# Supplemental material: Semi-structured interview guides, focus group topic guide, and coding trees

**Article: ‘How can we ensure the success of specialised palliative home-care? A qualitative study (ELSAH) identifying key issues from the perspective of patients, relatives and health professionals‘**

**Authors:** Hannah Seipp, Jörg Haasenritter, Michaela Hach, Dorothée Becker, Lisa-R. Ulrich, Dania Schütze, Jennifer Engler, Cathrin Michel, Stefan Bösner, Katrin Kuss

# Semi-structured interview guides (translated into English)

**Note**: Interview guides served as checklists. The interviews were semi-structured and guided according to the narrative flow of the interview. Topics were adapted throughout the study, based on the principles of Grounded Theory.

## Interviews with health professionals

* **Please tell me something about your professional background.**
	+ *Specialised palliative home-care team member*: Why did you start working in specialised palliative home-care?
	+ *Collaborating health professional*: How do you see your role in palliative care?
* **In your opinion: What contributes to the success of specialised palliative home-care? (Ideal)**
	+ What is special about specialised palliative home-care (in comparison to palliative care in general)?
* **Please describe the collaboration between specialised palliative home-care and partners (e.g. home-care hospice services).**
* **In your opinion, what is most important to patients and relatives receiving specialised palliative home-care?**
	+ What needs do patients and relatives have?
	+ How do you ascertain their needs?
	+ Can you describe how patients and relatives can influence care?
* **What goals do you pursue with your work?**
	+ How do you clarify what your assignments involve in any particular case?
	+ Could you describe cases in which something did not go well?
* **How do you address the topic of dying when dealing with patients and relatives?**
* **You discuss every case in your team. How do you structure such discussions? What subjects should always be discussed?**
* **We would like to develop a tool to enable the quality of specialised palliative home-care to be assessed. What criteria could be used to assess the quality of specialised palliative home-care?**
* **Do you have any suggestions? Are there other things you would like to discuss?**

## Interviews with patients, relatives and bereaved

**Would you like to tell me how you are doing today?** *Bereaved*: **Would you like to tell me how your specialised palliative home-care went?**

* + *Only patients*: What does physical and emotional well-being currently mean to you?
	+ *Only relatives*: Would you like to tell me how your relative is doing today?
* **What is the most important thing for you/your relative in the current situation? What was the most important thing for you/your relative at that time?**
	+ *Only patients/relatives:* What helps you/your relative most in the current situation?
	+ *Only bereaved***:** What helped you/your relative most at that time?
	+ What else could be done/have been done to help you/your relative?
	+ What could be done better?/What could have been done better?
	+ How do you/did you deal with the situation? (coping strategies)
	+ *Only patients*: What gives you strength?
	+ *Only patients*: What makes your life/the life of your relative worth living in the current situation?
	+ *Only patients*: What makes you happy?
	+ How are/were your private circumstances integrated into your palliative care?
* **Can you describe what kind of support you receive/received from the palliative care team?**
	+ What health care professionals are/were involved in your/your relative’s care?
	+ How are decisions about your/your relative’s care made?/How were decisions about your relative’s care made?
* **What has changed since the specialised palliative home-care team started caring for you/your relative?**
* *Only relatives/bereaved***: What support is/was offered to you as the relative of a palliative patient?**
* *Only bereaved***: How was care provided immediately before and after dying?**
* *Only bereaved***: Looking back, what would specialised palliative home-care ideally be like?**
* *Only bereaved***: We would like to develop a tool to enable the quality of specialised palliative home-care to be assessed. What issues are relevant in assessing the quality of specialised palliative home-care?**
* **Do you have any suggestions? Are there other things you would like to discuss?**

# Focus group topic guide (translated into English)

1. **How can successful specialised palliative home-care be defined**
	* Imagine you are working with a new colleague. How would you explain to him/her what successful specialised palliative home-care means?
	* Please summarise what is important to patients and their relatives?
2. **Assessing needs and objectives**
	* How do you assess needs/objectives?
	* What might encourage you to update, re-evaluate, or reconsider needs/objectives?
	* How do you ensure the objectives are met?
3. **Evaluation tools that are already used**
	* Do you already use evaluation tools in your team? How do you use them?
4. **Content of quality assessment**
	* Imagine you are working for a health insurance company. What information would you need in order to assess quality of care?
5. **Practicable and sensible implementation of assessment tools**
	* How can an assessment tool be sensibly integrated into your daily work?

# Coding trees (originals in German)

## Participant observations and interviews with health professionals

Table 1. Coding tree of participant observations (field notes) and interviews with health professionals (field notes, transcripts)

|  |  |
| --- | --- |
| **Code** | **Number of Codings** |
| 1 Experte | 0 |
|  1.1 Einstellung gegenüber ELSAH | 15 |
|  1.2 Person und Beruf | 49 |
|  1.3 Motivation, Einstellung | 74 |
|  1.4 Eigene Be-/Entlastung | 92 |
| 2 SAPV Team Charakteristika | 73 |
|  2.1 Teamarbeit, Teamstabilität | 45 |
| 3 SAPV-Arbeit | 2 |
|  3.1 Probleme | 42 |
|  3.2 Gelungene Versorgung | 65 |
|  3.3 "WIE" | 0 |
|  3.3.1 Vermitteln | 25 |
|  3.3.2 Aushalten | 20 |
|  3.3.3 Schwelle | 31 |
|  3.3.4 Sicherheitsempfinden | 82 |
|  3.3.5 Individualität | 61 |
|  3.3.5.1 zum individuellen Fall informieren | 25 |
|  3.3.6 "Beziehungsqualität" | 71 |
|  3.3.7 Zeit haben | 29 |
|  3.3.8 Fachkompetenz | 26 |
|  3.3.9 Antizipation | 34 |
|  3.3.10 Ganzheitlichkeit, umfassende Zuständigkeit, Komplexität | 40 |
|  3.4 "Tätigkeiten" | 0 |
|  3.4.1 Informieren | 0 |
|  3.4.1.1 über SAPV Arbeit | 50 |
|  3.4.1.2 early integration | 9 |
|  3.4.2 Erstassessment | 51 |
|  3.4.3 Zielerfassung, Auftrag | 54 |
|  3.4.3.1 Indikation SAPV | 44 |
|  3.4.4 Bedarfserhebung | 62 |
|  3.4.4.1 Erfahrung/Fingerspitzengefühl | 41 |
|  3.4.4.1.1 Sensible Arbeitsweise | 27 |
|  3.4.5 Verlauf | 50 |
|  3.4.6 Anlass und Frequenz | 27 |
|  3.4.7 Abschluss, Ausschleusung, Pausieren | 21 |
|  3.4.8 Fallbesprechungen | 45 |
|  3.5 Netzwerk, Koordination | 75 |
|  3.5.1 Regelversorgung | 87 |
|  3.5.2 Hospiz / amb. Hospizdienst | 70 |
|  3.5.3 Interdisziplinarität | 42 |
|  3.6 Teaminterne Evaluationen | 10 |
|  3.6.1 Selbstreflexion | 20 |
|  3.6.2 Retrospektiv | 24 |
|  3.7 Dokumentation(-ssystem) | 35 |
|  3.7.1 Inhalt Dokumentation | 39 |
|  3.7.2 Austausch abseits Dokumentation | 18 |
| 4 Patienten: Bedürfnisse | 7 |
|  4.1 Normalität/ Alltag | 9 |
|  4.2 Dinge ordnen | 11 |
|  4.3 Vertrauen | 37 |
|  4.4 Würde | 41 |
|  4.5 Autonomie, Mitbestimmung | 91 |
|  4.6 Empowerment Patient | 16 |
|  4.7 organisatorische Entlastung | 11 |
|  4.8 körperlich - Symptomkontrolle | 98 |
|  4.9 psychisch - Entlastung | 52 |
|  4.10 sozial - Teilhabe | 36 |
|  4.11 Spiritualität | 77 |
|  4.12 Ethisch | 20 |
|  4.13 Lebensqualität | 40 |
|  4.13.1 Wünsche, Ziele | 39 |
|  4.14 Sterben, Tod | 85 |
|  4.15 Zu Hause bleiben | 84 |
| 5 Zugehörige: Bedürfnisse | 8 |
|  5.1 Fürsorge für Zugehörige | 81 |
|  5.1.1 Entlastung (psychosozial, organisatorisch) | 40 |
|  5.1.2 Vorbereitung und Nachsorge | 34 |
|  5.2 Einbindung, Beteiligung in Versorgung | 44 |
|  5.2.1 Empowerment Zugehöriger | 30 |
| 6 Instrument: SOLL-Zustand | 11 |
|  6.1 Herausforderung Messen | 14 |
|  6.2 Perspektive | 20 |
|  6.3 Ideen Umsetzung | 10 |
|  6.3.1 Zeitpunkte Erhebung | 21 |
|  6.4 Ideen Inhalt | 26 |
| 7 Zitate | 22 |
| 8 Zusätzliche Aspekte | 11 |
|  8.1 Aufgaben Koordinatorin Hospizdienst | 7 |
|  8.2 Seelsorge | 43 |
|  8.3 Sichtweise Hausarzt | 17 |

## Interviews with patients and relatives

Table 2. Coding tree of interviews with patients and relatives (field notes, transcripts)

|  |  |
| --- | --- |
| **Code** | **Number of Codings** |
| 1 zur Person Patient/Nahestehender | 3 |
|  1.1 Leistungserbringer außer SAPV | 68 |
|  1.2 Erkrankung des Patienten | 62 |
|  1.3 Kennenlernen SAPV | 33 |
| 2 SAPV-Team | 0 |
|  2.1 Abläufe, Versorgungsverlauf | 36 |
|  2.2 Ziele der SAPV-Arbeit | 3 |
|  2.3 Zufriedenheit mit SAPV | 21 |
|  2.4 Beziehungsqualität | 21 |
|  2.4.1 Normalität, Fröhlichkeit | 6 |
|  2.4.2 Vertrauen | 21 |
|  2.4.3 den Menschen sehen | 33 |
|  2.5 umfassende Fürsorge | 21 |
|  2.5.1 Hilfsmittel | 47 |
|  2.5.2 Koordination, Kooperation | 41 |
|  2.6 Sicherheitsgefühl | 21 |
|  2.6.1 Verfügbarkeit | 80 |
|  2.6.2 Empowerment | 30 |
|  2.6.3 Antizipation + Informieren | 37 |
|  2.6.4 gegenseitiges Kennen | 14 |
|  2.6.5 Kompetenz des SAPV-Teams | 28 |
| 3 Patient/in, Erkrankte/r | 0 |
|  3.1 Normalität erhalten | 6 |
|  3.2 körperliches Befinden, Symptome | 107 |
|  3.3 psychisches Befinden, Symptome | 91 |
|  3.4 Lebensqualität | 145 |
|  3.5 Sterben, Palliativsituation | 97 |
|  3.6 spirituell | 36 |
|  3.7 Zu Hause sein | 64 |
|  3.7.1 Palliativstation | 9 |
|  3.7.2 Entscheidung zum Krankenhausaufenthalt | 19 |
|  3.7.3 stat. Hospiz | 9 |
|  3.8 soziale Dimension | 96 |
|  3.9 Entlastung | 6 |
|  3.10 Selbstbestimmung | 61 |
|  3.11 Individualität | 9 |
|  3.11.1 Zeit nehmen/Zeit haben | 7 |
| 4 Nahestehende/r, Angehörige/r | 0 |
|  4.1 Belastung/Entlastung Nahestehende | 82 |
|  4.2 Beteiligung in Versorgung | 82 |
|  4.3 Palliativsituation der Bezugsperson | 52 |
| 5 Zitate | 78 |

## Focus groups

Table 3. Coding tree of focus groups (video-analysis)

|  |  |
| --- | --- |
| **Code** | **Number of Codings** |
| 1 ELSAH Analyse | 0 |
|  1.1 Moderation | 69 |
|  1.2 Sequenz | 98 |
| 2 SAPV-Arbeit  | 0 |
|  2.1 Teamarbeit | 4 |
|  2.2 Probleme | 0 |
|  2.2.1 vorhandene Strukturen | 2 |
|  2.2.2 Grenzen der Versorgung | 7 |
|  2.3 Gelungene Versorgung | 4 |
|  2.4 Qualität | 20 |
|  2.5 "WIE" | 0 |
|  2.5.1 Fingerspitzengefühl | 1 |
|  2.5.2 Schwelle | 3 |
|  2.5.3 Vermitteln | 1 |
|  2.5.4 Sicherheit | 6 |
|  2.5.5 Zeit nehmen | 2 |
|  2.5.6 Autonomie | 15 |
|  2.5.7 "Beziehungsqualität" | 16 |
|  2.5.8 Antizipation | 2 |
|  2.5.9 Individualität | 9 |
|  2.5.10 Ganzheitlichkeit, umfassende Zuständigkeit | 1 |
|  2.6 "Tätigkeiten" | 0 |
|  2.6.1 Informieren, early integration, Öffentlichkeitsarbeit | 5 |
|  2.6.2 Erstbesuch | 5 |
|  2.6.3 Ziel/Auftrag | 25 |
|  2.6.3.1 Indikation SAPV | 13 |
|  2.6.4 Bedarfserhebung | 24 |
|  2.6.5 Verlaufssteuerung PCT | 6 |
|  2.6.5.1 Versorgungsplanung | 8 |
|  2.6.6 Fallbesprechungen | 5 |
|  2.7 Organisation, Koordination, Komplexität, Netzwerk | 14 |
|  2.7.1 Multiprofessionalität | 13 |
| 3 Teaminterne Evaluationen | 0 |
|  3.1 Selbstreflexion | 7 |
|  3.2 Evaluation während Versorgung | 2 |
|  3.3 Evaluation nach Versterben | 8 |
|  3.4 beurteilende Perspektive | 3 |
|  3.4.1 Beurteilung durch Professionelle | 5 |
|  3.4.2 Beurteilung durch Betroffene | 16 |
|  3.4.3 gemeinsame Beurteilung von Betroffenen und Professionellen | 2 |
| 4 Dokumentation | 17 |
| 5 Bedürfnisse von Patienten und Zugehörigen | 14 |
|  5.1 Würde | 1 |
|  5.2 Dimensionen der Palliativversorgung | 15 |
|  5.3 körperlich - Symptomkontrolle | 12 |
|  5.4 sozial | 18 |
|  5.5 psychisch | 12 |
|  5.6 spirituell | 19 |
|  5.7 ethische Dimension, Zielformulierung | 9 |
|  5.8 Angehörige, Familie | 8 |
|  5.9 Sterbeort bestimmen können | 3 |
|  5.10 Thematisierung des Sterbens | 1 |
| 6 Instrument | 40 |
|  6.1 Wünsche | 0 |
|  6.2 Ängste, Bedenken | 10 |
|  6.3 beabsichtigter Nutzen | 1 |
|  6.4 Inhalt | 22 |
|  6.5 Gestaltung, Anwendung, Umsetzung | 10 |
|  6.6 Verlaufsbeurteilung | 1 |
| 7 Zitate, Kernaussagen | 12 |