

Exploring the Implementation of the '*Caring for Someone with Cancer*' Booklet in Community Nursing Practice: A Stake Case Study

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Overview

- Background
- What and How
- Findings
- Usefulness of Normalization Process Theory
- Recommendations and Future Work

Why Family Carers and Practical Care Support?

- Most end of life patients prefer to be cared for and die at home; however, most die in acute care.
- Family carers are crucial to enabling patients' preference to die at home (Gomes and Higginson, 2006); key role in achieving home death (Funk et al., 2010).
- DoH policy can only be achieved with family carers' input; optimising services outside of hospital settings could reduce deaths in hospital by up to 60,000 a year by 2021.
- However, research highlights a lack of practical support and inadequate information exchange to prepare carers for this role (Bee et al, 2009).
- Family caregivers therefore often adopt a 'trial and error' approach to palliative care (Luker et al, 2015; Bee et al, 2009). This is a stressful experience for carers and may lead to hospital admission.
- Future research needs to develop and evaluate well-defined interventions on practical skills (Caress et al, 2009) to prepare carers for the role.

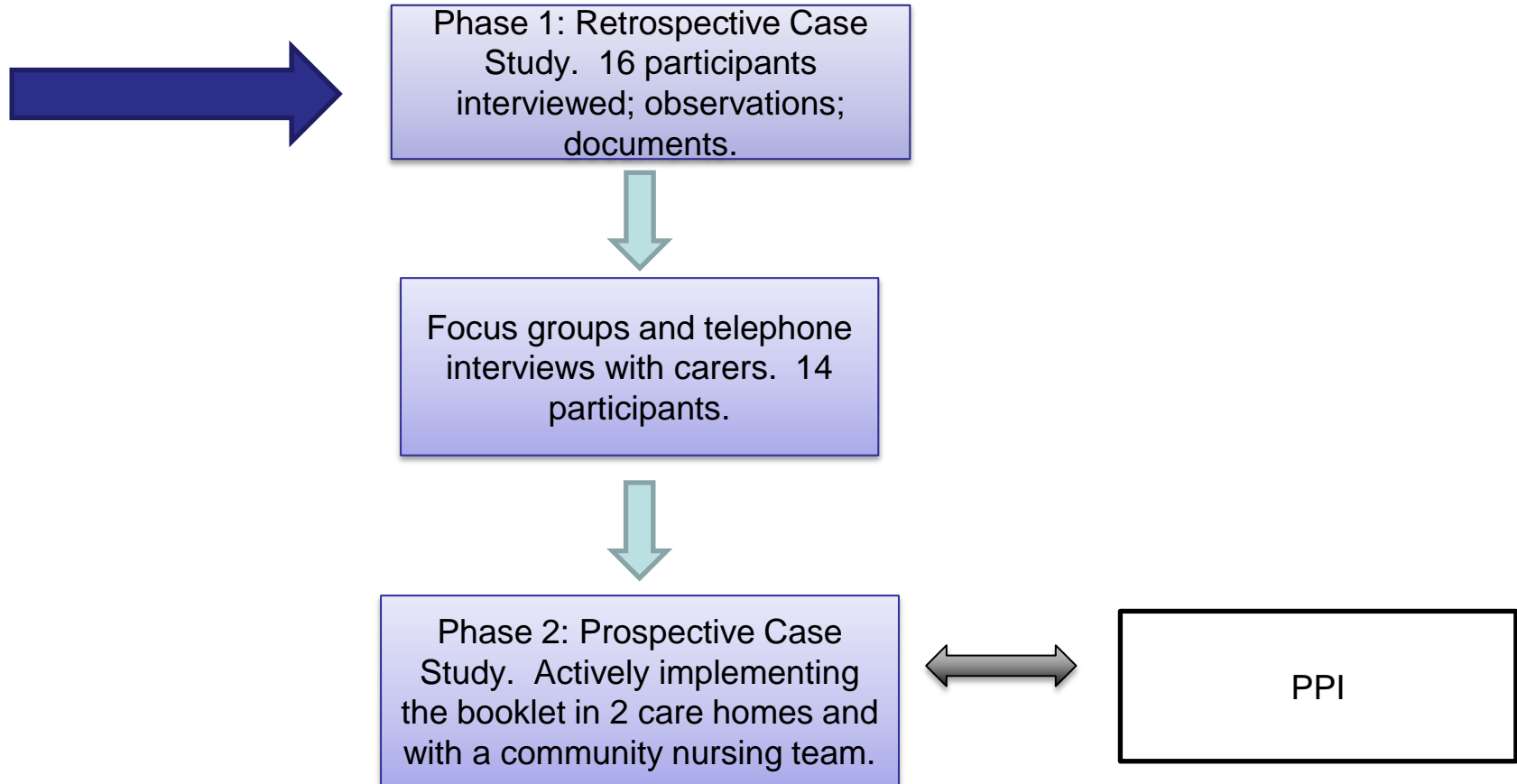
The Development and Evaluation of the Intervention



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- Intervention was developed in consultation with service users to meet practical information need of people caring for somebody with cancer near the end of life.
- Guided by the MRC Framework for the Design and Evaluation of Complex Interventions.
- Feasibility study suggest the booklet may have the potential to have a positive impact for carers, and district nursing teams.
- Testing however, raised some important questions regarding the timing and delivery of the booklet.

Case Study Plan



Setting - The Trust



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- Trust involved in the development of the booklet, which requested copies instead of payment.
- A large Community and Mental Foundation Trust employing 6,000 staff.
- Care provided to 1.3 million people across six boroughs of Greater Manchester.
- Since its formation in 2002, the Trust has undergone restructuring and services have gone through formal tender.
- Approximately 400 community nursing staff across 4 boroughs.
- Approximately 40 District Nurses.
- Focused on 3 out of the 4 boroughs providing community services.



- Case study approach to provide an insight into a specific phenomenon of interest – the adoption of the ‘Caring for Someone with Cancer’ booklet.
- An instrumental case study design (Stake: 1995).
- Semi-structured interviews with 16 key stakeholders – group and individual.
- An adapted version of the hierarchical mapping technique (Antonucci, 1986) was used.
- Formal and informal observations.
- Documents were collected.
- Field notes and a personal diary were kept.

Normalization Process Theory (NPT)

Construct	Description	Components
Coherence (sense-making) The value of the booklet over other resources/support	Sense making work that people do individually and collectively. The meaning behinds practice and how it is shared with others.	Differentiation Communal Specification Individual Specification Internalisation
Cognitive Participation (buy-in) People's commitment to using the booklet	Relational work to build and sustain a community of practice.	Initiation Enrolment Legitimation Activation
Collective Action (work involved) Working with others to implement the booklet	Operational work that people do to enact a set of practices.	Interactional Workability Relational Integration Skill Set Workability Contextual Integration
Reflexive Monitoring (evaluating) Evaluating the booklet	Appraisal work that people do, individually or as a group, to understand the way that a new practice affects them and others around them.	Systematization Communal Appraisal Individual Appraisal Reconfiguration

1. Understanding of the Booklet and the Availability of Other Resources (**Coherence and Relational Integration**)
2. Utilising the Booklet for Different Purposes, Conditions and in Different Settings (**Reflexive Monitoring – Reconfiguration**)
3. Culture of Change (**Contextual Integration**)

1. Understanding of the Booklet and the Availability of Other Resources



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- Trustworthiness and suitability for their work
- “Another booklet”
- Tailoring information and use in conjunction with other resources
- Personal preference and decision to use it over other resources
- Building confidence in the new practice
- “Opening Pandora's Box”

Coherence: Understanding the Intervention and their Work



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“We found a box of them left in our office. We didn’t quite know who...you know, where have these come from? On the address was...I think it was addressed to the PA of the chief exec. And I don’t think she was quite sure why they’d come to her. She just, sort of, looked and thought, oh it’s something for the nurses. So she just said, oh I’ve left them in your office just wondering whether you might find them useful [...] So I think we had a little flick through, as you do with a booklet and...yeah, I mean, it’s all really, you know, useful information but I think we’ve just not, sort of...you know...because I think we didn’t quite know where it had come from and what’s it all about, and, sort of, looking through it...I mean, everything’s completely relevant. But as I say, all of those things that are in there, when we’re going...doing our assessment and then doing our visits, they’re all, sort of, things that we are discussing” – Angela, Hospice@Home Nurse

Differentiation: Understanding and Organising the Differences

“Yeah and I think because the other booklet that we, and we are Macmillan, seem to suffice a bit more of what we were needing because you've got to be very wary of information overload haven't you and if you have one booklet that sort of says everything that you were hoping to back up or you have to use more than one you tend to lean that way just because of you know the experience that you've trying to help with but no I definitely do see from what we've already said where there is value in this I do think it's nice” – Erin, Macmillan 1-1 Clinical Coordinator

Relational Integration: Building and Sustaining Confidence



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“I think when things change they are needing some more support in understanding why things have changed and what is going to happen I think you can use that resource to say "this is what is expected, is going to happen, and this is what we can do" it's there for them.” – Shirley, District Nurse Sister

“And also district nurses you're so busy and I know from being a district nurse myself so I can say this you're so busy, you have this list of patients that if you open up Pandora's box in that person's house you haven't got the time to deal with that...” – Linda, Specialist Palliative Care Nurse

2. Different Purposes, Conditions and Settings

- Confidence in the new practice led nurses to use it with non-cancer patients and in different settings.
- “Cancer” on the front cover is a “limiting factor” and is “a disservice” to the innovation.
- With a “few tweaks” it could be used for any life-limiting illness.
- Used to educate staff.

Reconfiguration: Redefining and Changing the Shape of the Innovation



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Shirley: ...we given her the booklet didn't we, the family were quite irate, we give her the booklet we said "although it's not everything it's not aimed at your mum, there's things that you may find helpful"

Donna: So she wasn't a cancer patient

I: Right, but you gave her the booklet?

Donna: Yeah

I: Ah OK so what, you said...

Donna: Ignore the front cover [laughs]

I: Yeah

Shirley: Yeah, "you'll pick things out that will be relevant to you, to make you understand, a better understanding of what's going on and what can be done"

3. Culture of Change

- Restructuring of the Trust, key people leaving and staff morale
- Funding cuts
- Changes to District Nurses' role and caseload
- Achieving organisational goals
- Need for integrated services, community of practices, and standardisation across the boroughs serviced by the Trust

Contextual Integration – Resource Work and Managing the Practice



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I: And you mentioned Linda about them being in a box on a shelf for a long time, why do you think they weren't used? What happened?

Linda: Obviously I left and came back didn't I [laughs] it went to the wrong place first of all, it went over to [Site A] who didn't know anything about this and then we were re-located and then we put them on a shelf and with all the other leaflets

Ruth: I think we moved from here didn't we, then we moved to [Name of Building] and we'd not unpacked we had er a corner where we had all of our stationary and we were finding different things everyday and then we found this

Contextual Integration – Resource Work and Managing the Practice



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“Linda: And we used to have an evidence-based group didn't we

Brenda: We did. Yeah we used to meet on a regular basis and if you wanted to do something you could take it to the evidence-based practice group and say you know "this is what I'm thinking of doing" because again I think a lot of nurses erm like myself god forbid I was 50 I think when I got my degree and as part of that you had to do research not that I particularly wanted to do it but you know it was a module you had to do isn't it [laughs] you had to do it erm and I remember going ooh years and years and years before that when I was doing my diploma I think and something to do with leg ulcers I did because again I quite like them and all erm taking something that I wanted to do erm because you used to pick people's brains from that group you know somebody would say "Oh right you know well I read this on such a thing" erm but again that group

Linda: Fell by the wayside”

Contextual Integration – Resource Work and Managing the Practice



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“I think we become change obsessed because we’ve been doing it for so long that there is no stability. So we’re constantly trying to reinvent ourselves because of the new whatever white paper’s coming out, whatever this is coming out. We are, kind of, behind the times [laugh]. There is no Bill Gates working in the NHS who can go this is the new big thing so we get a service like text messaging, oh, that’s amazing, that’s a newest thing ever. You’re like, really, is it [laugh]? I suppose in some ways we’re trying to keep up and we’re trying to do that but because of the speed and the expectation, we’re not good at forward planning but I think that’s the nature of health care now.” – Heather, Clinical Programme Manager

What has NPT told us?

- Teams not interacting with each other and lack of integration across the Trust has acted as barrier to building and sustaining confidence and accountability in the intervention.
- More relational work should have been done between the University and community practitioners as it was being developed, after the research was conducted, and when it was delivered to the Trust.
- More interactional work could have been done to match skill sets and target potential adopts
- The absence of resource work may explain why the booklet has not be implemented or mainstreamed with the organisation, and has only been adopted on a community level.
- For some the timing of the intervention (when to give it to family carers) remains an unresolved issue and as result they have not integrated the booklet into their everyday practice

Conclusion

- Data supports the idea that the booklet and the processes surrounding its delivery is a complex intervention.
- Cognitive Participation has been useful to identify and think through barriers and facilitators to enacting the implementation of the intervention.
- Collective Action explains some of the work required to implement the booklet, and other innovations, in the future.
- Few examples of the component ‘Communal Appraisal’; difficult to measure effectiveness in end of life care context.
- Overlap in some of the constructs and components.
- How to sustain change?
- Is community nursing ready to implement change?
- Phase 2: actively implementing the booklet in 2 care homes and community nursing team.

Thank you!

Any Questions?

For Further Information Please Contact:

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