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## OP.018 Ethical challenges when studying the use of anticipatory medication in home palliative care research

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**Background:** Patients at the end of life often experience uncontrolled and distressing symptoms, are under-medicated and therefore do not experience adequate relief. Evidence shows that 70 to 90% of patients with advanced cancer experience pain, and symptoms are highly prevalent in the weeks/months before death. Anticipatory prescribing is used to controlling these symptoms and is designed to ensure that medication and medical devices are present at home when needed. Research on the use of anticipatory medication in home palliative care is paramount. However, conducting research with palliative care patients at the end of life raises ethical concerns surrounding research risks in vulnerable populations.

**Aim:** To review and synthesize ethical challenges in performing research with persons receiving anticipatory medication in home palliative care at the end of life. **Methods:** Systematic review, following PRISMA 2009. Thirteen databases were searched. **Inclusion criteria:** studies reporting the use of anticipatory medication in home palliative care, in English, German, Spanish and Portuguese. Data were analyzed using both inductive and deductive content analysis.

**Results, Outcomes and Implications:** 5,387 results were returned from initial searches, of which 48 were included in the synthesis. Articles included in the analysis covered a wide breadth of designs and topics. The main ethical challenges identified were: (1) Research recruitment process; and (4) Ethical approval for research involving vulnerable persons. First, ethical challenges surrounding recruitment of patients receiving anticipatory medication in palliative care formed a large part of the evidence. Gatekeeping by carers and professionals was identified as one of the main issues that may impact research participation. Second, risk within the research continuum was a recurrent feature in several articles. Risk was represented from an ethical perspective, as participants, both patients and family carers, were perceived as being physically and psychologically vulnerable. Third, challenges with the informed process were also highlighted and require researchers to gain permission to access potential participants, establish the basis for informed consent, gain initial and ongoing process, and consider requirements for support and feedback. Finally, gaining ethical approval was a major challenge in some studies because of the vulnerability of the participants, palliative care patients at the end of life, and the fact that they are perceived as experiencing a devastating condition. These findings add to the existing literature on palliative care research by identifying and systematizing its main ethical challenges. In order to ensure that palliative care patients are not unnecessarily excluded from participating in relevant research, these findings can build the basis for the development of specific guidelines for involving vulnerable patients and families in research.

**Conclusions:** This systematic review highlights the ethical challenges in performing research with persons receiving anticipatory medication in home palliative care at the end of life. The quality and relevance of future palliative care research requires the development of specific ethical guidelines. **Acknowledgments:** Fundação Grünenthal.

*Keywords:* anticipatory medication; palliative care; research ethics.