

Continuing to live or dying?

Decision-making processes
of physically, chronically ill patients

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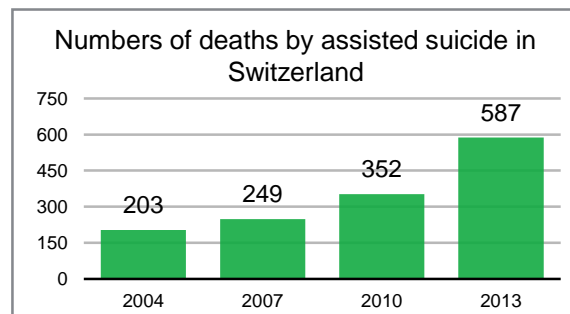


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Assisted suicide in Switzerland



Number of people who are dying because of assisted suicide in Switzerland is rising → 2013 → 587 deaths through assisted suicide = 1.9% of all deaths (Bundesamt für Statistik, 2015)

Since 2001 prohibitions of assisted suicide in Swiss public health care institutions have been gradually abrogated.



Scientific knowledge over subjective perspectives and decision-making processes of physically, chronically ill people to stay alive or to die by assisted suicide are still missing (Schweizerischer Nationalfond, 2011)

Assisted suicide & legal situation



Definition Assisted Suicide	A lethal substance is conveyed to the patient which the suicidal person takes by her/his own without external influence. (Bundesamt für Justiz, 2010)
Legal situation Assisted Suicide	The misguidance or achievement of assisted suicide out of selfish motives is punishable (Art. 115 StGB). (Bundesamt für Justiz, 2010)
Criteria Assisted Suicide	Ability to judge, unbearable suffering caused by illness, persistent wish to die, without pressure from outsiders, near of death, examination of alternatives, the suicidal person carries out the last act which leads to death by her/his own etc. (Nationale Ethikkommission im Bereich Humanmedizin, 2006)

Research question, study design & sample



Abb. 2

Why do physically, chronically ill people decide not to go on living while others in comparable situations want to stay alive?

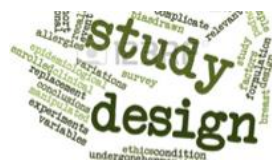


Abb. 3

Grounded theory methodology → theory building



Abb. 4

Physically, chronically ill

37 interviews → age between 35-97 years old

Diseases of sense organs, gastrointestinal tract, cardiovascular system, musculoskeletal system, nervous system, respiratory system

1/3 cancer, 1/3 multimorbid

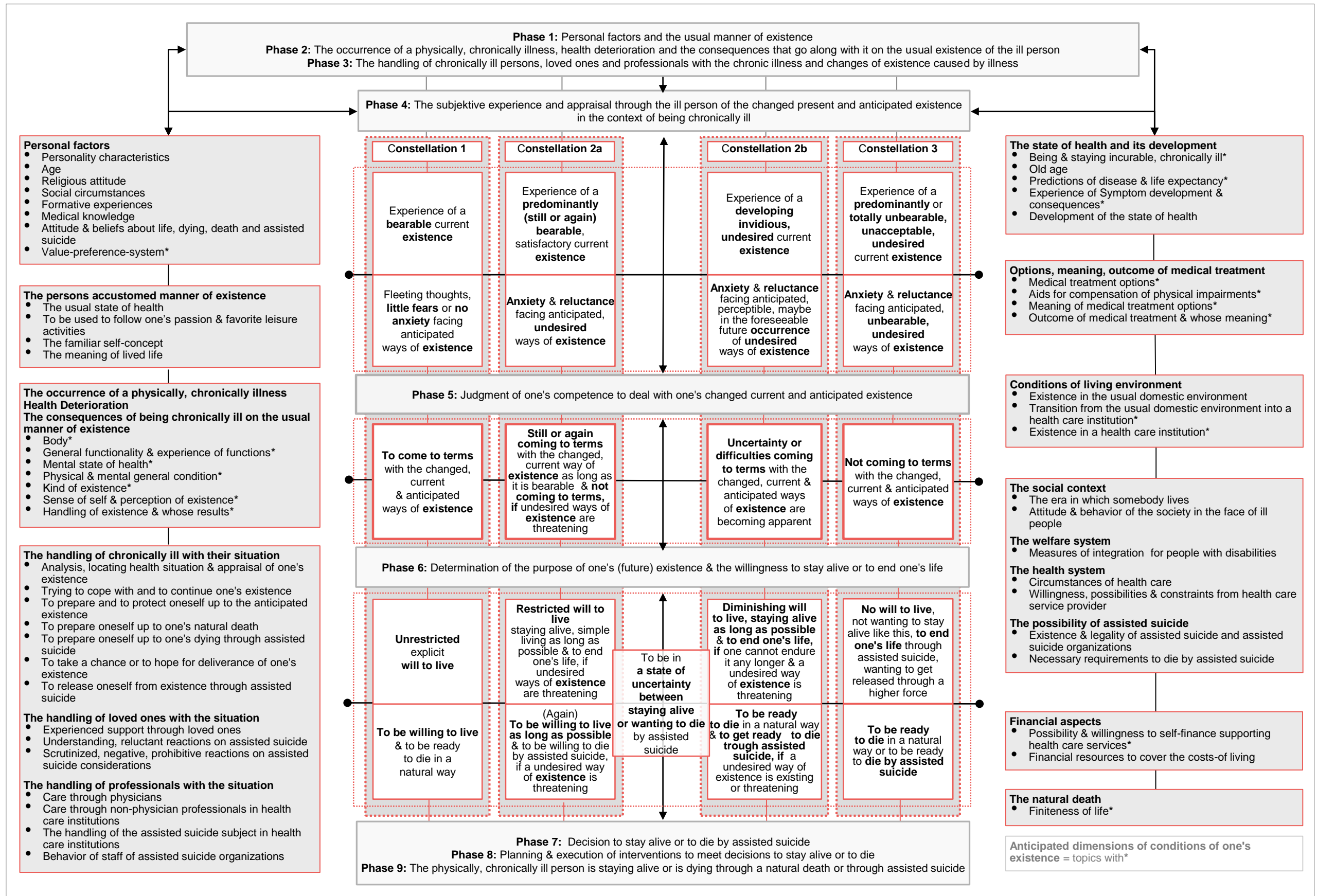
Significant others

3 interviews with relatives from people who died by assisted suicide

2 interviews with staff members of a Swiss assisted suicide organization

Central research findings

Conceptual model about the decision-making processes of physically chronically ill people to stay alive or to die by assisted suicide



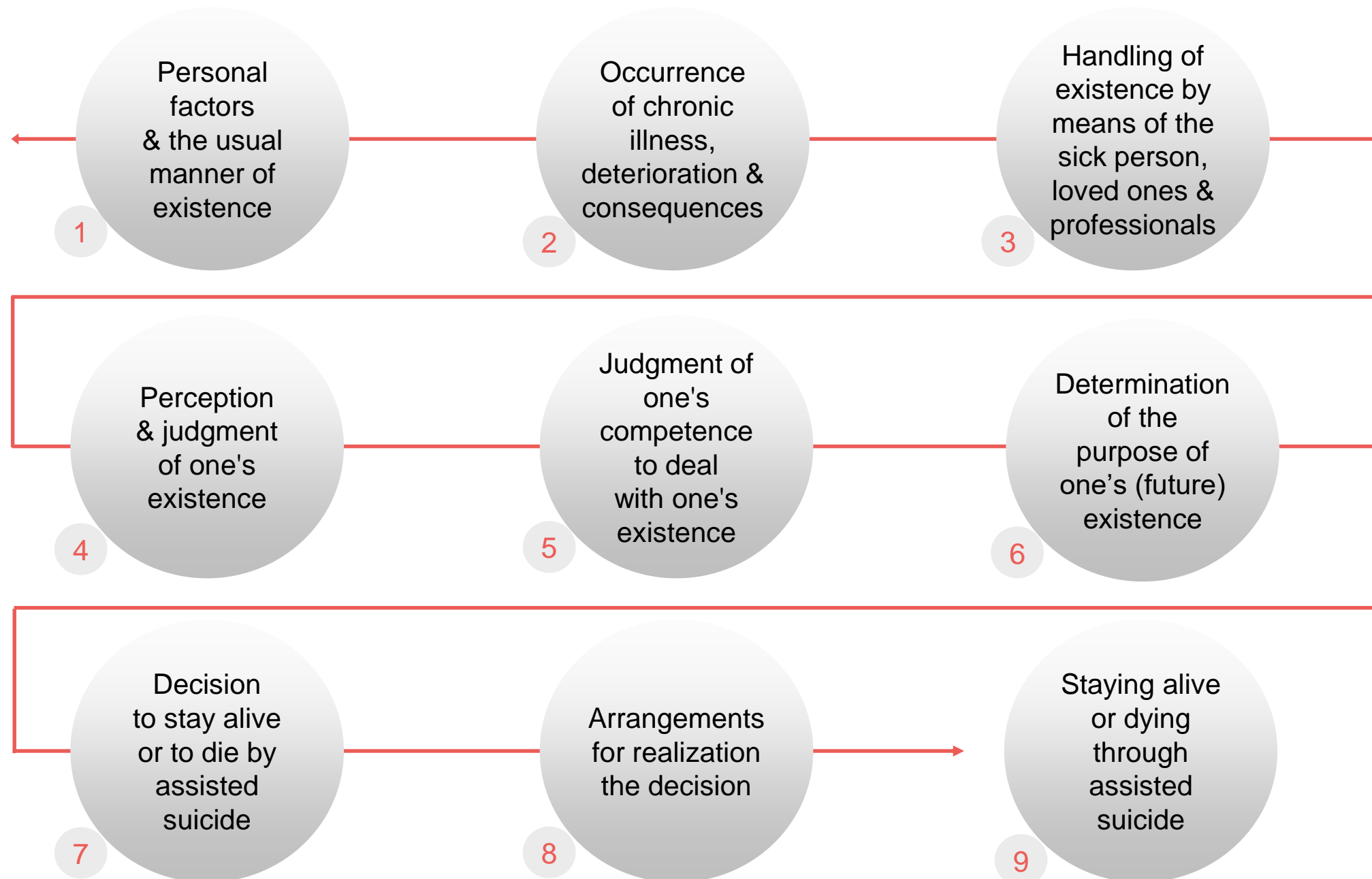
Findings about decision-making processes to stay alive or to die by assisted suicide

9 phases,
which patients
undergo in
relation to
consideration
staying alive or
dying

**Motives &
influencing
factors,** which
promotes
decisions to stay
alive or to die by
assisted suicide

4 constellations
of human existence

Phases, who people undergo in relation with considerations to stay alive or to die



(Bernhart-Just, 2015, S. 144-145)

Motives & influencing factors who promote to stay alive or to die by assisted suicide

Personal factors

- Personality characteristics
- Age
- Religious attitude
- Social circumstances
- Formative experiences
- Medical knowledge
- Attitude & beliefs about life, dying, death and assisted suicide
- Value-preference-system*

The persons familiar manner of existence

- The usual state of health
- To be used to follow one's passion & favorite leisure activities
- The familiar self-concept
- The meaning of lived life

The occurrence of a physically, chronically illness

Health deterioration

The consequences of being chronically ill on the familiar manner of existence

- Body*
- General functionality & experience of functions*
- Mental state of health*
- Physical & mental general condition*
- Kind of existence*
- Sense of self & perception of existence*
- Handling/management of existence & whose results*

The handling of chronically ill with their situation

- Analysis, locating health situation & appraisal of one's existence
- Trying to cope with and to continue one's existence
- To prepare and to protect oneself up to the anticipated existence
- To prepare oneself up to one's natural death
- To prepare oneself up to one's dying by assisted suicide
- To take a chance or to hope for deliverance of one's existence
- To release oneself from existence by assisted suicide

The handling of loved ones with the situation

- Experienced support through loved ones
- Understanding, reluctant reactions on assisted suicide
- Scrutinized, negative, prohibitive reactions on assisted suicide considerations

The handling of professionals with the situation

- Care through physicians
- Care through non-physician professionals in health care institutions
- The handling of the assisted suicide subject in health care institutions
- Behavior of staff of assisted suicide organizations

(Bernhart-Just, 2015, S. 144-145)

Motives & influencing factors who promote to stay alive or to die by assisted suicide

The state of health and its development

- Being & remaining incurable, chronically ill*
- Old age
- Predictions of disease & life expectancy*
- Experience of Symptom development & consequences*
- Development of the state of health

Options, meaning, outcome of medical treatment

- Medical treatment options*
- Aids for compensation of physical impairments*
- Meaning of medical treatment options*
- Outcome of medical treatment & whose meaning*

Conditions of living environment

- Existence in the usual domestic environment
- Transition from the usual domestic environment into a health care institution*
- Existence in a health care institution*

The social context

- The era in which somebody lives
- Attitude & behavior of the society in the face of ill people

The welfare system

- Measures of integration for people with disabilities

The health system

- Circumstances of health care
- Willingness, possibilities & constraints from health care service provider

The possibility of assisted suicide

- Existence & legality of assisted suicide and assisted suicide organizations
- Necessary requirements to die by assisted suicide

Financial aspects

- Possibility & willingness to self-finance supporting health care services*
- Financial resources to cover cost-of living

The natural death

- Finiteness of life*

Anticipated dimensions of conditions of one's existence = topics with*

(Bernhart-Just, 2015, S. 144-145)

Selected motives & influencing factors which promote to stay alive or to die by assisted suicide

Factors which promote that ill peoples are staying alive	... dying through assisted suicide
Formative experiences	<ul style="list-style-type: none"> Acceptable dying and death events 	<ul style="list-style-type: none"> Bad dying and death situations
Attitude & beliefs about life, dying, death	<ul style="list-style-type: none"> I have to bear my fate → only god determines when a person leaves the world 	<ul style="list-style-type: none"> Every person should decide over one's dying by oneself
Value-preference-system (desired & undesired aspects)	<ul style="list-style-type: none"> Secondarily → little dissonances between values, preferences and someone's existence 	<ul style="list-style-type: none"> Dominant → need to be prepared compared to the undesired existence Self-determination in life and death
The state of health and its development	<ul style="list-style-type: none"> Possibility to postpone the disease Experience health improvement, ↑ QoL 	<ul style="list-style-type: none"> Bad or not any therapeutic options → persistent, unbearable complaints
Kind of existence*	<ul style="list-style-type: none"> Feeling (more) independently To be engaged in meaningful things 	<ul style="list-style-type: none"> Trouble with ↑ dependence Impossibility to live one's passion
The handling of the chronically ill	<ul style="list-style-type: none"> To give meaning to one's life Learning to handle one's illness & consequences 	<ul style="list-style-type: none"> Anticipating undesired ways of existence Searching for ways out by oneself & taking the way of assisted suicide
The handling of relatives, loved ones	<ul style="list-style-type: none"> Support, helpfulness, caring, solicitousness, appreciation, affection Refusal stand to assisted suicide 	<ul style="list-style-type: none"> Disregard of values & preferences Acceptance, support, disinterest to the plan to die by assisted suicide
The handling of health professionals	<ul style="list-style-type: none"> Excellent nursing care → positive needs-oriented, humane care experiences Acceptable alternatives to assisted suicide 	<ul style="list-style-type: none"> Negative, degrading nursing care, suggestions of care are incompatible with the values & preferences of the ill person Non-willingness to discuss assisted suicide
Possibility & criteria to die by assisted suicide		<ul style="list-style-type: none"> Anxiety not to fulfill requested requirements to die by assisted suicide

(Bernhart-Just, 2015)



Constellations of existence

Constellation 1	Constellation 2a	Constellation 2b	Constellation 3
Bearable existence No or little fears	Still bearable existence Anxiety & reluctance	Invidious, undesired existence Anxiety & reluctance	Unbearable existence Anxiety & reluctance
To come to terms with one's existence	Still come to terms with one's existence	Difficulties to come to terms with one's existence	Can't come to terms with one's existence
Nonrestrictive will to live To be willing to live	Limited will to live To be willing to live as long as possible	Diminishing will to live To get ready to die	No will to live To be ready to die
No decision to die	(No) decision to stay alive as long as ... & to die by assisted suicide if ...	To get ripe to die by assisted suicide if one can't bear it	(No) decision to die by assisted suicide

(Bernhart-Just, 2015, S. 144-145)

Findings about decision-making processes to stay alive or to die by assisted suicide

Influencing factors, motives

- Multifactorial
- Trigger factors, co-factors & main factors
- Meaning of factors is a matter of discretion

Decision/ decision-making process

- Complex
- Individual reaction of a persons experience on one's experience of existence as well as one's appraisal to come or not come to terms with one's existence in the context of being chronically ill
- Consistent or fluctuating - turning points
- If the termination of one's life is no option
→ no decision to die

(Bernhart-Just, 2015)

Findings about decision-making processes to stay alive or to die by assisted suicide

Decision to die by assisted suicide

- Beginning years before a chronically disease occurs
- Result of a speedy or slowly maturing process
- Individual deliverance & protection strategy
- Non urgent or current-urgent
- Short-term & however early
- Decision-making processes to die by assisted suicide are becoming forced through certain factors
- The point of time & terms of dying by assisted suicide → a matter of discretion

The fact respectively the decision to stay alive

- Nonrestrictive will to live
- Religious attention & belief that only god or another act of nature beyond control can decide
- Notion to have no other choice as to come to terms with one's existence & to have to bear it until deliverance

(Bernhart-Just, 2015)

Recommendations for health professionals, health care institutions, politics and research

Dignified care of people on the path of life	<ul style="list-style-type: none">• Investigate ideas about life & end-of-life arrangements• Respect for self-determination in life & dying• Direction on the needs, values & preferences of the ill person → excellent <i>Life-Care</i> as well as <i>End-of-Life Care</i>• Future care planning, life care planning, advanced care planning
Percipience of uncertainty To come or not come to terms with one's existence	<ul style="list-style-type: none">• Investigate the burden of consequences on the existence & the current constellation of existence• Support & facilitation of coming to terms with one's existence → comprehensive, anticipatory arrangement of existence
Notice of assisted suicide thoughts & suicide prevention	<ul style="list-style-type: none">• Detect warning signs, thoughts of suicide, respond to them• Develop acceptable alternatives for assisted suicide
Institutional discussion - Should we allow assisted suicide?	<ul style="list-style-type: none">• Guideline about the procedure in the case of a wish to die by assisted suicide (incl. role and tasks of persons who are involved)
Legislation	<ul style="list-style-type: none">• Requirements & criteria of carefulness concerning assisted suicide
Research	<ul style="list-style-type: none">• Needs & preferences of chronically ill people → patient-oriented provision of medical specifically palliative care• Effect of self-management programs & patient-oriented care and person-focused care on the wish to stay alive or to die by assisted suicide

(Bernhart-Just, 2015)

For further information



Bibliography & figures

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Figures

Figure 1: http://blog.world-mysteries.com/wp-content/uploads/2012/10/subjective_Experience_icn.jpg

Figure 2: http://ro.uwe.ac.uk/FileStore/LearningObjects/LearningObject296/qda_researchquestion.jpg

Figure 3: <http://us.123rf.com/450wm/radiantskies/radiantskies1212/radiantskies121201544/16720034-abstract-word-cloud-for-clinical-study-design-with-related-tags-and-terms.jpg>

Figure 4: <https://6eb38ff1cafc12dd43c-a15ea43485746d596cd662ba2dccda73.ssl.cf2.rackcdn.com/jzs4qcnfw6OAvP1q35cGFtNR>

Thank you for your attention!



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