Hospice at Home: Enabling Person Centred Care

Evaluation April 2020 - March 2021

A participatory person-centred approach to establishing a hospice at home service. Understanding the component of the service and outcomes using pluralist evaluations.

Executive Summary

Authors
Erna Haraldsdottir
Anna Lloyd
Fiona Cruickshank

June 2021

Contents

Executive Summary

Background

In 2020 St Columba's Hospice Care started a new Hospice at Home service which is a service delivered in patients' home by a small team of health care assistants who have specific experience and education in palliative care. The leadership team at the hospice recognised an important unmet need for more community-based end of life care model, facilitating more targeted use of hospice service including death and at home when patients and families wish for this. Previous study undertaken by research teams at both Lothian hospices identified that admission of patients into the inpatients ward was often due to circumstances at home and lack of sense of emotional safety at home. Prior to the service starting a comprehensive education programme was designed and delivered by the hospice practice development facilitator for the new team and ran from April to May. The service subsequently opened in June 2020.

The Hospice at Home Service

The Hospice at Home service aims to provide a **person-centred approach** in the prevention of admission or to facilitate discharge from inpatient unit, crisis management and support at times of rapid change including end of life care, provide respite support for families and carers and the promotion of independence through enabling, empowering and educating patients and families. The service runs 7 days a week from 8am-8pm. The service was set up with a staffing team of 3 band 5 nurse co-ordinators, 6 CCSWs (community care support workers) who were previously working as health care assistants in the hospice and a Practice educator.

Methods

The evaluation aim was to:

- Evaluate the new Hospice at Home service with particular reference to the benefits and impact of the service for patients and families.
- Identify the factors that have underpinned the outcomes of the Hospice at Home Service.
- Support the development of a model of care that underpins the Hospice at Home service.

The evaluation was informed by a pluralist approach (Gerrish 2001), allowing for evaluating the complexity and diversity of a service by taking into account the organisational context in which the service is delivered within. The pluralist model encourages participation of stakeholders when assessing the success of the service.

In order to establish outcome measures for the evaluation, interviews were conducted with senior managers and team members of the service to elicit their views in terms of aims of the service and what would be successful outcomes. One to one interviews were held with managers comprising of the chief executive of the hospice, the clinical services director, and those managing the service. Two focus groups were held with team members including 2 coordinators and 6 nursing care.

In order to provide an overview of the nature and use of the service in practice, quantitative data was collected over a period of 10 months from June 2020 to March 2021 inclusive. This included:

- Patients' demographics age, gender and diagnosis.
- Reasons for referral and length of time that the service is in place.
- Time of day the visit took place and how many staff visited the patient (1 or 2).
- Reasons why the service finished (death, discharge, referral to alternative service).

In order to gain more insight and understanding of the nature of the service and the experience for patients and family members, qualitative data from 15 patients' cases were gathered through patients/family member interviews, case note stories from staff and proformas sent to patients and families.

Interviews and focus groups were transcribed and analysed to establish what key stakeholders considered the core aims and elements of the service and the criteria that would make the service successful. Key themes were identified by reading the patients' stories and case note stories from staff and asking the questions - what was the benefit to the patient/family - what elements of the hospice at home service underpinned this benefit? The focus group and interviews with stakeholders were analysed to identify the key themes or element of the service and linked with the thematic analysis from the patients' stories and case notes stories from staff.

Quantitative data was analysed using Excel to provide descriptive statistics of the service. These were then integrated together with the qualitative findings to fully illustrate and contextualise the outcomes from the service.

Results

During the period of the study 140 patients were admitted to the service. 54% were male and 46% were female. 61% were between 65 and 84 years old. The majority of those referred (84%) had cancer.

The different purposes of support that were required for the Hospice at Home service were divided into 6 key areas of facilitating discharge, providing respite, enabling independence, admission prevention, awaiting other service or psychological support. Psychological support was the most frequently referral need cited for 34% of patients, followed by awaiting another service for 31% and prevention of admission for 18%.

Once in receipt of the Hospice at Home service the majority of patients were visited by 2 members of staff per visit. Activity was distributed relatively equally over morning and afternoon visits with relatively few evening visits required and were distributed equally across the week from Monday to Sunday. August and January were the busiest months with June and October being the quietest.

The mean duration of service was 17.1 days and median duration was 8.0 days. 40% of patients died at home within the Hospice at Home service, 37% were referred to another service and 22% were discharged from the service.

Based on the qualitative analysis, three key themes reflected the underpinning processes of a successful Hospice at Home service, this included flexible and responsive care, building relationships and modelling education. Three themes highlighted the benefit of the Hospice at Home service as seen by all stakeholder and evident in the patients' case studies. These were support for families, avoiding/delaying inpatient admissions and facilitating death at home if this was what the patients and family wished for.

The Hospice at Home service was seen as not the right service for patients when symptom burden was high and, on few occasions, it was felt that patients had been referred too early to service.

Discussion

The new Hospice at Home service has been able to provide a person-centred approach to care delivered in the community enhancing the care in the community through:

Providing level of care that adds a new layer to care within the community that may be meeting the needs of patient that need less specialist clinical palliative care. The Hospice at Home team provided more fundamental palliative care with strong focus on building relationship and providing care that met the needs in a holistic and person-centred way. Hence, being more predominately guided by what matters to the patient and the families in the service than clinical symptoms. Furthermore, in addition to this it was evident that being integrated into the hospice services enabled familiarity with the service that was reassuring when people were reluctant to receive care at in their own homes.

Flexibility and responsiveness in the service which allowed the Hospice at Home team firstly, to respond quickly to changing needs for care and increase their level of care which may have prevented crisis to escalate. Secondly, they were able to scale up the service gradually according to need and in that sense move seamlessly with the need. Thirdly they were able to gently build up the service in the patients' homes so the patient and family member got used to having to rely on outside help for care. This meant that those who were reluctant to get help in the home, even though that was needed, felt that the service was not intrusive. Finally, the Hospice at Home team were able to respond quickly to new referrals which that support was in place nearly immediately.

Building of relationships meant that the relationship between the Hospice at Home team and the patients and family members/carers was person-centred. This was evident in the trust and friendship that was felt by both patients and family members.

Enabling family member/carer to feel more empowered through learning skills and technique that made them more confident and able to care for the patient at home. Furthermore, the capacity to support families appears to be a particular strength of Hospice at Home through the ability to be flexible in the approach and responsiveness to needs as they change over time.

Support for families enabled the family/carer to feel that the patient was in good hands and gave them a sense of security. It was also evident that the relationship the Hospice at Home team built with the patients and family members gave a sense of joy and warmth enabling positive atmosphere in the home. The way of working in person centred care enabled the Hospice to be present and give time to the patients and family in a flexible way. Having a specific number to call when a need would arise gave family members sense of security even though they did not need to use this service. Knowing it was there was important and gave sense of a safety net.

Avoid/delay inpatient admissions and facilitating care and death at home. The qualitative data analysis indicates that having the service in place enabled patients to be cared for at home. Being able to upscale the service and respond quickly to need for service can be argued as a key to avoid crisis point whereby the patient might be admitted to a hospice or hospital. Likewise, it was evident that the person-centred ways of working made people more accepting of the service within the home which enabled the patient to be and stay at home.

77% of the patients who received the Hospice at Home service either died at home (40%) or were discharged to other services (33%) in order to be able to stay at home longer term. This indicates that the Hospice at Home team enabled patients to be cared for and die at home who without this service would not have been able to do so.

A clear factor that has contributed to the success of Hospice at Home has been the interpersonal dynamics of the team from the inception of the service right through to the delivery. The service was set up with engagement from the staff who would be delivering the care. In initial focus groups there were some concerns raised about how difficulties could be managed if they arose however in practice the capacity to contact co-ordinators who could give advice or get guidance from medical colleagues has meant that Hospice at Home staff are empowered to trust their judgements, build on their own skills knowing that they have the back up and support from the hospice team. Further evidence of the cohesion of the team with the hospice can be found in the very high degree of concurrence regarding the vision for the service that was voiced by those in management and by those who were delivering care. Terms used may have differed but general statements about providing care at different levels of need and to address the unmet needs in the community including supporting families and facilitating discharge or delaying admission and enable home deaths as wished for.

Conclusion/Next steps

Research evaluation of the first year of the new Hospice at Home service has proven how St Columba's Hospice Care has expanded its services to increase high quality fundamental person-centred hospice care being delivered in the patients' home. High quality physical care delivered through person centred approach, presence and strong relationship as well as empowering family members through teaching of skills were key ingredients in providing the emotional and psychological safety needed for the patients to be cared for and die at home. Within this approach the Hospice at Home team has moved the unique hospice approach, as traditionally only provided within the inpatient unit, into patients Home and truly offering a Hospice at Home.

It is evident that the Hospice at Home service is meeting an existing gap in service in the community as the person-centred approach enables the service to meet specifically patients' and family member/s needs and this makes the Hospice at Home stand out in comparison with the more traditional service or so called package of care provided within the council. The prospective study of the reasons for patients being admitted into an inpatient hospice (Milton et al 2020) highlighted how for many patients, who were close to death, the standard package of care did not meet their specific needs, as was lacking in responsiveness, flexibility and sense of having a relationship with the team who provided the care. On some occasions this triggered admission to the inpatient hospice unit.

Identifying key outcomes of the Hospice at Home services and the processes that enables the service to be successful, has provided valuable insights and evidence. This research evaluation will inform future directions as St Columba's' Hospice aims to build on and expand community service further, this includes possible expansion to East Lothian area. The findings from the study will also be shared with key stakeholders to refine the already established service and build on its success further.

The findings from this research evaluation are also valuable for developing further the overall scientific knowledge in relation to the Hospice at Home services across UK and beyond. Whilst Hospice at Home services are increasing and expanding across the UK there is very little evidence on the key elements of the service that enables it to be beneficial. Model of care differs and there is a need to understand better the model of care that provides most benefit and maximises how this service can complement other existing hospice services. We aim to present the findings from this research evaluation at the Hospice UK conference in November 2021. We also aim to publish a paper in academic palliative care journal. The findings from this study will also be used in our palliative care teaching programmes.

Whilst the findings of the research evaluation are strongly highlighting the benefit of the Hospice at Home service, the sample of the qualitative findings is small and representing mainly people who were positive about the service. Building on this evaluation and repeating after another year might ensure representation of a larger sample for qualitative analysis might identify areas of practice which there is a scope for improvement. Data collection occurred during Covid-19 which impacted on smaller sample.