

Abstract

Respect for patient autonomy stands as a fundamental principle within contemporary bioethics and medical ethics. Alongside principles of beneficence, non-maleficence, and justice, it constitutes a foundational element of the principlist approach in bioethics, which has profoundly shaped bioethical considerations and clinical practice since the 1970s. Within this theoretical framework, autonomous action necessitates intentionality, information, and freedom, wherein it remains unaffected by undesirable influences. However, this conceptualization of autonomy, rooted in rational reflection of possibilities and subsequent free decisions by independent individuals, often faces critique for its perceived individualistic nature and overemphasis on rational choice. Within the realm of healthcare, the principle of informed consent has emerged as an ethical and legal instrument to fortify patient autonomy, emanating from this theoretical foundation. Nonetheless, the context of patients facing end of life due to advanced incurable diseases exposes the limitations of this autonomy concept and, by extension, the institution of informed consent.

The theoretical introduction of this thesis delineates various conceptions of autonomy beyond principlism, particularly those grounded in phenomenological and feminist theoretical underpinnings. These alternative conceptions shed light on crucial aspects pertinent to the context of advanced incurable diseases. The subsequent research component presents five studies. The initial study proposes an alternative structural model suitable for patients at the end of life, drawing on George Agich's phenomenologically based concept of actual autonomy. Subsequent studies delve into specific facets of these patients' life situations, encompassing factors they deem important, prognostic awareness, and the preferences of involved parties in decision-making concerning healthcare actions.

This thesis advocates an alternative theoretical model of autonomy that encapsulates the unique circumstances of the end of life. Our data reveal that patients in this context seek comprehensive information, including unfavorable news. Their prognostic awareness remains rather stable throughout their illness trajectory and may not necessarily correlate with heightened emotional distress. Additionally, when determining their healthcare choices, patients at the end of life express a preference for shared decision-making.

Key words: autonomy, decision-making, end of life, communication, quality of life, prognostic awareness, cancer