

61

RETHINKING THE ETHICAL FOUNDATION OF ADVANCE CARE PLANNING

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Research aims This interpretive descriptive study was designed to explore the process of advance care planning (ACP).

Study design and methods Patient-centred ACP was undertaken with persons diagnosed with advanced lung cancer and a significant other. Nine family dyads participated (18 participants; 15 conjoint interviews). Follow-up interviews occurred 3 and 6 months after the ACP conversation. The participants were asked about their experience of ACP and its impact on their thinking, conversations and relationships. All interviews were audio-recorded and transcribed verbatim. The accounts were analyzed using the constant comparison method.

Results Most dyads completed the ACP process. Although the conversations were difficult, the dyads appreciated the opportunity to engage in these important and intimate discussions and evaluated the conversation positively. While the researcher structured the topics of the ACP discussion, the dyad led the interactional process. The process that unfolded during the ACP conversation was deeply relational and was characterized by mutuality, interdependence and shared decision making.

Conclusions The ethical foundation of ACP has been rooted in individual autonomy and patient self-determination. However, the concept of individual autonomy is contested and there have been many theoretical critiques. Further, the importance of family involvement in all aspects of end-of-life care has been widely acknowledged. Yet, the orientation to individual autonomy remains, which invites clinical tension about the appropriate role of family in ACP related to the notion of avoiding 'undue influence'. The findings of this study support the adoption of a re-visioned ethical stance encompassing a relational approach to autonomy.