

“Unfiltered” voices of patients - lessons to be learned from an alternative media project. An audio-visual presentation

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Background and aim

“*DU bist Radio*” (*YOU are radio*) is a newly developed radio format which has first been broadcast in Switzerland in March 2009.¹

For the first time ever, five patients suffering from devastating Amyotrophic Lateral Sclerosis get together to produce a radio program. They talk about their lives before being diagnosed and about the impact the disease has had on them and their families since the disclosure. Suffering from this incurable motor neuron disease and facing death possibly in the near future, this one-hour-program gives remarkable insight into five biographies which are dominated by suffering, yet guided by hope.

The aim is to allow and enable them to speak for themselves, as a possible paradigm case for encouraging the inclusion of patients' and relatives' “unfiltered” voices in clinical ethics consultation as well.

Approach

“*DU bist Radio*” (DBR) follows closely the concept of dialogical philosophy as developed for example by Martin Buber: “*I become through my relation to the Thou.*” DBR hands over the microphone to vulnerable groups (patients, prisoners, disabled or terminally ill adults, children in a hospice and drug addicts) and teaches them radio skills and craft. The final product - the radio show - including all content is solely created by the DBR groups.

Results and discussion

The project showed that the ‘experimental’ approach worked out well: ALS patients were able to communicate important messages to a large audience stimulating awareness for their needs and problems such as neglect for patients, esp. after retirement; the need to restart communication processes e.g. in their families; the need to formulate and realize dreams and goals.

This means that a radio program in which no “journalistic filter” is being applied and no journalistic questions are asked, is a fruitful media setting: it seems to be particularly the absence of the investigative approach which allows for unexpected answers and authentic insights. The impact of this experience shall be put to discussion in the context of clinical ethics consultation.

Conclusion

If we don't ask questions we will receive different answers; this rather unusual statement apparently sums up the DBR experience so far. Especially when working with patients, questions and questionnaires oftentimes emphasize the interviewer's quest for knowledge (which includes his / her attitude and prejudice). Thus, the degree of authenticity of the interviewee's answer is at least questionable. Providing a setting where patients solely are responsible for the content of a discussion, we may gain greater insight into their overall condition – and this may also be true for clinical ethics consultation.

¹ It has been awarded with the “Deutscher Alternativer Medienpreis” (German Alternative Media Award) and is nominated for the European “Prix Europa”.