Carer administration of as-needed subcutaneous medication for breakthrough symptoms in people dying at home: the CARiAD feasibility RCT

Marlise Poolman,[1*] Jessica Roberts,[1] Stella Wright,[1] Annie Hendry,[1] Nia Goulden,[2] Emily AF Holmes,[1] Anthony Byrne,[3] Paul Perkins,[4,5] Zoe Hoare,[2] Annmarie Nelson,[3] Julia Hiscock,[1] Dyfrig Hughes,[1] Julie O'Connor,[5] Betty Foster,[6] Liz Reymond,[7] Sue Healy,[8] Penney Lewis,[9] Bee Wee,[10] Rosalynde Johnstone,[11] Rossela Roberts,[12] Anne Parkinson,[5] Sian Roberts[11] and Clare Wilkinson[1]

[1]School of Health Sciences, Bangor University, Bangor, UK
[2]North Wales Organisation for Randomised Trials in Health, Bangor University, Bangor, UK
[3]Marie Curie Research Centre, School of Medicine, Cardiff University, Cardiff, UK
[4]Gloucestershire Hospitals NHS Foundation Trust, Gloucester, UK
[5]Sue Ryder Leckhampton Court Hospice, Cheltenham, UK
[6]Public Contributor, North Wales Cancer Patient Forum, North Wales Cancer Treatment Centre, Bodelwyddan, UK
[7]Brisbane South Palliative Care Collaborative, School of Medicine, Griffith University, Southport, QLD, Australia
[8]Metro South Palliative Care Service, Brisbane, QLD, Australia
[9]Centre for Medical Law and Ethics, King's College London, London, UK
[10]Harris Manchester College, University of Oxford, Oxford, UK
[11]Betsi Cadwaladr University Health Board, Bangor, UK
[12]School of Psychology, Bangor University, Bangor, UK

*Corresponding author m.poolman@bangor.ac.uk

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Plain English summary

CARiAD feasibility RCT

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Plain English summary

Most people in the UK would prefer to die at home, but only half of them achieve this. This usually depends on having able and willing lay carers (family or friends) to help look after them. Once swallowing is not possible, medicine is given continually under the skin (syringe driver). If common problems such as pain, vomiting or agitation break through, health-care professionals attend to give extra doses. The wait for a health-care professional to arrive can be distressing.

In the UK, it is legal (but not routine) for lay carers to give needle-free subcutaneous injections themselves. We reworked an Australian carer education package for UK use. The best way to find out if this would work well is to do a randomised controlled trial. This is a test in which, at random, half of the people taking part receive 'usual care' and the other half receive the 'new care' or intervention. A pilot randomised controlled trial (a 'test' trial to see if a larger one is worth doing) was carried out to determine if lay carer injections were possible in the UK.

We approached 90 dyads (a dying person and a key carer) and, of these, 40 were willing to take part and 22 completed the follow-up visit, so we could analyse their data. Of these 22 dyads, 16 were in the intervention group (lay carer injects) and six were in the control group (usual care). All carers were asked to keep a diary. Carers and health-care professionals were interviewed (qualitative study) and carer preferences were assessed.

This new practice was safe, acceptable and welcomed. Carer confidence increased rapidly, symptom control was quicker and the interviews backed up these findings.

Recruitment was low owing to overstretched health-care professionals. Only certain families were picked. Dyads in the usual-care group often wished they were in the intervention group. Carers found it difficult to complete some of the questionnaires that were used to measure the effect of the intervention.

Therefore, uncertainty remains as to whether or not a full trial should proceed. Because the practice is already legal, some areas in the UK are already undertaking it. We plan to study what makes this practice possible or less possible to achieve.

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This report

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