were qualitative papers, which makes our conclusions less generalizable. However, we included papers that describe WPL in sufficient detail, and, during our process of including and excluding papers, it became clear that papers using quantitative research methodologies were less likely to describe the learning process in any detail (i.e. one of the inclusion criteria).

Conclusion

The results of this review indicate that interprofessional WPL through collaboration in primary healthcare is multifaceted. When situated within the context of existing social learning theories, our findings indicate that WPL does indeed take place when primary care professionals work together, within the same profession or with professionals from other disciplines, and that the mechanisms involved do not differ in major ways from those known from studies about other professionals, both inside and outside healthcare. As such, WPL should be considered to be an essential part of the continuing professional development continuum during lifelong practice. The findings of this review have a number of implications for practice. Future research should focus on clarifying and exploring the processes identified in this review further so as to optimize WPL and, ultimately, patient care.

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Conflict of interest statement

No conflict of interest to declare for any member of the review group.

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Supplementary table: Included papers

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Author, date, country	Title paper	Research question/aim	Research approach/design	Participants	Conclusion	Learning theory and/or learning method used
Allan, 2005, UK (55)	Developing an interprofessional learning culture in primary care	To evaluate a project to develop an interprofessional learning culture within a primary care setting. To situates the findings and the experiences of the project in the context of the policies and literature on interprofessional learning	Combination of semi-structured and two focus group interviews with nurses and receptionists and process evaluation methodology with documentary data and secondary analysis.	Four members of the steering group and the project manager, six general practitioners, five nurses 14 receptionists	There is a need to recognize responsibility for one's own learning as individuals as well as learning as teams of work colleagues if interprofessional learning is to be successful. Even when these pre-requisites of interprofessional learning are agreed and acknowledged openly in the workplace, participants in the development of a learning culture need to recognize that there are structural controls which influence and constrain such developments which are external to participants and beyond their immediate control.	Work-based learning, interprofessional learning, lif long learning
Arora S, 2010, USA (72)	Expanding Access to Hepatitis C Virus Treatment—Extension for Community Healthcare Outcomes (ECHO) Project:	To desciribe the ECHO model and its application in HCV care in New Mexico in detail and to present data from initial surveys of the providers that have participated in the program	Observation of ECHO weekly clinics and database of ECHO clinic participation and patient presentation by clinical provider + surveys	255 partner teams participating in ECHO clinics, expert interdisciplinary specialists and community-based primary care providers	ECHO expands access to best practice care for underserved populations, builds communities of practice to enhance professional development and satisfaction of primary care clinicians, and expands sustainable capacity for care by building local centers of excellence	Bandura's social cognitive theory, Vygotsky's situated learning theory, community c practice theory

		knowledge and self-efficacy on a variety of diseases not usually considered within their scope of practice. As a result, these providers can deliver best-practice care for complex health conditions in federally qualified health centers and other community-based sites where this specialty care was previously unavailable.				
Beam RJ, 2010, USA (39)	Reflective Practice Enhances Public Health Nurse Implementation of Nurse-Family Partnership	To describe the development and integration of reflective practice as a foundational concept of public health nursing practice in the Nurse-Family Partnership (NFP)	Description of the NFP program model, exemplars from the experience of NFP nursing supervisors	nurse supervisors and nurse home visitors	Comments from NFP nurses and supervisors are cited to suggest how the regular use of reflective practice has the potential to improve implementation of the program with families, the authors further propose that research is needed to more rigorously examine the benefits that reflective practice may have on the quality of program implementation, family outcomes and the retention of nurses working in the NFP program	Reflective learning cycle by Gibbs
Brown, 2011, USA (53)	The Phenomenon of Collaboration: A Phenomenologic Study of Collaboration between Family Medicine and Obstetrics and Gynecology Departments at an Academic Medical Center	To explore the essential invariant elements of collaboration between the departments of obstetrics and gynecology (OB/GYN) and family medicine (FM) at an academic medical center.	Phenomenologic methods, interviews	Departmental leaders and senior faculty in key positions residents of both departments from intern through senior level and nurses on Labor and Delivery L&D. Sample size was 33, consisting of six family medicine (FM) faculty, seven obstetrics and gynecology (OB) faculty, six FM residents, seven OB Residents and seven nurses	Key collaborative structures included a shared vision and commitment by leaders, rigorous quality improvement, clear delineation of roles with built-in flexibility, ongoing commitment to formal and informal communication channels and conflict resolution, relationship development grounded in respect and responsiveness, and shared training in a supportive learning environment with legitimate participation fostering skill development.	Mutual learning, lea practice

Bunniss S, 2008, UK (56)	‘The unknown becomes the known’: collective learning and change in primary care teams	To explore how collective learning and change happen in primary care teams and how the process varies across the disciplines of general medical practice, pharmacy and dentistry	Qualitative research design, observational visits of 10 primary care teams and 38 semi-structured interviews	4 general medical practices, 3 pharmacies, 3 dental practices	Teams share their knowledge because they believe it has value, not because they are driven by external incentives or are monitored. This challenges the assumption that, to be effective, interprofessional learning should be externally managed. As health care develops, it will become increasingly important to consider how to support the internal learning processes of care teams as they navigate complex organisational changes and the shared learning experiences that characterise those changes. Those who support learning and development within the NHS should therefore focus on how relational processes, as well as educational content, contribute to a team's collective learning capability and the quality of care its members provide	Informal collective learning - practice-based learning
Burgess J, 2011, Canada (68)	Community of Practice: A Nurse Practitioner Collaborative Model	To report on the CoP and the five characteristics describing this collaborative CoP model, including sanctioned social structure, knowledge exchange network, practice discovery and innovation, generating meaning and value, and power sharing for strategic improvement.	Participatory action research approach	Nurse practitioners	A collaborative CoP model addresses the internal interests and needs of participating members while attending to the external concerns of the organization, and thus contributes to healthcare improvement.	Community of practice theory
Carr ECJ, 2012, UK (77)	Improving services for back pain: putting the patient at the centre of interprofessional education	To explore and capture the processes and experiences of the practice teams and patients in the interprofessional learning within a quality improvement project	Eight half-day IPE workshop on quality improvement of back pain management. Evaluation through focus groups with practice teams, before and after the workshops	44 practice staff of nine general practice teams and 11 patients	True engagement with patients and their inclusion in IPE, in ways that reinforced practice-based learning, was a catalyst for the sort of behavioural change, which leads to improved patient outcomes. Opportunities for patients to share their personal stories of back pain appeared to improve communication and in particular listening. Their presence challenged the unhelpful medical model in favour of a more integrative bio-psychosocial one.	Interprofessional education, practice-based learning
Coleman K, 2014, USA (67)	Unlocking the Black Box - Supporting Practices to Become Patient-centered Medical Homes	To describe the multimodal technical assistance approach used by the SNMHI (Safety Net Medical Home Initiative) and the participating practices' assessment of its value and helpfulness in supporting their transformation	Multimodal technical assistance approach. Practice survey about the perceived value of technical assistance overall and by component	Primary care associations, clinical membership organizations skilled in quality improvement and stakeholder engagement who partnered with 10-15 primary care	There is an important role for both local and national organizations to provide non-duplicative, mutually reinforcing support for primary care transformation. How (in-person, between peers) and by whom technical assistance is provided may be important to consider	Community of practice theory

				practices in their region		
Collins F, 2012, UK (49)	Relationships, learning and team working in UK services for children	To report on education, health, and social care practitioners' experiences of working across traditional boundaries and establishing new relationships in the context of the Common Assessment Framework (CAF) in UK children's services	Qualitative research design, semi-structured interviews	20 education, health and social care practitioners, and operational managers	Owing to infrastructure and resource issuses the move to co-located, integrated teams has occurred relatively recently within many local authorities. This research prioritises the perspective of the practitioner generating further understanding of what it means to work collaboratively; it highlights how relationships between agencies and practitioner groups have been subjected to tensions during a period of transition holding potential to impact upon service delivery. Change in the composition and leadership of teams in multi-contextual settings has also provided stimulus for new relationships, learning and ways of working. The research suggests that participation in the multi-agency forums associated with the CAF increased practitioners' individual and collective skills, facilitating information sharing and joint decision making about how best to meet a child's needs.	Experiential learning
de Araujo, 2013, Brazil (80)	Primary Health Care workers' view on the presence of nursing students	To explore the view of the workers at a basic health unit on the presence of nursing students at the service	Semi-structured interviews (18)	18 workers of the Basic Health Unit who related to nursing students in their work schedules: six community health agents (CHA), nine nursing assistants, one nurse technician and two nurses.	There is a multiplicity of views that vary according to the professional category, the place occupied in the social and technical division of work and the year of education of the student. Views that prevailed were the ones in which students help with work, update the worker's knowledge, but slow the care. It was found that the presence of students questions the manner of care in which minimal listening, fragmentation and a focus on procedures prevails. There was a predominance of teaching-learning concepts, such as passing information hierarchically among sectors and agents of this process. The process of formation of these workers, students themselves, with a predominance of a discipline teaching a discipline, fragmented and hierarchical, although with advances, such as the early immersion in health services. The approach between university and primary healthcare services exposes tensions which, collectively analyzed, can engender new ways of caring, teaching and learning.	Interprofessional learning

Guirguis-Younger M, 2009, Canada (62)	Learning and Knowledge-Integration Strategies of Nurses and Client Care Workers Serving Homeless Persons	To explore the learning and knowledge-integration strategies used by nurses and client care workers employed by health-care organizations that target homeless persons	Qualitative research design, semi-structured interviews	4 registered nurses, 1 registered practical nurse, 3 client care workers	Knowledge exchange has the potential to improve care by accounting for the diverse needs and experiences of homeless persons and to equip health-care workers with the skills they need to face complex challenges and achieve improved outcomes	Community of practice theory
Halcomb EJ, 2012, Australia (40)	Practice nurses experiences of mentoring undergraduate nursing students in Australian general practice	To explore the experiences of Practice Nurses when supervising undergraduate nursing students	Qualitative research design	12 Practice nurses who had supervised undergraduate nursing students on clinical placement in a general practice setting	It is clear that providing clinical placement opportunities in general practice benefits undergraduate nursing students in terms of providing them with additional opportunities for skills consolidation and alternative employment options. Further, supervising these students was considered by Practice Nurses as being beneficial for not only their own personal development but also their development of the Practice Nurse role.	Mentoring, reciprocity of learning
Hjalmarson , 2011, Sweden (74)	Forming a learning culture to promote fracture prevention activities	To explore interprofessional experiences of incorporating fracture prevention activities in clinical practice inspired by an empowerment approach.	Combination of focus groups interviews (8) and in depth interviews(2) and a workshop.	19 professionals participated: four nurses, five occupational therapists, eight physiotherapists and two physicians from primary health care and orthopedic departments.	Learning processes through patient-centred interaction and face-to-face collaboration based on the professionals' owns requests and experiences are one important motivator to promote fracture prevention activities in everyday-work. These learning processes became a driving force for the joint efforts to manage fracture prevention in clinical practice, here identified as breaking professional patterns, creating empowering meetings, making the preventive links visible and constructing a sense-of-prevention community. The inspiration of empowerment as a health-enhancing strategy for patients may also generate an empowered organisational process including individual development and improved community competence. Such a bottom-up approach might be an essential key to managing the implementation of fracture prevention.	Learning processes through patient-centred interaction and face-to-face collaboration based on the professionals' owns requests and experiences, empowerment

Hoare, 2013, New Zealand (57)	New graduate nurses as knowledge brokers in general practice in New Zealand: a constructivist grounded theory	To investigate practice nurses' use of information	Combination of initial ethnographic fieldwork and there after interviews with practice nurses	Etnographic fieldwork in the practice of four general practitioners and 10 practice nurses from different practices	Experienced practice nurses role modelled clinical skills to new graduate nurses. Unexpectedly, new graduate nurses were unconscious experts at sourcing information and role modelled this skill to experienced practice nurses. Once this attribute was acknowledged by the experienced practice nurse, mutual learning occurred that enabled both groups of nurses to become better practitioners. Graduate nurses of the millennial generation were identified as a resource for experienced practice nurses who belong to the baby boomer generation and generation X.	Supportive multidiscipl learning, reciprocal rol modelling
Humphreys J, 2013, UK (63)	A collaborative project to improve identification and management of patients with chronic kidney disease in a primary care setting in Greater	To reduce the difference between expected and recorded prevalence of chronic kidney disease by 50%, to treat 75%of chronic kidney disease patients to relevant NICE blood pressure targets	A 12 -month improvement collaborative supported by an evidence-informed implementation framework and financial incentives.	19 general practices from four primary care trusts.	Evidence-based improvement can be implemented in practice for chronic disease management. A collaborative approach has been succesful in enabling teams to test and apply changes to identify patients and improve care. The model has proved to be more succesful for some practices, suggesting a need to develop more context-sensitive approaches to implementation	Shared learning, learni doing
					that influence the succes of the collaborative	
Jones, 2003, UK (41)	Some benefits experienced by hospice nurses from group clinical supervision	The aims of the research study were to gain some understanding of the different aspects of the group process concerning clinical supervision for distinct groups, i.e. hospice nurses. And to evaluate experiences of group clinical supervision that hospice nurses found most and least helpful to promoting good professional practice.	Combination of audiotaped one-hour facilitated supervision meetings, questionnaires and group interview	Five nurses working in a hospice	Clinical supervision is an effective format for exploring issues concerning professional practice, allowing nurses to: learn from each other, offer support, recognize how others see and esteem them as fellow workers, and moderate concerns and anxiety related to their work. Group work is likely to raise anxiety in all participants, however, and preparation and support are required for the group facilitator. Carefully chosen membership is also considered important to the safety of members and successes of the group.	Reflective learning
Kousgaard MB, 2012, Denmark (78)	Positive experiences with a specialist as facilitator in general practice	To explore the experiences and assessments of GPs and nurses participating in a project in which a medical specialist (endocrinologist) acted as facilitator for quality improvement	Observation of facilitation sessions and interviews with the health professionals	Nine participating clinics (general practice); 13 GPs, 4 nurses, 1 endocrinologist	The combination of specialized knowledge and hands-on clinical experience seems to be an important advantage when using a medical specialist as facilitator in quality improvement efforts directed at pharmacological issues in general practice.	Learning in facilitation sessions

Leslie, 2003, UK (65)	Education to achieve symptom control for patients with cancer	To evaluate if shared interprofessional education across primary and secondary care could improve symptom control for patients with cancer.	Combination of training two facilitators of the group, action learning group sessions to implement a quality improvement tool and analysis the reflective diaries in three steps, with feedback meetings for health professionals and the project development team.	Group of 16 health care professionals: cancer nurse specialist from community and hospitals	Both participants and facilitators developed skills in working with other health care settings, as well as experience of using a continuous quality improvement tool. Participants developed a greater understanding of how the NHS worked and what was required to enable patients to receive improved care. The project enabled professionals to work more effectively with both primary and secondary services, agencies, and helped patients to enhance symptom control	Action learning in a group with trained faciltators
Liveng, 2010, Denmark (76)	Learning and recognition in health and care work: an inter-subjective perspective	To discuss the role of recognition in learning processes among female nurses, social and health care assistants and occupational therapists working with people with dementia and other age-related illnesses.	Case study semi-structured focus group interviews with employees in the home based care of the elderly and in hospitals respectively	Social- and health care assistants, nurses and occupational therapists among other professional groups	The main argument is that learning is related to recognition – especially when it comes to groups of professionals, who are low ranked in the workplace hierarchy and therefore seldom experience recognition in their daily work. According to interviews with members of the mentioned professional groups, learning spaces, in which the medical and professional hierarchies are suspended, promote learning processes. The relational nature of human learning processes and the need for recognizing contexts concludes that this need is particularly imperative in health and care work for the elderly, but may also promote learning more generally.	Recognizing learning spaces
MacFarlane, 2006, Republic of Ireland (44)	A qualitative study of the educational potential of joint teleconsultations at the primary–secondary care interface	To explore the processes by which educational exchanges may occur from the perspective of participating clinicians through teleconsultations	Combination of semi-structured interviews (n=39) with specialists and GPs and focus groups (2 groups with specialists; 6 groups with GPs)	Specialists and general practitioners	The results showed that the teleconsultation was a complex situation in which some learning took place for the generalists, but overall participants were disappointed. Three themes emerged that could enhance the educational potential in future: generalists' reasons for referral as an influence on perceived learning; lack of clarity among clinicians regarding their role and conduct; and the presence of patients as an inhibitor in doctor–doctor interactions.	Non-formal learning and the value of observation, tacit knowledge in professional work
Mann K, 2011, Canada (58)	Tensions in Informed Self-Assessment: How the Desire for Feedback and Reticence to Collect and Use It Can Conflict	To explore the tensions described by learnes and professionals when infrorming self-assessments of clinical performance	Qualitative research design, seventeen focus groups	134 participants, involving learners at undergraduate and postgraduate levels, as well as practicing physicians	Multiple tensions, requiring ongoing negotiation and renegotiation, are inherent in informed self-assessment. Tensions are both intraindividual and interindividual and they are culturally situated, reflecting both professional and institutional influences. Social learning theories and sociocultural theories of learning may inform our understanding and interpretation of the study	Social cognitive theory, situated learning and communities of practice

					findings. The findings suggest that educational interventions should be directed at individual, collective, and institutional cultural levels. Implications for practice are presented.	
Marshall, 1998, UK (45)	Qualitative study of educational interaction between general practitioners and specialists	To identify the main barriers to effective educational interaction between general practitioners and specialists and to suggest ways of overcoming these barriers.	Combination of semistructured interviews (24) and 4 focus groups	General practitioner principals (28) and hospital consultants (28)	The two main branches of the medical profession have to address several significant problems before the full potential of teaching and learning together can be realised.	Three models of educational interaction were identified: traditional didactic lectures given by specialists to general practitioners, interactive clinically based teaching, and informal interaction based on referrals.
Moore, 2006, UK (69)	Partnerships and work-based learning: an evaluation of an opportunity to pioneer new ways to care for the older people in the community	To explore and examine the impact of work-based learning on practice, the sustainability of the preferred mechanisms that have supported the outcomes in practice. Report on the learning that has been sustained and developed over time. Explore the nurses experience of work-based learning and changing contexts.	Case study, triangulation of evaluation methods, self-assessment, reflection, action learning sets and time to practice new skills in a workshop and in practice settings	12 new advanced primary nurses	Evidencing work-based learning was a new but positive experience. The evidence suggests that the expanding partnerships and synergy between practice and academia is evolving, but needs organizational support. The new ways of working, including multidisciplinary mentorship, have developed both acute and community nurses to undertake health needs assessments of identified caseloads, and in partnership with doctors and pharmacists, to diagnose, review and prescribe drugs in an attempt to reduce re-hospitalization. Evolving themes from the evaluation and the learning from the partnerships have influenced further developments in both practice and academia.	Work-based learning module was triangulated to include both individual and group responses
Morton J, 2011, USA (64)	Transcultural healthcare immersion: A unique interprofessional experience poised to influence collaborative practice in cultural settings	To describe a model for interprofessional and transcultural learning established by the author and supported by the University of New England and Ghana Health Mission	Cultural-clinical experience known as Transcultural Immersion in Healthcare - in an urban setting in Ghana	In partnership with the Ghana Health Mission, Inc and local community health workers, students and faculty from a range of health professions took part	The transcultural immersion in healthcare experience achieved its "bounty" as seen in the enchanced cultural proficiency of students and faculty, seamless interprofessional communication and collaboration and provision of primary care and related services to patients and the Ghanaian community.	Shared cultural-clinical learning

Nilsen, 2011, Norway (46)	Workplace learning among general practitioners and specialists The use of videoconferencing as a tool	To explore the use of videoconferencing for information exchange and consultation throughout the patient trajectory and to investigate how collaboration affects learning and the patient's treatment.	Combination of observation interaction analysis of videoconferences (7) supplemented by interviews.	General Practitioners and specialist (42 of both)	General practitioners and specialists use a different repertoire of knowledge and experiences to report and consult throughout the course of treatment. Over time, new medical problems arose, and the treatment had to be adjusted. The activity remained continuous and contributed to an integrated knowledge and information exchange. Collaboration using videoconferencing across levels of care created opportunities for workplace learning in health services and can lead to continuity, improved coordination, and a higher quality of care.	Workplace learning
O'Brien JL, 2008, USA (60)	Negotiating transformational leadership:A key to effective collaboration	To explore how medical doctors, in order to be transformative, should negotiate with advanced practice nurses while work in collaboration with them	Qualitative research design, semi-structured interviews	5 medical doctors, 8 advanced practice nurses	Effective leadership involves negotiating along these dimensions (MD and APN should negotiate levels of supervision, mentoring should be a reciprocal communication process, educating necessitates mutual learning), which will contribute to effective team-building	Transformational leadership
Orzano, 2008, USA (75)	Family medicine practice performance and knowledge management	To identify how family medicine practices exhibit knowledge management	Combination of developing a preliminary conceptual framework by the research team enriched with a synthesis of an extensive literature search of diverse disciplines. Constructing tables who identify knowledge management-associated processes and tools. Refining the tables and secondary analysing excisting data from the Prevention and Competing Demands in Primary Care Study with two higher perfomaning practices and two lower performing practices.	Prevention and Competing Demands in Primary Care Study that examined organizational dimensions of 18 Midwestern family medicine practices. From this a selection of two higher performing practices and two low performing practices.	Differences in knowledge management (KM) occur within family practices and between family practices and other organizations and may have implications for improving practice performance. Understanding interaction patterns of work relationships and KM may explain why costly technical or externally imposed ''one size fits all'' practice organizational interventions have had mixed results and limited sustainability.	Organizational learning
Pype P, 2014, Belgium (42)	'I beg your pardon?' Nurses' experiences in facilitating doctors' learning process – An	To clarify the views and preferences of specialized palliative care nurses toward their role as facilitator of physicians' learning	Qualitative research design, semi-structured interviews	21 palliative care nurses who were trained in the role of learning facilitator	Training palliative care nurses as facilitator of GPs' workplace learning is feasible. Preferences toward sharing knowledge and toward the focus of care (just the patient or the whole team) leads to different behavioral styles. Nurses have personal preferences toward one of the styles but shift between them according to the	Workplace learning

	interview study				circumstances (e.g. actual patient care needs and GP's attitude).	
Pype P, 2015, Belgium (43)	Preparing palliative home care nurses to act as facilitators for physicians' learning: Evaluation of a training programme	To describe the development and evaluation of a training programme for nurses in primary care. The programme aimed to prepare palliative home care team nurses to act as facilitator for general practitioners' workplace learning.	A multifaceted train-the-trainer programme was designed. Evaluation was done through assignments with individual feedback, summative assessment through videotaped encounters with simulation-physicians and individual interviews after a period of practice implementation	35 palliative home care team nurses	Training palliative home care team nurses as facilitator of general practitioners' workplace learning is a feasible but complex intervention. Personal characteristics, interpersonal relationships and contextual variables have to be taken into account. Training expert palliative care nurses to facilitate general practitioners' workplace learning requires careful and individualised mentoring.	Workplace learning
Randström B, 2012, Sweden (66)	Working with 'hands-off' support: a qualitative study of multidisciplinary teams' experiences of home rehabilitation for older people	To explore multidisciplinary teams' experiences of home rehabilitation for older people.	Five focus group interviews (28 participants)	Participants of five multidisciplinary teams with seven different professionals physiotherapists (n = 6), occupational therapists (n = 3), district nurses (n = 5), nurse assistants (n = 5),one home helper (n = 1), home help officers responsible for needs assessment (n = 3) and home help officers in charge of home help (n=5)	Common goals, communication skills and role understanding contributed to facilitating the teams' performances of rehabilitation. A potential benefit of home rehabilitation, because the older person is in a familiar environment, is to work a rehabilitative approach into each individual's activity in their everyday life in order to meet their specific needs. At an organisational level, there is a need for developing services to further support older people's psychosocial needs during rehabilitation.To address difficulties and to provide adequate rehabilitation, the teams developed strategies for exchanging experiences and enabling interprofessional learning. Supervision from a therapist developed knowledge in the team to work with a rehabilitative approach.	Interprofessional learning and supervison

Rowlands, 2001, UK (59)	Referrals and relationships: in-practice referrals meetings in a general practice	To conduct a qualitative study running parallel with a RCT to investigate the effect of in-practice meetings on referral rates, and to describe the learning needs of the participants as a result of the meetings.	Combination of audio-taped and video referrals meetings, participants diaries and evaluation forms	A four-partners practice that trained both registrars and medical students with a patient population of 11.000	The findings of this study raise important questions for developing practice-based learning. The outcomes of self-directive interventions in practices will be influenced by interna and external events both past and present. Such outcomes may be qualitative difficult to measure. They are likely to differ from outcomes seen when interventions are applied to groups of doctors who are not member of the same practice.	Individual and group learning, self- reflective and directive learning and interprofessional learning
Shaw EK, 2012, USA (79)	How Team-Based Reflection Affects Quality Improvement Implementation: A Qualitative Study	How does reflection affect team processes and QI implementation?	Qualitative approach: qualitative analysis of recorded RAP meetings (Reflective Adaptive Process) and associated fieldnotes	4 primary care practices	Team-based reflection can affect the QI change process. Building an environment of trust where members of the organization can openly and critically reflect while implementing changes can address many of the social and relational elements that so often hinder effective change. As health care researchers develop approaches to improve health care organizations and patient care, they should consider ways to intentionally integrate reflective practices into these efforts.	Team-based reflection
Shershneva, 2006, USA (47)	A Model of Teaching Learning Transactions in Generalist-Specialist Consultations	To explore physicians'learning through participation in generalist-specialist consultation.	Interviewing ten primary care physicians and 9 internal medicine subspecialists regarding their approaches to learning and teaching during generalist-specialist consultations.	Ten primary care physicians and 9 internal medicine subspecialists	Learning and teaching are embedded in consultations. The discovered theory of teaching learning transactions in generalist-specialist consultations does not provide all the answers for how to facilitate, yet not disturb, the natural flow of an educational dialogue between consulting physicians. A complete teaching-learning transaction in a generalist-specialist consultation includes (1) recognizing one's own or a colleague's learning needs (or both),(2) an exchange of valuable information in a noncondescending way and (3) satisfying learning needs, to the extent possible.	A teaching-learning transaction in consultation may be best understood as a dialogue. Teaching-as-dialogue approach
Siriwardena, 2008, UK (50)	Drivers for change in primary care of diabetes following a protected learning time educational event: interview study of practitioners	To investigate the perceptions of practitioners involved in a specific educational intervention in diabetes as part of a protected learning time scheme for primary health care teams, relating to changing processes of diabetes care in general practice.	Semistructured interviews with key informants (12)from a sample of practices stratified according to the extent they had changed behaviour in prescribing of ramipril and diabetes care more generally, following a specific educational intervention	General Practitioners and practice nurses of urban and rural primary care practices	A protected learning time scheme, using interprofessional learning, local opinion leaders and early implementers as change agents and audit and feedback, was one of a number of factors supporting changing systems of diabetes care in some practices. But also how other confounding factors played an important part in changes that occurred in practice.	Protected learning time for primary care, interprofessional learning

Stamp GE, 2008, Australia (51)	Aboriginal maternal and infant care workers: partners in caring for Aboriginal mothers and babies	To explore the views of the AMIC (Aboriginal Maternal and Infant Care) workers and midwives about their roles, their partnership and the program, following the first 45 births	Qualitative research design, semi-structured interviews	5 AMIC workers and 4 midwives	Development of the partnership took commitment and time. There were issues initially with resistance from hospital staff. Skill sharing and two-way learning engendered mutual respect. Clear benefits of the care model were highlighted by both the AMIC workers and midwives while cultural safety was maintained for the Aboriginal mothers and families. The AMIC worker role will continue to require acknowledgement, support and development. This equivalent inter-cultural partnership model has the potential for much wider application and evaluation	Skill sharing and two-way learning
Stenner K, 2008, UK (54)	The role of inter-professional relationships and support for nurse prescribing in acute and chronic pain	To explore nurse prescribers' views on the role of inter-professional relationships and other means of support for nurse prescribing for patients in acute and chronic pain	Qualitative research design, semi-structured interviews	26 nurses who prescribed medicines for patients with acute and/or chronic pain	Factors that promote understanding of nurse prescribing and support inter-professional relationships are likely to have a positive impact on the effectiveness of nurse prescribing. A more consistent approach is required within organisations to support nurse prescribing	Sharing knowledge across professional boundaries
Sullivan, 2007, UK (48)	Shared geriatric mental health care in a rural community	To explore opportunities to increase the capacity of the rural primary care system as a resource for older people with mental health needs.	Pilot project in shared mental health care in Canada was initiated to explore opportunities to increase the capacity of the rural primary care system as a resource for older people with mental health needs.	Four family physicians from a rural town get 2 geriatric urban-based psychiatrists as mentor	Geriatric shared mental health care services were successful initiated in a rural setting achieved by the development of a respectful partnership between 2 different cultures of service providers (GPs and psychiatrist), ease at which specialty services are accessible, the provision of alternative strategies to build capacity to provide geriatric mental health services in the primary care setting, and a continual exchange of knowledge underpinning clinical practice.	Consultation-liaison service, adult learning, and knowledge exchange, formal lecturing and interactive discussion using case examples.
Taber, 2008, Canada (52)	“Grey” areas and “organized chaos” in emergency response	To explore the interaction between organizational policies and daily work practices of paramedics and firefighters within two emergency response organizations. How do paramedics and firefighters learn their practice?	Combination of In-depth, semi-structured interviews, observations of training sessions, ride alongs with paramedics and firefighters in the field. The ride alongs were in essence extended, running interviews and observing their work, leading to a deeper understanding of their practice.	Senior administrators, training staff, and front line personnel: paramedics and firefighters	Paramedics and firefighters value learning in their daily work above initial qualification training. They learn in practice through increasing collaboration with others, and in the broader context of legitimate peripheral participation. Organizational policies can help in guiding their decision making processes, but learning in practice and relying on experience is most helpful in their daily work.	Learning in communities of practice, situated learning

van der Dam, 2013, The Netherlands (61)	The discovery of deliberation. From ambiguity to appreciation through the learning process of doing Moral Case Deliberation in Dutch elderly care	To evaluate the implementation of Moral Case Deliberation (MCD) within two elderly care institiutions and to present lessons learned from organizing this kind of clinical ethics support in elderly care	Combination of individual interviews (N = 16), two focus groups, participant observation	Stakeholders and employees from different wards and disciplines in two Dutch elderly care organizations	In doing MCD, participants develop competencies for reflection and deliberation, experience the benefits and therefore become internally motivated. Participation in MCD is a crucial factor and accelerator in the implementation process. Poor awareness of moral issues and ambiguous attitudes toward MCD make bottom-up stimulation and top-down facilitation needed.	Dialogical ethics and pragmatic hermeneutics
Walters L, 2011, Australia (70)	Demonstrating the value of longitudinal integrated placements to general practice preceptors	To consider why general practitioners (GPs) teach, in particular by defining the longitudinal supervisory relationships between rural clinican-preceptors and students.	Qualitative research design, 41 semi-structured interviews	GPs, practice managers, students	The evolution of doctor-student relationships in long-term student placements explains how students become more useful over the academic year and sheds light on how GPs are changed through precepting as part of the complex process by which they come to recognise themselves as central members of the rural generalist community	mutual learning, situated learning in a community of practice
Wilcock, 2002, UK (73)	The Dorset Seedcorn Project: interprofessional learning and continuous quality improvement in primary care	To arrange a facilitated practice-based project where five general practices formed interprofessional teams that worked over a six-month period, 3 meetings using a continuous quality improvement (CQI) approach to make a change in areas of importance to them and their patients.	Combination of questionnaire and a number of face-to-face and telephone interviews with participants, facilitators, and practice staff not directly involved in the project.	Primary care teams (5) with at least one general practitioner (GP) principal, one nurse, and one administrator. Practices were free to invite other team members or external people as appropriate.	Qualitative enquiry showed changes in relationships and teamworking that extended beyond the specific topic of the project, with teams reporting an enhanced sense of competence and achievement. The project facilitators were able to develop a model of learning that acknowledges and utilises the depth of experience and understanding within interprofessional practice teams. Protected time and an environment and processes that encourage full participation of a wide range of team members is essential.	Improvement-focused learning, Team learning in practice settings through use of continuous quality improvement (CQI) model

Appendix 1: Search syntax

Initial Pubmed search syntax

1 “Learning”[MeSH] OR “Learning”

2 “Models, educational”[MeSH] OR “Models, educational”

3 “Problem-based learning”[MeSH] OR “Problem-based learning”

4 “Professional development”

5 “Workplace learning”

6 “Participatory learning”

7 “Shared learning”

8 “Collective learning”

9 “Community-based learning”

10 “Informal learning”

11 “Work-based learning”

12 “Team-based learning”

13 “Interprofessional learning”

14 “Practice-based learning”

15 “Open learning”

16 “Situated learning”

17 “Self-regulated learning”

18 “Action learning”

19 “Lifelong learning”

20 1 OR 2 OR 3 OR 4 OR 5 0R 6 OR 7 OR 8 OR 9 0R 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19

21 “Cooperative behavior”[MeSH] OR “Cooperative behavior”

22 “Interprofessional relations”[MeSH] OR “Interprofessional relations”

23 “Patient care team”[MeSH] OR “Patient care team”

24 “primary health care team”

25 “Peer collaboration”

26 “Community of practice”

27 “Collaborative practice”

28 Multi-profession* OR Multiprofession*

29 Multi-disciplin* OR Multidisciplin*

30 Inter-profession* OR Interprofession*

31 Inter-disciplin* OR Interdisciplin*

32 Teamw*

33 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32

34 “Primary health care”[MeSH] OR “Primary health care”

35 “Family practice”[MeSH] OR “Family practice”

36 “Health personnel”[MeSH] OR “Health personnel”

37 “Medical practice”

38 “Family care”

39 “Primary care practice”

40 “Family medicine”

41 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40

42 20 AND 33 AND 41

43 42 + filter publication date (1990 – 21/12/2013)

Adapted Pubmed search syntax, based on ERIC-search syntax

1 “Learning”[MeSH] OR “Learning”

2 “Models, educational”[MeSH] OR “Models, educational”

3 “Problem-based learning”[MeSH] OR “Problem-based learning”

4 “Professional development”

5 “Workplace learning”

6 “Participatory learning”

7 “Shared learning”

8 “Collective learning”

9 “Community-based learning”

10 “Informal learning”

11 “Work-based learning”

12 “Team-based learning”

13 “Interprofessional learning”

14 “Practice-based learning”

15 “Open learning”

16 “Situated learning”

17 “Self-regulated learning”

18 “Action learning”

19 “Lifelong learning”

20 “Active learning”

21 “Adult learning”

22 “Associative learning”

23 “Aural learning”

24 “Cooperative learning”

25 “Discovery learning”

26 “Experiential learning”

27 “Incidental learning”

28 “Intentional learning”

29 “Interference learning”

30 “Multisensory learning”

31 “Nonverbal learning”

32 “Observational learning”

33 “Prior learning”

34 “Sequential learning”

35 “Serial learning”

36 “Transfer of training”

37 “Transformative learning”

38 “Verbal learning”

39 “Visual learning”

40 “Learning experience”

41 “Learning strategies”

42 “Learning at work”

43 “Learning in practice” OR “Learning at practice”

44 1 OR 2 OR 3 OR 4 OR 5 0R 6 OR 7 OR 8 OR 9 0R 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19… OR 43

45 “Cooperative behavior”[MeSH] OR “Cooperative behavior”

46 “Interprofessional relations”[MeSH] OR “Interprofessional relations”

47 “Patient care team”[MeSH] OR “Patient care team”

48 “primary health care team”

49 “Peer collaboration”

50 “Community of practice”

51 “Collaborative practice”

52 Multi-profession* OR Multiprofession*

53 Multi-disciplin* OR Multidisciplin*

54 Inter-profession* OR Interprofession*

55 Inter-disciplin* OR Interdisciplin*

56 Teamw*

57 Cooperation

58 “Interprofessional relationship”
59 “Interdisciplinary approach”
60 “Compliant behavior*”
61 “Collaboration*”
62 “Interprofessional practice” OR “Inter-professional practice”
63 “Interprofessional collaboration” OR “Inter-professional collaboration”
64 “Medical care team*”
65 “Interdisciplinary health team*”
66 “Healthcare team*” OR “Health care team*”
67 “Care team”
68 45 OR 46 OR 47 OR 48 OR… OR 67
69 “Primary health care”[MeSH] OR “Primary health care”
70 “Family practice”[MeSH] OR “Family practice”
71 “Health personnel”[MeSH] OR “Health personnel”
72 “Medical practice”
73 “Family care”
74 “Primary care practice”
75 “Family medicine”
76 “Primary healthcare”
77 “Primary care”
78 “General practice”
79 “Health care provider*” OR “Healthcare provider*”
80 Fieldworker* OR “Field worker”

81 Caregiver*
82 69 OR 70 OR 71 OR… OR 81
83 44 AND 68 AND 82
84 83 + filter publication date (1990 – 31/12/2013)

ERIC (Proquest) search syntax

1 SU.EXACT.EXPLODE(“ Learning”) OR “learning”
2 “Active learning”
3 “Adult learning”
4 “Associative learning”
5 “Aural learning”
6 “Cooperative learning”
7 “Discovery learning”
8 “Experiential learning”
9 “Incidental learning”
10 “Intentional learning”
11 “Interference learning”
12 “Lifelong learning”
13 “Multisensory learning”
14 “Nonverbal learning”
15 “Observational learning”
16 “Prior learning”
17 “Problem based learning”
18 “Sequential learning”
19 “Serial learning”
20 “Transfer of training”
21 “Transformative learning”

22 “Verbal learning”

23 “Visual learning”

24 “Workplace learning”

25 SU.EXACT.EXPLODE(“Learning experience”) OR “Learning experience”

26 SU.EXACT(“Learning strategies”) OR “Learning strategies”

27 SU.EXACT.EXPLODE(“Professional development”) OR “Professional development”

28 “Learning at work”

29 “Participatory learning”

30 “Shared learning”

31 “Collective learning”

32 “Community-based learning”

33 “Informal learning”

34 “Work-based learning”

35 “Team-based learning”

36 “Interprofessional learning”

37 “Practice-based learning”

38 “Open learning”

39 “Situated learning”

40 “Self-regulated learning”

41 “Action learning”

42 “Learning in practice” OR “Learning at practice”

43 “Collaborative learning”

44 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 … OR … OR 42 OR 43

45 SU.EXACT(“Cooperation”) OR “cooperation”

46 SU.EXACT.EXPLODE(“Interprofessional Relationship”) OR “interprofessional relationship”

47 SU.EXACT.EXPLODE(“Communities of Practice”) OR “communit* of practice” OR “CoP*”

48 SU.EXACT.EXPLODE(“Interdisciplinary Approach”) OR “interdisciplinary approach”

49 SU.EXACT.EXPLODE(“Teamwork”) OR “teamwork” OR teamw*

50 “cooperative behavior*”

51 “compliant behavior*”

52 “collaboration*”

53 “peer collaboration”

54 “interprofessional practice” OR “inter-professional practice”

55 “interprofessional collaboration” OR “inter-professional collaboration”

56 “collaborative practice”

57 Multi-profession* OR multiprofession*

58 Multi-disciplin* OR multidisciplin*

59 Inter-profession* OR interprofession*

60 Inter-disciplin* OR interdisciplin*

61 “patient care team*”

62 “medical care team*”

63 “interdisciplinary health team*”

64 “healthcare team*” OR “health care team*”

65 “care team*”

66 “primary health care team*” OR “primary healthcare team*”

67 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR… OR… OR 65 OR 66

68 SU.EXACT.EXPLODE(“Primary Health Care”) OR “primary health care” OR “primary healthcare”

69 “primary care”

70 SU.EXACT.EXPLODE(“Family Practice(Medicine)”) OR “family practice*”

71 “family care”

72 “medical practice”

73 “general practice*”

74 “primary care practice”

75 “family medicine”

76 SU.EXACT.EXPLODE(“Health Personnel”) OR “health personnel*”

77 “health care provider*” OR “healthcare provider*”

78 Fieldworker* OR “field worker”

79 SU.EXACT.EXPLODE(“Caregivers”) OR caregiver*

80 68 OR 69 OR 70 OR … OR… OR 78 OR 79

81 44 AND 67 AND 80

82 81 + filter publication date (1/1/1990-31/12/2014)

Embase search syntax

1 ‘learning’/exp OR ‘learning’

2 ‘educational model’/exp OR ‘educational model’

3 ‘professional development’/exp OR ‘professional development’

4 ‘workplace learning’

5 ‘participatory learning’

6 ‘shared learning’

7 ‘collective learning’

8 ‘community-based learning’

9 ‘informal learning’

10 ‘work-based learning’

11 ‘team-based learning’

12 ‘interprofessional learning’

13 ‘practice-based learning’

14 ‘open learning’

15 ‘situated learning’

16 ‘self-regulated learning’

17 ‘action learning’

18 ‘active learning’

19 ‘adult learning’

20 ‘aural learning’

21 ‘cooperative learning’

22 ‘discovery learning’

23 ‘incidental learning’

24 ‘intentional learning’

25 ‘interference learning’

26 ‘multisensory learning’

27 ‘nonverbal learning’

28 ‘observational learning’

29 ‘prior learning’

30 ‘sequential learning’

31 ‘transfer of training’

32 ‘transformative learning’

33 ‘visual learning’

34 ‘learning experience’

35 ‘learning strategies’

36 ‘learning at work’

37 ‘learning in practice’

38 ‘learning at practice’

39 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 … OR … OR 37 OR 38

40 ‘problem-based learning’ OR ‘lifelong learning’ OR ‘associative learning’ OR ‘serial learning’ OR ‘verbal learning’ OR ‘experiential learning’

41 39 OR 40

42 ‘cooperation’/exp OR ‘cooperation’

43 ‘cooperative behavior’

44 ‘interprofessional relations’

45 ‘patient care team’

46 ‘primary health care team’

47 ‘peer collaboration’

48 ‘community of practice’

49 ‘collaborative practice’

50 Teamwork*

51 Multi NEXT/1 profession* OR multiprofession*

52 Multi NEXT/1 disciplin* OR multidisciplin*

53 Inter NEXT/1 profession* OR interprofession*

54 Inter NEXT/1 disciplin* OR interdisciplin*

55 ‘interprofessional relationship’

56 ‘interdisciplinary approach’

57 Compliant NEXT/1 behavior*

58 Collaboration*

59 ‘interprofessional practice’ OR ‘inter-professional practice’

60 ‘interprofessional collaboration’ OR ‘inter-professional collaboration’

61 ‘medical care’ NEXT/1 team*

62 ‘interdisciplinary health team’ OR ‘interdisciplinary health teams’

63 Healthcare NEXT/1 team* OR ‘health care’ NEXT/1 team*

64 ‘care team’

65 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR … 63 OR 64

66 ‘primary health care’/exp OR ‘primary health care’

67 ‘general practice’/exp OR ‘general practice’

68 ‘health care personnel’/exp OR ‘health care personnel’ OR ‘health personnel’

69 ‘medical practice’/exp OR ‘medical practice’

70 ‘family care’/exp OR ‘family care’

71 ‘primary care practice’

72 ‘family medicine’/exp OR ‘family medicine’

73 ‘primary healthcare’/exp OR ‘primary healthcare’

74 ‘general practice’/exp OR ‘general practice’

75 ‘health care provider’/exp OR ‘health care provider’

76 ‘health care providers’

77 ‘healthcare provider’/exp OR ‘healthcare provider’

78 ‘healthcare providers’

79 ‘field worker’

80 Fieldworker*

81 ‘caregiver’/exp OR caregiver*

82 66 OR 67 OR 68 OR 69 OR 70 OR… 80 OR 81

83 ‘family practice’ OR ‘primary care’

84 82 OR 83

85 41 AND 65 AND 84 AND [1990-2015]/py AND ([dutch]/lim OR [English]/lim OR [French]/lim OR [german]/lim) AND [humans]/lim

86 85 AND [embase]/lim NOT [medline]/lim AND ([article]/lim OR [article in press]/lim OR [conference paper]/lim OR [conference review]/lim OR [short survey]/lim)

Cinahl search syntax

1 (MH “Learning+”) OR TX learning

2 (MH “Models, Educational”) OR TX “models, educational”

3 (MH “Problem-Based Learning”) OR TX “Problem-Based Learning”

4 (MH “Professional Development+”) OR TX “Professional Development”

5 “workplace learning” OR TX “workplace learning”

6 “participatory learning” OR TX “participatory learning”

7 “shared learning” OR TX “shared learning”

8 “collective learning” OR TX “collective learning”

9 “community-based learning” OR TX “community-based learning”

10 “informal learning” OR TX “informal learning”

11 “work-based learning” OR TX “work-based learning”

12 “team-based learning” OR TX “team-based learning”

13 “interprofessional learning” OR TX “interprofessional learning”

14 “practice-based learning” OR TX “practice-based learning”

15 “open learning” OR TX “open learning”

16 “situated learning” OR TX “situated learning”

17 “self-regulated learning” OR TX “self-regulated learning”

18 “action learning” OR TX “action learning”

19 (MH “Lifelong Learning”) OR TX “Lifelong Learning”

20 “active learning” OR TX “active learning”

21 “adult learning” OR TX “adult learning”

22 “associative learning” OR TX “associative learning”

23 “aural learning” OR TX “aural learning”

24 “cooperative learning” OR TX “cooperative learning”

25 “discovery learning” OR TX “discovery learning”

26 (MH “Experiential Learning”) OR TX “experiential learning”

27 “incidental learning” OR TX “incidental learning”

28 “intentional learning” OR TX “intentional learning”

29 “interference learning” OR TX “interference learning”

30 “multisensory learning” OR TX “multisensory learning”

31 “nonverbal learning” OR TX “nonverbal learning”

32 “observational learning” OR TX “observational learning”

33 “prior learning” OR TX “prior learning”

34 “sequential learning” OR TX “sequential learning”

35 “serial learning” OR TX “serial learning”

36 “transfer of training” OR TX “transfer of training”

37 “transformative learning” OR TX “transformative learning”

38 “verbal learning” OR TX “verbal learning”

39 “visual learning” OR TX “visual learning”

40 “learning experience” OR TX “learning experience”

41 “learning strategies” OR TX “learning strategies”

42 “learning at work” OR TX “learning at work”

43 “learning in practice” OR TX “learning in practice”

44 “learning at practice” OR TX “learning at practice”

45 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR… 43 OR 44

46 (MH “Cooperative Behavior”) OR TX “Cooperative Behavior”

47 (MH “Interprofessional Relations+”) OR TX “Interprofessional Relations”

48 “patient care team” OR TX “patient care team”

49 “primary health care team” OR TX “primary health care team”

50 “peer collaboration” OR TX “peer collaboration”

51 “community of practice” OR TX “community of practice”

52 “collaborative practice” OR TX “collaborative practice”

53 “multi-profession*” OR TX “multi-profession*” OR “multiprofession*” OR TX “multiprofession*”

54 “multi-disciplin*” OR TX “multi-disciplin*” OR “multidisciplin*” OR TX “multi-disciplin*”

55 “inter-profession*” OR TX “inter-profession*” OR “interprofession*” OR TX “interprofession*”

56 “inter-disciplin*” OR TX “inter-disciplin*” OR “interdisciplin*” OR TX “interdisciplin*”

57 (MH “Teamwork”) OR TX “teamw*”

58 “cooperation” OR TX “cooperation”

59 “interprofessional relationship” OR TX “interprofessional relationship”

60 “interdisciplinary approach” OR TX “interdisciplinary approach”

61 “compliant behavi*” OR TX “compliant behavi*”

62 (MH “Collaboration”) OR TX “collaboration*”

63 “interprofessional practice” OR TX “interprofessional practice” OR “inter-professional practice” OR TX “inter-professional practice”

64 “interprofessional collaboration”

65 “interprofessional collaboration” OR TX “interprofessional collaboration” OR “inter-professional collaboration” OR TX “inter-professional collaboration”

66 “medical care team*” OR TX “medical care team*”

67 “interdisciplinary health team*” OR TX “interdisciplinary health team*”

68 “healthcare team*” OR TX “healthcare team*” OR “health care team*” OR TX “health care team*”

69 “care team” OR TX “care team”

70 46 OR 47 OR 48 OR 49 OR 50 OR… 68 OR 69

71 (MH “Primary Health Care”) OR TX “primary health care”

72 (MH “Family Practice”) OR TX “family practice”

73 (MH “Health Personnel+”) OR TX “Health Personnel”

74 (MH “Medical Practice”) OR TX “Medical Practice”

75 “family care” OR TX “family care”

76 “family medicine” OR TX “family medicine”

77 “primary healthcare” OR TX “primary healthcare”

78 “primary care” OR TX “primary care”

79 “general practice” OR TX “general practice”

80 “health care provider*” OR TX “health care provider*”

81 “healthcare provider*” OR TX “healthcare provider*”

82 “field worker” OR TX “field worker” OR fieldworker*

83 (MH “Caregivers”) OR TX caregiver*

84 “primary care practice” OR TX “primary care practice”

85 71 OR 72 OR 73 OR 74 OR… 83 OR 84

86 45 AND 70 AND 85 Limiters - Published Date: 19900101-20151231; Exclude MEDLINE records; Human; Language: Dutch/Flemish, English, French, German

Appendix 2: Examples of C-M-O configurations of included papers per research question

Example of C-M-O configuration for 'Who learns?':

'Developing an interprofessional learning culture in primary care' (55)
Summary: Qualitative analysis of an interprofessional learning project in a primary healthcare centre focusing on the development of a learning culture in practice. A process evaluation methodology was chosen to collect the data using 11 semi-structured interviews (conducted with four members of the steering group, the project manager and six general practitioners) and two focus groups (one with five nurses and one with 14 receptionists) and documentary data from records written during the project. The aim was to describe the views and experiences of participants on multidisciplinary learning and at mapping the processes and outcomes of change as a result of the project.
In a primary care practice with general practitioners, nurses, midwifes, managers, secretaries and receptionists [C] an explicit group learning needs assessment aimed at identifying strengths and weaknesses of the group to adopt a learning culture [M] resulted in the recognition of the need for teaching skills to be spread over all the staff and to the introduction of personal development plans [O].

Example of C-M-O configuration for 'When does learning take place?':

'The unknown becomes the known': collective learning and change in primary care teams (56).
Summary: Qualitative study using an interpretative epistemology design (meaning is constructed in the researcher-participant interaction in the natural environment) and iterative research design with seven successive phases. Data (49 hours of team observations and 38 semi-structured interviews) gathered during a 1-year time period of 10 primary care teams in general medical practice (4), pharmacy (3) and dentistry (3). All teams had recently undergone one or more practice changes involving the whole team. The focus of the study was to explore how collective learning and change happen in primary care teams and how the process varies across the disciplines of general medical practice, pharmacy and dentistry.
When a diverse team of medical professionals has the security of a collective learning relationship, [C] individuals did not feel solely responsible for the success or failure of a particular initiative, could draw on the expertise of the rest of the team, knew one another's strengths and were able to call upon each other [M] where necessary to perform a task or learn something new [O].

Example of C-M-O configuration for 'How does learning occur?':

'I beg your pardon?' Nurses' experiences in facilitating doctors' learning process – an interview study. (42)
Summary: Qualitative study based on 21 semi-structured interviews with specialised palliative care nurses who were trained to act as facilitator of GPs' learning during collaboration. The data were analysed using Grounded Theory principles. This interview study explores the views and preferences of the nurses toward their role as facilitator of learning.
In the context of GPs and specialised palliative home care nurses collaborating in primary palliative care [C] in order to provide high quality of patient care and to improve the doctors' palliative care competences [M], the nurses stimulate joint reflection leading to doctors' better understanding of palliative care practice and a better interprofessional relationship [O].

Example of C-M-O configuration for 'What is being learned?':

'The discovery of deliberation. From ambiguity to appreciation through the learning process of doing Moral Case Deliberation in Dutch elderly care' (61).
Summary: Qualitative thematic content analysis of the naturalistic evaluation of the implementation of Moral Case Deliberation (MCD) in two elderly care organisations (two nursing homes and three locations with a mix of nursing and assisted-living units). Participants' (managers and caregivers) experiences were examined through: individual interviews (16) with directors, middle managers, (para)medics and nursing assistants; three focus groups; participant observations in a number of ways: recordings of clinical site visits and project group meetings and participant observations during the MCD sessions (47 sessions of 2h each). The aim of the study, besides the evaluation, is to present lessons learned from organising this kind of clinical ethics support (MCD) in elderly care.
During MCD with healthcare professionals (nurses and physicians) in elderly care institutions [C] the sharing of frustrations and emotions and the search for relief of moral distress [M] leads to learning to postpone their own judgment and to examine an issue from another, different point of view [O].

GENERAL DISCUSSION

Chapter 8:

General discussion and conclusions

1. Introduction

This dissertation aimed at gaining a deeper understanding in aspects of inter-professional collaboration in palliative care. It comprises three parts, each consisting of two research aims.

The first part was concerned with inter-professional collaboration in palliative home care and across care settings, with a focus on how this collaboration occurred within fluid teams (Chapter 2). Next, we described perceptions of healthcare professionals regarding inter-professional collaboration during a patient's transfer between care settings in palliative care (Chapter 3).

The second part concentrated on patients' transfers between care settings in palliative care and described their experiences (Chapter 4) as well as those of family carers (Chapter 5) with respect to these transfers.

The third part was devoted to inter-professional collaboration from a complexity science perspective and workplace learning as emergent behavior of inter-professional collaboration. In Chapter 6, we described insights into how the team taking care of the palliative patient at home functions, by using the principles of complex adaptive systems. Also the interactional factors influencing workplace learning as emergent behavior of inter-professional collaboration were examined in this chapter. Chapter 7 explored the process of workplace learning through inter-professional collaboration in primary healthcare and the conditions and contextual factors influencing this workplace learning.

This current chapter of the dissertation discusses the main findings of the included studies. Firstly, study findings are summarized, adhering to the three-parts structure of this thesis. A subsequent section is devoted to an in-depth discussion of the most important findings, followed by methodological reflections. Finally, recommendations for clinical practice, education, policy makers and future research are put forward.

2. Summary of the findings

2.1. Inter-professional collaboration in palliative home care and across palliative care settings

Inter-professional collaboration within fluid teams in palliative home care

In Chapter 2, we focused on the palliative home care setting. In this chapter we reported on the experiences of 20 community nurses (CN) in their collaboration with the general practitioner (GP) and the specialist palliative care nurse from the palliative home care team (PHCT). Furthermore, we explored the factors they perceived to influence this collaboration.

All respondents of this study were members of ad hoc teams whose composition varied for each palliative patient, a characteristic also referred to as team membership fluidity (1, 2).

Study findings revealed that positive aspects of collaboration were associated with healthcare professionals being approachable, being open for asking questions, allowing for opportunities to discuss the patient's case and allowing for the involvement of CNs in the deliberation process. Meeting other care providers rather occurred unplanned and formal meetings were not common practice. Collaboration with the PHCT nurse was particularly highly valued and most CNs frequently relied on their expertise.

Several notable factors negatively influenced working together with the GP, putting stress on the inter-professional collaboration. Firstly, hierarchy and income dependency affected the teamwork. In order to deal with the GP's hierarchical style and to safeguard future patient referrals, participants admitted to behaving cautiously to avoid jeopardizing the inter-professional relationship. Secondly, collaboration was negatively influenced when open communication with GPs was perceived futile. Several respondents reported they held back from expressing their doubts or objections with respect to treatment decisions. Alternatively, they strategically allowed GPs to take credit for solving the problem, while they were actually the ones to prompt the solution. The PHCT nurses were regarded as equals and the communication with them was perceived open. Apart from relying on PHCT nurses for expertise, the CN relied upon PHCT nurses as a coalition partner and important mediator, when disagreements between the CN and the GP arose. Our study findings showed that CNs were dedicated to providing quality patient care, but often felt hindered to act accordingly for fear of harming the relationship with GPs. Their coping strategies were a compromise between behavior focused on the patient and on the professional relationship.

Healthcare professionals' experiences of inter-professional collaboration during patient's transfers between care setting in palliative care

In chapter 3 we explored how 53 diverse professionals, involved in palliative care from different care settings, experienced inter-professional collaboration during a patient's transfer. Furthermore, we explored how they experienced the involvement of the patient and family members during patient's transfer between care settings.

Study findings generally revealed that timely and effective inter-professional information exchange was considered essential, yet insufficient. This was partially attributable to a shortage of exchange of psychosocial information. The current electronic health record system also did not provide enough opportunities for inter-professional information exchange, both within and across settings. Similarly, the efficiency regarding multidisciplinary team meeting attendance, inter-professional communication and the willingness to discuss shared care goals were points of improvement. Another important finding concerned the practical organization and the timing of a patient's discharge towards palliative home care, which was often perceived as inadequate, thus negatively influencing the continuity of care. In addition, home care professionals indicated their involvement came too late in the patient's care trajectory, a fact which was recognized by hospital professionals. Furthermore, non-physician healthcare professionals expressed a perceived lack of open communication of some specialists towards patients and the lack of shared decision-making. Our data showed that shortcomings in effective team functioning and open and effective provider-patient communication, hampered the timely communication of advance care planning and the early integration of palliative home care. As a result of a lack of action taken by doctors (e.g. regarding provider-patient communication), other professionals felt limited in how they functioned professionally towards patients, affecting their own professional well-being.

2.2. Patients' transfers between care settings in palliative care: caregiving experiences of patients and family carers

Patients' experiences of transfers between care settings in palliative care

In chapter 4 we described the experiences of 20 palliative patients with respect to their transfers between care settings.

Home was considered the preferred residence, although perceptions of unsafety arose when symptom burden increased, when activity of daily living diminished and when the organization of home care was insufficiently aligned with the patient's needs. Furthermore, while a number of home care facilities were available to support patients and family, the manner of its implementation did not always meet patient's needs. In addition, home was not necessarily regarded as the preferred place to die, depending on the perceived added value of staying at home, the patient's sense of dignity and the capacities of informal carers. To some participants, both the nursing home and palliative care unit were regarded as a more suitable last residence, offering safety and good care when home residence became unfeasible. Notable experiences were reported on how hospitals responded to patients' needs during temporary admissions. Sometimes the hospital setting failed to meet a patient's expectations, but experiences varied depending on the hospital, the type of ward and the reason for hospitalization. Some participants reported perceived shortcomings in inter-professional communication, resulting in the wrong medication being administered and insufficient symptom control. Cancer patients admitted to being treated more humanely in the oncology ward compared to other, non-oncology, wards. Perceived issues regarding hospital discharge were: a premature release, lack of seamless care and home care insufficiently tailored to the patients' needs. For some, the family physician played a central role, but others indicated the family physician took a position in the background or was only minimally involved. Patients especially expected their family physician to ensure continuity of care.

Family carers' experiences regarding patient transfers between care settings in palliative care

In chapter 5 we reported on the experiences of 21 family carers regarding patient transfers between care settings in palliative care.

Study findings showed that the decision to transfer a patient was affected by the balance between care provision (both professional and informal care) and changes in the patient's needs.

Family carers displayed a high degree of adaptability to meet the changing needs of patients. Their capacity was influenced by the possibility of reorganizing daily life in function of the patient's illness, and the concomitant extra support. Additional professional home care helped family carers sense they were not alone in providing care. Regular contacts with the PHCT nurse and the family physician were highly valued. Changes to patient's care needs resulted in organizing additional professional care or in a patient's transfer when home care provision was ultimately deemed insufficient.

Transfer decisions were taken by patients, family carers or professional caregivers, often in mutual agreement. In case of patient transfers from home to the nursing home or the PCU, the weight of family carers in these decisions augmented in situations when capacity problems were encountered. The choice of the care setting was influenced by factors practical in nature, the life expectancy of the patient and the perception of the setting itself.

Multiple and varied experiences were reported pertaining to the changed care environment. The palliative care unit was considered the 'final station'. However, because of the manner in which the patient and the family carer were welcomed and treated as persons, the time dedicated by the personnel and the grief and bereavement support, the PCU was regarded as 'heaven on earth'. Carers also reported positive experiences about treatment and communication in the case the patient was transferred to a nursing home. The hospital was considered a setting where the patient received temporary help. However, experiences at this setting were diverse and depended on the hospital and the hospital ward. Furthermore, the assessment of conduct towards family carers and patients ranged from extremely positive to rather negative. There were also concerns about inter-professional communication within and across hospitals. Carers expressed a clear need for information concerning the patient's condition but experiences varied greatly, ranging from approachable physicians taking time to provide tailored information, to physicians who were difficult to approach.

Although participants regarded their efforts as carers as self-evident, the patient's transfer was sometimes accompanied by feelings of relief. This occurred when carers were able to transfer the responsibility of care to others, thus liberating themselves from the fear of doing wrong and causing harm in the case of sudden events. Similarly, a feeling of anxiety arose when hospital discharge was imminent while the patient's condition had insufficiently improved.

2.3. Inter-professional collaboration in palliative home care from a complexity science perspective and workplace learning as emergent behavior of inter-professional collaboration

Healthcare teams as complex adaptive systems: understanding team behavior through team members' perception of interpersonal interaction.

In chapter 6 we focused on the healthcare team (GP, CN and PHCT nurse) taking care of the palliative patient at home and described team members' interactions based upon the complexity science framework. We explored the origin of the healthcare team behavior and the factors influencing workplace learning (WPL) as emergent behavior.

All complex adaptive system (CAS) principles were identified in the three (PHCT nurses, CNs, GPs) professional groups' accounts of their perception of the way they interact on a day-to-day basis in the team. The most prevalent principles were: "team members act autonomously guided by internalized basic rules", "attractors shape the team functioning", "a team has a history and is sensitive to initial conditions" and "a team is an open system, interacting with its environment". Principles present to a lesser extent were: "team members' interactions are non-linear", "interactions between team members can produce unpredictable behavior" and "interactions between team members can generate new behavior".

Patterns reflecting team behavior were recognized in the coding of each CAS principle and can be linked to inter-professional competencies of the Interprofessional Education Collaborative. For example, CAS Principle 1 ('Team members act autonomously guided by internalized basic rules') and CAS principle 7 ('Attractors shape the team functioning') relate to the aspect of professional and inter-professional identity and match competency 1 (Values/Ethics for inter-professional practice) and competency 4 (Teams and teamwork) of the Core Competencies for Interprofessional Collaborative Practice of the competency framework (3).

Furthermore, interview analyses revealed many factors facilitating or hampering information exchange and the sharing of experience within the team, which are prerequisites for workplace learning. An example of a facilitating factor was: the tradition of systematic and frequent communication facilitates the initiation of a deliberation in case of problems; while one of a hindering factor: GPs insufficiently informing CN on patient's medical status or ignoring expert palliative care advice results in an atmosphere of distrust.

Workplace learning through collaboration in primary healthcare

In chapter 7, we described the process of WPL through collaboration in primary healthcare and the conditions influencing WPL. We included 42 publications - out of 6930 references – in the review, both qualitative and quantitative in design.

Findings of the realist review revealed that any professional can learn from others in the workplace. The motivation to learn, as an individual or within a group, is a necessary mechanism to enhance learning. People aware of their own learning needs or those of others or of the group, are more motivated to learn. Facilitating others to learn is a competence that can be learned over time.

With respect to when learning takes place, findings suggested that WPL may be influenced by the manner in which the workplace or work environment is equipped and laid-out. Difficult case management provides opportunities for learning. Both planned and unplanned learning opportunities lead to WPL, but unplanned activities seem to be more motivating. Furthermore, a high workload affects WPL, both directly and indirectly. Also having a shared aim or responsibility facilitates learning. Finally, strong relationships between healthcare professionals can facilitate learning.

Regarding how learning occurred, studies showed that professionals were often unaware of the learning that occurs during collaboration. Performing an action is very important to the learning outcome, whereas merely observing the action or hearing an explanation on how to do it seems less efficient. Reflection is an important part of the learning process. This reflection can be either spontaneous or triggered, individual, guided or collective. Any professional can trigger another professional to learn.

During collaboration and through interaction with each other, professionals acquire patient-related outcomes, such as a broader understanding of the clinical problem. Other outcomes can be associated with professional development or with other non-patient related topics.

3. Discussion of the findings

In the following sections, structured according to the three parts of this thesis, in-depth reflections on the main results and comparisons with literature are provided.

3.1. Inter-professional collaboration in palliative home care and across palliative care settings

In this section, we discuss aspects pertaining to the process of inter-professional collaboration within palliative home care, within the hospital setting and across settings. The subject 'team structure and team membership fluidity' is discussed further on, in section 3.3. of this chapter.

In chapters 2 and 3 of this dissertation, home and hospital healthcare professionals reported on several factors that positively influenced inter-professional collaboration, such as: collaborators knowing each other; healthcare professionals being approachable and open to queries; being willing to share information and sharing it timely and effectively; having the opportunity to discuss the patient's case; and the absence of a hierarchical mindset. By contrast, lack of open communication and the presence of collaborators with a hierarchical attitude were perceived to interfere with positive collaboration. These findings are consistent with previous research reporting on factors fostering effective teamwork and inter-professional collaboration in palliative care: good communication, clear definition of roles and responsibilities, access to specialist palliative care, coordinated and continuous support and opportunities for education (4-6). Conversely, communication breakdown, hierarchical structures, role ambiguity and lack of inter-professional team training, all impede the collaborative practice in palliative care (4-6). These factors can be considered within the broader context of 'comprehensive care co-ordination and interdisciplinary teamwork across all settings where palliative care is provided', described as one of the core competencies in palliative care (7, 8). Interdisciplinary teamwork has been addressed under the theoretical framework of inter-professional practice or collaboration. It is characterized by a focus on the users' needs, a shared aim and common objectives, complementary skills and interdependence of professional actions, mutual respect and trust among professionals, acknowledgement of the role and work of the different professional groups, negotiation between professionals, shared decision making and shared accountability for the outcomes (9-12). With respect to these characteristics, we will highlight some other findings, that add nuance to the current body of evidence.

A striking study finding described in chapter 2, concerns the CNs' approach when confronted with GPs who exercised a hierarchical style or with whom a lack of open communication was perceived. Several participants in our study reported they held back from expressing their doubts on treatment decisions. They had learned through experience how to cope with the GPs' communication style and used a cautious approach, in order to avoid confrontation. An alternative strategy was to make the GPs feel as though they had solved the problem, while the CNs had actually prompted the solution. Some CNs in our study did not enter into a discussion with the GP, even when it affected the quality of patient care. For instance, despite knowing that the dose of administered medication was insufficient, they preferred to wait for the outcome and report back to the GP. In doing so, they allowed the GP to make treatment conclusions and propose adaptations. This strategy not only influenced the quality of patient care, but also impacted the professional well-being of the nurses. Conversely, in a GP-CN relationship that was less affected by hierarchy, CNs felt treated more like equals and were subsequently more relaxed to put forward suggestions and discuss the patient's case. The above illustrated dynamics have been described by Stein in 1967, in 'The Doctor-Nurse game' (13). In 1967, though hierarchical, the relationship between doctors and nurses was based on mutual respect and interdependence. The cardinal rule of the doctor-nurse game was that open disagreements between the players had to be avoided at all costs. The nurse had to be bold, take the initiative and be responsible for making significant recommendations, while seeming passive at the same time. She had to make her recommendations in such a way that they appeared to be initiated by the physician. Both players were rewarded when the game was successful: the doctor was able to further count on the nurse as a valuable consultant, while the nurse gained self-esteem and satisfaction. By contrast, if the nurse failed to play the game, e.g. if she made recommendations openly, this would negatively affect or stop the inter-professional collaboration (13). It is remarkable that CNs in our study still felt the need to behave in a similar manner, when open communication was perceived absent, even at the expense of the patient's comfort.

Some reflections can be formulated with respect to this above discussed result. Whereas the Doctor-Nurse game left CNs feeling satisfied and gaining self-esteem more than fifty years ago, the result is markedly different today. Indeed, the absence of open communication or the GP's hierarchical attitude was perceived to negatively influence the inter-professional relationship. Besides the professional well-being of the CN, it additionally affected the quality of patient care. This is consistent with other study results, stating that ineffective and poor communication between nurses and physicians has been associated with both patient harm as well as nurses feelings of diminished value and decreased job satisfaction (14-16). When CNs in our study felt the need to use such a communication strategy, we do not know whether this perception was based on and resulted from the behavior and attitude of GPs towards CNs, or whether it is still grounded in the professional socialization of CNs during their undergraduate education, or even whether it is rooted within our social context (e.g. the stereotypical image of the nurse as a servant), or a combination of all these factors. From the perspective of the GP, study findings of Pype et al. (17) suggested the hypothesis that hierarchy can be overruled by competence. Authors did so, as GPs in their study acknowledged that PHCT nurses were highly competent and allowed them to be involved in discussions concerning the patient's condition. Researchers therefore hypothesized that GPs did not consider PHCT nurses as 'nurses' but regarded them as specialists in palliative care, thus treating them accordingly (17).

A next reflection on this result concerns the CNs' income dependency, especially for those self-employed. Nurses in our study indicated they did not want to jeopardize their relationship with GPs since their income depended on GPs' patient referrals. This resulted in CNs restraining themselves from communicating openly with regard to suggestions about diagnosis or treatment decisions. With this in mind, it has been suggested that funding structures that support patient-team encounters, in which doctors and nurses are employed colleagues, are some of the factors that enhance efficiency and promote teamwork (18, 19).

A positive remark in our study in chapter 2, is that some CNs reported perceiving a general evolution in the inter-professional relationship with GPs in recent years, being less affected by hierarchy. We did, however, not explore their explanations for this change. We do know that there has been a significant change in the healthcare workforce the last decades – compared to the era of the 'doctor-nurse game': over the past century, there has been the trend of 'the feminization of medicine', with the majority of new graduates in medicine being women (20). Although female medical graduates may have become familiar with the doctor-nurse game during training, the elements of the game that reflect the stereotypical roles of the male dominance and the female passivity, are missing (21). Simultaneously, there is an increasing demand for healthcare in general and for more specific patient treatments which resulted in the introduction of new nursing roles, such as nurse practitioners, registered nurses, nurse specialists, etc. (22, 23). As such, nursing roles have evolved to certified advanced practitioners with independent duties and responsibilities and physicians increasingly depending on nurses' special expertise (21). The above described elements may partly explain the CNs' perceived evolution in inter-professional relationship with GPs.

A next noteworthy result to discuss, from chapters 2 and 3, concerns multi-disciplinary team (MDT) meetings, both in palliative home care and in the hospital. Although these meetings were considered desirable, they were not always common practice, nor were they perceived efficient due to an improper composition or an incomplete attendance (e.g. the GP, who was often not able to attend the meeting due to time constraints; the chief hospital physician who was absent at the meeting and was represented by a resident). Furthermore, in chapter 3, remarks were reported on the inter-professional communication during these meetings, in particular about the possibility of discussing opinions openly and about the influence of hierarchy. To be judged an equal partner in the discussion was considered crucial and it is to be noted that hospital nurses, in chapter 3, had experienced a positive evolution and the beginnings of improvement with regard to open communication and discussing shared care goals ever since hospital physicians had started to participate in MDT meetings. Important benefits of MDT meetings have been stressed in other research, situated both at the level of patient care and of team functioning (24-26). Next to the benefits of MDT meetings, issues regarding the composition, the attendance and the process are subject to discussion. In the study of Ellis et al. (27), concerning geriatric medicine, core principles of an MDT meeting are: 'Establish patient centered goals'; 'Cover the domains of medical problems, functional ability, cognitive or psychiatric health and social circumstances'; 'Have representation from key disciplines'; 'Bring opinions openly'; 'Agree an overall aim'; 'Agree next steps with time frames'; 'Allocate responsibility'; 'Reconvene to revisit progress regularly' and 'Communicate outputs from the MDT meeting' (27). In addition, inefficiencies regarding cancer MDT meetings have been described with factors negatively impacting effective decision-making. These include: the failure to present adequate information; professional hierarchies; lack of open discussion; failure to consider holistic information or patient views; lack of personal knowledge on the patient being discussed; logistical issues (administrative, attendance); and time and workload pressures (28). Our study results are consistent with the existing evidence, although it should be noted that the focus of our study was not specifically to investigate in-depth how MDT meetings were performed and what the outcomes of these meetings were. Nevertheless, our results clearly demonstrated that points of improvement remain with respect to the implementation of MDT meetings in daily practice, their composition (e.g. the attendance of key professionals involved) and the process of the meetings (e.g. being able to discuss opinions openly, being regarded as an equal interlocutor). Improvements in this area may consequently positively influence the quality of patient care and team functioning.

A last and major result that merits attention concerns provider-patient communication (chapter 3). Informing patients about their illness status and prognosis was considered the physician's role. Non-physician hospital professionals reported perceiving some hospital physicians employing an insufficiently open manner of communication towards patients. They experienced a therapeutic obstinacy rather than a discussion of appropriate treatment options. Moreover, non-physician hospital professionals felt insufficiently involved to contribute towards a shared decision-making process. Specialists' lack of open communication towards patients directly affected both the organization of appropriate patient care as well as inter-professional collaboration. For instance, hospital nurses were impeded to involve the specialized palliative care nurses when the patient was not informed about being palliative. And another example: additional support organized by the social assistant was difficult when patients were unaware of their prognosis. As such, patients were perceived to be informed late during the course of their illness trajectory of their condition and prognosis and were hence also late in being given the option to transfer to the home care setting or the palliative care unit. Home care professionals too indicated being involved late in the patient's care trajectory, e.g. in case of oncology patients. These results are linked to those, described in chapter 5, which reported on family carers' experiences regarding patient transfers between care settings in palliative care. In that chapter, one of the experiences was the choice of the patient to die at the oncology ward, because the option of a transfer to the PCU was given late. Findings in chapter 3 also showed that hospital nurses experienced a different view than physicians on when advance care planning discussions should be initiated. Compared to physicians, who were more reserved, hospital nurses wanted to initiate this earlier. We hypothesize, based on the experiences of our study participants, that time constraints and focus on the patient's diagnosis and treatment may contribute to physicians' reluctances to discuss illness goals sooner. However, exploring this reluctance was not the specific focus of our study.

A multitude of studies have been published regarding interventions to facilitate provider-patient communication about end-of-life issues and advance care planning These include communication tools and training for healthcare professionals, patients and their family (29-34). However, by sharing these responsibilities among team members, the burden of end-of-life communication does not have to rest solely on the shoulders of one physician. Furthermore, a team-based approach requires all healthcare professionals involved to work cohesively and to support the patient's care goals through coordinated communication (35). This links to another dimension of caregiving and integration, namely normative integration. Normative integration achieves connectivity and spans the micro, meso and macro levels in a system. It is defined as: 'The development and maintenance of a common frame of reference (i.e. shared mission, vision, values and culture) between organizations, professional groups and individuals (36). Our study results in chapter 3 revealed essential shortcomings with respect to attaining shared care goals, which is related to having common visions and values. In addition, our study findings confirmed the existing evidence that a lack of effective team functioning and open and effective provider-patient communication hampered the timely communication of end-of-life issues and early integration of palliative home care (35, 37-39). The promotion of an inter-professional culture during early socialization, within an educational and practice environment, is therefore essential to enhance inter-professional collaboration when referring to these communication issues (37, 40-42).

Our findings are furthermore adding results related to professional well-being. Due to the lack of open physician-patient communication, non-physician professionals experienced limitations in how they functioned professionally towards the patient.

They described this as a barrier towards their own professional well-being. Concerns may be formulated that this impact on professional well-being could result in moral distress. Moral distress occurs when, due to external constraints, particularly those related to hierarchy or institutional culture, a professional is unable to act in accordance to his or her ethical beliefs (43). Even though we did not further examine this in our study, we recommend this topic be investigated further.

3.2. Patients' transfers between care settings in palliative care: caregiving experiences of patients and family carers

Findings of the interview study with patients (chapter 4) and family carers (chapter 5) demonstrated that home was considered the preferred residence, even when patients' illness issues limited the quality of day-to-day life. This finding confirms the results of earlier research that patients with palliative care needs prefer to remain at home, in familiar surroundings (44-46). Further, results in chapter 5 illustrated the preparedness and high degree of adaptability that family carers exhibit in caregiving, taking up their responsibility and constantly modifying priorities to meet the changing needs of patients.

A notable study finding, described in chapter 4, concerned the topic of 'feeling (un) safe'. Despite being in the preferred residence, patients reported experiences of feeling unsafe at home, situations which arose when symptom burden and care needs increased, when the professional care organization was insufficiently geared towards the patient's needs or when the capacity of informal care proved insufficient. Whether or not a patient felt (un)safe, touches on the pivotal role which is reserved for GPs – in collaboration, among others, with CNs - regarding the coordination and the timely organization of palliative home care, tailored to the needs of the patient and their family. For instance, patients and family carers in our study felt relieved when they had the phone number of the PHCT nurse, knowing that someone could be reached 24/7 in case of a problem or in situations when the GP was unavailable. PHCT nurses were regarded competent professionals for both pain and symptom management and mental support, and were furthermore perceived to work pro-actively and be methodical in their follow-up. Patients and family carers in our studies felt supported when the family physician was approachable, by taking time to listen, by conducting home visits on a regular basis and by maintaining contact with the treating specialist. Also, the additional support of professional home care (CN, PHCT nurse, domestic care) resulted in feelings of not having to cope with the situation by oneself. These findings are consistent with other literature results, describing the essential elements of high quality palliative home care (47, 48) and the results of Sarmento et al. (49) who performed a meta-ethnography of qualitative evidence to understand patients and family caregivers' experiences with home palliative care services. They identified the patient's and family carer's feeling of security at home as the core mechanism of action, enabling patients to stay at home. Feeling secure allowed patients and caregivers to pursue the goals of living a family life on the one hand and preparing for death on the other. Specialist palliative care teams had a major role in providing security at home for the following reasons: their availability at all times, their possibility to carry out home visits and being able to provide symptom control (49). Our findings confirm this and highlight the importance of an early integration of palliative home care, the efficient organization of care and an effective inter-professional collaboration to deliver high quality care. In doing so, it contributes to the patient's and the family carer's sense of being safe.

Findings in chapter 4 and 5 showed that a patient's transfer was decided upon when an imbalance arose between the patient's care needs on the one hand and the care provision (both professional and informal care) on the other. In situations of gradually changing needs of patients residing at home, additional professional homecare (e.g. a community nurse, a PHCT nurse, domestic or cleaning services) was organized. However, when the patient's care needs became too extensive and family carers were unable to address these needs, a permanent transfer was the logical next step, either to the PCU for terminally ill patients, or to the nursing home for elderly patients (in case of frailty). When acute changes to the patient's needs occurred (e.g. due to vomiting, pain, shortage of breath, mobility disorders) it necessitated a sudden shift in care delivery, which was not always feasible, nor effective, nor sufficient to organize within a short time span. It resulted in a patient's transfer to the hospital which was considered a better place to receive the care required. Earlier research reported that a number of these patient transfers were indeed unavoidable (e.g. an ultimate transfer to the nursing home due to inadequate caring capacity at home or a hospital admission when medical conditions could only be managed in the hospital) (50), while other transfers have been described as avoidable, in particular between home and the hospital at the end of life (e.g. due to the 'rescue' culture of contemporary medicine) (51, 52). Five key strategies have been described to minimize avoidable hospitalizations at the end of life: (1) marking the approach of death and shifting the mindset, (2) being able to provide acute treatment at home, (3) holding anticipatory discussions and preparing to deal with expected severe problems, (4) guiding and monitoring the patient and family in a holistic way throughout the illness trajectory, and (5) ensuring continuity of treatment and care at home (51). Prerequisites for these strategies are, however, related to findings discussed in section 3.1, above, namely an inter-professional team-based approach to palliative care, end-of-life communication and decision making across settings, and early integration of palliative home care. Furthermore, the issue of 'continuity of treatment and care at home' (the fifth key strategy to avoid hospitalization at the end of life) is linked to the problem of patients with palliative care needs that live alone. Aside from an efficient and effective organization of professional home care, non-resident family carers in our study reported that the presence of the patient's spouse and the spouse's condition was an important factor in determining whether or not a patient could remain at home. However, in developed countries in the past decennia, family constellations have changed due to higher divorce rates. This has resulted in altered and more complex family constellations (e.g. remarriages, (non-)co-habiting households, single-parent households), which may leave older people living alone and thus negatively influence home care provision 24/7 (53). Apart from providing respite care for family carers, (palliative) day-care centres, as discussed in chapters 4 and 5, were perceived to be of added value by filling in lonely gaps and providing company, distraction and protection. This result confirms other study findings reporting on the benefits of palliative day-care centres (54-56). Furthermore, in the last decade, there has been a growing interest in the development of Compassionate Communities and Compassionate Cities. This public health approach to end-of-life care promotes communities to take more responsibility in their own healthcare, improving the care of people at the end of life, where palliative care and community support work together (57-59). This promising evolution may positively contribute to the continuity of palliative care at home, considering the demographic and epidemiological challenges we are facing.

Another important finding deserving discussion, regards the patient's and family carer's expectations and experiences with regard to hospitalizations. Our study findings showed that the hospital was expected to guarantee safety and immediate and continuous aid when home care was perceived to be insufficient, ineffective or unfeasible. The experiences, however, varied depending on the hospital, the hospital ward and the reason for hospitalization. Participants expressed mixed experiences regarding inter-professional communication, the way the patient and family were treated by staff and how information was exchanged. Issues with respect to hospital discharge were: a premature release, patients and family carers feeling unprepared, insufficient organization and a lack of seamless care. In chapter 3, healthcare professionals reported similar experiences of insufficient information exchange within and across settings, home care professionals being involved too late in the patient's care trajectory and an inadequate organization of the patient's discharge, thus hampering the continuity and coordination of patient care. Integrated palliative care has been increasingly proposed to achieve continuity of care for patients with a life-limiting illness and focuses on the coordination of care around the palliative care needs of patients (60-63). Integrated palliative care involves bringing together administrative, organizational, clinical and service elements in order to realize the continuity of care by all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, both paid and unpaid (64, 65). Findings of chapters 3-5 have highlighted several areas of improvement on different levels of care and collaboration, such as the information flow across settings, effective inter-professional and provider-patient communication, the discussion of shared care goals and the organization of care that is tailored to the needs of patients and family carers.

Experiences with regard to the oncology ward, described in chapters 4 and 5, were positive. Personnel was portrayed as gentle and friendly, taking time for the patient and family and delivering tailored care. Some cancer patients and family carers indicated they contacted the oncologist for advice and assistance directly when something went wrong, rather than consulting the family physician. Participants also spoke about their choice of the oncology ward to die, instead of the PCU, since they were unfamiliar with the PCU or the patient was no longer in a condition to be transferred from the oncology ward to the PCU. These findings show that patients and family members felt safe and well-treated at the oncology ward.

Despite the positive feedback about the oncology ward, hospital healthcare professionals reported, in chapter 3, that patients were informed late about their illness status and were hence only then given the option to be transferred to the home care setting or to the PCU. Home care professionals also indicated they were involved too late in the patient's care trajectory, a problem which was admitted to by hospital professionals. Both hospital and home care professionals experienced that initiating palliative home care on time allowed family carers to prepare themselves for the patient's dying process, both practically and emotionally. Conversely, the goal of caring and dying at home was impeded when palliative home care was started late and family carers were insufficiently supported. Our findings once again stress the importance of early integration of palliative home care and an inter-professional, team-based approach across settings as a prerequisite for qualitative home care, allowing for the possibility of dying at home for those choosing to do so.

3.3. Inter-professional collaboration in palliative home care from a complexity science perspective and workplace learning as emergent behavior of inter-professional collaboration

Chapter 6 of this dissertation described healthcare team members' interactions based upon the complexity science framework. We explored the origin of healthcare team behavior and factors influencing workplace learning as emergent behavior. Three of the findings, related to CAS (Complex Adaptive Systems) features, merit further discussion.

The first CAS feature to contemplate is: "Attractors shape the team functioning". This means that the actions and interactions of team members are influenced by a set of basic rules, which push a team member towards a certain action. Attractors are the driving forces of a team and attract team members towards a particular action. The trajectory of a team (i.e. the usual pattern of behavior) is mainly determined by its attractors. The precise behavior of a team at any precise moment is still unpredictable, but the 'usual' behavior will always incline towards the attractors (66, 67). Findings of our study revealed three attractors that shape daily care delivery and the goals that healthcare team members in palliative home care aimed to achieve: the quality of patient care, inter-professional relationships and personal and professional well-being. As shown in chapter 6, healthcare professionals were primarily devoted to deliver quality patient care, being a first attractor. In doing so, they collaborated with team members having both the same and different professional backgrounds and combined their complementary knowledge and skills. Inter-professional relationships, the second attractor, were highly regarded by team members. Team members, respecting and appreciating the complementary knowledge and skills of others, positively affected inter-professional relationships. Remarkably, in the case of conflicting views on patient treatment, both PHCT nurses and CNs reported to sometimes avoid confronting discussions with GPs in order not to endanger the inter-professional relationship, which resulted in perceptions of suboptimal care delivery. Similar experiences have been reported in chapter 2, which are related to Stein's description of the 'doctor-nurse game' (13). Professional well-being was a third attractor, that shaped the interactions between team members. An example of this is when team members sought the support of other team members after a conflict with a patient or family member, or after an emotional event. Further results in chapters 6 and 2 showed that team members altered and adapted their behavior depending on the circumstances, often balancing between the quality of patient care against maintaining a good inter-professional relationship. Previous research described that despite PHCT nurses' strong focus on patient care, they also invest in the relationship with the GP, reasoning that this may benefit future patient care (68). In addition, the importance of inter-professional relationships for effective teamwork to deliver high quality care has been clearly stated (17, 69, 70).

A second CAS feature to discuss is: "Team members act autonomously guided by internalized basic rules". When considering a healthcare team as a CAS, team members respond to their environment by using internalized rules that drive action. These rules can be expressed as instincts, constructs and mental models (66). Results of chapter 6 revealed three basic rules that shaped the team members' professional attitude and the way they engaged in the collaboration: 'We are here for the patient', 'GPs carry the final responsibility in palliative home care', and 'Tasks and responsibilities need to be clear for everybody'. 'We are here for the patient' was the most important basic rule in our study and is closely related to the attractor 'quality patient care'. Furthermore, both are associated with the issue of professional and inter-professional identity. During the formation of a professional identity, norms, values and characteristics of the profession are internalized, resulting in the individual acting accordingly (71). In addition to a professional identity, professionals can also develop an inter-professional identity (72, 73). Inter-professional identity can be defined as 'a professional identity that has been reconfigured and extended with an inter-professional commitment, values, beliefs and capabilities, consequently resulting in the doing and being together as inter-professionals' (74). Building on this reasoning, in chapter 3, we reported on the lack of open communication by specialists towards patients regarding end-of-life issues, which hampered the early integration of palliative home care. In section 3.1. of this general discussion we emphasized the need to share responsibilities as a team and to promote an inter-professional culture during early socialization of healthcare professionals in order to enhance communication regarding end-of-life issues. Considering the study results of chapter 3, we might question to what extent this inter-professional identity is currently sufficiently developed.

The third CAS feature that merits examination is: "A team is an open system and interacts with its environment". This means that teams are connected with their environment in different ways. Some of the internalized rules come from the environment, and emergent behaviors of teams can be seen as adaptations to environmental conditions, also called "self-organization". Next, the boundaries of a team are not static, but can be open or closed as a response to interactions with the environment. Finally, the environment also consists of teams which all influence each other. For instance, a GP can be part of the CAS of a palliative home care team, and simultaneously belong to the CAS of the local organization of GPs and to the CAS of the primary health care system, etc. A team and its environment co-evolve during this interaction (66, 67). In alignment with this CAS feature, we reported in chapter 2 on the experiences of CNs within the temporary team structure of a fluid team and highlighted their adaptability to manage palliative home care in an ever-changing context. This is exemplary for teams who today operate in a complex and rapidly changing environment. Furthermore, next to the palliative home care team, described in chapters 6 and 2, multiple other healthcare professionals are often involved in the care trajectory of patients with palliative care needs. For example, in the case of an oncology patient, the following healthcare professionals could be involved: the care professionals of the oncology team at the hospital, team members from another hospital (e.g. in case of a specific cancer treatment), and specialists from other departments (e.g. a cardiologist or endocrinologist and dietician in case the patient suffered of additional cardiac problems or diabetes). This illustrates that teams currently often change and have to adapt frequently, operating with looser boundaries than was the case in the past (2). With respect to this subject, Bleakly (75) clearly stated that healthcare professionals need to adapt to the fact that clinical teams are constituted on an ad-hoc basis and that cross-team activities are growing in number and are becoming increasingly complex. Today's clinical teamwork thus shifts between established routines and improvisation under uncertain conditions (75). In that respect, coordination, communication and adaptability have been identified as teamwork competencies that can increase the effectiveness across teams (76).

A last topic to discuss concerns workplace learning (WPL) as emergent behavior of inter-professional collaboration. Findings in chapter 6 showed multiple factors influencing the exchange of information and the sharing of expertise, which are prerequisites for WPL. Examples of facilitating factors were: 'Acknowledging and respecting each other's competences results in deliberation and shared decision-making as peers' and 'A tradition of systematic and frequent communication facilitates the initiation of a deliberation in case of problems'. Examples of hindering factors were: 'Doctors stressing the hierarchical structure might hinder open communication' and 'Nurses sometimes avoid confronting doctors with their differing views not to harm relationships'. This results in missed learning opportunities. These examples correspond to some of the results of the realist review in chapter 7, where it was found that hierarchy can hinder WPL, since it can impede a learners' willingness to ask questions or to seek feedback. Having confidence and recognizing others as experts within their professional domain was one of the mechanisms that were conductive to learning. Conversely, if others were not seen as experts and there was limited communication or trust in the others' expertise, learning might be impeded. This result in chapter 7 is also related to the results described in chapter 2, where the demonstration of technical procedures by the expert PHCT nurse resulted in CNs' learning and feeling more confident. Furthermore, in chapter 7, difficult case discussions in multidisciplinary teams or during joint patient visits provided opportunities for learning. Difficult patient case discussions during end-of-life care not only allow for opportunities to learn with, from and about each other at the workplace, but through WPL, they also serve as a means to achieve shared care goals and consequently may improve the continuity of patient care. As such, this is also associated with the topic of 'normative integration', as discussed in section 3.1. Eraut described a set of learning activities for people working together that result in learning as a side-effect of their collaboration. These learning activities are: asking questions, getting information, locating resource people, listening and observing, reflecting, learning from mistakes, receiving feedback and using mediating artefacts (77). These activities can be used in both formal and informal learning situations. Findings in chapter 7 showed that the desire to provide high-quality patient care was an important driving mechanism to learn. Knowing that this has been described as an essential attractor in chapter 6, more attention can be paid to the potential learning opportunities arising from inter-professional collaboration to optimize WPL of healthcare professionals, as an essential part of continuing professional development (78, 79).

4. Methodological reflections

In this dissertation, we used a combination of a qualitative research design and a realist synthesis to address our research aims.

In the following section, methodological reflections are provided. Reflections with respect to the performed qualitative research are presented first, followed by considerations regarding the realist review.

For strengths and limitations of each specific study, refer to the respective chapters in this dissertation.

4.1. Qualitative research

A qualitative research methodology was used in chapters 2-6.

All research questions for the studies in chapters 2-5 aimed to understand the viewpoints of and gain profound insight into the participants' perspectives and experiences regarding inter-professional collaboration in palliative care and patient transfers between care settings in palliative care. A qualitative research design, using both focus groups as well as interviews, was considered most suitable to address these questions.

We chose focus groups to explore the experiences of healthcare professionals (in chapter 3) regarding patient transfers across care settings in palliative care. Conducting focus groups with diverse professionals from different care settings allowed us to collect a wide variety of experiences, through the exchange of views and opinions, and the discussion of similarities and differences. It was regarded the most suitable method for this study. Experiences of patients (in chapter 4) and family carers (in chapter 5) were collected through interviews, because of the sensitive nature of the subject. Furthermore, it enabled participants to speak freely and researchers to thoroughly explore the experiences individually. Similarly, interviewing CNs (in chapter 2) enabled us to carry out an in-depth exploration into their individual experiences of inter-professional collaboration in palliative home care. A key strength of our studies lies in the fact that we have included the experiences and perspectives of a diverse range of people involved in palliative care: patients with palliative care needs, family carers and healthcare professionals of diverse professional backgrounds and working in different care settings, i.e. home care, the nursing home and the hospital. In total, we conducted 9 focus groups and 59 interviews, involving a total of 114 participants. This number ensured a wide variety of views and perspectives embodied in the data.

A next consideration pertains to the data collection for the patient transfer studies (in chapters 3 to 5), which was performed within one of the fifteen palliative care regions in Flanders. The choice of region was influenced by the opportunity to examine its present delivery of palliative care, since the network was planning to reorganize and reform. One of the key strengths is that data collection regarding experiences of the same care processes (i.e. the patient transfers) was carried out simultaneously from the perspectives of healthcare professionals from different settings, as well as those from patients and family carers. This multi-perspective approach not only resulted in an amount of rich data, but also increased the internal validity of the research. A limitation may be the generalizability of the results, as we did not compare our insights to experiences in other regions.

Some additional reflections can be formulated regarding data collection. We cannot exclude the risk of socially desirable answers of CNs in chapter 2, as both interviewers were practicing GPs. However, to mitigate this risk, participant recruitment did not happen within the region of the interviewers' practice. Also, interviews with patients (in chapter 4) and family carers (in chapter 5) were carried out by master students in 'primary healthcare' and 'science in health care management and policy'. Since they were relatively unfamiliar with interview techniques, the principal researcher organized an extensive interview training before interviews were carried out. In addition, feedback on their interview technique was given after the first interviews, to allow for optimization. All master students were practicing clinicians in healthcare, familiar with the topic. Although we obtained a rich data set, we cannot fully rule out that, when addressing such a complex and sensitive subject, the combination of being relatively inexperienced in interviewing and the young age of interviewers may have affected the quality of the collected data.

A last consideration concerns how the secondary analysis of interviews with CNs, PHCT nurses and GPs in chapter 6 was performed. The primary data set was collected by, or under the supervision of, the principal and second author, less than five years before the publication of the research paper. The data set included the experiences of key professionals in palliative home care with regard to aspects of inter-professional collaboration and learning: experiences during collaboration, communication with other professionals, learning from each other during collaboration, and sharing tasks and responsibilities. This was similar to the focus of our study. As such, the data were considered appropriate to study the way a palliative home care team functions from another perspective (80), namely by using CAS principles as a theoretical framework. A strength of using this framework is that it provided insights into inter-professional collaboration, while looking at the perceived interactions of team members (e.g. the meaning of the attractors: 'quality of patient care delivery' and 'inter-professional relationships' and the ways in which healthcare professionals balance between these two attractors). It should be noted that the insights of this study are gained from data based on interactions between team members of ad-hoc teams in palliative home care. We do not know to what extent these insights may be generalized and applied to other contexts and teams. It would therefore be interesting to perform similar studies in fixed teams (e.g. within nursing homes or certain hospital wards) and to compare them against ad-hoc teams for similarities and differences with regard to team behavior and performance.

4.2. Realist review

We used a realist review methodology in chapter 7 to synthesize evidence with respect to workplace learning (WPL) in primary healthcare.

A realist review is an interpretative, theory-driven evidence synthesis that uses cross-case comparison to understand and explain how and why different outcomes are observed in a sample of primary studies (81). A strength of this methodology is its explanatory rather than judgmental focus (81). As we were particularly interested in gaining insights into the circumstances of WPL (when, why, in what circumstances and how it occurred) rather than in the effectiveness of WPL (whether it occurred), a realist methodology was thus regarded as the most suitable review methodology to use.

Another strength is its suitability for studying complex interventions. Workplace learning results from complex interactions in daily practice, during which contextual factors trigger underlying mechanisms to generate different outcomes. To understand the process of WPL through collaboration, the links between context (C), mechanism (M) and outcomes (O) needed to be explored. These C-M-O-links were best explored using the realist methodology.

A notable consideration concerns the scope of the review. We aimed to better understand the process of WPL in primary healthcare. By using this scope, we have been able to provide insights into learning through collaboration in primary healthcare, which include, but are not restricted to, palliative home care.

Furthermore, it should be noted that a realist review is not reproducible in the same way as in a Cochrane systematic review, where key quality features are the technical standardization and clarity of presentation. By contrast, in a realist review, the key quality features are the judgements of the reviewer and the interpretative pathway that demonstrates how the included studies led to the judgements made (81). However, this does not imply that conducting a realist review entails a review process of lesser quality. To ensure the quality of the review, RAMESES training materials and quality standards for realist synthesis (82) and the RAMESES publication standards (83) provide guidance to researchers, enabling them to assess the quality and rigor of the review. Our research group used these materials and standards extensively throughout the review process.

5. Implications and recommendations

Based on the results of our studies, several recommendations can be formulated to improve inter-professional collaboration in palliative care and palliative care delivery, within and across settings. In the following section, a number of implications and recommendations for practice, education, policy and research are brought forward.

5.1. Implications and recommendations for clinical practice

Improve Inter-professional communication

This dissertation revealed several aspects of inter-professional communication that can be improved.

Firstly, study findings in palliative home care showed that the CN-GP collaboration was negatively influenced by a GP's hierarchical style or the absence of open communication. The CNs' resulting coping mechanisms entailed the risk of affecting both the quality of patient care in favor of the relationship with GPs as well as the CNs' professional well-being. It is important that GPs are made aware of these underlying mechanisms, when collaborating with CNs. It is therefore recommended that GPs and CNs collaborate in an atmosphere of trust, openness and equality, respecting each other's roles. Suggestions in this regard may be to increase the opportunities to communicate face-to-face, such as: organizing a CN-GP meeting before the start of a new patient case to streamline patient care or organizing regular meetings to jointly discuss patient issues and treatment goals. This allows for CNs and GPs to exchange and share the necessary information and to agree upon care goals. Furthermore, it enables both parties to gain a better understanding of each other's role. It is furthermore recommended that GPs communicate calmly and clearly and show interest in CNs' views and suggestions (16).

Secondly, results in this thesis illustrated that MDT meetings can be improved in terms of implementation, composition and team meeting performance. Furthermore, next to the aim of achieving shared care goals, a culture of open and joint deliberation is recommended, including a shared decision regarding palliative care options. Similar to the suggestions described in the previous paragraph, the habit of holding regular MDT meetings allows team members to discuss and agree upon patient care goals. It is known, however, that the efficiency of MDT meetings declines when key professionals are absent (24, 25, 84). It is therefore suggested that the meetings are organized in such a way that key professionals are able to attend, for example: by using fixed hours, which simplifies agenda planning or by enabling participants to attend through video-conferencing. Furthermore, it is recommended that attention is paid to the process of the meeting, e.g. that all participants put forward opinions openly and that participants are encouraged to listen to one another.

Thirdly, our studies revealed shortcomings in information exchange, both within and across settings. Experiences described in this dissertation clearly illustrated that poor informational continuity of care negatively affected the quality of patient care. An efficient and effective informational continuity of care remains a major challenge for healthcare professionals involved. It is therefore recommended that more attention is paid to providing information on time (e.g. through timely briefings or discharge reports), registering essential information (e.g. registering the content of ACP discussions rather than registering that it had taken place; providing enough psycho-social and contextual information in case of hospital admission or hospital discharge), and ensuring the information is accessible to those concerned.

Improve physician-patient communication

Next to inter-professional communication, recommendations with respect to physician-patient communication can be formulated. The lack of specialists' open communication towards patients directly affected the organization of appropriate patient care and the collaboration with other healthcare professionals. Hospital specialists should be aware of these consequences. We therefore advocate a team-based approach to end-of-life communication and decision-making in order to overcome barriers of ineffective communication. A suggestion to this end is to include this topic in the agenda of MDT meetings, where agreements can be made on what, when and how information will be given to the patient. This could be advantageous to avoid misunderstandings about what will be said to patients at what point in time. In addition, it allows for colleagues to evaluate how the patient communication went. Finally, sharing such responsibilities can result in the burden of end-of-life communication not resting on the shoulders of a single physician only.

Home care professionals' role is essential to guarantee palliative home care

Study findings in this dissertation confirmed the pivotal role of GPs, CNs and PHCT nurses, in combination with domestic services. They all contributed to high quality palliative home care delivery and patients and family carers feeling supported. It is therefore recommended that GPs are actively involved in an early palliative home care trajectory, where they can pro-actively evaluate the patients' and family carers' changing needs in order to adapt the care organization accordingly. It is suggested that GPs take this initiative themselves rather than wait for a trigger from the specialist, the patient or the family carer before becoming involved.

5.2. Implications and recommendations for education

Develop inter-professional education modules

In line with the implications of practice described above, we believe that the further development of inter-professional education (IPE) modules in health- and social care is essential to improve inter-professional practice. IPE modules can foster a positive interaction among professionals, improve attitudes towards others by bringing different professionals together to learn with one another, but also from and about one another (85). During these IPE modules people learn to collaborate; gain clarity about one's own and others' roles and boundaries; and acquire competences, such as communication with other professionals and disciplines and working within teams, including the ability to resolve inter-professional conflicts (3, 86).

Communication training of physicians

Consistent with the implications and recommendations mentioned above regarding physician-patient communication, more communication training is needed for physicians. Apart from communication training during undergraduate education, advanced communication skills for residents should be trained during postgraduate education. For example, training should address providing clear and tailored information to the patient and the family, initiating advance care planning discussions, and shared decision making on end-of-life care options. Furthermore, it is recommended that advanced communication training modules be provided as part of the continuing medical education program.

5.3. Implications and recommendations for policy

Improve e-health record

In the last decade, much effort has been made to develop e-health record systems – taking privacy regulations into account. However, we believe that the further development is required to improve information exchange between professionals within and across settings in a manner that is easy to use and is easily accessible.

Organize workplace layout to enhance WPL

It has been suggested, in chapter 7, that the electronic patient record not only serves as a means to exchange information, but as an artefact also plays a meaningful role during learning conversations in the workplace. Accordingly, policy makers and managers working in healthcare should stimulate the use of such artefacts. Building on the topic of WPL, study findings in chapter 7 showed that the layout of the workplace affects learning. We therefore recommend that managers organize the workplace layout in such way that it enhances communication between professionals. Facilitating casual encounters between professionals provides opportunities to ask feedback and exchange ideas, thus enhancing WPL, e.g. by organizing coffee breaks.

5.4. Implications and recommendations for research

Research on how aspects of inter-professional collaboration affect the professional well-being of healthcare professionals

Study results in chapter 3 showed that, as a result of professional actions taken by hospital physicians (e.g. insufficient provider-patient communication), other professionals experienced limitations in how they functioned professionally towards the patient, which in turn affected their own professional well-being. There are multiple factors that determine a professional's job satisfaction and mental health. Among others, these include: high job demand, low job control, low workplace support, organizational change, and job insecurity (87). Mental ill health of healthcare workers can lead to an increased risk of patient safety incidents and poorer quality of care (87). Further research can be recommended to explore to what extent and how aspects of inter-professional collaboration influence the professional well-being of healthcare professionals, aside from the factors described above. Additionally, it can also be interesting to investigate to what extent a diminished professional well-being affects inter-professional collaboration.

Research on the effect of physicians' hierarchical attitude and communication style on nurses

In chapter 2 we described the impact of GPs' hierarchical attitude and communication style on CNs' actions and the subsequent side-effect on the quality of patient care. In addition to the suggestions put forward in the previous paragraph, we believe that it would also be useful to further investigate the effect of physicians' hierarchical attitude and communication style on nurses. Remaining research questions that can be formulated are: how often do these conditions occur? How often does it result in affected patient care? Why do CNs continue to act this way? Is there a difference between nurses working in mono-disciplinary practices and those working in multi-disciplinary practices or in other contexts (e.g. hospitals)? To what extent do these conditions influence the CNs' professional well-being? How can this situation be avoided?

Interventions to improve informational continuity of care

Study results in chapters 2 and 4 of this dissertation highlighted a lack of informational continuity of care and illustrated some of its consequences on the quality of patient care. We recommend that more effort is be taken to improve informational continuity between healthcare professionals, both within and across settings. Firstly, it can be suggested to perform a deeper investigation on the current types of sources used to share information, the content of the shared information and the information needs of the professionals involved. Based on these results, interventions can be developed and evaluated to improve informational continuity of care. It has been suggested that electronic palliative care coordination systems may be useful in promoting informational continuity. However, more work is needed to develop and test these strategies (88).

6. Conclusions

This dissertation has increased insights into inter-professional collaboration in palliative care delivery by exploring the experiences of various professionals that deliver palliative care from diverse settings, as well as family carers and patients with palliative care needs. While many positive experiences have been reported with respect to healthcare professionals' commitment and dedication to provide high quality patient care, other results have revealed several aspects of inter-professional collaboration that require improvement, e.g. inter-professional communication and information exchange, agreeing upon shared care goals, and a timely organization of palliative home care that is tailored to the patient's needs.

Additionally, viewing healthcare teams as complex adaptive systems offered explanations for multiple aspects of team behavior, e.g. the meaning of the attractors 'quality of patient care delivery', 'inter-professional relationships' and 'personal and professional well-being', workplace learning as emergent behavior. Finally, we found that WPL through collaboration can be considered an essential part of continuing professional development.

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SUMMARY
SAMENVATTING

Summary

The global need for palliative care increases due to population ageing and rises in incidence of cancer and other non-communicable diseases. Also medical developments have turned deadly diseases into more chronic conditions. Both demographic changes and evolutions in biomedical science have resulted in a growing complexity of the needs of patients with advanced progressive illness.

Healthcare professionals involved in palliative care delivery today are expected to be competent and keep pace with ongoing changes within healthcare, to collaborate inter-professionally, within and across palliative care settings and adapt to rapidly changing and uncertain conditions, in order to provide care that is tailored to the patient's and family's palliative care needs.

In Belgium, the first palliative care initiatives originated in 1980. In the light of the complexity of today's palliative care, it is unclear how palliative care services currently collaborate to provide high-quality care. This thesis aimed to gain a deeper understanding in aspects of inter-professional collaboration in palliative care delivery.

In the first part of this thesis we investigated inter-professional collaboration in palliative home care and across palliative care settings. In the second part, we explored the experiences of patients and family carers with respect to transfers between care settings in palliative care as well as how these settings respond to patients' needs. The third part investigated inter-professional collaboration in palliative home care form a complexity science perspective and workplace learning as emergent behavior of inter-professional collaboration.

This dissertation has increased insights in inter-professional collaboration in palliative care delivery, through exploring the experiences of various professionals from diverse settings delivering palliative care, as well as family carers and patients with palliative care needs. Many positive experiences have been reported with respect to healthcare professionals' commitment and dedication to provide high quality patient care. Results have nevertheless highlighted several aspects of inter-professional collaboration which can be improved, e.g. inter-professional communication and information exchange, agreeing on shared care goals, timely organizing of palliative home care – tailored to patient's needs. Furthermore, viewing healthcare teams as complex adaptive systems offered explanations of multiple aspects of team behavior, e.g. the meaning of the attractors 'quality of patient care delivery', 'inter-professional relationships' and 'personal and professional wellbeing', workplace learning as emergent behavior. Finally, we found that WPL through collaboration can be considered an essential part of the continuing professional development.

SAMENVATTING

1. Inleiding

Wereldwijd is er een toenemende nood aan palliatieve zorg, door de vergrijzing van de bevolking, de hogere incidentie aan kanker en andere niet-overdraagbare aandoeningen, en de medische ontwikkelingen die de levensverwachting van mensen met een ongeneeslijke aandoening hebben verlengd. Als gevolg van deze ontwikkelingen is de complexiteit van de zorgnoden voor mensen met een gevorderde ongeneeslijke aandoening sterk toegenomen.

Om tegemoet te komen aan de complexe palliatieve zorgnoden van patiënten en hun familieleden, is samenwerking tussen zorgverstrekkers essentieel. De betrokkenheid van meerdere zorgverstrekkers die, elk vanuit hun specifieke professionele achtergrond, palliatieve zorg bieden over zorgsettings heen, heeft echter een versnippering van de zorg tot gevolg. Een goede coördinatie en continuïteit van de geboden zorg is dan ook een uitdaging.

De eerste palliatieve zorgorganisaties in België kennen hun ontstaan sinds 1980.

Professionals betrokken in palliatieve zorg de dag van vandaag, worden verwacht om competent te zijn en bij te blijven met de continue veranderingen in de gezondheidszorg. Verder worden ze geacht interprofessioneel samen te werken – zowel binnen als tussen settings – en zich aan te passen aan snel veranderende en onzekere situaties, om zorg te kunnen bieden afgestemd op de palliatieve zorgnoden van patiënten en hun familie. Vanuit de geschetste achtergrond is het niet duidelijk op welke manier professionals in palliatieve zorg dit momenteel realiseren om kwaliteitsvolle palliatieve zorg te kunnen bieden.

2. Onderzoeksdoelstellingen en onderzoeksvragen

Het doel van dit thesisonderzoek is inzichten te verwerven in bepaalde aspecten van de huidige interprofessionele samenwerking in de palliatieve zorg. Deze inzichten kunnen bijdragen tot het optimaliseren van de samenwerking.

Dit thesisonderzoek bestaat uit 3 delen en zes onderzoeksdoelstellingen (elk van de delen heeft 2 onderzoeksdoelstellingen).

De focus van deel I is de interprofessionele samenwerking binnen de palliatieve thuiszorg en overheen settings. De eerste onderzoeksdoelstelling is inzicht verwerven in de teamdynamieken van samenwerkende professionals (huisarts, thuisverpleegkundige en verpleegkundige van de palliatieve thuiszorgequipe) in de palliatieve thuiszorg. Dit wordt onderzocht vanuit het perspectief van de thuisverpleegkundige. De geformuleerde onderzoeksvragen zijn:

- Hoe ervaren de thuisverpleegkundigen de samenwerking met de huisarts en de palliatief verpleegkundige in de palliatieve thuiszorg?
- Welke factoren beïnvloeden deze samenwerking?

Naast zorgverstrekkers uit de thuiszorg zijn ook andere zorgverstrekkers betrokken in de zorg voor patiënten met een ongeneeslijke aandoening. Een transfer tussen zorgsettings (bv. tussen thuis of rusthuis en ziekenhuis en omgekeerd, tussen thuis en palliatieve eenheid) is bij deze patiënten gebruikelijk. Een tweede doelstelling is inzicht verwerven in de samenwerking tussen professionals over settings heen. De geformuleerde onderzoeksvragen hierbij zijn:

- Wat zijn de belevingen van verschillende professionals m.b.t. de interprofessionele samenwerking bij een transfer van patiënten tussen settings in de palliatieve zorg?
- Hoe ervaren ze de manier waarop de patiënt en zijn familieleden worden betrokken tijdens een transfer?

In deel II worden de ervaringen onderzocht van patiënten en mantelzorgers over transfers tussen zorgsettings en hoe deze beantwoorden aan de zorgnoden van patiënten.

Aanvullend op deel I, wordt in deel II verder onderzoek gedaan naar transfers van patiënten tussen verschillende zorgsettings. Een derde en vierde onderzoeksdoelstelling is het exploreren van de ervaringen van patiënten en zorgende familieleden m.b.t. de transfers tussen zorgsettings.

De onderzoeksvragen hierbij zijn:

- Welke zijn de ervaren factoren die de beslissing tot een transfer beïnvloeden?
- Hoe ervaren patiënten de manier waarop zorgsettings aan hun noden beantwoorden?
- Wat zijn de verwachtingen van patiënten t.a.v. de behandelende huisarts m.b.t. het begeleiden van de transfer?

Vanuit onderzoeksdoelstelling 4 worden volgende onderzoeksvragen geformuleerd:

- Hoe ervaren familieleden het ziektetraject van hun naaste m.b.t. de transfers die plaatsvonden?
- Wat is hun houding tegenover de beslissing tot een transfer en welke ervaringen hadden ze hierbij?
- Wat zijn de ervaringen van familieleden t.a.v. de transfers van hun naaste?

In deel III bestuderen we interprofessionele samenwerking in de palliatieve thuiszorg vanuit de theorie van complex adaptieve systemen en het optreden van werkplekleren als gevolg van samenwerken.

De vijfde onderzoeksdoelstelling is om meer inzicht te verwerven in het functioneren van het team zorgverstrekkers dat voorziet in de palliatieve thuiszorg, nl de huisarts, de thuisverpleegkundige en de verpleegkundige van de palliatieve thuiszorgequipe. Dit gebeurt aan de hand van de principes van complex adaptieve systemen (CAS). Daarnaast willen we onderzoeken welke factoren het werkplekleren (WPL) als gevolg van de samenwerking, beïnvloeden.

De onderzoeksvragen bij onderzoeksdoelstelling 5 zijn:

- Hoe kan het functioneren van een team zorgverstrekkers worden beschreven, gebruik makend van de CAS-principes?
- Welke factoren beïnvloeden het werkplekleren, dat voortkomt vanuit een CAS?

De zesde onderzoeksdoelstelling is om het proces van WPL door samenwerking binnen de eerstelijnsgezondheidszorg te begrijpen en de omstandigheden die dit WPL beïnvloeden.

De geformuleerde onderzoeksvragen zijn:

- Wie leert er bij WPL door samenwerking en de eerstelijnsgezondheidszorg?
- Wanneer vindt dit WPL plaats?
- Hoe gebeurt dit WPL?
- Wat wordt er geleerd?

3. Methodes

Om tegemoet te komen aan de onderzoeksdoelstellingen 1 - 5 werd er gebruik gemaakt van een kwalitatieve onderzoeksmethode.

Voor het eerste onderzoeksdoel werden interviews gebruikt gemaakt met 20 thuisverpleegkundigen uit verschillende regio's in Vlaanderen.

M.b.t. onderzoeksdoelstelling 2-4 werd er geconcentreerd op de palliatieve zorg die werd geleverd in één van de vijftien palliatieve zorgnetwerken in Vlaanderen. Deelnemende organisaties waren: de regionale palliatieve thuiszorgequipe, 2 rusthuizen, 2 ziekenhuizen (waarvan 1 met een palliatieve eenheid) en een palliatief dagcentrum van een aanpalende regio. Voor onderzoeksdoelstelling 2 werden 9 focusgroep discussies georganiseerd met zorgverstrekkers van verschillende disciplines en uit verschillende settings. Allen waren betrokken in palliatieve zorg en/of transfers van patiënten met palliatieve zorgnoden. Voor doelstelling 3 en 4 werden interviews afgenomen van 20 patiënten en 21 familieleden. Inclusiecriteria voor patiënten waren: fysiek en mentaal in staat zijn om te worden geïnterviewd, zorg krijgen van één van de voorzieningen uit de regio die palliatieve zorg biedt, recent betrokken zijn in een transfer tussen zorgsettings. Het inclusiecriterium voor interviews met familieleden was: een dicht familielid zijn van een patiënt die zorg kreeg van één van de voorzieningen uit de regio die palliatieve zorg biedt en die recent betrokken was in een transfer tussen zorgsettings.

Voor onderzoeksdoelstelling 5 werd een secundaire analyse verricht van interviews met 21 verpleegkundigen van het palliatieve thuiszorgteam, 20 thuisverpleegkundigen en 18 huisartsen. De principes van Complexe Adaptieve Systemen (CAS) werden gebruikt als kader voor de analyse.

Om tegemoet te komen aan onderzoeksdoelstelling 6 werd een literatuurstudie gebruikt, meer specifiek een realist review methode.

4. Resultaten

4.1. Interprofessionele samenwerking in de palliatieve thuiszorg en overheen settings

In de eerste studie (hoofdstuk 2) bevroegen we de ervaringen van thuisverpleegkundigen over hun samenwerking met huisartsen en met verpleegkundigen van de palliatieve thuiszorgequipes. Elementen die een positief effect hadden op de samenwerking waren: professionals die bereikbaar waren, open stonden voor vragen, de mogelijkheid boden om de situatie van de patiënt te bespreken en die de thuisverpleegkundige betrokken in gezamenlijk overleg. De samenwerking met de palliatief verpleegkundige werd erg gewaardeerd en de meeste thuisverpleegkundigen gaven te kennen vaak op hun expertise beroep te doen. Verschillende elementen hadden een negatief effect op de samenwerking met de huisarts en zette deze samenwerking onder druk. Dit gebeurde in situaties waarbij de huisarts een hiërarchische stijl hanteerde, als er een inkomensafhankelijkheid was en als er geen open communicatie mogelijk was. Dit kon ertoe leiden dat thuisverpleegkundigen terughoudend waren in het uiten van bedenkingen of bezwaren m.b.t. behandelingsbeslissingen. Een alternatieve strategie kon hierbij zijn dat ze de huisarts lieten geloven dat hij/zij het probleem oploste, terwijl zijzelf de oplossing suggereerden. De palliatief verpleegkundigen werden daarentegen beschouwd als gelijkwaardige collega's met wie de communicatie open verliep. Ze hadden bovendien een belangrijke functie als bemiddelaar, in geval van meningsverschillen tussen de thuisverpleegkundige en de huisarts.

In de volgende studie (hoofdstuk 3) bevroegen we de ervaringen van 53 professionals over de interprofessionele samenwerking bij transfers van patiënten. Tijdige en effectieve informatie-uitwisseling werd belangrijk bevonden, doch bleek onvoldoende. Multidisciplinaire teambesprekingen konden worden verbeterd, voor wat betreft de aanwezigheid van deelnemers, de interprofessionele communicatie en de bereidheid om gezamenlijke doelstellingen te bespreken. Ontslag van patiënten uit het ziekenhuis werd vaak als ontoereikend ervaren. Dit had een negatieve invloed op de continuïteit van de patiëntenzorg. Professionals uit de thuiszorg gaven tevens te kennen dat ze te laat betrokken werden in het zorgtraject van de patiënt. Daarnaast werd er een gebrek aan open communicatie ervaren tussen sommige ziekenhuisartsen en patiënten. Tekorten in effectief team functioneren en een effectieve open arts-patiëntcommunicatie verhinderde het tijdig voeren van gesprekken rond vroegtijdige zorgplanning en vroegtijdige integratie van palliatieve thuiszorg. Bijkomend werden andere niet-arts zorgverstrekkers gehinderd in hun zorg t.a.v. de patiënt als gevolg van onvoldoende open arts-patiëntcommunicatie.

4.2. Transfers van patiënten tussen zorgsettings in palliatieve zorg: ervaringen van patiënten en familieleden

In hoofdstuk 4 werden ervaringen van patiënten over hun transfers tussen zorgsettings beschreven.

Thuis was de verblijfplaats bij voorkeur, hoewel er een gevoel van onveiligheid werd ervaren bij toenemende symptomen, bij verminderde activiteiten van het dagelijks leven en als de organisatie van de thuiszorg onvoldoende was afgestemd op de noden van patiënten. Hoewel er verschillende faciliteiten zijn om patiënten en hun familie te ondersteunen bleek dit in praktijk niet steeds te beantwoorden aan de noden. Het rusthuis en de palliatieve eenheid boden veiligheid en goede zorg en werden ervaren als een geschikt alternatief, als thuis verblijven niet meer haalbaar was. Ervaringen met ziekenhuizen varieerden afhankelijk van het ziekenhuis, de afdeling en de reden voor opname. Sommige deelnemers ervaarden een tekortkomingen in de interprofessionele communicatie. Kankerpatiënten voelden zich menselijker behandeld op de oncologie afdeling dan op andere afdelingen. Ervaren problemen bij ontslag uit het ziekenhuis waren: vroegtijdig ontslag, gebrek aan naadloze zorg en de thuiszorg onvoldoende aangepast aan de noden van de patiënt. De rol van de huisarts varieerde van een centrale rol tot eerder een rol op de achtergrond. De huisarts werd vooral verondersteld om de continuïteit van zorg te verzekeren.

In hoofdstuk 5 beschreven we de ervaringen van familieleden over transfers van patiënten tussen zorgsettings.

De beslissing voor een transfer werd bepaald door de balans tussen de zorgverlening (zowel professionele als informele zorg) en de veranderingen in de noden van patiënten. Het vermogen van familieleden om zorg te bieden werd beïnvloed door de mogelijkheid om het dagelijks leven te reorganiseren in functie van de ziekte van de patiënt en de bijkomende extra ondersteuning. De aanvullende professionele thuiszorg (van thuisverpleegkundige, palliatief verpleegkundige, thuiszorgdienst) zorgde ervoor dat familieleden zich niet alleen voelden in het zorgen voor patiënten. Toegenomen zorgnoden van patiënten resulteerde in het organiseren van bijkomende professionele zorg, of een transfer van patiënten als de geleverde thuiszorg onvoldoende werd geacht. De keuze voor de setting werd beïnvloed door praktische factoren (wachttijd, kostprijs, accommodatie en faciliteiten, afstand), levensverwachting van de patiënt en de beleving t.a.v. de setting zelf (bv. Vertrouwd zijn met de setting, de confrontatie met de dood). De palliatieve eenheid werd ervaren als ‘de hemel op aarde’, omwille van de wijze waarop de patiënt en familie werden behandeld en de tijd die door het personeel werd gewijd aan de zorg. Positieve ervaringen werden ook gemeld over de communicatie en de behandeling van patiënten die werden getransfereerd naar het rusthuis. Ervaringen bij transfer naar het ziekenhuis varieerden sterk en waren afhankelijk van het ziekenhuis en de afdeling. Bezorgdheden werden geuit over de interprofessionele communicatie binnen het ziekenhuis en tussen ziekenhuizen. Familieleden hadden nood aan informatie over de toestand van de patiënt. Hun ervaringen varieerden hierbij, gaande van toegankelijke artsen die tijd namen om informatie te geven tot artsen die moeilijk toegankelijk waren.

4.3. Interprofessionele samenwerking in de palliatieve thuiszorg vanuit het perspectief van complex adaptieve systemen en werkplekleren als gevolg van de interprofessionele samenwerking

In hoofdstuk 6 werd er gefocust op het team zorgverstrekkers in de palliatieve thuiszorg, nl de huisarts, de palliatief verpleegkundige en de thuisverpleegkundige. Hierbij werden team interacties en team gedrag bestudeerd volgens de principes van complex adaptieve systemen (CAS) en werkplekleren als gevolg van de samenwerking. De meest voorkomende principes waren “teamleden handelen autonoom, geleid door geïnternaliseerde basisregels”, “attractoren geven vorm aan het functioneren van een team”, “een team heeft een voorgeschiedenis en is gevoelig voor zijn begintoestand” en “een team is een open systeem, dat reageert met zijn omgeving”. Verschillende factoren bevorderden of verhindereden de uitwisseling van informatie binnen het team, wat randvoorwaarden zijn voor werkplekleren.

In hoofdstuk 7 werd het proces van werkplekleren (WPL) door samenwerking in de eerstelijns gezondheidszorg beschreven en de omstandigheden die dit beïnvloeden. Resultaten toonden dat elke professional kan leren van een andere. De motivatie om te leren, als individu of als groep, is een noodzakelijk mechanisme om het leren te laten toenemen. Het leren van anderen bevorderen, kan worden aangeleerd met de tijd.

Werkplekleren wordt beïnvloed door de manier waarop de werkplek is uitgerust en ingericht. De behandeling van moeilijke casussen creëert leerkansen. Zowel geplande als ongeplande activiteiten kunnen leiden tot WPL. Een hoge werkdruk beïnvloedt WPL. Ook gedeelde doelstellingen of verantwoordelijkheden bevorderen het leren. Verder kunnen sterke interprofessionele relaties tussen zorgverstrekkers het leren bevorderen.

Studies toonden aan dat professionals zich vaak niet bewust zijn van het leren dat ontstaat door samen te werken. Observeren of luisteren naar een uitleg is minder efficiënt om te leren dan zelf doen. Reflectie is een belangrijk deel van het leerproces. Dit kan spontaan gebeuren of getriggerd, individueel of gezamenlijk.

Door samenwerking en gezamenlijke interactie verwerven professionals een vollediger begrip van het klinisch probleem. Andere uitkomsten zijn geassocieerd met professionele ontwikkeling of met niet-patiënt gerelateerde topics.

5. Discussie en conclusies

5.1. Interprofessionele samenwerking in de palliatieve thuiszorg en overheen settings

Verschillende factoren hadden een positief effect op de interprofessionele samenwerking, zoals elkaar kennen, toegankelijk zijn en open staan voor vragen, bereid zijn om informatie te delen en dit tijdig en effectief doen, de mogelijkheid voorzien om de situatie van de patiënt te bespreken. Daarentegen, gebrek aan open communicatie en een hiërarchische stijl hadden een negatief effect op de samenwerking. Deze bevindingen sluiten aan bij eerdere onderzoeksresultaten.

Een opmerkelijk resultaat was de aanpak van sommige thuisverpleegkundigen die geconfronteerd werden met de hiërarchische stijl van huisartsen, met wie een gebrek aan open communicatie werd ervaren. Bij bedenkingen over het beleid was hun aanpak soms eerder terughoudend, om de samenwerking met de huisarts niet in het gedrang te brengen. In plaats daarvan gaven ze de huisarts het gevoel dat dat hij het probleem had opgelost, terwijl zijzelf de oplossing hadden gesuggereerd. Deze aanpak beïnvloedde in de eerste plaats de kwaliteit van zorg voor de patiënt, maar ook het professioneel welbevinden van de thuisverpleegkundige. Daarentegen voelden thuisverpleegkundigen zich meer op hun gemak indien ze als gelijkwaardige partners werden behandeld en als de samenwerking met de huisarts niet werd beïnvloed door een hiërarchische stijl.

Multidisciplinaire teambesprekingen werden zinvol bevonden, maar bleken niet altijd gebruikelijk of efficiënt op vlak van samenstelling of de wijze waarop ze verliepen. Onze studieresultaten toonden duidelijk aan dat er mogelijkheden tot verbetering zijn op dat vlak. Deze kunnen de kwaliteit van de patiëntenzorg positief beïnvloeden, alsook de samenwerking binnen het team bevorderen.

De arts-patiënt communicatie binnen de context van het ziekenhuis werd door niet-artsen soms als problematisch ervaren. Een therapeutische hardnekkigheid werd eerder ervaren dan een open gesprek, waarbij de verschillende gepaste behandelingsopties werden besproken. Patiënten werden laattijdig geïnformeerd bevonden over hun toestand en prognose en kregen aldus laattijdig de mogelijkheid tot een transfer terug naar de thuissituatie of de palliatieve eenheid. Professionals in de thuiszorg erkenden dat ze te laat betrokken werden in het palliatief traject van patiënten. Verder bleek er geen eensgezindheid over de timing om gesprekken over vroegtijdige zorgplanning te voeren. Studieresultaten toonden essentiële tekortkomingen m.b.t. het bekomen van gedeelde zorgdoelstellingen. Deze resultaten bevestigen de bestaande evidentie dat een gebrek aan effectief team functioneren en gebrek aan open en effectieve arts-patiëntcommunicatie, de tijdige bespreking van levenseinde beslissingen en vroegtijdige integratie van palliatieve thuiszorg verhindert.

5.2. Transfers van patiënten tussen zorgsettings in palliatieve zorg: ervaringen van patiënten en familieleden

Het onderwerp 'zich veilig voelen' was een belangrijke factor die bijdroeg tot het al dan niet kunnen thuis verblijven van patiënten. Dit gegeven raakt aan de centrale rol van de huisarts, in samenwerking met andere professionals uit de thuiszorg, m.b.t. het coördineren en tijdig organiseren van de palliatieve thuiszorg, aangepast aan de noden van de patiënt en zijn familie. Onze studieresultaten bevestigden het belang van vroegtijdige integratie van palliatieve thuiszorg, efficiënte organisatie van de zorg en effectieve interprofessionele samenwerking om bij te dragen tot het zich veilig voelen van patiënten en hun familie en kwaliteitsvolle zorg te kunnen bieden.

Een transfer van patiënten werd beslist in geval van onevenwicht tussen de zorgnoden van patiënten enerzijds en de geboden zorg anderzijds. Uit eerdere literatuur blijkt dat sommige van deze transfers bij het einde van het leven kunnen worden vermeden. Continuïteit van de geboden thuiszorg is dan ook essentieel.

De verwachtingen en ervaringen van patiënten en familieleden t.a.v. het ziekenhuis varieerde sterk. Het ziekenhuis werd beschouwd als de plaats waar er directe en continue hulp kon geboden worden in situaties waarbij de thuiszorg ontoereikend of onhaalbaar was. Echter, onze studieresultaten brachten verschillende domeinen op gebeid van samenwerking aan het licht, die kunnen worden verbeterd, zoals: informatie-uitwisseling tussen zorgsettings; effectieve interprofessionele communicatie en arts-patiëntcommunicatie; bespreking van gedeelde zorgdoelstellingen; en organiseren van de zorg afgestemd op de noden van patiënten en familieleden.

5.3. Interprofessionele samenwerking in de palliatieve thuiszorg vanuit het perspectief van complex adaptieve systemen en werkplekleren als gevolg van de interprofessionele samenwerking

Eén van de CAS-kenmerken is: "Attractoren geven vorm aan het functioneren van een team", zijnde de drijvende kracht van een team. Studieresultaten toonden 3 attractoren die het dagelijks functioneren van het team bepaalde, nl: de kwaliteit van de patiëntenzorg; interprofessionele relaties en persoonlijk en professioneel welbevinden. Afhankelijk van de omstandigheden wijzigden en pasten teamleden hun gedrag aan, waarbij ze balanceerden tussen de kwaliteit van zorg voor de patiënt enerzijds en het in stand houden van een goede interprofessionele relatie anderzijds.

Een ander belangrijk CAS-kenmerk is: "teamleden handelen autonoom, geleid door geïnternaliseerde basisregels". De belangrijkste basisregels die de professionele attitude van de teamleden vormde was: "We zijn hier voor de patiënt". Deze regel staat ook nauw in relatie tot de attractor "kwaliteit van de patiëntenzorg" en is geassocieerd met de topic professionele en interprofessionele identiteit.

Het CAS-kenmerk: "een team is een open systeem, dat reageert met zijn omgeving", betekent dat teams op verschillende manieren verbonden zijn met hun omgeving. De dag van vandaag werken teams vaak in lossere verbanden en teamstructuren, waarbij een zorgverstrekker tijdelijk kan deel uitmaken van een team en simultaan kan behoren tot meerdere teams. Zorgprofessionals dienen zich aldus continu aan te passen aan het gegeven dat klinische teams op ad-hoc basis worden gevormd en dat verantwoordelijkheden over de teams heen toenemen in aantal en in complexiteit.

Verschillende factoren werden aangetoond die een bevorderende of belemmerende invloed hadden op werkplekleren door samenwerking. Een belemmerende factor kan de aanwezigheid van een hiërarchische stijl zijn, als dit het stellen van vragen of feedback verhindert. Hebben van vertrouwen en de ander erkennen als expert binnen zijn domein, waren condities die het werkplekleren bevorderden. Bespreken van moeilijke patiëntsituaties in multidisciplinaire teams bood niet enkel de gelegenheid om te leren met, van en over elkaar, maar laat ook toe om gedeelde zorgdoelstellingen te bespreken, wat de continuïteit van zorg kan bevorderen. Kwaliteitsvolle zorg willen bieden bleek een belangrijke drijfveer om te leren. Meer aandacht kan besteed worden aan potentiële leerkansen die resulteren uit interprofessionele samenwerking, om het werkplekleren - als deel van het levenslang leren - te bevorderen.

DANKWOORD

Ithaka

Als je de tocht aanvaardt naar Ithaka
wens dat de weg dan lang mag zijn,
vol avonturen, vol ervaringen.
De Kyklopen en de Laistrygonen,
de woedende Poseidon behoef je niet te vrezen,
hen zul je niet ontmoeten op je weg
wanneer je denken hoog blijft, en verfijnd
de emotie die je hart en lijf beroert.
De Kyklopen en de Laistrygonen,
de woedende Poseidon zul je niet treffen
wanneer je ze niet in eigen geest meedraagt,
wanneer je geest hun niet gestalte voor je geeft.

Wens dat de weg dan lang mag zijn.
Dat er veel zomermorgens zullen komen
waarop je, met grote vreugde en genot
zult binnenvaren in onbekende havens,
pleisteren in Phoenicische handelssteden
om daar aantrekkelijke dingen aan te schaffen
van parelmoer, koraal, barnsteen en ebbehout,
ook opwindende geurstoffen van alle soorten,
opwindende geurstoffen zoveel je krijgen kunt;
dat je talrijke steden in Egypte aan zult doen
om veel, heel veel te leren van de wijzen.

Houd Ithaka wel altijd in gedachten.
Daar aan te komen is je doel.

Maar overhaast je reis in geen geval.
’t Is beter dat die vele jaren duurt,
zodat je als oude man pas bij het eiland
het anker uitwerpt, rijk aan wat je onderweg verwierf,
zonder te hopen dat Ithaka je rijkdom schenken zal.
Ithaka gaf je de mooie reis.
Was het er niet, dan was je nooit vertrokken,
verder heeft het je niets te bieden meer.

En vind je het er wat pover, Ithaka bedroog je niet.
Zo wijs geworden, met zoveel ervaring, zul je al
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K.P. Kavafis (1911). Vertaald uit het Grieks: Hans Warren en Mario Molengraaf

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Publications

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- Mertens F, Pype P, Deveugele M. Managing evidence on communication in healthcare : an introduction to realist reviews. International Conference on Communication in Healthcare 2017, Baltimore. (conference workshop)
- Mertens F, de Groot E, Meijer L, Wens J, Cherry G, Deveugele M, et al. Workplace learning through collaboration in primary healthcare : a realist review of what works, for whom, and in what circumstances. International Conference on Communication in Healthcare 2017, Baltimore.
- Mertens F, Pype P, Debrulle Z, Lindskog E, Deveugele M. Health care professionals' experiences with palliative patients' transfers : a focus group study. International Conference on Communication in Healthcare 2017, Baltimore.
- Fien Mertens. Suboptimale palliatieve sedatie in de eerstelijnsgezondheidszorg: een exploratie. 14de Vlaams Congres Palliatieve Zorg 2017, Gent.
- Mertens F, Pype P, Derycke A, Naert L, Deveugele M. Patient involvement in the decision making process of transfer : palliative patients' perspective. European

Association for Communication in Healthcare, EACH International conference 2016, Heidelberg.

- Mertens F, Pype P, Deveugele M. Managing evidence on communication in healthcare : an introduction to realist reviews. Communication in Healthcare, 13th International conference. American Association for Communication in Healthcare (AACH); 2015, New Orleans (conference workshop)

Poster presentation

- Fien Mertens, Zoë Debrulle, Evelyn Lindskog, Luc Deliens, Myriam Deveugele, Peter Pype. Ervaringen van zorgprofessionals bij transfers van palliatieve patienten tussen settings: een focusgroep onderzoek. Nederlands-Vlaamse Wetenschapsdagen Palliatieve Zorg 2019, Antwerpen.
- Mertens F, Callewaert Ch, Coppé H, Pype P. Palliative patients' use of Potentially inappropriate medication: how to reduce this in clinical practice? European Association for Palliative Care 2019, Berlijn.
- Mertens F, Pype P, Deveugele M. Managing evidence on palliative care: are realist reviews feasible? European Association for Palliative Care, 9th World research congress 2016, Dublin.
- Pype P, Mertens F, Belche J, Duchesnes C, Kohn L, Vrijens F, et al. GPs' participation in multidisciplinary oncology consultations interview study in Belgium. European Association for Palliative Care, 14th World congress 2015, Kopenhagen.
- Pype P, Mertens F, Belche J, Duchesnes C, Kohn L, Vrijens F, et al. GPs' participation in multidisciplinary team meetings in oncology : interview study in Belgium. Communication in Healthcare, 13th International conference, Abstracts. American Association for Communication in Healthcare (AACH); 2015, New-Orleans.
- Pype P, Mertens F, Deveugele M. Can nurses be trained as facilitators for physicians' learning? European Association for Palliative Care, 8th World research congress 2014, Lleida.

Other:

- Training Vroegtijdige zorgplanning binnen de huisartspraktijk – in kader van gerandomiseerd gecontroleerd onderzoek PhD project Julie Stevens 2020
- Basisopleiding palliatieve zorg voor artsen – topic communicatie 2019
- Training werkplekleren voor PST-medewerkers 2018-2019, 2021
- Training werkplekleren voor MBE-medewerkers 2017-2018
- Invited workshop RCSI Dublin 1/7/16: "From idea to reality. How to perform a realist review?"
- LOK-trainer LOK pakket Palliatieve sedatie en Delier