Wishing to die and the concept of ‘hastening death’

Posted by cehmann-sutter on 21 Dec 2016 at 10:41 GMT

A WTHD, according to Albert Balaguer, Cristina Monforte-Royo, Josep Porta-Sales et al. [1], is "a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death." (p. 8/14) All the components of this statement and the international Delphi process used to develop it are well explained in their paper. We believe this is a very important contribution that will lead to a further, urgently needed clarification of concepts involved. However, we want to comment on this proposal from the perspective of our own empirical research on the phenomenon of patient’s wishes to die. We have conducted qualitative interviews with 62 terminally ill patients in palliative care, their nurses, physicians and relatives, in and outside of oncology [2,3,4,5,6].

The aim of the project on which the paper is based was to counteract “both clinical and terminological aspects” of the lack of clarity in our thinking about “the phenomenon of the desire for hastened death” (p. 2/14). The paper attempts to define the concept of a WTHD, which in turn should adequately target the phenomenon. This distinction is crucial. The phenomenon of a WTHD is, like all wishes (desires, hopes or wills), essentially subjective: the wish to die and the wish to hasten death are subjective experiences of the person who ‘has’ such wishes. The concept however can be a shared idea with a certain degree of objectivity in the sense of shared understanding. Concepts can be defined, but phenomena, since they are experiences, cannot in the strict sense of the term be defined. Experiences can only be described, analysed, evaluated, or explained.

When we check the wording of the above quoted ‘consensus definition’ in the paper, we see both aspects are present: it provides a genus proximum (reaction to suffering – there are reactions to suffering other than wishes) and proposes a set of specific differences (patient sees no way out other than to accelerate his/her death). On the other hand, it also explains the phenomenon by providing a mechanism for how it comes about (suffering and circumstances lead to a situation in which the patient sees no other way out than to accelerate death).

The proposed consensus statement is not a definition in one of the classical forms [7]. It seems rather to be an explanatory description of the phenomenon.

For instance, it does not say which reactions to suffering are actually wishes. It presumes that we know what a wish is, and that we are only interested in learning what kind of wish is a WTHD. And the proposed specific distinction between the WTHD and other wishful reactions to suffering is just a synonym of the term ‘hastening’: hastening is ‘accelerating’. The definition is therefore circular.

Let us understand the consensus statement as an explanation of the phenomenon of a WTHD, and concede that in a more loose way, such an explanation can indeed tell how we should use the term WTHD: we use it precisely to name this kind of phenomena. This has an important consequence for the issue of whether, and for what reasons, we should agree with the proposed consensus statement. On the basis of our own empirical research we raise three questions that relate to the key elements of the above quoted explanatory statement.

(1) A WTHD is a reaction to suffering. The statement links the definition of a phenomenon (the WTHD) with an underlying reason. This poses the risk of narrowing down the explanation too much. Why must a wish to hasten death, probably any wish to die, necessarily be an answer to an unbearable/burdensome situation? How can this presumption be proved? What are the underlying attitudes toward life, death, afterlife? Are they shared with all patients? Should a phenomenon that is known to be exceptionally complex not be described in a way that leaves open the possibility of diverse forms of experiences? For instance, in our study we have seen WTHD that are not motivated by suffering. One of our patients in the oncology group, a man in his 70ties with bronchial carcinoma, explicitly said that he was not suffering but wished to have his life shortened:

"Look, I am just too well. I can’t die, (laughing) I am too well. I have no pain, nothing. I don’t want to have pain, I can do without it. But I’ve already been waiting for death to come for such a long time. … I’m … how shall I put it, I’m actually quite content. I want it to be knocking-off time soon.” (P12-I)

There are many WTHD that can be explained by the underlying suffering; indeed, perhaps this is most commonly the case. But it still does not seem to be a necessary condition of WTHD, and therefore should not be part of a defining explanation. The question raised by this is what different motivating factors can be a subjective reason for WTHD? Suffering is one of these factors, perhaps the most important, but there can be others.

(2) A WTHD emerges in the context of a life-threatening condition. However, there are also WTHD that are not caused by a life-threatening disease. We have seen patients who are old and frail, and who wish to hasten their death. And there are of course all kinds of WTHD beyond the end-of-life context. Each
case of suicidality in the absence of life-threatening disease would fall into this category. Why should a WTHD only emerge in a life-threatening condition? If we apply the proposed definition, do we want to consider patients who do not fulfil the condition of the life-threatening condition as having an 'illicit' WTHD or would they simply fall outside of the category? One of our patients in the oncology group for instance said that she wanted to die because her twin sister, with whom she had a strong bond, had already died. She then refused treatment of her breast cancer, in order to die more quickly. But her reason was not the cancer itself; this life-threatening condition merely provided an opportunity for her to die. Confining the WTHD to life-threatening conditions seems to imply an already normative evaluation of the conditions, when such a wish should be permissible, rather than being based on a descriptive account of its properties. Equally if not more important are the practical implications for the care of frail elderly persons who express a WTHD. Applying the definition as it is could mean missing opportunities to talk with elderly persons about their wishes around dying, as their WTHD fails to fit the definition's criteria and would therefore not be acknowledged as such. (3) The patient who wishes to accelerate his or her death can see no way out other than this. This statement implies that patients hold one single or one very prominent wish. As our research revealed, the wish to die more quickly may be one of several possible ways out, and is the one preferred by the patient above other alternatives that are also seen as possible options. The question raised by this observation is whether the concept of a WTHD (and wishes to die in general, including those without the 'hastening' element) is more narrowly tied to patients' preferences and subjective evaluations rather than to being the only possible way forward. Wishes at the end of life can be understood as reflected hopes. They are often fine-tuned by the patients with their second-order volitions, for instance by wishes not to wish certain things [3,8]. The amount of tension a person experiences through holding seemingly contradictory wishes that are present simultaneously may also be important.

There is a further element of the definition we would like to discuss: A WTHD implies an acceleration of death. This is of course analytically true: hastening means acceleration. However, there are wishes to die whose intentions are in close proximity to hastening and include everything a WTHD possesses, including the wish that death may come sooner, except the plan to contribute actively to the acceleration. In the four different patient groups of our own study (cancer, organ failure, neuro-degenerative disorders, frailty) we have now and then seen patients who want death to come more quickly but do not wish actively to contribute to its acceleration. It is a wish to die for it to come now, or more quickly, but the hastening agent is not the patient. The accelerating force in such examples of WTHD is found in the progress of the disease, in fate, nature, or in God. Here is an example from a man (86 years) with a bile duct carcinoma: ‘My wife said: ’It would be the worst thing for me, if you did that i.e. to kill myself.’ But it’s out of the question. But I wouldn’t have anything against it moving more quickly.” Patient, 86 years old, bile duct carcinoma (P8-I)
The explanation of WTHD as involving ‘accelerating death’ therefore is ambiguous in regard to the agency of the acceleration: who or what is doing the hastening? The patient or those forces responsible for the progress of the disease?

This raises another interesting question: modern medicine’s dying trajectories also cover the space in-between a death that is hastened by the patients’ activity or decision, and a natural death. The whole concept of a ‘natural’ death is culturally dependent, and according to sociologists of dying such as Talcott Parsons and Clive Seale, must be understood as a typically modern construction [9, p. 54]. Naturalness is questionable in each individual case when so much is influenced by medical care. There is space in between the death hastened by patients’ activities and the non-accelerated, natural death, a space in which patients can simply hope that death would come more quickly. Can we so clearly distinguish between these variations in the marginal zone of a wish to hasten death without losing an important part of them?

If the examples that we refer to cannot be dismissed by saying that they do not qualify as ‘true’ WTHD, the explanatory statement about WTHD needs to be modified. The paper by Balaguer et al. offers an opportunity to raise such questions in a more nuanced way, on the basis of an international process. We therefore hope that discussion of the appropriate and meaningful definitions of different kinds of wishes to die and their contexts remains open rather than being prematurely closed.

Christoph Rehmann-Sutter1, Heike Gudat2, Kathrin Ohnsorge2

1 Institute for History of Medicine and Science Studies, University of Lübeck, Germany
2 Hospiz im Park, Klinik für Palliative Care, Arlesheim, Switzerland

For correspondence: rehmann@imgwf.uni-luebeck.de

Acknowledgment: Our research was funded by Oncosuisse and the Swiss National Science Foundation, National Research Programme 67 ‘End of Life’. We thank Nina Streeck for comments.

References
6. Ohnsorge K, Gudat H, Rehmann-Sutter C. What a wish to die can mean. Reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients. BMC Palliative Care 2014;13(38).

No competing interests declared.