INTRODUCTION

- People cultivate self-images that they wish to maintain, especially in critical medical situations of illness, weakness, and care dependency at the end of life. They talk about these situations both in the public and private spheres.
- Perceptions of autonomy and dependency, vulnerability and care significantly influence the process of health provision planning. One of the main issues of the project is to identify arguments produced in different discourses.
- The analysis considers medical ethical and advisory literature on advance directives (AD), debates in the media and on Internet forums, but also the experience of advisory doctors and lawyers as well as the perspectives of those affected.

LEADING RESEARCH QUESTIONS & AIDS

- The project explores and analyses perceptions of autonomy, vulnerability, and dependency. To what extent do they affect the decisions and arrangements for the final stages of life? What do men and women think about life and death? What desires and fears move them in view of the final stages of life and how do they anticipate the decline in their own self-determination?
- The knowledge of different argumentation and the interplay of gender, confessional, and socio-cultural factors open up new research perspectives and enable optimization of personalized consulting services in clinical practice and through media awareness campaigns.

METHODS

- Since human existence oscillates between autonomy and dependence, we analyse four public and private areas (academia, hospitals, families, media) that contribute to the current discussions in different ways. This holistic approach allows a deeper understanding of the debates on AD in times of medicalization of life.
- To achieve this, the project includes: (1) Diachronic and synchronic analysis of professional discourses about advance care planning and anticipatory decision-making. (2) Standardized content analysis of texts from consulting practices and debates in mass media. (3) Qualitative content analysis of advisory literature and discussions about AD on Internet platforms. (4) Semi-structured interviews with experts (n=25) and group discussions (n=10) with persons concerned.

RESEARCH PLAN

1. PROFESSIONAL DISCOURSE

Analysis and systematization of medical ethics professional discourse on anticipatory decision-making focusing on AD. Identification of key concepts and arguments also taking into account the contributions of disciplines such as philosophy, theology, palliative medicine, and care ethics.

2. TEXTS OF CONSULTING PRACTICE

How are professional discourses prepared for laypeople? Examination of advance directive templates and advisory literature to validate lines of arguments worked out in phase 1.

3. MEDIA DEBATES

Complex professional discourses are simplified by the mass media. The capture and analysis of discussions about end of life decision-making and their simplification in newspapers and television form the core of this research phase.

4. DISCUSSIONS ON SOCIAL MEDIA

The investigation of Internet forums to assess individual attitudes and experiences of laypeople with the regulation of hypothetical decision-making incapacity in a medical crisis or end of life situation. We consider the possibility of gender roles and patterns of arguments in the debate.

5. INDIVIDUAL MOTIVATIONS

Reconstruction of decisions, motives, and arguments of conducting AD for care plans, on the basis of group discussions with people concerned.

6. CONSULTING PRACTICE

Discussion of phase 1 - 4 results in semi-structured interviews with experts. The aim is to develop a consulting practice sensitive to gender- & cultural-difference in cooperation with the University Hospital Klinikum rechts der Isar, TUM, Munich, Germany, and the European Institute of Oncology, Milan, Italy.

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