CARer-ADministration of as-needed sub-cutaneous medication for breakthrough symptoms in home-based dying patients: a UK study (CARiAD)

Record Status
This is a bibliographic record of an ongoing health technology assessment being undertaken by a member of INAHTA. Links to the published report and any other relevant documentation will be added when available.

Citation
CARer-ADministration of as-needed sub-cutaneous medication for breakthrough symptoms in home-based dying patients: a UK study (CARiAD) Health Technology Assessment

Authors' objectives
Most people want to be cared for and die at home. As people get weaker in the last weeks or days of life, they usually can't swallow. In the UK, when this happens, it is standard practice for medicines to be given by a drip under the skin to relieve symptoms. Four symptoms are common in dying people: pain, agitation, nausea and noisy breathing (rattle). These can happen even when a drip is in place, and are called breakthrough symptoms. When they do, a family member is advised to call a healthcare professional (HCP), usually a district nurse. The nurse will visit and give the patient an injection under the skin. But, it can take a long time, often much more than an hour, for the nurse to arrive and give the medicine. This wait can be distressing for patient and carer and the symptom can worsen by the time the nurse arrives. Carers tell us that this makes them feel powerless to help their loved ones. In some countries, like Australia, carers are trained to give symptom-relieving medicine to their dying relatives at home. We are working with a team from Brisbane, who have 30 years' experience of this. We cannot be sure that this approach would be welcomed in the UK, so we need to test it out. When there is uncertainty, the best way to resolve it is to do a randomised controlled trial (RCT). This is a test where, at random, half the patients get usual care and the other half the new care. We hope to conduct a RCT comparing injections given by carers to dying patients looked after at home (the new care) versus HCP-given injections (the usual care). Before doing a large trial, it is good practice to first test the feasibility in a smaller group of patients. Our study is such a feasibility study. Firstly, we will ensure that everyone understands it is legal for carers to give symptom-relieving injections to dying patients as long as they are supported to do so. Our Australian partners have a time-tested education package: we will ensure this is reworked for UK patients, carers and HCPs. We will hold workshops to do this, and decide how best to explain the study to carers and patients. Then we will ask patients and their carers whether they are willing to be randomised to usual care or new care. Carers in the new care part will be trained how to recognise symptoms, to give injections and then see if they work to relieve the symptom. Carers in the usual care group will be asked to call a HCP if their loved one has breakthrough symptoms. Carers in both parts will be asked to keep a diary of symptoms and treatments. They will be invited to talk about how they found the study and the experience of giving injections. Information from this feasibility study will help us to understand if a large trial, to give a final answer, is possible. We have discussed our study with patients, carers and HCPs. They are greatly in favour of it and have given us their views, particularly with regard to the things we should measure. Two members of the study team are bereaved carers, and one has administered injections to her loved one. They have helped to design the study and will be involved throughout the study time. Study results will be fed back to carers who took part in the study if they wish to receive them, be published in scientific journals and discussed at national / international conferences.

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