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Constructing a new role for family carers and volunteers providing care towards the end of life: An Action Research approach exploring a new model of hospice care.

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Abstract

The objective of this study was to understand the conceptualisation and development of a novel way of providing end-of-life care in a 'Cottage Hospice' setting, with a focus on the role of family carers and volunteers within this care model. A participatory action research design enabled a situational analysis, together with change processes. The study setting was a hospice in the South of England, and its network of wider associates in the local health economy. Participants were purposively sampled to provide relevant information. Data collection (2017-8) included documents (e.g. meeting minutes) and interviews (individual and group) with external (e.g. GPs) and internal (e.g. staff, managers, volunteers, patients, family carers) stakeholders. These were followed by action cycles conducted by a core action group which explored issues related to family and young carers, the relationship between the Main and Cottage Hospices, and workforce engagement with the change process. Iterative, inductive, thematic analysis was followed by axial coding facilitated within NVivo. Twenty-six individual and eight 'follow up' interviews, two group interviews, and five discrete action cycles were completed. At the core was a focus on 'disruption' of the norm of professionally provided and mediated care, with three main themes; imagining the future of Cottage hospice (growing demand, a home-like space, innovative roles for families and volunteers); developing the role of family caregivers (making agreements, meeting needs, social inclusion, and the 'unknown' expectations); and quality and safety issues (negative perceptions, personalised care, volunteer roles). Change was viewed as both a threat and an opportunity. Cottage hospice represents the possibility of a truly new way of meeting the needs of dying people and their families, and could act as a template for progressive service developments elsewhere. (281 words)

What is known about this topic and what this paper adds?

What is known about this topic:

- There is an increasing need for palliative and end-of-life care as people live longer into old age
- Many people express a preference to die at home in the company of those who are close to them
- Involving local communities in supporting dying people is a policy recommendation

What this paper adds:

- Cottage Hospice provides a novel volunteer and family led approach to care at the end of life
- Developing a new service reliant on volunteer and family caregiver work presents significant challenges
- Engaging all stakeholders in a substantive service development requires sustained attention and commitment

Keywords

Palliative Care, Hospice Care, Terminal Care, End-of-Life Care, Caregivers, Volunteers, Public Health, Health Services Research

Introduction

Palliative care providers, and the communities they serve, are encouraged to develop new ways of providing care towards the end of life. Policies encourage and support changes in care, emphasising the need for patients and families to be closely involved in care decisions; that high-quality care should be integrated, coordinated and available regardless of location; and that local communities need to be engaged (Health, 2008). Statutory and third-sector organisations have been encouraged to find new ways to work alongside families, neighbours and community organisations to give them practical support, information and training (Partnership, 2015). In particular, the past decade or so has witnessed the development of compassionate communities as a public health response to palliative and end-of-life care (Kellehear, 2013; Sallnow, Richardson, Murray, & Kellehear, 2016). This approach roots such care in communities and social networks where the majority of us, especially when death results from progressive illness or old age, spend the last months and weeks of our lives (Abel et al., 2013; Greene, Aranda, Tieman, Fazekas, & Currow, 2012; Leonard, Horsfall, & Noonan, 2013; Reeves et al., 2014; Sampson et al., 2018). It reminds us that dying, death and bereavement are universal experiences and part of the normal life course.

A particular challenge was issued by Leadbeater and Garber (2010) to: *Create new places for people to die close to home where they could be with friends and family, have their personal care looked after and their pain relieved, while calling in medical support when it is needed.....* (p.17). This was supported by the Commission into the Future of Hospice Care which exhorted hospices to test more radical adaptations, exploring the encouragement of new organisational forms for hospice-owned but volunteer-led volunteer services at the end-of-life (Calanzani, Higginson, & Gomes, 2013). In response to this, a UK hospice worked to develop a new model of end-of-life care, anticipated here to mean care likely to be in the dying phase of the last weeks or months of life, but which could be earlier if care needs indicate. This new 'Cottage Hospice' approach is intended to be resourced largely by volunteers, providing support to family caregivers who continue to provide direct care, with paid staff

acting to support and facilitate care. This is ambitious but has been demonstrated to work elsewhere, as in the 'almost home houses' in the Netherlands, albeit these operate in a different cultural context (Goossensen, 2018). The intention is that they will deliver care in a purpose-built environment, supported by a range of learning materials to enhance confidence and capacity in caregiving.

As part of this initiative, an action research study exploring the model of 'Cottage Hospice' was conceptualised and developed. The purpose of this paper is to focus on the central role within the developing model that family carers and volunteers are expected to play.

Methods

Research design

The methodology of participatory action research (hereafter: action research) was used (Baum, MacDougall, & Smith, 2006). Action research has been defined as a 'period of inquiry, which describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement' (Waterman, Tillen, Dickson, & De Koning, 2001)(p.18). Two defining features of action research are: firstly, the cyclic process that involves an intervention followed by reflection on the action, and secondly, research partnership with key stakeholders (Waterman et al., 2001). Crucially, action research requires close collaboration by the researcher(s) with the research participants. The researcher's role is to facilitate the process, but it is the participants who decide what actions need to be undertaken within the action cycles.

This study was designed in two phases. In Phase 1, a detailed situational analysis was conducted to understand the conceptualisation of Cottage Hospice. In Phase 2, action cycles consisting of planning, implementation of change, and evaluation were undertaken, led by a Core Action Group of key stakeholders, facilitated by the researcher. NHS Research Ethics approval was granted for the project (ID REDACTED) together with required organisational governance approvals.

Setting

The setting for the study was a hospice in the South of England and its network of wider associates in the local health economy, in particular, those involved in the provision and utilisation of palliative and end-of-life care services.

Sampling

A purposive sampling strategy was pursued to facilitate a degree of representation from those within and connected to the hospice: the senior management team, hospice paid staff and volunteers, service users, and external stakeholders (local residents and those involved in planning and commissioning the project). For the Core Action Group, key individuals were identified who were invited to initiate and participate in action cycles. Snowball sampling was used to identify others with a potential interest or expertise in a given area and these were invited to participate in turn.

Participants

Our overall sampling strategy was governed by broad inclusion criteria (Table One).

< Insert Table One around here >

Recruitment

Information packs about the study were made available through the project working groups. We recruited those who expressed an interest in the project in relation to our purposive sampling strategy. In order to achieve a sample beyond this expressed interest, we used snowballing techniques to send information about the study to staff groups that were underrepresented following the initial tranche of those interested. We also sent information to those external to the hospice regarding potential participation in an individual interview. Patient and caregiver participants were recruited from those receiving care services from the hospice, identified by hospice clinical staff. Potential participants were sent a letter of invitation, a participant information sheet (PIS); and an expression of interest reply slip for returning to the research team. Written consent was obtained prior to data collection.

Data collection

Phase one. Exploring the conceptualisation of cottage hospice.

Documents relevant to the Cottage Hospice development such as business plans, meeting minutes and other documentary outputs from the developmental stages of the project (some of which pre-dated this research) were gathered for analysis, augmented with publicly available hospice data on needs assessment for palliative care in the locality (Dy et al., 2015; Murtagh et al., 2013). Face-to-face individual interviews were held with a range of internal and external stakeholders (e.g. service users, volunteers, trustees, managers and clinical staff). Two group interviews were conducted, one with hospice staff and a second with interested local residents. Non-participant observation of project working groups and other meetings was also carried out. Meetings observed included those already established for project management including working groups focusing on different aspects of the development; fitting out of the building: furnishings, layout, managing the tension between 'homely' and 'clinically functional'; and other groups looking at learning and training needs of volunteers and family members 'staffing' Cottage Hospice.

Phase two. Action Cycles.

A Core Action Group (CAG) was established, including staff and volunteers involved in planning and executing the Cottage Hospice concept. Meetings of the CAG were held regularly throughout Phase 2, and run using the principles of co-operative inquiry. Findings from Phase 1 were used to identify initial possible action cycles. Action cycles consisted of a number of key steps: reviewing existing plans to identify priority areas; agreeing a plan of action to address a priority area; action to bring about desired change; evaluation. Each action cycle pre-dated the opening of the Cottage Hospice, and hence had a focus on planning, not implementation. At the end of Phase 2, the findings from the action cycles were presented to and explored with participants using a deliberative workshop format bringing together stakeholders who have been involved in the action cycles (Phase 2) and interviews (Phase 1).

Presentations from the research team outlined the key findings from the analysis to inform discussion and debate. A range of participatory exercises and activities were then used to crystallise the key learning from the whole research process (what went well, what worked, what were the challenges?), and how this could inform the future plans and opening of Cottage Hospice.

Data analysis

Analysis followed principles of thematic analysis. Documents not available in electronic format were scanned and uploaded. Interviews were transcribed verbatim, and written field notes added. Audio recordings of CAG and action cycle meetings, and their minutes, were uploaded to NVivo.

The analysis was iterative, with identified themes explored in succeeding interviews, and used to design questions for subsequent phases. Initially, broad descriptive themes were used, which arose from the nature of the programme development work being undertaken by the hospice – for instance grouping data on different stakeholders such as family caregivers and volunteers and issues such as the funding model and workforce planning. From these, cross-cutting themes were identified, such as ‘sustainability’, ‘workforce concerns’ and so on. Axial coding was used to determine relative positioning on responses to the Cottage Hospice concept, such as whether respondents could imagine using the facility themselves. Additionally, broader themes were inductively developed from the data as the analysis proceeded, for instance around ideas of safety and risk, whether the new concept was seen as offering something inferior or superior to existing hospice care, and whether it could be viewed as a threat. These became the focus of the deliberative panels towards the end of the research and informed the final phase of the analysis, providing a sense of the relative ‘weight’ to accord each issue.

Findings

Data were collected in 2017 - 2018. Details of individual and group interview participants are in Table Two.

<Insert Table Two around here>

The Core Action Group consisted of nine members and met regularly (initially fortnightly and subsequently every month) between October 2017 and September 2018 engaging in five discrete action cycles. Twenty-five people – a mix of staff, volunteers and family caregivers – attended the deliberative panel.

< Insert Table Two around here >

Findings are presented here thematically, drawing from a range of data sources, and cycles across the research. The overarching concept of Cottage Hospice is depicted in Figure One, explaining expectations about the type of patients to be admitted, and the roles of family caregivers, volunteers and paid staff.

< Insert Figure One around here >

Three main themes were identified from the data and action cycles: imagining the future of Cottage Hospice, developing the role of family caregivers, and quality and safety issues.

Theme One: Imagining the future: Planning Cottage Hospice

Cottage Hospice was imagined as part of the future for the hospice because of growing demand on hospice services and a desire to enhance the quality of care and dying available locally. Internal reports such as a business case and minutes of key meetings documented the thinking behind the project. The building, and the home-like environment that could be created within it was important:

Our overarching intention is to provide a community embedded facility for people in the dying phase who, under any other circumstance, would “be and die” at home. The building and its facilities are intended as more supportive of “caring” than “clinical”. Meaning it will be more like “home” than “hospital”. [Document 2; July 2016]

However, the focus of this analysis will not be on the structural elements of the project, but on the innovative aspects of care, where the important role of families in caring for people who are dying is central to the concept of Cottage Hospice:

...patients want their carers and families to be around them in the dying phase and to play an active role in caring for them, and that likewise, carers and families want to be near their loved one during the dying phase and to be able to play an active role in caring for the patient. [Document 1; April 2015]

Concepts underpinning this proposed approach to care therefore focus on care, family but also importantly empowerment – enabling patients and families to be more actively engaged, rather than passive recipients of care. The power imbalance between patients and families and their health care providers is well rehearsed in the literature (Berry, Danaher, Beckham, Awdish, & Mate, 2017; Joseph-Williams, Edwards, & Elwyn, 2014). Putting family caregivers and volunteers, rather than professionals at the forefront of care in situ in Cottage Hospice aimed to demonstrate a commitment to altering this power dynamic in a physical and tangible sense. Whilst this is an ambitious vision, concerns about whether this would be viable were raised from inception, especially around family carers' willingness or capacity to provide such care:

Workshops with hospice staff have thrown up the concern that families and friends do not and will not be willing or capable of playing an active role in the care of their loved ones; that when faced with the reality of giving bed-baths or dealing with bed-pans and vomit-bowls, they opt out again, leaving these types of tasks to nurses. In addition to this, their other commitments (to children, jobs and other dependants) would prevent families and friends from being in attendance on a 24-hour per day, seven-day per week basis. [Document 1; April 2015]

The centrality of the active family carer role to Cottage Hospice vision, however, meant that the focus of discussion continued to be how this care could be enabled; concerns raised about the viability of this aspect were not viewed as constituting a fundamental challenge to the model :

Cottage Hospice will seek to go a step beyond this in enabling and encouraging relatives to play an active role at the bedside rather than playing a passive "waiting and watching" role in which they are sent outside whilst professional carers provide the personal care, administer drugs, food and drink and make interventions to make the patient more comfortable. [Document 3; October 2016]

As planning progressed, a need was identified to secure an agreement from the family caregiver making explicit their continued role as primary carer for the dying person:

We will need some sort of agreement from patients that are eligible for the Cottage Hospice Service and their family caregivers which makes clear that it is the family caregivers who will provide the care. [Document 5; February 2017]

This focus on an agreement is a perhaps contentious formalisation of a role which is typically informal, and generally thought to be enacted through love or a sense of a duty.

Volunteers are also critical to the care imagined in Cottage Hospice. The role of volunteers is an area which initially generated some concern among existing paid staff, with the proposed reliance on volunteers seen as risky and potentially compromising patient care. This is an issue which has been reported as evolving over time:

We have moved away from workforce models that are entirely dependent on a paid workforce and are embracing the role of volunteers in all service models. Some members of the group found this hard to grasp initially, but the group now seems to be comfortable with this idea. [Document 4; January 2017]

Theme Two: Developing the role of family caregivers

The intention was that those admitted to Cottage Hospice would not have complex needs, but bring with them family members or friends who were willing and able to continue to act as the primary caregiver, as at home. Additional support would be available from volunteers, paid staff, and potentially emotional support from others within the community hospice. It is proposed that a 'compact' is signed by family caregivers before admission can be planned. These plans caused some degree of concern, both about under-occupancy if family caregivers do not come forward, but also equity issues if a person in need does not have a family caregiver available:

What happens to the man of 84 with his 85-year-old wife whose children live in Yorkshire because they work up there? [Volunteer]

Similarly, another respondent argued that there is a need for:

An acceptance that there will be exceptions and a reminder that one of our missions [sic] is individualised care. [Staff]

Others argued that these types of situations are not problematic, since those without a family caregiver could simply be admitted to the main hospice, as now, and that Cottage Hospice exists to serve a different group. Alongside these plans, a suite of educational resources to help prepare family caregivers to provide care within Cottage Hospital was planned and developed.

Can a typical user of Cottage Hospice be anticipated and planned for?

Some felt that it was not possible to say, as 'anyone' could potentially be a patient. Others did identify particular groups which they felt might be more likely to make use of Cottage Hospice, for a variety of reasons. Some interviewees felt that Cottage Hospice might be ideal for those with young families, who might struggle to reconcile the needs of the children and the dying person, or prefer to avoid their home becoming associated with memories of a parent's death:

Because I just think that those younger patients who want to die at home but don't want to leave that lasting impression on children would be a real gap in the market as it were, for the Cottage Hospice. [Staff]

Others felt that the practicalities of having the children to stay in the Cottage Hospice would militate against this and so tend to favour older age groups.

Not always, but I think that'll be quite frail elderly, settled with family that probably aren't working themselves, or don't need to work themselves... Because if you've got young children, you can't really bring all the young children in. You know, it's not going to have cots and bunk beds and [those things]. [Staff]

However, for frail older couples, while the Cottage Hospice might offer more support than remaining at home, they were seen as likely to make use of the facility only where they had adult children who could take on the family caregiver role. The requirement for a partner to act as a family caregiver, at the same time as learning to cope with a new and alien environment, was viewed as a potential deterrent to older people lacking wider family support. It was also recognised that sole carers might struggle with the lack of respite from caring responsibilities, especially if they are in older age groups:

I think where it's going to be difficult is where you've got... where you've only got kind of one relative, as it were. So, if there's an elderly husband and wife and they're just them, so actually, you know, the one spouse is never going to be able to provide 24/7 care. [External stakeholder]

In terms of whether the Cottage Hospice will be socially inclusive and accessible to a wide range of people, respondents had mixed views, but it was generally regarded as having positive potential. While it was argued that those who are 'middle-class, articulate and well-informed' are likely to be well represented because of their awareness of the Cottage Hospice, some of the other factors which might encourage people to use the service, such as being inadequately housed or having a large family, were seen as likely to apply to less privileged groups and it was argued that this might tend to increase diversity among service users.

Others envisaged Cottage Hospice as being attractive to some patients and their families by offering a 'safety net' of additional support, both emotional and practical, compared to the experience of caring at home, and 'a safe place to die' for those who might find it 'isolating' and 'frightening' to do so at home.

I think having at least somebody that they can ask how to help. I mean, I've had friends who, my friend's parents who I helped look after for a bit when he was dying, and... knowing how much morphine to give or whether you can give more or... Just advice, you know, that is hard to get when you're on your own at home. [External stakeholder]

The Cottage Hospice was also identified as having the potential to sustain the capacity to provide care:

I think it's the idea of the support...not being alone in the night if something is going wrong or he's not well...the benefit of having somebody where you can go, "Oh, can you just help me with this? I don't know how to do this" - rather than struggling on your own the whole time. [Staff]

However, the willingness and capacity of family members to provide care is an unknown quantity at present:

So this idea that families will be prepared to drop everything and do all the caring, they (i.e. external stakeholders) know isn't real. It is for some but not for all. [Staff]

Equally, there is evidence of some unease about how this will work in practice, particularly in the context of the intention to introduce a formalised signed 'compact' with the family caregiver:

I do worry about what level of expectation there is on these people, especially now we are talking about agreements...also what would be on that agreement and contract. [Staff]

Theme Three: 'Different from' doesn't have to mean 'less than' – safety and quality issues

Views on this theme depended on feelings about the medical model of care. Some participants initially responded negatively to the idea of Cottage Hospice, fearing that the greater involvement of volunteers with minimal paid staff support could result in a loss of professional expertise in supporting end-of-life care:

The caring bit would have to be carried out by qualified nurses, as you have here, and qualified staff, and indeed medical staff like you have here... [Volunteer]

Others felt that there was potential to offer an enhanced experience at Cottage Hospice by providing more personalised and less overtly medical care:

You might even be coming from another hospice or hospital, but it would be that bit more personal and special for the person to be free from what I call the clinical side. I'm not being detrimental about that... It's just that it would be a different kind of atmosphere. [External stakeholder]

Crucially, it was argued that Cottage Hospice needed to be 'different from' – to provide a distinctive new service supplementing, rather than supplanting, the traditional hospice offer:

Well, my understanding was that it was a halfway house, if you like. Because it's clear now that most people would prefer to die at home than in an institution, I think we all accept that... But that isn't always feasible, because of the structure of the house, or the carers, or whatever, whatever. And this, to me, seemed a perfect solution. It was a smaller setup, so more personalised. It was involving the community. [Volunteer]

What was seen as important was that this care should be different to the care that people may already be receiving in their own homes. For those who become unable to cope with providing care at home as the dying person's needs increase, the support offered by Cottage Hospice was understood as enabling the caregiving journey to be completed:

I've cared for him for a long time. It gets tedious. I get worn down sometimes. That's been my life's work, looking after him... if someone takes that away from me at the last minute, I would feel cheated, because I haven't finished what I started. The Cottage Hospice gives you the opportunity to do that. [Carer]

For a patient participant, being able to have the 'other half' close at Cottage Hospice was an important consideration:

Yes, because you can have your other half there and they will be allowed to stay there, so I think that will be really lovely to have that so you'd still have that closeness of being together which again I think's important. [Patient]

A number of respondents expressed concern about the proposed heavy reliance on a volunteer workforce to run the Cottage Hospice, arguing that their reliability could not be guaranteed and that the types of tasks required, such as routine cleaning, might not be appealing to volunteers, especially at different times of the day and night:

... if you're having a very high ratio of volunteer workforce, there's nothing to stop them just downing tools and disappearing. You've got people you're caring for, you have to have something in place to make sure that that care will be delivered 24/7, every day of the year, rain, snow, shine, sickness. [Staff]

It was also argued that volunteers need to be well trained for their roles and routinely monitored to ensure that their everyday work practices remain of a consistently high standard. It was clear that for some respondents the idea of patient safety was closely linked to the availability of a doctor on site, whereas others appeared much more comfortable with the idea of a nurse-facilitated unit, largely staffed by volunteers:

I think there's so much nowadays that is nurse-led that people are pretty confident in that...I mean, nurses now are trained to do so many more things that they used to be. And actually, at this sort of stage, really, they are the best people to lead. [Volunteer]

Discussion

The action research presented here demonstrates the challenges of planning an innovative service, with a novel offer. It lays out some of the process by which ideas were generated and shaped, and the influence of external policy drivers, internal hospice processes, and innovators and pragmatists in shaping the final service offer. Central to this service development was a focus on 'disruption' of the

norm of professionally provided and mediated care, with a move to care ownership by patients and family carers, and volunteers as core care providers. There was tension between the perceived hospice ideal of 'individualised, person centred care', and how this could be delivered within what some perceived to be a reduced, rather than a different service model. Integral to the challenges of planning this service were the difficulties of imagining what a service user might look like, whether it would promote or reduce inclusivity, and debates about risk.

Innovations have the characteristics of novelty, an application component, and an intended benefit (Länsisalmi, Kivimäki, Aalto, & Ruoranen, 2006). Disruptive (or radical, transformational) innovations are those that disorder old systems, and have potential to deliver dramatic value (Varkey, Horne, & Bennet, 2008). Disruptive innovations have been described as those that should enable a larger number of people to do things in a more convenient, lower-cost setting, which traditionally could only be done by specialists – empowering control and reducing costs (Christensen, Bohmer, & Kenagy, 2000). Whilst the potential benefits of wide-ranging disruptive innovations are often promoted, caution is also noted that such innovations should take heed of the wider systems within which they operate, and with a concern for health equity (Galea, 2018). Cottage Hospice can be seen as such a disruptive innovation, a bold move to provide a new setting for care that moves care away from being professionally mediated, but with supportive mechanisms that may not be available within the home. It is this betwixt and between that made the disruptive nature of this innovation challenging for those imagining it; it is hospice, but not how it is currently provided. It depends upon family carers, but outside the usual home settings. It asks volunteers to be involved, but not in usual volunteering roles.

Other new models of palliative and end-of-life care that build on the skills of volunteers, or where there is not healthcare professional input, are also posited. These, however, tend to be less disruptive, adding a layer of care and input to existing health care services. Examples include volunteer befrienders, visiting people towards the end of their lives at home, or non-clinical supportive care services, all in addition to existing palliative care services (Dodd, Preston, Payne, & Walshe, 2020;

Walshe et al., 2016). In these care models, volunteers add a layer of care, rather than being primary caregivers.

Family carer involvement is equally, if not more, central to the Cottage Hospice concept. Family carers are already known to provide large amounts of care to those towards the end of life (Morris, King, Turner, & Payne, 2015; Turner et al., 2016), with estimates of up to 69 hours a week caring time in the last three months of life (Rowland, Hanratty, Pilling, van den Berg, & Grande, 2017). Such intensive caring comes at a cost though, with 83% experiencing psychological morbidity (Grande, Rowland, van den Berg, & Hanratty, 2018). It will be important for such burden to be studied within Cottage Hospice to understand whether the support network of Cottage Hospice ameliorates the burden, or potentially takes family carers away from their community and other local support networks.

Strengths and limitations of an action research approach

Action research intends a collaborative approach identifying 'ground up' solutions to identified problems or concerns. To this end, it is a process that begins at the beginning. In this instance, Cottage Hospice was already in a relatively advanced state of preparedness when the action research process was initiated. For example, the developmental working groups were already working on aspects of the project while the situational analysis and early stages of the research study were being conducted. This meant that when the Core Action Group began to identify issues that required 'solutions' to be tested, these found themselves in some conflict with the work underway in developmental working groups. This exposed some tension and raised issues about which group predominated. Was it possible for the Core Action Group to supersede or change decisions or actions of the development working groups? In the event, the Core Action Group had to 'shelve' some ideas as these hierarchical tensions were not sufficiently resolved.

A further issue in deploying an action research approach in a small organisation with a dominant leadership team similarly involves a power dynamic and how much 'bottom up' is allowed or enabled

to trump 'top down'. Ultimately, the senior team were the final arbiters and decision makers, arguably rightly so, but this again led to some hesitation within the Core Action Group about what was possible in the real world of management structures of this type. On reflection, clearer 'permissions' and the parameters of possible change led by the outcomes of actions cycles should have been established with hospice managers and trustees at the outset.

Conclusion

Estimates suggest a rapidly increasing need for palliative and end-of-life care as the population ages and lives longer but perhaps burdened with increasing frailty and chronic ill health. At the same time, moves away from expensive professionalised palliative and end of life care services, allied with a need to relocate death and dying in supportive communities where possible, drove the development of Cottage Hospice as an innovative model of care. This study demonstrated that embarking on such a change in service delivery, relying as is planned on family caregivers and volunteers, is frequently viewed as a threat and resistance to change, particularly among those staffing the established hospice service – but also with caution on the part of local resident stakeholders and some in the local health economy. Service users and volunteers proved more enthusiastic seeing the advantages of a service that provides for a wider group of people in a setting over which they could exercise more control, but with the support of professionals where needed. It remains to be seen how the service will operate in reality and what unforeseen challenges may lie ahead, but Cottage Hospice represents a truly new way of attempting to meet the needs of dying people and their families and has the capacity to act as a template for progressive service developments elsewhere in the palliative and end-of-life care field.

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Table one: Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Adults aged 18 years and over	Children aged 17 years and under
Staff and volunteers working for the hospice	People in the locality with no working relationship with the hospice
Service users of the hospice	People who lack capacity to participate
Stakeholders in the locality with a working relationship with the hospice	

Table Two Interviewed participants

Individual interviews		
Initial interviews	N=26 (mean 53 minutes; range 30-85 minutes)	
Follow-up interviews	N=8 (mean 44 minutes; range 32-57 minutes)	
Sex	F = 18; M = 8	
Role	Staff	13
	External stakeholder	6
	Volunteer	4
	Family caregiver	2
	Patient	1
Group interviews		
Staff group	F = 4 (35 minutes)	
External stakeholder group	F = 5; M=5 (42 minutes)	

Figure One: Cottage Hospice: A new model of care

