**Supplementary tables**

**Table S1**

**English version of the questionnaire used for registering deaths in the Swedish Register of Palliative Care since January 1 2012**

|  |  |  |
| --- | --- | --- |
| **No.** | **Question** | **Reply options** |
| 1 | Unit identification code |  |
| 2 | Personal identity number of the deceased person |  |
| 3 | First and last name of the deceased person |  |
| 4 | Date of death (year/month/day) |  |
| 5 | Date (year/month/day) when the person was admitted to the unit where the death occurred (for home care, please state the date when home care was initiated) |  |
| 6 | The place of death is best described as: | * Nursing home – permanent stay * Nursing home – short‑term stay * Hospital ward (not hospice/palliative in‑patient care) * Hospice/palliative in‑patient care * Own home with support from specialised home‑care team * Own home with support from general home‑care team * Other, specify |
| 7 | Disease/basic state that caused the death (more than one answer is possible): | * Cancer * Cardiovascular disease * Respiratory disease * Dementia * Stroke * Other neurological disease * Diabetes * State after fracture * Multimorbidity * Other, namely: |
| 8 | Will there be a post‑mortem examination of the deceased? | * Yes, forensic * Yes, regular clinical * No   If the answer is Yes, forensic, only answer questions 28-30. If the answer is No or Yes, regular clinical, go to question 9. |
| 9 | Based on the disease trajectory, was the death expected? | * Yes * No * Don't know   If the answer is Yes or Don't know, answer all the following questions. If the answer is No, answer only questions 14, 16, 18, 28-30. |
| 10 | How long before death did the person lose the ability to express his/her will and take part in decisions concerning the content of medical care? | * Retained ability until end of life * Hour/hours * Day/days * Week/weeks * Month or more * Don't know |
| 11A | Do the medical records include a documented decision by the physician responsible to shift treatment/care to end-of-life care? | * Yes, in free text * Yes, as a classification code * No * Don't know |
| 11B | Did the person receive information about the transition to end-of-life care, i.e. an individually tailored and informed conversation with a physician that is documented in the medical records about being in the final stage of life and about care being focused on quality of life and symptom relief? | * Yes * No * Don't know |
| 12 | Was the place of death in line with the person's last stated wishes? | * Yes * No * Don't know |
| 13A | Did the person have pressure ulcers upon arrival at your unit (specify highest grade occurring)? | * Yes, grade 1 * Yes, grade 2 * Yes, grade 3 * Yes, grade 4 * No * Don't know   If the answer is Yes (grades 1-4), answer question 13B. If the answer is No or Don't know, skip to question 14A. |
| 13B | Were the pressure ulcers documented? | * Yes * No * Don't know |
| 14A | Did the person die with pressure ulcers (specify highest grade occurring)? | * Yes, grade 1 * Yes, grade 2 * Yes, grade 3 * Yes, grade 4 * No * Don't know   If the answer is Yes (grade 1-4), answer question 14B. If the answer is No or Don't know, skip to question 15A. |
| 14B | Were the pressure ulcers documented? | * Yes * No * Don't know |
| 15A | Was the person’s oral health assessed during the last week of life? | * Yes * No * Don't know   If the answer is Yes, answer question 15B. If the answer is No or Don't know, skip to question 16. |
| 15B | Was any disorder noted during assessment? | * Yes * No * Don't know   If the answer is Yes or No, answer question 15C. If the answer is Don't know, skip to question 16. |
| 15C | Was the assessment of oral health documented? | * Yes * No * Don't know |
| 16 | Was anyone present at the time of death? | * Yes, close friend(s) or relative(s) * Yes, close friend(s)/relative(s) and staff * Yes, staff * No * Don't know |
| 17 | Did the person’s close friend(s)/relative(s) receive information about transition to end-of-life care, i.e. an individually tailored and informed conversation with a physician that is documented in the medical records about being in the final stage of life and about care being focused on quality of life and symptom relief? | * Yes * No * Don't know * Had no close friend(s)/relative(s)   If the answer is Yes, No or Don't know, go to question 18. If the answer is Had no close friend(s)/relative(s), skip to question 19. |
| 18 | Was/were the person’s close friend(s)/relative(s) offered a follow-up talk within 1-2 months of the death? | * Yes * No * Don't know |
| 19 | Did the person receive parenteral fluids/nutrition or enteral‑tube feeding during the last 24 hours of life? | * Yes * No * Don't know |
| 20 | Did the person display any of the following symptoms (20A-F) at any time during the last week of life? |  |
| 20A | Pain | * Yes * No * Don't know   If the answer is Yes, answer the following question. If the answer is No or Don't know, skip to question 20B. |
|  | Pain was relieved: | * Completely * Partially * Not at all |
| 20B | Death rattle | * Yes * No * Don't know   If the answer is Yes, answer the following question. If the answer is No or Don't know, skip to question 20C. |
|  | Death rattle was relieved: | * Completely * Partially * Not at all |
| 20C | Nausea | * Yes * No * Don't know   If the answer is Yes, answer the following question. If the answer is No or Don't know, skip to question 20D. |
|  | Nausea was relieved: | * Completely * Partially * Not at all |
| 20D | Anxiety | * Yes * No * Don't know   If the answer is Yes, answer the following question. If the answer is No or Don't know, skip to question 20E. |
|  | Anxiety was relieved: | * Completely * Partially * Not at all |
| 20E | Dyspnoea | * Yes * No * Don't know   If the answer is Yes, answer the following question. If the answer is No or Don't know, skip to question 20F. |
|  | Dyspnoea was relieved: | * Completely * Partially * Not at all |
| 20F | Confusion | * Yes * No * Don't know   If the answer is Yes, answer the following question. If the answer is No or Don't know, skip to question 21. |
|  | Confusion was relieved: | * Completely * Partially * Not at all |
| 21 | Was the person’s pain assessed at any documented time during the last week of life using VAS, NRS or another validated pain-assessment tool? | * Yes * No * Don't know |
| 22 | Did the person experience severe pain at any time during the last week of life (e.g. VAS/NRS > 6 or severe pain according to another validated pain-assessment tool)? | * Yes * No * Don't know |
| 23 | Were the person’s other symptoms assessed at any time during the last week of life using VAS, NRS or another validated symptom-assessment tool? | * Yes * No * Don't know |
| 24 | Was there an individual prescription of injectable PRN drugs on the drug list before death? |  |
|  | Opioids against pain | * Yes * No * Don't know |
|  | Drugs against death rattle | * Yes * No * Don't know |
|  | Drugs against nausea | * Yes * No * Don't know |
|  | Drugs against anxiety | * Yes * No * Don't know |
| 25 | How long before death was the person last examined by a physician? | * Day/days * Week/weeks * Month or more * Don't know |
| 26 | Were specialists outside the team/ward consulted concerning the person’s symptom relief during the last week of life (more than one answer option is possible)? | * Yes, pain clinic * Yes, palliative-care team * Yes, other hospital unit * Yes, social worker/physiotherapist/ occupational therapist/dietician * Yes, spiritual counsellor * No * Don't know |
| 27 | How satisfied is the team with the care delivered to the person during the last week of life? | A 5-point scale ranging from Not at all (1) to Completely (5) |
| 28 | Date (year/month/day) of answering the questions |  |
| 29 | The questionnaire was answered by: | * A single employee * Staff jointly |
| 30 | Name and e-mail address of registrant, occupation | * Physician * Nurse * Other staff |

**Table S2**

**Items from the end-of-life questionnaire selected as indicators of care quality**

|  |  |  |  |
| --- | --- | --- | --- |
| **Question number** | **Question content** | **Theme** | **Type of indicator** |
| 11 A | Did the medical records include a documented decision by the physician to shift treatment/care to end-of-life care? | Decision making | Care process |
| 12 | Was the place of death in line with the person's last stated wishes? | Patient participation | Outcome |
| 11 B | Did the person receive information about the transition to end-of-life care, i.e. an individually tailored and informed conversation with a physician that is documented in the medical records about being in the final stage of life and about care being focused on quality of life and symptom relief? | Information | Care process |
| 17 | Did the person’s close friend(s)/relative(s) receive information about transition to end-of-life care, i.e. an individually tailored and informed conversation with a physician that is documented in the medical records about being in the final stage of life and about care being focused on quality of life and symptom relief? | Information | Care process |
| 18 | Was/were the person’s close friend(s)/relative(s) offered a follow-up talk within 1-2 months of the death? | Bereavement upport | Care process |
| 21 | Was the person’s pain assessed at any documented time during the last week of life using VAS, NRS or another validated pain-assessment tool? | Symptom screening | Care process |
| 23 | Were the person’s other symptoms assessed at any time during the last week of life using VAS, NRS or another validated symptom-assessment tool? | Symptom screening | Care process |
| 24 | Was there an individual prescription of an injectable PRN opioid against pain on the drug list before death? | Symptom control | Care process |
| 24 | Was there an individual prescription of an injectable PRN drug against death rattles on the drug list before death? | Symptom control | Care process |
| 24 | Was there an individual prescription of an injectable PRN drug against nausea on the drug list before death? | Symptom control | Care process |
| 24 | Was there an individual prescription of an injectable PRN drug against anxiety on the drug list before death? | Symptom control | Care process |