

Johansen S, Hølen JC, Kaasa S, Loge JH, Materstvedt LJ. (2005) "Attitudes towards, and wishes for, euthanasia in advanced cancer patients at a palliative medicine unit". *Palliative Medicine*; 19: 454-460.

Appendix

Table A1 Themes and questions from the interview guide – entire list of questions:

12. THE INTERVIEW

12.1. The patient's comprehension of the expression (the concept of) "active help in dying" – and the public debate concerning active help in dying

1. What does *the expression* "active help in dying" mean to you – what is your understanding of this expression? [Notice: In Norway, this is the most commonly known expression – which in Norwegian reads "aktiv dødshjelp".]

NB! Before the interviewer moves on to question 2, the patient must be informed of the project management's description/conception of active help in dying – so that it is absolutely clear to both parties what we are talking about during the remains of the interview.

- ⇒ (Concerning the two variants of *voluntary* active help in dying: see below, sect. 12.3., the explanations given in connection with questions 7 and 8. Since the interview is about patients' (voluntary) *request* for active help in dying, both nonvoluntary and involuntary active help in dying are ruled out as issues – i.e., active help in dying performed on the incompetent (patient has no free will) or on the competent without they having asked for it (patient has free will), respectively.)
- ⇒ (If the interviewer doubts that the patient realizes that active help in dying is in fact illegal in Norway, he must inform the patient about this; cf 7.2. in the research protocol. However, it is important that the interviewer refrains from making too much of this fact since such underlining might cause patients who have a favourable view of active help in dying to be reluctant to express their point of view. The interviewer also needs to make sure that the patient does not believe that abstention from life-prolonging treatment in the terminally ill – which is perfectly legal – is a form of active help in dying, and accordingly misunderstands what the interview is about; cf 6.3. in the research protocol. It is here appropriate to focus on the fact that such abstention has to do with letting the patient die (from his/her underlying disease), whereas active help in dying is about intentionally ending the patient's life here and now. Furthermore, if necessary, it must be made clear to the patient that aggressive pain treatment has nothing to do with active help in dying and that it will not cause a premature death in the patient; cf also 6.3. in the research protocol.)
- ⇒ (The following information is for the interviewer: In the Netherlands, active help in dying has been practiced openly for nearly 30 years. In 1995 the numbers concerning *voluntary* active help in dying were: Physician-assisted suicide (PAS): 0,3% of all deaths in the country = 400 cases; euthanasia (E): 2,4% = 3200 cases.

This means a daily average of 10 cases (3600 cases divided by 365 days). Both E and PAS remain technically illegal according to the penal code, articles 293 and 294, respectively. Yet the justification of necessity, provided for in article 40 of the penal code, is available to doctors who perform E and PAS; cf 6.2. in the research protocol. Doctors must also abide by the guidelines for reporting in order to avoid legal prosecution. There is no requirement that the person be terminally ill; E and PAS may also be legitimate in the chronically, somatically ill and in the mentally ill (cf the 1994 Dutch Supreme Court ruling in the Chabot case). The "official opening" of the Dutch practice of E and PAS may be said to be in 1973, with the ruling in the Postma case. It is expected that the Dutch parliament will enact laws making E and PAS legal in the near future. About 90% of Dutch doctors support the practice, which is actually a higher percentage than found in the population. In Norway, only 17% of doctors say they are in favour of E and PAS – that is, in a terminally ill patient. In the population, the support varies around 60% and 70%. 80% of those who received E or PAS in the Netherlands had cancer.)

2. Have you kept yourself posted in the *public debate* concerning active help in dying – by reading newspapers, listening to the radio and watching TV?
3. If you have *not* kept yourself posted in this debate, why is that so?
4. If you happen to have any knowledge of the Sandsdalen case, what is *your opinion* of Sandsdalen's actions? [Notice: The Sandsdalen case concerns a physician who intentionally injected a MS patient with a lethal overdose of mainly morphine, at the patient's explicit and repeated request. The case is well known in Norway and has been much debated in the media. The case even made it to the Supreme Court, which convicted Sandsdalen of murdering the patient – even though the sentence did not entail imprisonment.]
5. Regardless of your having knowledge of, or no knowledge at all of, the Sandsdalen case, could you say a few words as to your *basic attitude* towards active help in dying? – Or perhaps you do not have a fixed opinion in relation to this issue?
 - ⇒ (It might be that the patient has not made up his or her mind about the issue and so does not hold a particular point of view. This may be due to the complexities of the issue and that accordingly the patient might find it difficult to take a stance. But if the patient does hold a particular point of view, we would like to know what reasons he or she is prepared to give to substantiate this view; reasons of an ethical nature; reasons connected with outlook on life; legal, psychological, religious, and medical considerations; and so on and so forth. Also of interest is to elucidate, if possible, whether or not the particular point of view is compatible with the patient's eventual point of view as far as the Sandsdalen case is concerned. It might be that a patient thinks that this case is so special and of such an extreme nature that he or she has a sympathetic view of the doctor's actions, even when the patient's basic attitude is nonetheless anti active help in dying. Or perhaps the opposite is true: That a patient's basic attitude is, provided certain conditions are met, pro active help in dying but that he or she thinks that Sandsdalen should not have performed active help in dying in the particular case of the woman suffering from MS.)

12.2. Life at present/right now

1. All things considered, how are you today – what is your judgement of your own *quality of life*?
2. Is there anything that is of particular importance or value to you *in daily life here at the hospital*?
3. Is there anything that is of particular importance or value to you *in daily life at home*?
4. What *positive* aspects in your life would you say there are right now? – Things you think make life worth living?
 - ⇒ (Every single day has value; the company of those nearest to me; one sees clearly what is important and what is not in life; life is a stronger experience when one is seriously ill; and so on and forth.)
5. What in life right now is most *worrying*, thus making life *harsh*?
 - ⇒ (Pain; nausea; vomiting; dyspnoea; fatigue; being dependent upon the help and support of others; worry regarding the stress and suffering that next-of-kin experience; loss of dignity; loss of autonomy (self-determination); the feeling of hopelessness; depression; and so on and forth.)
6. Do you feel that you are being *less valued* than patients who have a fair chance of recovering from their illness?
7. In your present condition, would you *consider* asking a physician for active help in dying?
 - ⇒ (Concerning the two variants of active help in dying: see below, sect. 12.3., the explanations given in connection with questions 7 and 8.)
8. As of today, do you have a *definite wish* for active help in dying?
9. If the answer is "yes", what do you think *it would take* to make you stop having this wish – what is needed in order that this wish of yours be "annulled" or changed?
10. In case you are unable to come up with any suggestions as to what would have made you change this wish, would you today consider *discussing* the issue of active help in dying with some of the health care workers?

12.3. Life as ill up until this point/this moment

1. What do you think life has been like *in general* from the time you got ill and up until this point?
2. Have you received satisfactory treatment and care?
 - ⇒ (Has one, the way the patient sees it, done what is *necessary* to do in his/her situation – has one done everything one is able to do? If so, is this *enough*?)
3. What has the relationship with *next-of-kin* been like?
4. Have you ever been *thinking* that it would have been good if you were released from life? – Have you been thinking that it would have been better if you were already dead?
5. If yes, did you have a *definite wish* for death to come as soon as possible due to *natural* causes?

6. Have you ever, in connection with your being ill, had any thoughts about *taking your own life*? – Have you been thinking that *you yourself* could have produced the outcome of death coming as soon as possible?
7. Have you ever *wished for a physician to help you take your own life*, for instance by prescribing a sufficiently large dose of medication which you could have used for that particular purpose?

⇒ (Physician-assisted suicide. Even though this is the "official" designation of this variant of *voluntary* active help in dying, the interviewer should nevertheless avoid using the morally contestable word suicide and instead settle for the more neutral "taking one's own life", which, as we see, is the wording of the question here. It is of importance that the patient is aware of the following: We are not here talking about a situation in which a patient collects medication prescribed by the doctor, so that the patient at a later stage may use the collected medication in order to take his or her life should the patient wish to – for example, without the doctor being aware of or having any knowledge of this. The situation is such that both patient and doctor are fully aware of the fact that the patient is about to take his or her life, and both parties intend the patient's death by suicide and know perfectly well that the medication is meant for suicide exclusively – not for any kind of treatment.)

⇒ (More technically, we take physician-assisted suicide to entail the following, thus being in line with the Dutch understanding:

Physician-assisted suicide (PAS) – definition (interpretation) of

What?

- A doctor's intentionally helping/assisting/co-operating in the suicide of a person who is suffering "unbearably" and "hopelessly" at the latter's voluntary, explicit, and repeated, well-considered and informed request for the doctor's participation.

How?

- Usually (but not exclusively) by prescribing, preparing and giving a lethal dose of (different) drugs/medication to the person for self-administration.)

8. Have you ever *wished for a physician to release you from life/end your life* by lethal injection?

⇒ (Euthanasia. In connection with this (second) variant of *voluntary* active help in dying, the interviewer should refrain from using the morally contestable word "kill" even though the doctor who performs euthanasia does indeed kill the patient, both medico-technically and juridically speaking. Not using the word kill here is a way of trying to avoid immediate negative associations in the patient as far as euthanasia is concerned.)

⇒ (More technically, we take euthanasia to entail the following, thus being in line with the Dutch understanding:

Euthanasia – definition (interpretation) of

What?

- A doctor's intentionally killing a person who is suffering "unbearably" and "hopelessly" at the latter's voluntary, explicit, repeated, well-considered and informed request.

How?

- Usually (but not exclusively) by administering intravenously a lethal dose of (different) quick-acting drugs/medication.)
9. If your answer to questions 7. and/or 8. is a "yes", have you ever *expressed* a wish for active help in dying to anybody (physician, nurse, next-of-kin, or others), or have you kept this wish to yourself?
 10. If you did have such wish but decided *not* to express it to anyone, what were the reasons for your decision (to keep it to yourself)?
 11. If you did express such a wish, did you simultaneously *ask* for your wish too to be *carried out*?
 12. In that case, *who* in particular was it you wanted to carry out your wish?
 - ⇒ (We do not here want the patient to *name* anyone in particular. What we want to know, is primarily if the patient did ask a doctor for active help in dying. This need not be the doctor who currently treats the patient, or any other doctor, at the ward in which the patient is placed. It could be the patient's GP, a doctor he happens to know not in the capacity of a doctor but as someone with whom he has acquaintance, and so on. If the patient did ask anyone else, such as a nurse or a next of kin, or a close friend, or a neighbour he knows well, for that matter, these other individuals (i.e., other than a physician), had they in fact gone on to do what the patient wanted them to do, would by definition not have carried out active help in dying – that is to say, not according to our definition which, like the Dutch definition, involves a physician only (cf. above, sect. 12.3., the explanations given in connection with questions 7 and 8.) It may be remarked that in the Netherlands, only physicians are allowed to perform active help in dying. This is not to say, of course, that no one else than a doctor is capable of actively helping someone to die; it is to say, however, that these others' helping someone die is neither PAS nor euthanasia.)

12.4. Life before you fell ill – and at the time you became ill

1. Before you became seriously ill, did you ever think about the *possibility* of your becoming seriously ill some day?
2. If the answer is "yes", did you think about how you *might react* in such a situation?
3. Did you *react differently* from what you thought you would when you really fell ill?
4. If "no" to question 1., how did you react when you fell ill?
5. Did you have any thoughts at all concerning the topic active help in dying in the seriously ill *before* you became ill? – What thoughts?
6. If so, what did you think in connection with this topic when you *did* become ill?

12.5. Active help in dying in relation to health care personnel – and in relation to other patients

1. What is your reading of the *attitudes of health care personnel* regarding active help in dying?
2. Have you ever *discussed* the topic active help in dying with any of the health care personnel at the ward?

3. Have you ever *wished* you could discuss the topic active help in dying with any of the health care personnel at the ward?
4. Do you feel that active help in dying is a topic that is *difficult to raise* at the ward? – Why/why not?
 - ⇒ (In case the answer is "yes", reasons given might include the fact that active help in dying is illegal; that merely discussing the topic might be interpreted as criticism of/complaint against the treatment the patient receives ("it's not good enough") – something that is perhaps felt to be illegitimate "when all are really nice and do their very best" to make sure the patient is as comfortable as possible, and so on. Also, in case the answer is "no", a deepening of the answer is to be desired.)
5. How do you think health care personnel would take it in if you *had* asked for active help in dying – that is, if you try to *imagine* yourself (hypothetically) having asked for this?
6. If you have discussed the topic active help in dying with other *patients*, what is your reading of their attitudes regarding the topic?
7. Have you ever seen other patients in such a state that it made you think that *they* should have had the opportunity to choose active help in dying?
8. If yes, what kind of state was this and was it a situation in which *you yourself* would have wished for active help in dying presuming you were in such a state?
9. Even though active help in dying is *illegal* in Norway, would you nevertheless consider asking the doctor currently treating you for this sort of help?
10. Supposing active help in dying were *legal* in Norway, would you *then* have considered asking the doctor currently treating you for this sort of help?
11. If you did have such a legal right to ask for active help in dying, do you think this would have *changed your perception of doctors* – that is, if doctors were given the legal power not only to preserve life but to take life as well?

12.6. Active help in dying in relation to family/next-of-kin

1. Do you feel free to discuss the topic active help in dying with *those nearest to you*?
2. If you have *not* discussed the topic active help in dying with those nearest to you, what is your reading of their attitudes?
3. If you *have* discussed the topic active help in dying with those nearest to you, what is your reading of their attitudes?
4. Have you *explicitly asked* anyone in the family to help you die?
 - ⇒ (For example, the patient might have asked the next-of-kin to collect/keep an overdose of medication; might have called on them to talk to a doctor or other health care personnel signalling that the patient has got a wish for active help in dying; and so on.)
5. What do you think would be the *reaction* of your next-of-kin in case you told them that you *considered* asking the doctor currently treating you, or other health care personell, for active help in dying?
6. Would their reaction be of *vital importance* to your choosing or not choosing to ask for active help in dying?
7. Is the *strain* on your next-of-kin, due to your being ill, something that *bothers* you?

⇒ (Here we are interested in the patient's thoughts that have to do with *self-reproach* – if possible, without the interviewer bringing up this adversely charged word.)

8. Do you feel that the strain on your next-of-kin is *so great* that you ought to ask for active help in dying in order that they be spared additional strain?

12.7. Life henceforward/ahead

1. When you look ahead, what are your thoughts about the future?
2. Is there anything that you *hope* for?
3. Have you been thinking that you *could end up in a situation* in which you might wish for active help in dying?
4. If the answer is "yes", what kind of situation might that be?

⇒ (Here we would like to learn what the patient believes would make him or her conceive of the situation as unbearable. Also, we would like to hear about the relative strength of the different factors that may generate a possible wish for active help in dying; that is, which of these factors does the patient think would carry most weight. Catchwords: More severe pain than is the case today; future intractable and comprehensive pain; extreme nausea and vomiting; extensive dyspnoea (the feeling of choking); fatigue of a very troublesome nature; being much more dependent upon the help and support of others; being significantly more bothered than before as to the strain and suffering that next-of-kin experience; a more intense feeling of helplessness and/or of hopelessness than is the case as of today; a larger loss of autonomy ("self-government") and dignity; strong and persistent depression; and so on.)

12.8. The patient's experience of being interviewed about active help in dying

1. How did you experience being interviewed about active help in dying?
2. Was participating in the interview different from what you thought it would be like?
3. What are your thoughts and feelings right now, after having performed the interview?

12.9. Closure

The interviewer finalizes the interview by thanking the patient for his or her willingness to take part, thus providing us with valuable information on the topic active help in dying. The interviewer reminds the patient that he will be back the next day for a conversation about the interview and the time that has lapsed since it took place. It must be made clear that if the patient should feel a need to talk to anyone else after having performed the interview, he or she *may at any time* contact a doctor, a nurse, the chaplain or any other individual working at the ward. All of these are informed that the study is being carried out at the ward, and will know that this particular patient has performed the interview. What they do not know, is the patient's response – unless the patient wishes to inform them about what she or he said under this or that item (cf the combined written information and informed consent form).