‘To wait or not to wait’: Lessons from running a wait-list controlled trial (ELSA) of a volunteer befriending service at the end of life within NHS, hospice and voluntary sectors

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Background: Many innovations in palliative care are implemented without robust understanding of their effect. Trials are underused as they can be considered ethically and pragmatically challenging. Wait-list designs show promise as they enable all participants to receive the intervention, but with the rigour of a controlled trial.

Design: Wait-list trial testing volunteer delivered befriending service to those in their last year of life. Local staff are responsible for site management and informed consent. Random allocation to receive intervention immediately or after a four week wait. Data collection at baseline, 4, 8 weeks: WHO QOL BREF, Loneliness scale, mMOS-SS, social networks.

Participants: 11 sites (NHS, hospice & other voluntary sector). N=196, baseline response rate 90%). 90 immediate, 86 wait arm. 60% female, mean age 72 (range 37-92 SD 12), 60% live alone, 93% white ethnicity, 47% with cancer.

Issues of the wait for the trial:
- Training & supporting staff to deliver intervention in wait list context
- Training staff in informed consent procedures
- Expressed disappointment at the wait from local staff
- Allocating volunteers appropriate to the wait list context
- Understanding effect and determining length of follow up

Lessons for running wait list trials
- Involving all staff in protocol development to promote ownership
- Determining the appropriate length of wait.
- Participants wait for an intervention anyhow – ‘wait’ more negatively perceived by staff than participants
- Considerations of managing any delays in the immediate intervention arm

Conclusions
- Local staff appreciate involvement in rigorously conducted research that answers questions important to them.
- Wait list trials are feasible and acceptable to staff who believe in offering an intervention to participants.

I’d have come out my shell, started getting more confidence a bit more, pushing myself a little bit more, if I’d had it [befriending service] earlier. (Patient, Immediate Trial Arm, discussing that they had waited for the intervention anyhow irrespective of the trial design)

There was one client who’d got five weeks to live [comment made after death] and then we got him on the waiting list so we couldn’t do any work with him in those last five weeks. And actually with our client group you don’t know when this is going to be the last bit. (Befriending service staff)

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