Team Interactions in Specialized Palliative Care Teams: A Qualitative Study

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Abstract

Background: Teamwork is a standard of care in palliative care and that is emphasized by leading organizations. When interdisciplinary teams communicate their varied assessments, outcomes may be more than additive due to the synthesis of information. Interprofessionality does not guarantee multidimensionality in health care interventions, however, and that interprofessional teams promote collaboration may be questioned.

Aim: The aim was to explore team interaction among team members in specialized palliative care teams.

Design: Semistructured interviews were conducted with health professionals working in specialized palliative home care teams. The interviews were analyzed by content analysis. Setting/participants: Participants were recruited from specialized palliative care units in Sweden. The 15 interviewees included 4 men and 11 women. Physicians, nurses, paramedical staff, and social workers were included.

Results: Organizational issues like resources and leadership have a great impact on delivery of care. Competence was mirrored in education, collaboration, approach, and support within the team; while communication was described as key to being a team, resolving conflict, and executing palliative care.

Conclusion: Communication and communication patterns within the team create the feeling of being a team. Team climate and team performance are significantly impacted by knowledge and trust of competence in colleagues, with other professions, and by the available leadership. Proportions of different health professionals in the team have an impact on the focus and delivery of care. Interprofessional education giving clarity on one’s own professional role and knowledge of other professions would most likely benefit patients and family caregivers.

Introduction

Teamwork is a standard of care within palliative care and that is emphasized by leading organizations.1,2 However, depending on context, the definition of a team may be unclear.3 Teamwork may be defined as a dynamic process involving at least two health professionals, having a common or tangential goal, which includes assessing, planning, performing, and evaluating patient care. Interdependent collaboration, open communication, and shared decision making are defining attributes. Interdisciplinary collaboration has been defined by Bruner as an interpersonal process that leads to achieving goals that could not have been reached by a single team member.4 Team researchers in health care suggest a view of teams as being complex, adaptive, dynamic systems that exist in context and perform over time.5,6

Conceptual framework

Three models of organizing and executing teamwork are described in the literature and can be described in statements (see Table 1). Bronstein’s model identifies components for interdisciplinary collaboration.8 Interdependence is the reliance on other professionals in order to finish the task; newly created professional activities refers to collaborative acts that accomplish more than independent acts; flexibility refers to deliberate role-blurring, with roles changing due to an existing need; collective ownership of goals refers to all involved sharing responsibility for success; and finally, reflection on process refers to thinking and talking about the process, including feedback to improve outcomes.

Research in palliative care suggests that health professionals’ personalities and professional boundaries may
influence the quality of teamwork; quality of care; and, in effect, the quality of life for patients and families. Furthermore, indications are that ambiguity regarding teamwork may give room to local-level interpretations; and, consequently, lack of teamwork can easily be pointed out as the main problem even though organizational structures and issues may be contributing. Palliative care is a complex field including medical, ethical, psychological, social, existential, and emotional dimensions. Indications are that as interdisciplinary teams communicate their varied assessments, outcomes may be more than additive due to the synthesis of information. Joining expertise and knowledge from different professions may increase creativity, which is a benefit in today’s complex society. Teamwork is launched as a remedy for shortcomings, whether organizational, personal, or resource generated. However, interprofessionality does not guarantee multidimensionality in health care interventions; and the notion that multidisciplinary teams promote collaboration may be questioned.

The aim was to explore team interaction among the members of specialized palliative care teams.

Methods
To describe the inherent complexity in the palliative care setting, where multidimensional views of persons are a standard and where several independent professions are expected to collaborate, a qualitative approach was used.

Setting and participants
Purposive sampling of teams was used enabling a broader perspective by ensuring participants from different geographic locations, teams of varying sizes, and teams from both urban and rural areas in Sweden. Five specialized palliative homecare teams, including physicians, nurses, paramedical staff, and social workers were included. Inclusion criteria were health professionals working in specialized palliative care teams with the above professions (Table 2). All invited teams agreed to participate and interviews were scheduled via email.

Procedure
The interviews were conducted, by the first author, in a location convenient to the interviewees; all chose their place of employment. Open-ended questions were used with an interview guide consisting of categories in a mind-map fashion. Bronstein’s components for interdisciplinary collaboration were used in constructing the interview guide. A pilot interview was performed and consequently minor revisions were made. After consent, each interview was audiorecorded. Field notes were made of impressions and thoughts. After three initial interviews the research group listened to audiotapes to evaluate interview technique and to assess the interview guide with regards to aim congruence. An additional track regarding competence in coworkers was added to the interview guide at this time, since that factor had emerged as important in the initial interviews. Interviews lasted between 45 and 90 minutes.

Data analysis
Data was transcribed verbatim and analyzed through content analysis. The research group found that the qualifications of the coders were crucial, because the coders needed to be familiar with the material and investigated phenomena, as in the case of the research group. The research

Table 1. Team Functioning: Roles, Coordination, and Leadership

<table>
<thead>
<tr>
<th>Multiprofessional</th>
<th>Interprofessional</th>
<th>Transprofessional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Team roles are specialized and everyone concentrates on her or his own tasks.</td>
<td>Roles are specialized but everyone is expected to interact.</td>
<td>Although roles are specialized, everyone must also be prepared to replace each other when necessary.</td>
</tr>
<tr>
<td>Coordination is based on supervision or standardization.</td>
<td>Everyone has to coordinate their own activities.</td>
<td>Coordination is achieved by close interaction, flexibility, and improvisation.</td>
</tr>
<tr>
<td>The team leader functions as a traditional manager.</td>
<td>The team leader functions as a “coach.”</td>
<td>The team leadership varies with the situation; the team is self-regulated.</td>
</tr>
</tbody>
</table>

Table 2. Characteristics of Participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number of participants (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>30–40 years</td>
<td>1</td>
</tr>
<tr>
<td>41–50 years</td>
<td>5</td>
</tr>
<tr>
<td>51–60 years</td>
<td>6</td>
</tr>
<tr>
<td>61–70 years</td>
<td>3</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>11</td>
</tr>
<tr>
<td>Men</td>
<td>4</td>
</tr>
<tr>
<td>Years working in palliative care</td>
<td></td>
</tr>
<tr>
<td>5–8 years</td>
<td>5</td>
</tr>
<tr>
<td>9–14 years</td>
<td>5</td>
</tr>
<tr>
<td>15–20 years</td>
<td>2</td>
</tr>
<tr>
<td>&gt;30 years</td>
<td>3</td>
</tr>
<tr>
<td>Profession</td>
<td></td>
</tr>
<tr>
<td>Registered nurse</td>
<td>5</td>
</tr>
<tr>
<td>Physician</td>
<td>5</td>
</tr>
<tr>
<td>Paramedical staff</td>
<td>3</td>
</tr>
<tr>
<td>Social worker</td>
<td>1</td>
</tr>
<tr>
<td>Assistant nurse</td>
<td>1</td>
</tr>
<tr>
<td>Geographic location</td>
<td></td>
</tr>
<tr>
<td>Urban area</td>
<td>9</td>
</tr>
<tr>
<td>Suburban area</td>
<td>3</td>
</tr>
<tr>
<td>Rural area</td>
<td>3</td>
</tr>
</tbody>
</table>
group consisted of a physician and professor with extensive clinical and research experience in palliative care; one nurse with a PhD and long experience with palliative care and research in the field; one nurse and associate professor with extensive experience of qualitative methods; and a doctoral student, a nurse with palliative care experience. Content analysis was performed by immersion as described by Malertud.24 The transcribed material was read repeatedly, one interview at a time, and then sentences relevant to the aim were digitally colored alternately in yellow and green, and placed in one table per interview. Next the codes were condensed, close to the original meaning. The following step entailed interpretation of meaning and was documented in the table. Subthemes and themes emerged in an empirical fashion and were not preexisting categories (see Table 3).

When all interviews were preliminarily analyzed by the first author and reviewed by the research group, the group performed individual coding of 10% of all meaning units.19 Three categories from the empirical material were given, and each person sorted each meaning unit into one of the categories.25 The intent was to strengthen trustworthiness and to promote analytical rigor.21,24 Coding was compared; and where it differed, areas were reconsidered and discussed until consensus was reached.

The next step consisted of returning to the material trying to capture a sense of a whole. Each interpretation was re-evaluated and sorted into the categories. Sometimes similar words had been used in the individual analyses, aiming for congruence; choices were made as to use of words. For example, cooperation and collaboration had been used

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Condensation</th>
<th>Interpretation</th>
<th>Subtheme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I believe it is important to have one leader for all, because leading is a big issue. But the important part kind of is... it is not a flat line process, it is a hierarchical decision making process... It is based on material that benefits from input by several people and how you work in the team.”</td>
<td>I believe it is important to have one team leader since leadership is imperative. The decision making process is hierarchical and benefits from being based on impressions from several team members.</td>
<td>Leadership</td>
<td>Organization</td>
<td></td>
</tr>
<tr>
<td>“Well... we all have issues, tragic events that we were a part of and that keep building up all the time, eventually you’re had it! You might need to talk about it... We’re all different, maybe not all...” but... maybe you get stuck on things, going over it in your mind. Could I have done something differently? And maybe you want confirmation and stuff like that.</td>
<td>One has issues and tragic events that keep building up inside; eventually one cannot deal with it. You need to talk about it. We are different, but maybe we need confirmation.</td>
<td>Support group</td>
<td>Communication</td>
<td></td>
</tr>
<tr>
<td>“Needs change so fast, so you do an important assessment and come up with a result and then you start over again. That’s why I build on experience instead and that may be a problem since it makes it more difficult.... Because what I think in my head is not visible to others. It is difficult for others to understand that I actually perform this process in my head, that my conclusion of using this tool is only one of our options.”</td>
<td>Needs change so fast that as soon as you make an investigation you’ll need to start over. You’ll have to build on experience instead. It is more difficult because others cannot see the process in my head. This tool is only one of our options.</td>
<td>Approach</td>
<td>Competence</td>
<td></td>
</tr>
</tbody>
</table>

Table 3. Example of Analysis22
interchangeably—now cooperation was chosen for the theme organization, while collaboration was chosen for competence. After all data were sorted into different categories, each pile was read through several times and a summary was verbalized and documented.

Ethical approval was granted by the regional ethical review board, Stockholm, Sweden.

Results

Results are presented in themes and subthemes as illustrated in Figure 1. Narratives by participants were evenly distributed among the main three themes. Quotations are identified by profession only in order to protect participant confidentiality.

Organization

Resources. Inadequate resources and prioritizations were described by participants as resulting in a focus on solving immediate problems instead of promotion and prevention of suffering among patients.

“If I had more time I could do more for the patients. This is like putting out fires somehow. … One could be a step ahead and prevent in another way…being ahead.” (nurse)

Available resources influenced health professionals’ schedules and team constitution. Staff expressed that they needed interventions from paramedical staff, but that it was not always available.

“I miss professions in the team, I’d like more resources from others, paramedical resources, social worker, psychologist…. We write about this every year. I don’t think it has to do with team constitution, it is seen as too costly. I guess it is a question of money as always.” (nurse)

Coordination. Seeing the patient from a holistic perspective was facilitated by combining impressions and discussing patient and family caregivers’ situations in the team.

“If I go to a patient for five minutes, of course I have an impression, but if a physiotherapist, an occupational therapist, a nurse, and a social worker all spend five minutes each with the patient, you get a completely different picture.” (physician)

Coordination entailed combining forces to solve problems and optimize patient care. Participants expressed frustration at being limited by time and number of patients. Many felt that they could provide better care, but that present conditions and resources did not allow it.

Mission. This area was the one with most congruent answers. All were in agreement that their mission was to provide good palliative care in the home. Some used words like dignity, respect, and autonomy; while others stayed with more concrete interpretations.

“We make it possible to be at home during a difficult illness and we make it work with family…to find a well-being that is anything from good to acceptable, instead of long periods in the hospital…. All this to be able to offer a dignified life.” (physician)

Different health professionals tended to use different words when describing the purpose of care. Physicians often used dignity, paramedical staff independence, social workers self-image, and nurses tended to focus on everyday functioning, making life at home work.

Leadership. Leadership was an area with diverse ideas expressed by the participants. There were strong opinions regarding leadership; some felt that the team must be led by a physician with the longest formal medical education. Others regarded the profession of the leader as irrelevant; more important was personal aptitude to facilitate and lead groups.

“I think it is important to have a holistic perspective in the team as well, so I believe it is important to have the same leader…that it is a wise person who has the required attributes. Like if it is a physician that all categories of staff feel that they get support in the team. If a physiotherapist is the formal leader, well it is still important that all feel that it does not depend on the profession…all of this…that it creates security in the group.” (nurse)

Some units had different leaders for different professions.

“We have one manager/leader for the paramedical staff, one for the nurses, and one for the physicians…. So, the person charged with leading the team does not have power to be a leader…. Well, it’s complicated, but it clearly affects how the team functions.” (occupational therapist)

There was consensus among the participants that the formal leader is responsible for creating a team atmosphere and leading the team.

“It is a manager’s responsibility to create possibilities and to have an idea of what a team actually is and should be…and to have the ability to sort of shape it…. This is a team and this is how you achieve it.” (physiotherapist)

Competence

Education. All participants reported having no formal education for teamwork. Several reported having attended courses on communication, but nothing on teamwork. Furthermore, when asked about what other professions in the team do, only one participant could state this without doubt. Vague descriptions like “nurses care for patients” or “occupational therapists give practical aids” were common.

Collaboration. Collaboration included descriptions of how teams work to be efficient and the atmosphere needed to encourage collaboration.
“Each team member must have an assignment that they feel is theirs and that ‘I am not expendable.’ I think that is crucial, no one wants to feel that ‘I am replaceable’ and that nothing changes even if I disappear. Nothing happens if I disappear. … No one wants to feel that. You need to feel that it is good that you are here, because you bring us closer to our goal.” (nurse)

Some describe close collaboration in this manner: “It is like a borderland, we cross over into each other.” (physiotherapist)

**Support.** The support as described by the participants was directed both at patient and family caregivers and at health professionals in the team. Supporting each other in a demanding caregiving setting was regarded as a prerequisite for staying in the field.

“It is allowed to say that you’ve had a bad day and you get encouragement back. … You can say that I’ve made a fool out of myself, it did not go well at all, and someone will try to support you. I mean, the successful moments you can manage by yourself, it is when you feel like a failure that you need to discuss and talk to someone.” (nurse)

**Approach.** In this subtheme there were expressions of adapting to individual patients, family caregivers, and homes.

“When you come to a patient’s home you’ll have to sort of feel…. Some you can go in and ha ha, make jokes while others…you’ll have to be more timid and quiet and use a soft voice, again…. Others like a tougher jargon. You have to figure this out. It is a fun part of the job.” (nurse)

Approach was relevant with regards to personal coping in palliative care.

“You cannot bring it home and go over it again and again…. Life is like that. It is not fair, you’ll have to think that and make the best of it.” (occupational therapist)

**Communication**

**Modes of communication.** Modes of communication between team members were similar in all teams. Verbal communication, either face to face or by phone, was most common. All teams had patient conferences at least once a week and all teams had short morning meetings on weekdays. Not all health professionals were present at the morning meetings, because paramedical staff and social workers often had different schedules and other responsibilities beside the palliative care team.

**Being a team.** Responses about communication in the team and mindset in team communication were gathered here.

“The most important is to have respect for each other and that you listen to each other. Everyone’s opinion is equally important in a team context. There could be a medical decision that needs to be made and one that is not in line with what the rest of the team wants… but showing respect is most important.” (physician)

Some responses indicated need for defined responsibilities in order to avoid competition between health professionals. If the focus of the team effort was not clear, then professional boundaries and responsibilities were questioned and challenged. This was described as hindering patient care.

“When we are there together, we can combine our strengths and make sure that it does not become a competition… like, it is my turn to talk now! That is the type of problem that can occur if one does not see what needs to happen here.” (physician)

Being confident and assertive regarding performance in a team context was described as a positive characteristic. This assured that patients and family caregivers felt safe and taken care of.

“I think patients feel that early on here they get an impression that we communicate with each other and that we say the same things. I think that makes them feel safe, we are a team.” (physiotherapist)

If patients do not feel safe and taken care of, it was described like this:

“The risk is that you lay down too early sort of, you stop living and you’re just surviving…you are not living.” (social worker)

**Professional support group.** All teams and team members were offered time to participate in a professional support group. The support group offers sessions based on current issues or topics suggested by group members. These participants all chose to be a part of this kind of group and described it as beneficial to their work.

“I am talking from my own perspective here, I get support in my thinking, I get support in my doubts which make me walk out of a session stronger into a situation next time.” (nurse)

Some team members declined participation in the support group. This was described as difficult to understand by those who participated. Some felt that it should be mandatory in working with dying persons.

**Conflict.** In teamwork, with groups having to coordinate, collaborate, and plan together, conflict was described as a natural occurrence in group processes. Some participants chose to call it a disagreement rather than a conflict. A generic description was that someone was irritated about something, felt upset, and grumbled. Eventually, the issue was brought up for discussion in the group and solved one way or another.

“You will have to gather all impressions and try to find out what the problem is. Often conflicts surface when there is something outside the medical field that complicates matters with the patient.” (physician)

Responses were congruent; since palliative care is complex, issues outside medicine have a large impact on the teamwork. Social issues with substance abuse, interfamilial relations, or legal implications of impending death were described by several participants.

**Discussion**

Competence, communication, and organization are the three main themes in the results of this study. Indications are that working in a specialized palliative care team is influenced by organization, including allocated resources, individuals’ competence and leadership style. Furthermore, collaboration, which requires conscious effort, is imperative; and being a team is demonstrated in communication patterns within the team, as well as with patients and family caregivers. It is noteworthy that the participants had long experience of working in a palliative care team and yet indicate that
teamwork nonetheless is difficult. Since palliative care emphasizes teamwork, and working in a team is considered a core value, this is challenging. Maybe one function of the team is to support staff working in a zone of existential extremes (which palliative care can be), rather than performing as a team with patients? It seems difficult to move from working multiprofessionally to working intraprofessionally. Great trust is placed on teams in health care as instrumental to guarantee quality of care, patient satisfaction, and safety. The current specialization of services and professionalization of different occupations makes collaboration a necessity for successful teamwork.

The emerging picture of specialized palliative care teams in Sweden indicates that teams seem to function well and team members feel like they fulfill their purpose of providing end-of-life care in the home, maintaining dignity, autonomy, and a sense-of-self in patients. The teams themselves struggle with making ends meet, i.e., being there and providing care despite time constraints, insufficient staffing, and unclear professional roles, as well as absent or autocratic leadership. Participants in the teams describe discussions where all are invited to make their point irrespective of profession. Interdependence is one of Bronstein’s components of interdisciplinary collaboration; in the present study, interdependence does not seem to be acknowledged by all team members, thus presenting a major obstacle to collaboration. Newly created professional activities is another component that may or may not be fulfilled in these teams. All teams do not have structures to ensure that the expertise of each collaborator is maximized; specifically, paramedical staffs seem to be marginalized. Role-blurring and flexibility were described by some participants, as was collective ownership of goals. Some described goals in conflict with each other, depending on which profession set the goal and individuals guarding professional turf. The final component is reflection on process. This was described by all participants, but on a voluntary basis. This means that all team members do not participate in reflection. If Bronstein’s model is used as an ideal, it is clear that specialized palliative care teams in Sweden have challenges and need to target efforts to improve collaboration further.

Several participants expressed that other team members do not understand their profession nor what they do. Most participants could not describe what the other professions do. This is in accord with national research and needs to be studied further. Considering the structure of home care, this becomes problematic, since not all professions meet the patient in the home. Referrals are based on the knowledge in the person physically in the home with the patient. Patients’ symptoms and needs are filtered through one person’s competence and profession before they reach the intended person of another profession; in other words, one person meets the patient and then describes the situation to another. Health professionals seem to have different foci with their interventions: maintaining dignity, strengthening self-image, and “making it work at home.” Considering the lack of knowledge regarding competencies in other professions, this might present a problem, as confirmed by participants among paramedical staff, who expressed frustration at being alone in their profession and called in too late, causing unnecessary suffering in patients and family caregivers. Whether team members work toward a common goal or not has not been clarified by this study. Clearly, organized interprofessional teams do not guarantee multidimensional perspectives in patient care.

Collaboration takes time; and lack of time was emphasized by several participants. A recent study investigates time; these teams allocated approximately 10% of their working time to internal team meetings, but evidence suggests this is not a reliable predictor to team interdependence; rather team climate and team organization are key factors in team “tightness” or interdependence. Perhaps lack of time is an excuse to not engage in time-consuming collaboration, or teams do not have time to discuss or plan interventions and thereby lack a common purpose or strategy? Time is not the sole redeemer if team climate means more to team performance. Perhaps teams in the present study have a climate conducive to collaboration that overrules time constraints and insufficient staffing; so members underestimate the time invested in planning, because it flows smoothly and inconspicuously, without question.

Leadership was an issue that elicited highly intense but varying answers. Perhaps it can be understood from the perspective of territoriality. Territorial behavior among professionals and managers is a barrier to interprofessional collaboration. Territorialism means guarding your own turf and feeling threatened if someone else intrudes. Interprofessional teamwork entails sharing knowledge and planning care together with at least one other professional group. Territorial behavior may be triggered and thereby collaboration is prevented. Collaborating across professional boundaries means ceding territory and seeing beyond one’s own interests. Participants expressed differing opinions of which profession should be leader of the team. Most preferred their own profession as leader, stating that at least “they understand.” Moving beyond territoriality requires giving something up (professional territory) and putting someone else (the patient) first.

Education regarding work in a team structure was nonexistent in these participants even though palliative care is a complex field including multiple dimensions. These results are remarkable, since formal organization requires collaboration between independent professions. Indications from interprofessional education in health care are that there are multiple benefits of interprofessional education, for example clarity of one’s own professional role as well as knowledge of other professions. It seems probable that this knowledge would benefit health professionals in specialized palliative care, and therefore patients and family caregivers. Effective team functioning does not occur without effort; training and education are needed.

Teamwork can be executed in different ways; delineated models include descriptions of roles, coordination, and leadership within multi-, inter-, and transprofessional teams. Study participants described strategies and interventions belonging in several of these model categories—an uneven profile, that is commonly to be expected. The results suggest that the origin may be found in organizational issues and resources. If leadership is not in line with an interprofessional model, for example, this creates a barrier for team members. Teamwork is complex, dynamic, and adaptive; or it could be given supportive circumstances. Focused efforts on role clarification, leadership style, and development of interprofessional competence would increase odds for effective collaboration and higher quality of palliative care.
In this study professions seem to have different goals with their care. This raises questions of team constitution, since physicians and nurses numerically dominate teams in Sweden, while paramedical staff and social workers constitute smaller fractions. Looking at different proportions of the professions could radically change teams from a medical framework to embrace other dimensions. Palliative care is stated multiple times to have medical, ethical, psychological, social, existential, and emotional dimensions. Presently teams do not seem to mirror this, since medical and nursing perspectives are dominant by force of numbers. Possible dimensions may be lost due to lack of competence in certain areas. Additional studies are needed for more conclusive results.

The participants’ lengthy experience of working in specialized palliative care teams most likely affects the result; perhaps one can assume that they are comfortable in palliative care, having mostly positive impressions. Choosing the date for the interview and asking to interview a person on duty that specific day was an attempt at reducing this effect. Performing interviews and gathering information from the persons interviewed requires familiarity with the research area and skill in creating an atmosphere conducive to rich descriptions of opinions and experiences.

Limitations

This study concerns the staff perspective, i.e., the focus is how team members experience the team function. Maybe the findings would be more easily generalized if they also included the view of the patient as well as significant others. Several studies indicate that the patient and the significant others around him or her could be regarded as part of the palliative team.

From a methodological point of view, other methods might have produced more valid findings, for example the Delphi method or even questionnaires. However, we find strong indications that the interviews gave us rich and deep answers pertaining to the aim of this study.

Conclusion

Communication and communication patterns within the team create the feeling of being a team. Team climate and team performance is significantly impacted by knowledge and trust of competence in colleagues, with other professions, and by the available leadership. Proportions of different health professionals in the team have an impact on the focus and delivery of care. Interprofessional education giving clarity on one’s own professional role and knowledge of other professions would most likely benefit patients and family caregivers. Studying and implementing components of interprofessional cooperation from international examples is a way forward. Further studies are required to clarify these issues, for example including the patients’ and family caregivers’ perspectives.

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