Lay Summary

Understanding the wish to die in elderly nursing home residents: a mixed methods approach

Project team:

Dr. Stéfanie Monod, Anne-Véronique Durst, Dr. Brenda Spencer, Dr. Etienne Rochat, Dr. Claudia Mazzocato, Prof. Eckhard Frick, Prof. Armin von Gunten, Prof. Thomas Münzer, Dr. Pierluigi Quadri, Dr. Alessandro Levorato, Prof. Christophe Büla, Dr. Eve Rubli Truchard, Prof. Ralf J. Jox

Contact address:

Dr. Stéfanie Monod
Service de la santé publique
Avenue des Casernes 2
1014 Lausanne
Tél. +41 21 316 42 00
Fax +41 21 316 42 78
stefanie.monod@vd.ch

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1. Background

This scientific project was situated within the general funding programme « end of life » of the Swiss National Fund and concerns wishes to die in elderly people living in nursing homes. This is a topic that has long been neglected in research due to its sensitive nature, but that is nonetheless of high practical importance. People who approach the end of life and may suffer from chronic and often progressive diseases will understandably think about death and dying. Depending on the personality and the situation, they may also wish that their life ends. Sometimes, these wishes may lead to actions such as suicide or assisted suicide, but in other cases they may just remain thoughts and may even go alongside wishes to remain alive.

The previous research that has been conducted on wishes to die has shown that this is a rather complex phenomenon. In fact, there are a whole range of wishes to die with different qualities: there may be the passive wish that death comes naturally, but there may also be the active wish to hasten death by committing suicide with or without the assistance of others. The factors that lead to wishes to die are still poorly understood: often, there is psychological suffering, such as anxiety, depressive mood, sometimes there is also suffering due to extreme physical suffering or a difficult social situation, such as loneliness, complete dependence on others or the feeling to be a burden to others. Distress in the spiritual or existential domain of people's lives has rarely been studied as a factor that may contribute to wishes to die.

Surprisingly, this research has rather neglected the situation of elderly people, especially those living in nursing homes. Yet, in aging societies like the Swiss one, we see that the rates of suicide and assisted suicide increase particularly among elderly citizens. Moreover, the number of people living in nursing homes at the end of their lives, having more or less cognitive impairments, is also rising. It is not known at all whether elderly nursing home residents have wishes to die, how they look like and what may be the underlying reasons or factors that go along with such wishes to die.

2. Goals of the project

The project aimed to shed light on the wish to die in elderly nursing home residents. More specifically, it pursued the following goals:

- To test whether elderly nursing home residents in Switzerland are ready to speak about wishes to die, and whether this is also the case when they have minor cognitive impairments
- To assess how common wishes to die are among elderly nursing home residents in Switzerland and whether there are differences between those living in the German-speaking, French-speaking and Italian-speaking regions
- To determine the quality of the wishes to die that are present in this group, e.g. whether they are rather passive or active wishes to die
- To explore which kinds of problems and suffering are associated with the wishes to die in this group of people, in particular whether spiritual distress is among these factors.

3. Methods

This research project was an observational study in three culturally and linguistically different regions of Switzerland: the canton of Vaud (French-speaking), the canton of St Gall (German-speaking) and the canton of Ticino (Italian-speaking). For each of these regions, several nursing homes were contacted and residents who lived in these nursing homes were approached if they met certain criteria (> 75 years, fluent in the local language, living in the nursing home for 4-10 months, not being severely cognitively impaired, able to consent to the project, not being too ill to participate). All residents who met these criteria were informed about the study by research psychologists and offered the opportunity to participate. Those who gave their written informed consent were then presented questionnaires in a personal meeting with the research psychologist. The latter were specifically trained for this project. In addition, questions relating to spiritual distress were asked by specifically trained chaplains.

The questionnaires consisted of several parts that had each been proven to assess certain characteristics in previous research. To assess the wish to die we used two instruments, the “Schedule of Attitudes toward Hastened Death for Seniors” (SAHD-Senior) that had been tested in a group of elderly patients before and assesses mainly the intensity of the wish to die, and the “Categories of Attitudes toward Death Occurrence” (CADO) that had also been tested in this group and measures the quality of wishes to die. We also measured spiritual distress, depression, anxiety, the feeling to be a burden to others, the load of physical symptoms, the number of different illnesses at the same time (multimorbidity), and the degree of cognitive impairment.

We aimed to include 100 nursing home residents in each language region, but due to organizational difficulties we had to lower our goal for the German-speaking region of St Gall to at least 50 participants. After having obtained the information for all participants, the data were extracted from the written questionnaires into a database and then analyzed statistically.

4. Results

From a total of 769 nursing home residents we could include 280 residents, 107 in the Canton of Vaud, 117 in the canton of Ticino and 56 in the canton of St Gall. The others did not meet the criteria of inclusion; only very few residents who were approached declined to participate in the study. The impression of the research psychologists at all three sites of the study was unanimous: the nursing home residents were ready to talk about these sensitive topics, indeed many of them expressed an interest in the study and seemed grateful to be able to talk about someone about death and wishes to die.

Most of the study participants were living in ordinary geriatric nursing homes, very few were living in specialized institutions for elderly with psychiatric problems (psychogeriatric nursing homes). As known from the general population living in nursing homes, three quarters were women (74%) and only one quarter was men (26%). More than half of the residents were widows or widowers (61%), a fifth was still married (22%) and the others were either single or divorced. The average age

across all participants was 87.5 years – in fact, half of our participants were above the age of 88 years. Compared to the average age of nursing home residents in Switzerland, our group were rather older residents – a group that has rarely been studied before. This is because we deliberately excluded the younger nursing home residents below the age of 75 years.

In the total group of nursing home residents, we found the following distinct attitudes towards the occurrence of death: 4% were not ready for death to occur and didn't accept it; 50% were not ready to die but would accept it nevertheless; 30% said they would accept death and were ready to die; 16% wished that death would come naturally; only 1 resident (0.4%) actively wished to hasten death. This means that almost all wishes to die in this group of elderly nursing home residents were passive wishes to die: 16% wanted death to occur rather sooner than later but did not contemplate to hasten it by suicide or assisted suicide, and still another 30% of the residents would accept death if it came. According to the second measurement instrument for wishes to die (SAHD-Senior), we saw that about 11% had significant wishes to die. The latter instrument allowed us to see that the average intensity of the wish to die was rather low (mean of 3.4 on a scale from 1-20). The frequency of wishes to die was significantly higher in the regions of Vaud (French-speaking) and St Gall (German-speaking) than in the region of Ticino (Italian-speaking).

We also studied which factors were associated with wishes to die, that is which factors were more often present in the group of residents who had a wish to die, compared to the other residents who did not have a wish to die. If we studied the connection between each factor and the wish to die separately, we found that the following factors were associated with it: (1) depression (5 times higher risk to have death wishes), (2) unmet spiritual needs (2-6 times higher risk, depending on the domain of spirituality), (3) feeling to be a high burden to others higher (3-4 times higher risk), (4) demoralization, physical symptoms, anxiety and higher age (slightly elevated risk). The gender, marital state and the number of illnesses were not associated with wishes to die.

Looking at the different aspects of spiritual distress, wishes to die were most often present if the person had the impression that her own psychological identity was endangered. Also, if the people suffered from questions regarding the meaning of life

or regarding the existence of a transcendental being (God), this distress was also correlated with wishes to die.

Similar factors have also been found to influence the wish to die in younger patients suffering from life-limiting diseases. Yet, the finding that unmet spiritual needs play a role for death wishes is a rather new one. In a second step of analysis we wanted to identify only those factors that influence the wish to die independently from each other. This is important because many of these factors interact with each other, such as depression, anxiety and spiritual distress. When we applied this analysis, we found that depression and spiritual distress were not any more the major determinants, because they apparently interact with each other and with many other characteristics. The factors that independently influence wishes to die are mainly the age (the older, the more wishes to die), demoralization and the fact that the patients are treated with antipsychotic drugs. Interestingly, those patients who had more cognitive impairment less often expressed wishes to die. Whether cognitive impairment is in fact a protective factor or whether patients forget their previous death wishes with increasing cognitive problems, cannot be answered.

Our analysis also showed that spiritual distress is indeed a concept that is distinct from depression. In fact, many people had spiritual distress without having depression. The other way round, many of those with depression also had spiritual distress. So, spiritual distress may be a precursor or risk factor to depression and it may be very interesting to detect and respond to spiritual distress early in order to avoid depression and wishes to die.

5. Significance of the results for science and practice

The study has importance both for further research and for practice. As the first study it applied the newly developed instruments to identify and measure the wish to die in elderly people (SAHD-Senior and CADO). Thus, it paved the way for future researchers to apply these instruments and compare their results to ours. The study showed that depression and demoralization, two kinds of psychological suffering, are important determinants of death wishes. Thus, early detection and adequate management of these kinds of psychological suffering seem to be public health

priorities in nursing homes. It also yielded new data about some unmet spiritual needs as determinants of wishes to die, which has rather been neglected in research so far.

Finally, our study has the potential to encourage researchers and research ethics committees that addressing sensitive end-of-life topics with the very old is indeed possible and may even be welcome, including in a nursing home setting. Based on the experiences in our study, wishes to die should be openly and empathetically addressed, both within a family and in confidential, trusted relationships between health care professionals and their patients. As psychiatrists had learnt this several decades ago, speaking about such a taboo might in fact be relieving and helpful for those who hold these wishes.

Looking at the factors that were associated with wishes to die we see that some of them cannot be altered, for example age. Others, however, notably depression, spiritual needs and physical symptoms might be amenable to a comprehensive care approach. The use of antipsychotic drugs should be reduced to the minimum possible. Although we have not studied this in our project, the literature and clinical experience shows that depression is underdiagnosed and undertreated in elderly people in nursing homes. Even more so, spiritual distress does not even exist as a medical category, and no instrument to identify and detect it is being used in nursing homes. Chaplains, spiritual care assistants, but also nurses, doctors and volunteers may be helpful in identifying and reducing spiritual distress of nursing home residents.

Societal discourse should not reduce wishes to die to a narrow controversy about assisted suicide organizations such as Exit in Switzerland (which has largely been the case in recent years). Instead, a variety of appropriate responses might be considered, based on the individual situation of the person concerned. The fact that death wishes are influenced by multiple factors means that no single action will easily reduce or prevent death wishes. In any case, the question should be openly discussed in society which response may be most ethically appropriate to death wishes of nursing home residents.