

‘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

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)

I think that for us actually the wait list nature of the trial has been unfortunate. It's great that we've had so many yeses in the last month, but actually I think that we could have done some even better work if we'd have had just put people on without having to, you know ... (Befriending service staff)

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)

I know you're looking at patients having to wait, but, actually, the bigger picture of this is, this is going to be phenomenally useful to us to make sure that the service is there in the future but that we can use as evidence for other areas as well (Befriending service manager).



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



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