

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 evaluation.*

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1 Introduction

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 a more community-based end of life care model, facilitating more targeted use of hospice services including death and care at home when patients and families wish for this to happen. The vision for the initiative is reflected in the St Columba's Hospice Care strategy, 'Adapting to a Changing World' Strategic Plan 2020-2023 which aims to shape and develop services in response to the needs of the community it serves (St Columba's Hospice 2020). A previous study undertaken by the research teams at both Lothian hospices identified that admission of patients into the inpatients ward was often due to individual living circumstances and patients and families lacking a sense of emotional safety at home (Milton et al 2020). 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.

2 The Hospice at Home Service

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

2.1 Developing the Service

'Tell me and I forget, teach me and I remember, involve me and I learn' Benjamin Franklin

Hospice at Home was developed by applying a person-centred practice development method with the underpinning principles of participation, inclusion and collaboration (McCormack al 2013). This involved collaboration between the Director of Clinical Services, the Education and Research team and the new Hospice at Home service team. Initial discussions ensured that there was a clear shared vision for the service, at the start, and the development was a collaborative process. The infrastructure for the service including a definition of the service, policy development, job descriptions, risk assessments and training topics was designed jointly and agreed on. This approach ensured a sense of ownership, accountability and shared values and beliefs by all those involved in setting up, leading and working within the service. This approach impacted very positively on the Hospice at Home team as evident in the following quotes.

'It has been fun, educational and very rewarding being part of the team from the beginning' (co-ordinator)

'..Involvement in writing the policy and statement has been of great benefit' (CCSW)

'..with us all being involved in shaping the Hospice at Home policy it brought us all together as a team being listened to and taking ideas forward. Our input made us feel more part of the team' (CCSWs)

After the service started the 'whole collaborative team' approach continued with an ethos of shared decision-making and a focus on enabling and engagement (Appendix 1 timetable). This was nourished through regular meetings, feedback from practice and ongoing development/education as situations arose. For example, further training was arranged following a change in Covid-19 guidance using 'reflective practice case discussion' in relation to a real-life situation.

A comprehensive education programme was developed, and subsequently evaluated, based on the need of the team. This included a combination of face-to-face teaching, reflection on practice and 'homework'.

When the service had been running for 3 months a Fourth Generation Evaluation including Claims, Concerns and Issues exercise (Guba and Lincoln 1989) (Appendix 2) was conducted with staff to gain insight and understanding of what was going well, what was challenging and what needed to be changed as the service developed. This also served as a forum to elicit the teams' understanding of the service and to ensure staff felt that they were getting their voices heard and as well as to maintain their sense of ownership of the service as it was developing and growing. Reflective practice sessions were held as part of the team development and included an educational approach to nurture skills already present and to help develop new ones.

The Covid-19 pandemic greatly influenced the setting up of the service and the training involved. In one sense we were able to set up the service quickly and efficiently as planning stages, which often involve multiple meetings, were kept to a minimum. On the other hand, the whole team who ran the service e.g. nine staff members plus a practice educator were not able to meet face-to-face at any point during the setting up, training or implementing of the service. Although the service still had a practice development model at its core it meant that there needed to be creative thinking and adaptation particularly in relation to learning and observing in practice. We were unable to see staff as a one group or facilitate observation visits which would normally have been deemed crucial in developing the service. However, we were able to adjust using online meeting technology and through having smaller group sessions.

3 Evaluation

A service evaluation was carried out by the Research Team at the hospice over 12 months period.

3.1 Evaluation Methodology

The evaluation was informed by a pluralist approach (Gerrish 2001). Pluralist evaluation allows for evaluating the complexity and diversity of a service by taking into account the organizational context in which the service is delivered within. It provides detailed process information about what happens and why, yielding a deep and realistic illustration of the service, including of the components and structure of the service (mechanism) as well as its success (outcome). The pluralist model encourages participation of stakeholders when assessing the success of the service. It starts from the premise that criteria for judging the success of an innovation are largely situated and open to different interpretation by various stakeholders (Gerrish 2001).

Pluralist evaluation takes account of varied data sources. Within this study this consisted of interviews with stakeholders, including patients and family members and descriptive data regarding the service provided.

3.2 Aims

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

3.3 Data Collection

Engagement with stakeholders – establishing criteria for success for 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 considered to be successful outcomes. This was done both prior to the service starting and after the service had been running for 3 months. 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 (SM). Two focus groups (FG) were held with team members including 2 coordinators and 6 nursing care assistants (in 2 separate focus groups). Follow up interviews and focus groups focused on establishing whether the criteria for success had been met from the perspectives of the different stakeholders as well as key benefits and challenges so far.

3.4 Use and Experience of the Service

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 was in place.
- Time of day the visit took place and how many staff visited the patient (one or two).
- Reasons that the service finished (death, discharge, referral to alternative service).

In order to gain more insight into 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.

3.5 Data Analysis

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. Interviews with patients were written up in a narrative format. Key themes were identified by reading the patients' stories and asking the questions - what was the benefit to the patient/family - what elements of the Hospice at Home service underpinned this benefit? Case note stories from the staff were written up in a narrative format in the same way and same questions asked of the data. 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.

4 Findings

4.1 Who were admitted to the Hospice at Home Service and Why

Patient demographics gender, age, diagnosis.

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.

Chart 1. Service User by Gender

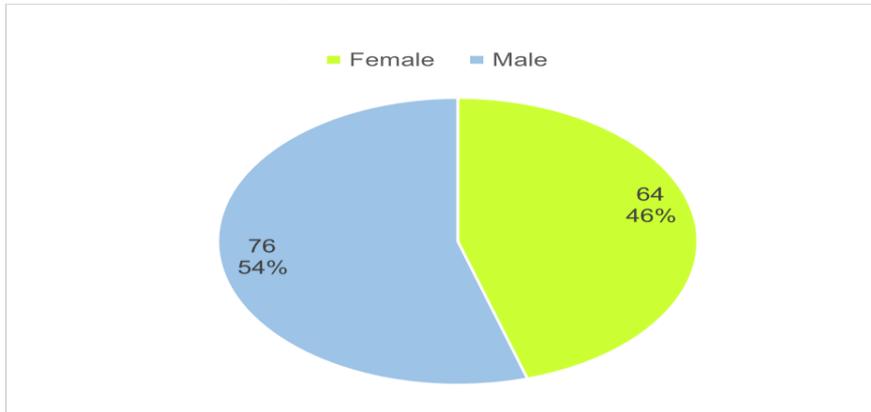


Chart 2. Service User by Age Band at Date of Referral

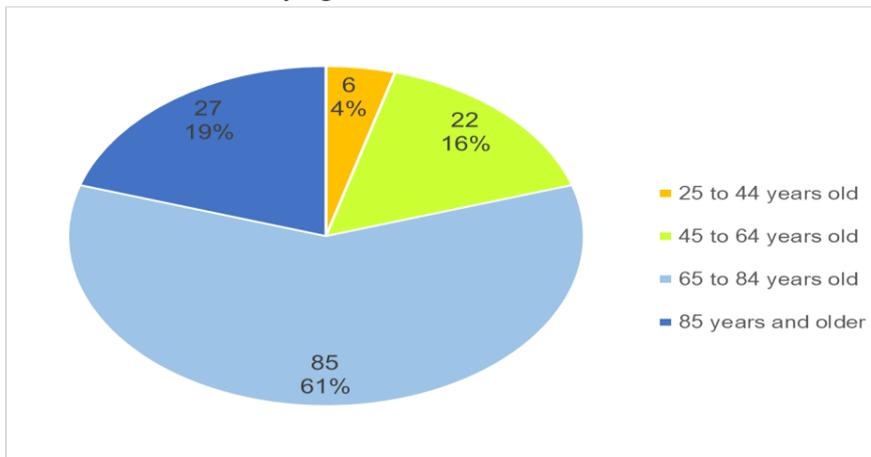
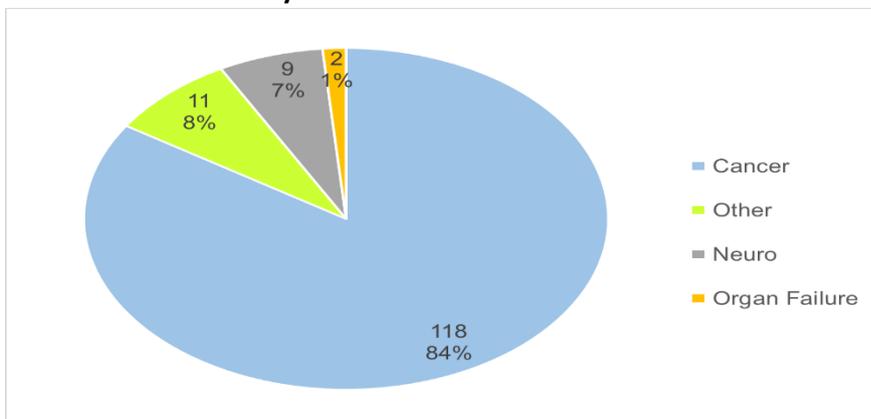


Chart 3. Service User by Condition

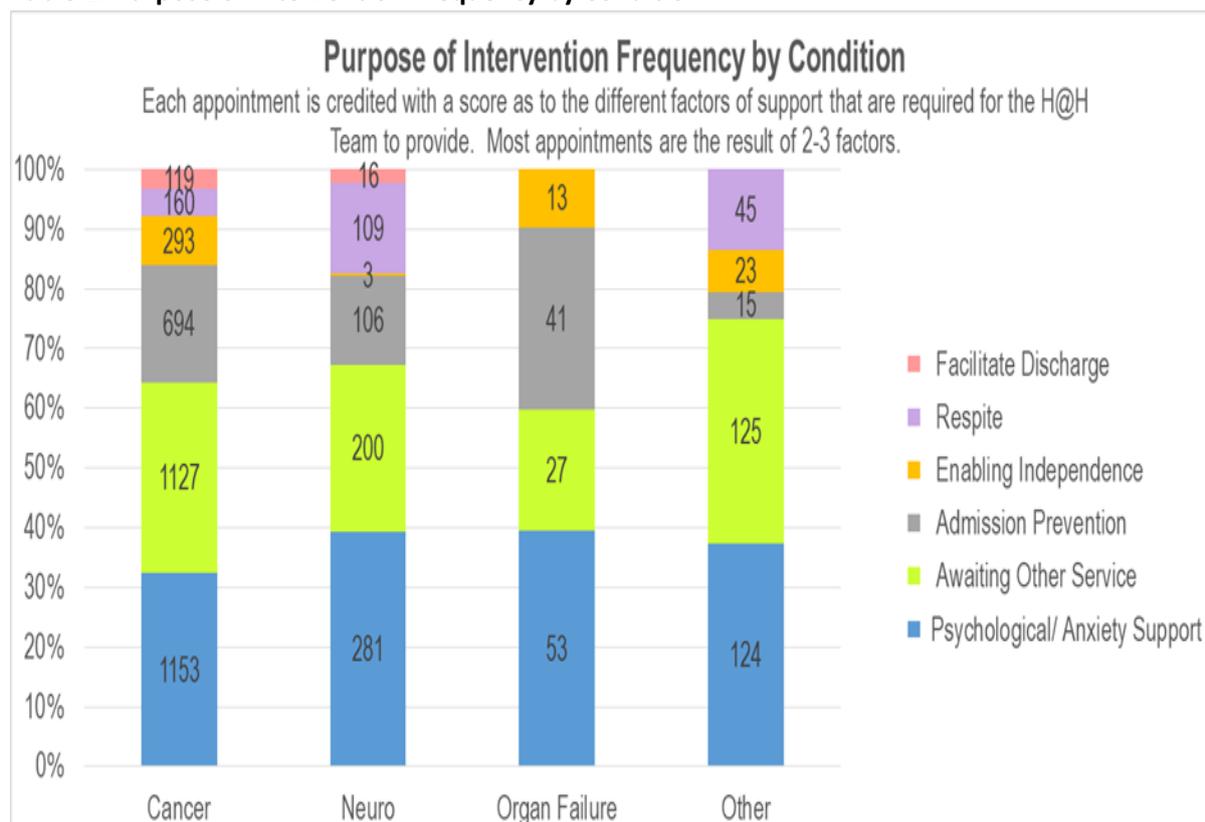


Reasons for referrals to the service

The different purposes of support that were required for Hospice at Home input 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 frequent referral need and was cited for 34% of patients, followed by awaiting another service cited for 31% of patients and prevention of admission cited for 18%.

Table 1. Purpose of Intervention Frequency by Condition



4.2 Overview of the Service

Once in receipt of the Hospice at Home service the majority of patients were visited by two members of staff per visit. Activity was distributed relatively equally over morning and afternoon visits with fewer 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.

Table 2. Appointment Activity (%) by number of staff support

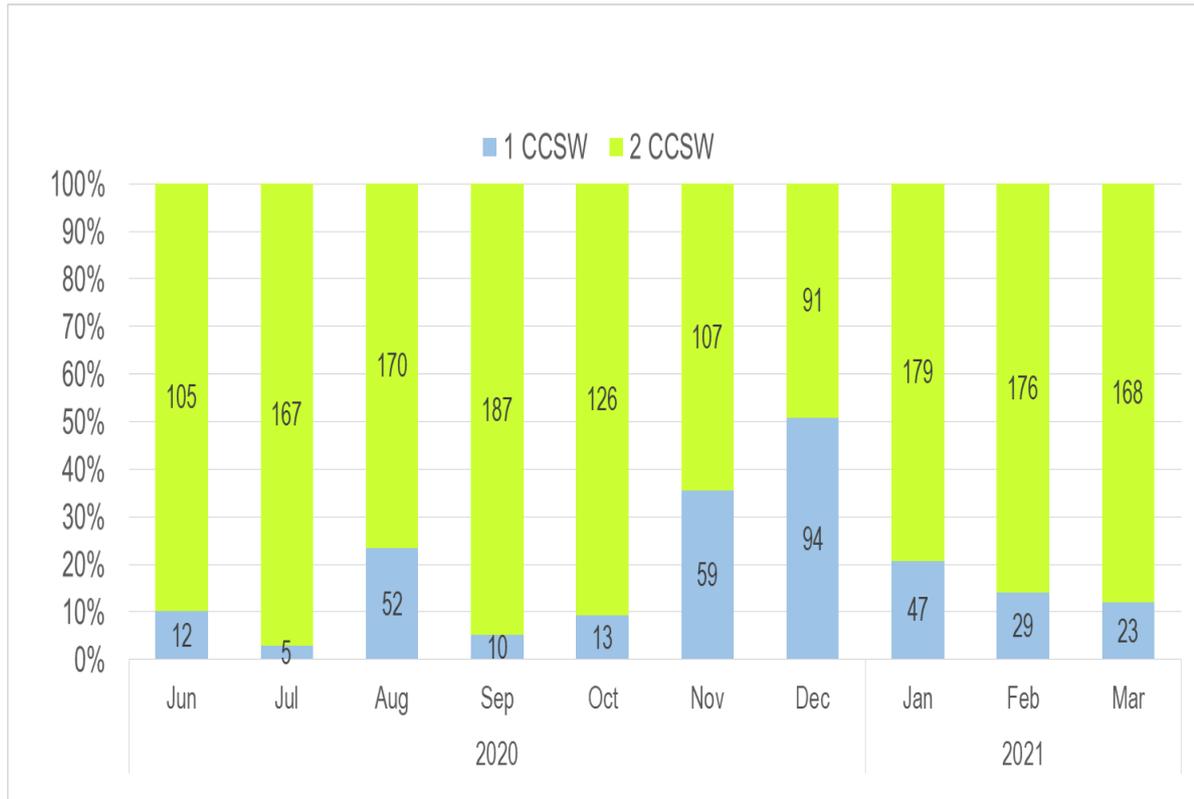


Table 3. Appointment Activity (%) by Time of Day

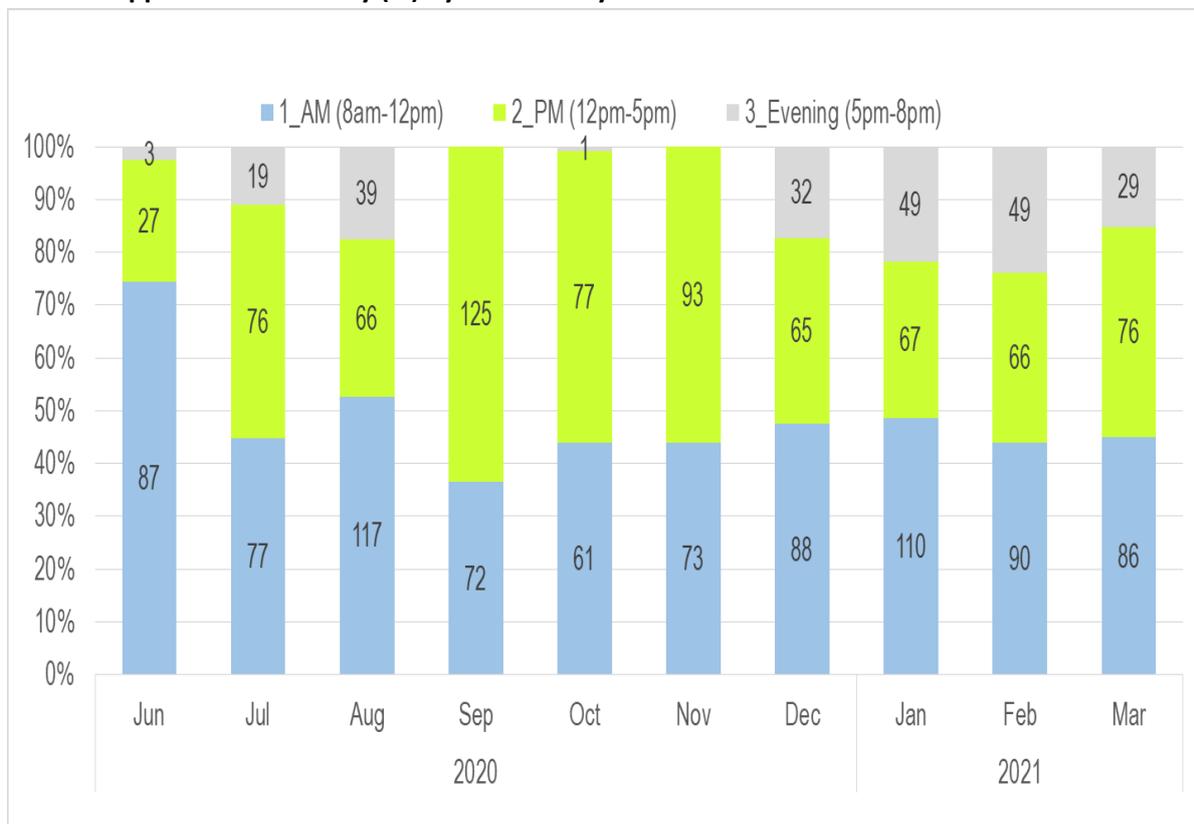


Table 4. Activity Numbers by Day and Time

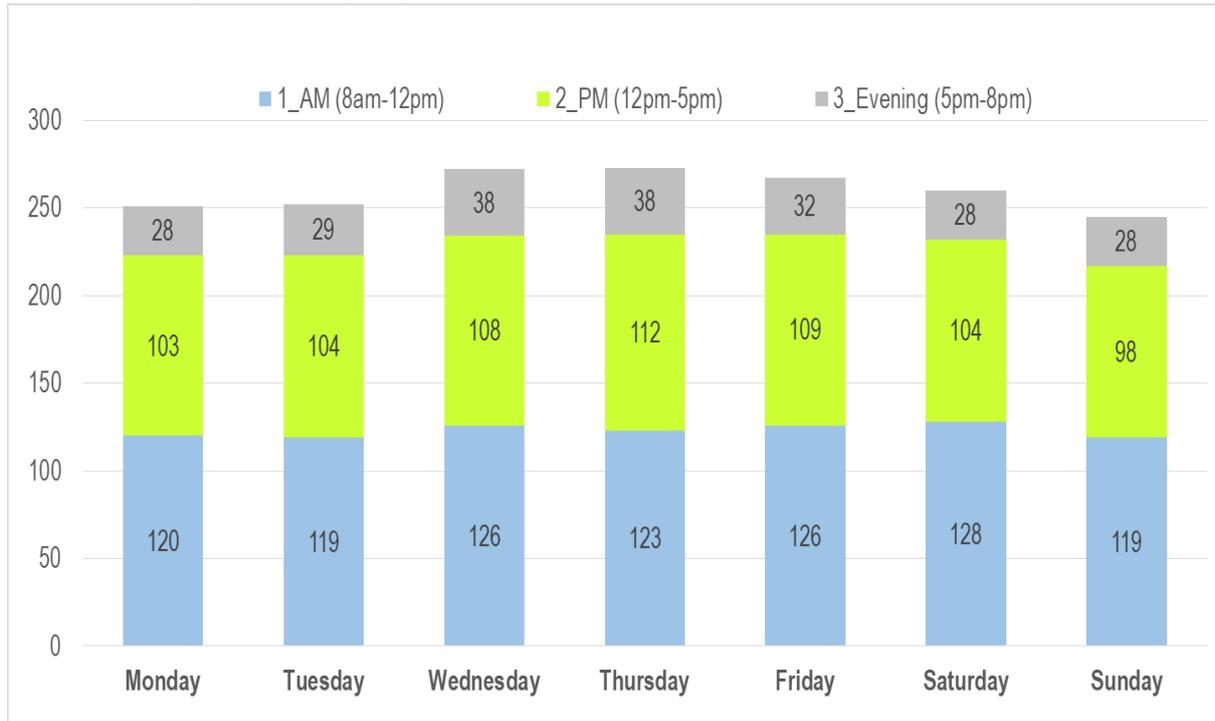


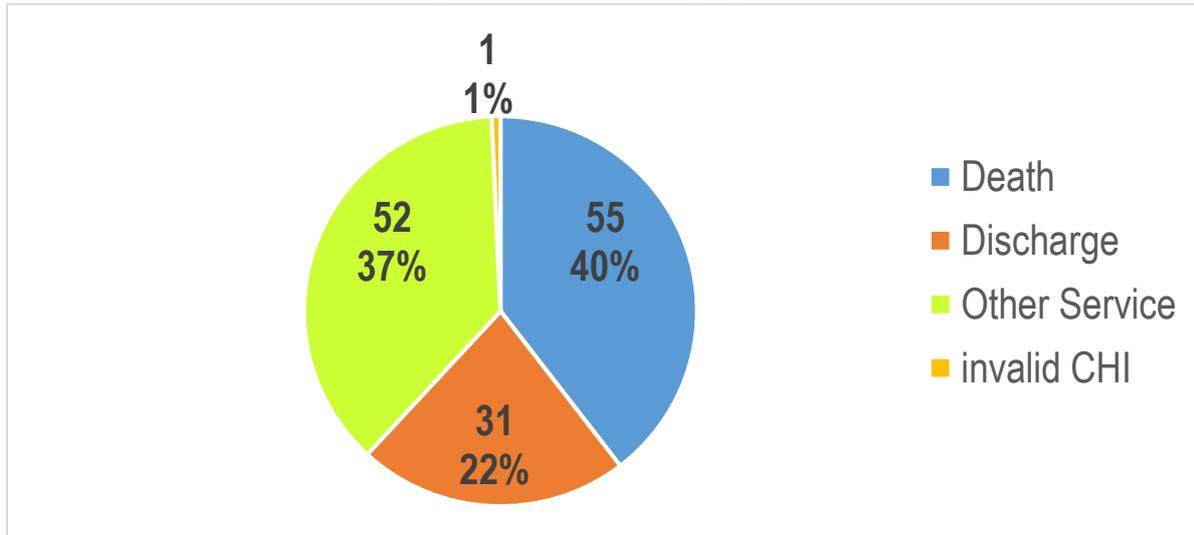
Table 5. Referrals and Appointment Activity



Length of stay in the service and outcome of the service

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.

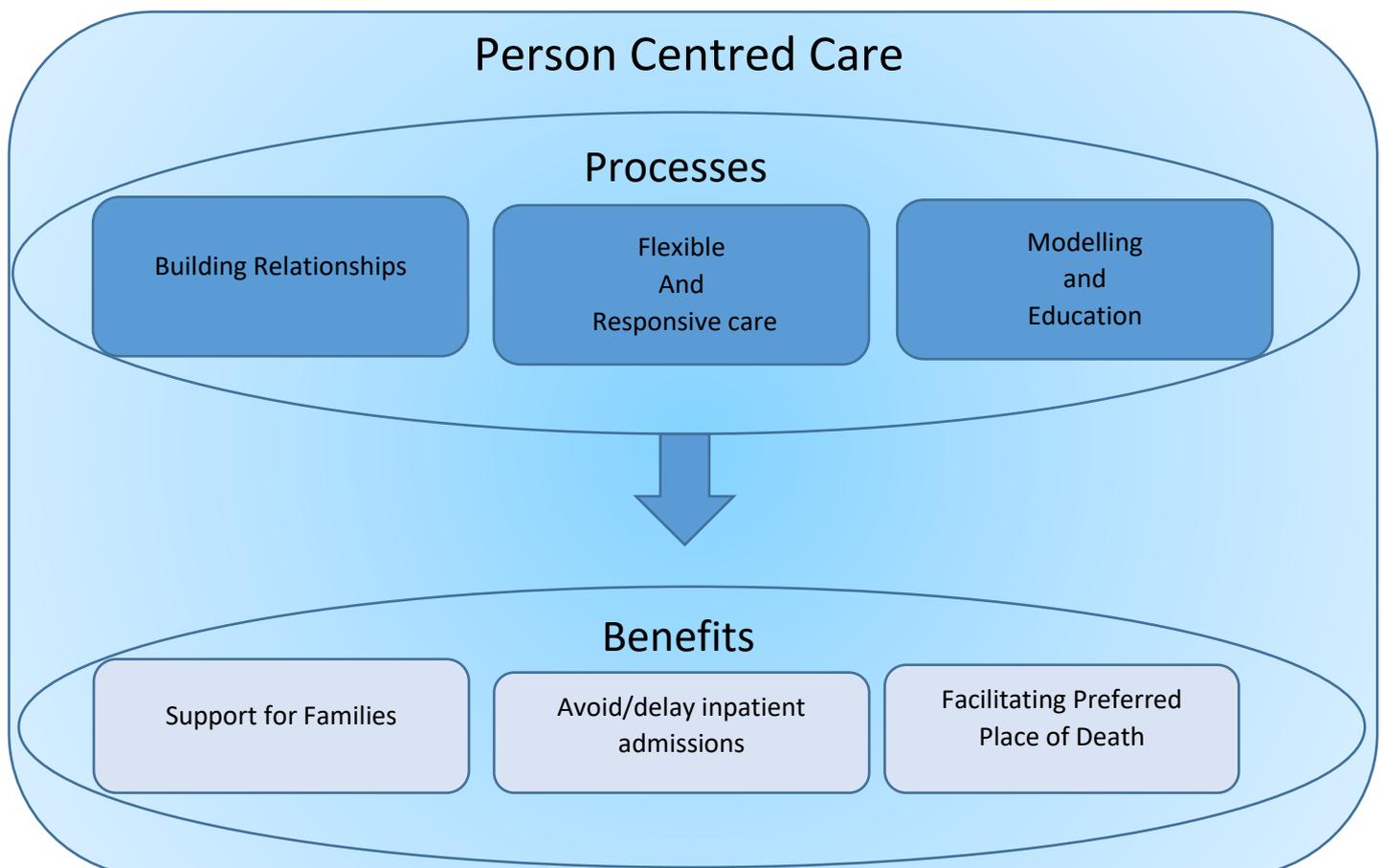
Chart 4. Number of Service Users by End of Service Category



4.3 Key processes of the service underpinning its success and benefits for patients and families

The qualitative data highlighted the key processes that underpin the Hospice at Home service as it has been set up within St Columba's Hospice Care and enabled the service to be successful, as well as identifying the key benefits.

Chart 5. Person Centred Care Processes and Benefits



4.3.1 Processes

Three key themes reflected the underpinning processes that made this Hospice at Home service successful. These were *Flexible and Responsive Care*, *Building Relationships* and *Modelling Education*. These were identified in the stakeholders' engagement interviews and focus groups as key elements of a successful Hospice at Home service and then subsequently identified within the patients case stories as being evident within the service.

Theme 1 - Flexible and Responsive Care in the Community

Senior managers (SM) described how they hoped the service would deliver palliative care broadly in the community and fill unmet needs. It was seen important that the service would complement the current hospice service within the community, provided by the clinical nurse specialist community service.

SM2 [Setting up the hospice at home service] is part of our strategy which is very much about moving the balance from inpatient over to community care

SM1: The Hospice at Home sits within community hospice. So they're all part of the community hospice team but there are different layers within it.I suppose that is my vision –it's integrated, so that the Hospice at Home [team] may be looking at some of the same patients that the CNSs are, or they may not be. Just depending on what's needed.

This integration proved very important and this was in particular evident in the case story of Sarah whereby the Hospice at Home being part of the overall hospice service was very beneficial.

Sarah was a 69 year old lady with lung cancer. She lived with her husband and had two adult sons, one of whom lived in Edinburgh. Sarah was referred to the Hospice at Home team following discharge from an inpatient hospice stay. She needed personal care support with shower, hair wash twice weekly and two carers to mobilise as she was unsteady on her feet and had frequent falls. She was beginning to appear confused and had poor appetite. There was no package of care in place and the family were reluctant to agree to one at this stage. They were, however, familiar with the team at St Columba's so agreed to help from the Hospice at Home team.

Sarah was known to the team from her inpatient stays which helped greatly with the initial visit. The team began at a level of low involvement for example supervising a shower, but were able to build this up over time as the couple became accustomed to them coming in. Social support for Sarah's husband was evident as they described how evident it was that he looked forward to their visits.

The purpose of the Hospice at Home service was described by both hospice senior managers and the Hospice at Home team (FG) as being the missing level of support that the hospice could provide and which was at a different level to a very specialist service in the community.

SM1 [It should be] a service that has layers rather than being very specialist.

FG1: The [Clinical nurse specialist service in the community] are focussed a lot on symptom control. They will increase their pain meds or steroids whereas we are looking at different things.

FG2: [It is important] just to provide different kind of support for patients at home, possibly for those that don't want to come in to an inpatient unit.

SM3: So the aim of the service is really looking at our patients who are cared for in the community and trying to work out where the gaps are in the care that's provided by all the different agencies that's involved with people who are palliative.

It was evident within the research evaluation that the Hospice at Home service was meeting a specific need for patients in the community as can be seen in the case story of Mrs D

Mrs D spoke of her father Mr E who lived with his other daughter in a family with complex and multiple needs. Hospice at Home provided support at the time that it was most needed and were flexible in their approach. The team managed to build their care around the needs of the family and offered guidance and education in managing Mr E's care. They built a strong relationship with the family members until they felt able to hand over care to social care services.

"I just thought they were there to help him die to be honest with you. They helped him live".

When discussing the criteria for what would be a successful Hospice at Home service, much emphasis was placed on the capacity for flexibility in terms of providing a timely response and preventing crisis situation. This was stated both by senior managers and the Hospice at Home team.

SM3: So the Hospice at Home team in that scenario would very much be going in on a practical level, doing a lot of these hands-on, practical skills to try and help out at that point of crisis. But then part of the [teams] role within that is also to take a wee bit of a step back and think, right, if this person is going to be staying at home, what we need to put in place. What would help in this situation? And what are they wanting – are they wanting to be at home, or actually are they thinking that they've had enough and are wanting to be in somewhere to be cared for. So it's that kind of immediate response to crisis

It was regarded as highly important that what the Hospice at Home service offered was different and adding to existing service. This was largely through allowing flexibility in the service and for the Hospice at Home team to be present and spend time with patients and families.

FG2: When you're in the community you'll give them time. It won't be half an hour to feed this person. You'll have time to chat to them.

FG1: I think [having one to one time with patients and families is] what's good for the families as well because if you're standing talking to a wife or husband and a buzzer goes and I have to leave them and maybe they want to tell you that wee bit more and then you go back and they shut down.

FG2: It's the response time, it's almost like an SAS hit team, because you get a referral and you can access it and get the squad in the next day. It's amazing. Or the same day.

It was evident that the flexible nature of the service and ability to respond to patients and family needs in a person centred way was beneficial for patients and families.

Mrs B: 'I got a phone call from the access team and then it just really – everything just happened very quickly so I was impressed at how quick it was.'

Mrs A: 'And they were very good at realising you know when things were – when I was needing a bit more help. They were very good at identifying that. And you know basically within a couple of weeks with the bath they realised that I was needing help with care on a daily basis. Mr A was deteriorating and his mobility was very poor so they started coming in twice a day.'

It was evident that having the flexibility in being able to scale up the care, from one staff member visiting to two, or increase the visits from one to two a day, was very valuable on occasions where the

patients' condition rapidly declined and the need for care increased suddenly. This was particularly evident in the case stories of Lesley and Elaine.

CASE STORY OF LESLEY: Lesley lived alone on 3rd floor flat she was experiencing rapidly declining health and her two sons were taking turns to help to take care of her but were coming increasingly anxious. The Hospice at Home team adjusted their input in response to her needs from one person visits to two people allowing for more intensive care at home.

CASE STORY OF ELAINE: It did not seem that Ed, Elaine's Husband, had quite accepted the rate of his wife's deterioration so the team tried to allow him to decide the level of assistance that he was comfortable with and to discuss the situation at each visit and to give him support and guidance. Over time Ed became more comfortable with the team and accepted visits twice a day.

Theme 2 - Building Relationships

The second theme that highlighted processes enabling successful services was building relationship. Relationships were built with the team and the patients and their carers/ family members.

Mrs A: He really enjoyed their visits I have to say despite the fact that he was so ill. I could hear laughter coming out of the room, which was just lovely. And that happened on a daily basis until he became comatose really'

Building relationships with patients and family members was facilitated by having continuity with people as well as uninterrupted time.

FG2: You don't feel that pressure to get in and out as quick as possible. You can take your time. You can chat to people. Just doing that wee bit extra, which people at the end of life care need. And I think that's very much appreciated on the feedback we get and from families as well.

Mrs D: There was a proper friendship. You could trust them. I think that's the point. You could trust them with a close relative. You know what I mean. With your dad or your mum or – whatever they were going to do was the same as you would want to do yourself if you could do it.

It was evident that the team was able to really getting to know the patients and this was much valued by patients and family members.

SM4: There was a gentleman the other day that they were seeing and he was a Geography teacher, they did a quiz with him and his wife actually sent a thank you card today.

Mrs A 'Somebody would come in and play dominos with him or whatever he wanted. Somebody did a jigsaw with him one day and he loved it.'

Mrs C: 'My husband just had such a good relationship with them. It would have been very sad in the last few weeks of his life if it had changed to another team. So it was very, very important to us that we were able to keep that same team until he actually died.'

It was also evident how much relationships with patients and families meant to the Hospice at Home team who described much joy and job satisfaction from the way they could work within the service.

FG: You get to see all the families and you really bond with them as well and you give them support as well because sometime you're – you think you're just there for the patient but you're there for the families as well.

FGs: I cannot – don't take this the wrong way, but do you not feel like a knight in shining armour sometimes?

FG: I love work, I love this job. I love working on the ward as well, but I love this.

SM1: When I speak to the nurses that are involved in it, they're loving it and they're getting a lot of job satisfaction out of supporting people to stay in their homes.

It was also important to the team that they had built good relationship amongst themselves.

FG2 'It's a small team as well. We all work well together, and I think the communication is really good. That's what I've really noticed'

Theme 3 - Education and Enablement

The third theme that highlighted processes indicating that the Hospice at Home service was a successful initiative was education and enablement for patients and families. It was evident that the senior managers saw this as important part of the service. They described hoping for the service to be able to help enable people to look after themselves or their loved ones by the Hospice at Home team giving them the skills or tools to manage.

SM2:[It would be important part of the service to] enable patients and families to have the tools to manage themselves, whether that will be learning how to care for the person or learning what is availability in their local community, their connections and where other support was available.

SM3: I need to use the word educate carefully, because we're not trying to tell people what to do or how to cope with this situation, but how help to work with patients and families and enable them to cope with their current situation. To enable them to learn skills that will be completely new to them and to be able to function in the community and in their own homes; whatever is kind of thrown at them.

FG 2: Again there's that education side. Teaching people ways of coping with – it could be symptoms of breathlessness. You can teach them ways of coping with that. If they're on their own and have an attack of breathlessness. Manage their time and pace themselves with fatigue. If they think they can't manage say a shower.

Although those in focus group one felt that they were not actually providing much education and enablement

FG1: It's definitely more of a care focus at the moment. Providing personal care and supporting people and obviously respite visits we're doing a lot of. We're not doing a lot of enabling and empowerment and promoting independence

This perception from Focus Group 1 is contrary to reports from Focus Group 2 and from the case story and patient story data.

FG2: Quite a young patient. Two sons. Quite young. So part of that was to - while they were in- was to show the family how to use the devices so that when the [Hospice at Home team] weren't there, and she needed any care, they could do that.

FG2: I think if there is a family member – sometimes some people are really quite interested and they want to know and they're amazed by the glide sheets and they want to see how things work and even just little tips; it's with families mostly isn't it. Like put a wee pillow at their hip to position them for a little while. You say if you just take the pillow out after a couple of hours or and they say wow; I would

never have thought of that. So we do talk with the family members. There's been a few times when we've been asked to show just how to get the family member comfortable and getting them up and into a seating position in the bed.

Perhaps a reason for the disparate views from the focus groups arises because the team don't always realise on a day to day basis that they are actually educating and enabling people as they don't recognise these as skills.

FG1: [teaching doing] Hair and mouth care. You just don't recognise that as a skill. It is.

Mrs B: 'They showed us how to do everything, everything that we needed to do, whether that was moving him from the bed to the commode, or the commode to the stair lift.' 'There were certain things like how am I going to manage to wipe him after he's been on the commode? And they said we'll help your dad to show him how to be able to wipe himself. And obviously he can't do all these things now but at the time when we had them there he could do so much more because they showed us other ways to make it easier for him.'

ALAN: Alan had lung cancer and COPD and could panic when he became short of breath. With Alan's adult son in the room with them the Hospice at Home team advised Alan not to talk while feeling this way, brought him a small fan and guided him in calming his breathing.

Mrs A (wife of Mr A) 'Sometimes one of the nurse team nurses from the Hospice and Home team would come in. Which was good, because she could just assess how things were going and give advice and so on.'

4.3.2 Benefits of the Service

Three themes highlighted the benefit of the Hospice at Home Service as seen by all stakeholders involved and evidenced in the patients' case studies. These were support for families, avoiding/delaying inpatient admissions and facilitating death at home if this was what the patient and family wished for.

Theme 1 - Supporting Families

Building relationships can be seen as supporting families and is shown in the quotes within that theme outlined above in this report. However, direct support to families was also seen as an important element of the service as evident in the following quotes from senior managers as well as the Hospice at Home team when asked what would make the service successful and what their vision for the service was.

FG1: The main one is supporting families as well as the patients. That's a big one.

FG2: It's important we support the families as well. Cause that's who we're going to be supporting; the patient and their families.

It was evident that it was seen that part of the support provided would be for the family to know that Hospice at Home team could be reached at any point when and if the need would arise.

SM2: a significant amount of the value of the service is just people having the phone number. Even though they'd never used it, never accessed it. And that came from the primary care of patients and families, but the knowledge that if I need it, I've got that support there, was huge. And I don't think we can underestimate that because people don't really know what they need. They just need to know that whatever it is will be there when they need it.

And this was hugely beneficial for the family as evident in the following quote from Mrs B who was looking after her husband at home.

Mrs B 'And there was always the number to phone for the co-ordinator. You know; if I was struggling, I could phone the co-ordinator and you know – I don't think I did ever do that but I think that choice was there'

It was evident that the presence of the Hospice at Home team provided a reassurance for the family like for Mrs D who looked after her aunt at home.

But just knowing that they weren't alone and knowing that in between having contact with GP, district nurses, that the hospice at home team will come in and give you that bit of extra support, and then again, obviously they left me the numbers of people that carry on call phones at the weekend and suchlike and said look, if you feel there's anything that you want to discuss, or you're feeling stressed, you can phone these people. So I think that's very reassuring

It was also evident that being present for emotional support was seen as an important part of the service being successful by the senior management team.

SM1: If you support people and hold their hands when they're struggling or having that crisis of confidence, it hopefully won't have as many people going into a crisis situation.

Providing a break and respite was also seen important support for families by senior managers.

SM2: We have said we would do some respite visits as well and that's something – any consultation we do; people say they want respite and actually the one thing that palliative care hospice has never done is formally do respite.

SM3: And there's the other bridge of it which is about the respite and really support carers. That's a huge miss in the community.

Prior to the service being set up the Hospice at Home team also expected respite visits to be beneficial for families.

FG1: I think [respite] would be of benefit to a lot of families. Because they do struggle. And they do have a lot more stress. If we could support them, that would be good.

This proved to be the case.

Focus Group 2: We have with the respite visits I think that has been really important because it gives people much needed time out. The respite offers the families such a – you know – psychological support

The following case story from Norma highlights how the Hospice at Home team provided direct support to the family, enabling Norma to stay at home and enhancing the wellbeing of the family

Norma was a 69 year old lady with lung cancer who lived with her husband and had three daughters living nearby. The family were described as very close and were currently providing for all of Norma's care needs. The house was a single story home with a large garden and no access difficulties. The family were struggling with a lot of anxiety which was the main reason for a Hospice at Home referral. At the first visit Norma was settled in bed. The team helped her to wash, to apply creams and to change into clean bed clothes. Norma was reserved at first but gradually became less so as she got used to the team. The main benefit that the Hospice at Home team felt they provided was to support the family until their package of care was started.

Theme 2 - Supporting care/death to happen in a preferred place

Enabling patients to be cared for and die at home was the second theme highlighted as a benefit of the service as evident in the quote below.

FG2: Hopefully Hospice at Home will allow people to stay at home longer without having to come into the hospice, so they can get the specialist support from the nurses and the doctors and the physios at home, but if they need a bit of hand-on support or the carers need a bit of education on how to look after somebody in the home, the Hospice at Home team should be able to do that.

As already highlighted in this report many examples demonstrate how the Hospice at Home team enabled patients to be cared for at home and more specifically die at home as reflected in the situation with Mrs and Mr A.

Mrs A talked of her husband Mr A who managed to achieve a desired death at home. This was made possible through the emotional support and brief periods of respite that Hospice at Home provided as well as hands on end of life care that was extended rather than handed over to another agency. *'He enjoyed the visits and they just had a lovely, lovely way with him. And nothing was too much trouble. And they had some difficult stuff to deal with him and they never complained. Nothing was too much trouble. It was – they were excellent.'* [without Hospice at Home support we] would probably have had to go to the hospice which wasn't what either of us wanted'

Theme 3 - Avoiding or delaying in patient admission

Avoiding or delaying admission to hospital or hospice was the final key benefit of the service that occurred through the capacity to facilitate discharge as well as simply delaying the point at which admission to hospice became unavoidable.

Facilitating discharge

FG1: We have to facilitate discharge for the ward the last wee while. We've had about three of four patients that have just needed a wee bit of help when they've gone home, and we've taken them on from there and that's worked out quite well.

Delaying admission

MORAG: Morag wished to stay in her own home with her daughter, who was supporting her, for as long as possible. Visits of the team enabled Morag to remain at home for a longer period of time than would have been the case without them and she expressed gratitude for their help.

4.4 When Hospice at Home was not the right service

The research evaluation using pluralist approach identified the underlying processes that enabled the Hospice at Home service to be successful as well as identifying benefits for patients and families. There were occasions, however where the team felt that the referral had not been completely appropriate as in the case of Irene who's family appeared to primarily be needing domestic assistance or for Gerry who struggled to look after himself but the team felt this was due to his uncontrolled levels of pain.

Gerry lived with his wife Mary who had been his sole carer, however, things were getting difficult with increasing tension between the couple that was reaching to the point of physical aggression from Gerry to his wife. Although the couple had 2 adult children and several grandchildren they had been unable to gain support from them due to Covid restriction. They were awaiting a package of care but had been referred to the Community Hospice Team for increased support, low motivation, to try to increase activity levels and low mood.

Hospice at Home team aimed to help Gerry with his motivation to stay out of bed and to encourage him to take care of his personal hygiene in order to allow Mary the time to leave the house and take time for herself. Follow up visits allowed the team to see the increasing stress in the house between the couple and the mounting tensions in the home. Mary was at the point of saying that she could no longer cope. Attempts to facilitate more self-care were relatively unsuccessful which Gerry attributed to his pain levels.

The team believed that they could only offer minimal support for the family and that more medical input to get better pain relief would have been of most benefit as it would have allowed Gerry to look after himself. Beyond this they believed that a befriending service and support via the Social Work department would have been more appropriate way to help alleviate the tensions in the household and de-escalate aggression.

There were also situations when the Hospice at Home team thought that service input had been requested too early.

FG2: I guess we've had a few referrals that have been a bit vague and we've gone in and we've not really been needed if you know what I mean. It's not been very specific – they are getting clearer certainly and now people are putting more information on the referral forms. But for a few patients it's kind of like they just need a little bit of this and they might need a little bit of that, and we actually go in and they're not really wanting that, and it's been difficult and we've had to come out again because we're kind of wasting their time and our time.

FG2: It's almost as if the referral is coming in too early. From what [staff member] just said, the work is what you're doing just now is what you want to do and what you expected it to be, but does it – should we be looking to extend the four weeks because we do extend the four-week cycle.

Finally disengaging from patients could be a distinct problem as patients and families can be unwilling to move to support from elsewhere.

FG2: recently I've heard a lot of feedback when the four weeks is coming up and how much they don't want us to go. And just today I had a wife of the patient almost in tears telling us how much she could keep us longer than the four weeks. So I think that's quite difficult, because the four weeks you're really getting to know the patient and the family, and at that point you're coming out and you've got to know people. But I feel that is needed because in that time they could end up in the hospital or hospice or whatnot. So there's been two incidents recently where it's come to that four weeks and they've got a package of care and we've stepped away – well actually three people where their package of care has started; we've stepped away and then a couple of weeks later we get another referral for them because they've then cancelled their package of care and then we have to go back in.

5 Discussion

Over the first year of the Hospice at Home service 140 patients received care and support from the Hospice at Home team and in most situations, this involved their family member/s as well. 54% were male and 46% were female. 61% of patients were between 65 and 84 years old and the majority had cancer (84%). The most frequent reason for the service being requested was for psychological support (34%) followed by awaiting other service (31%). The average length of stay in the service was 17.1 days with the majority of patients staying in the service for 8.0 days.

The new Hospice at Home service has been able to provide and enhance person-centred care in patients' homes. The elements and benefits of the service include:

- Providing a level of care that adds a new layer to care within the community that may be meeting the needs of patients with less specialist clinical palliative care needs. The Hospice at Home team provided fundamental palliative care with a strong focus on building relationships and providing care that met 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 by 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 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 crises 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 meant 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.
- Family members/carers were enabled to feel more empowered through learning skills and techniques 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 responsive to needs as they change over time.
- Support for families enabled the family/carer to feel that the patient was in good hands which 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 potentially facilitating a positive atmosphere in the home. Utilising a person-centred approach to care enabled the Hospice at Home team 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 a sense of security even if they did not need to use this service. Knowing it was there was important and gave them a sense of having a safety net.

- Avoiding/delaying inpatient admissions and facilitating care and death at home was key element of the service. 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 the 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 referred to other services (37%) 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.

It is evident that the service is meeting an existing gap in service within the community as the person-centred approach enables the service to meet specifically patients' needs.

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 were empowered to trust their judgements and, 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.

6 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 delivered in the patients' home. High quality physical care is delivered through a person-centred approach. Presence and strong relationships 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 homes 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 Care aims to build on and expand community service further, this includes possible expansion to the 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. Models of care differ and there is a need to understand better the model of care that provides most benefit for a given context 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 represented 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. This could identify areas of practice which there is a scope for improvement. Data collection occurred during Covid-19 which impacted on smaller sample.

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8 Appendices

Appendix 1 Time Table

The time line of the hospice at home team below illustrates the significance of the inclusion, collaboration and participation of all involved in the development of the service. Throughout this time there was continual communication with senior management and other teams within the hospice to help support and shape the service development.

The service development started on the 4/5/2020 with the first visit taking place on the 4/6/2020



Appendix 2 Claim, Concern and Issues Exercise

CLAIMS: WHAT HAS BEEN SUCCESSFUL/GOOD? WHAT HAS GONE WELL?
1: Patients wanting to stay at home and not come into the hospice
2: Getting to know new staff
3: Seeing patients in their own home
4: Stopping patients being admitted to the hospice
5: To receive positive feedback direct to the service from families
6: Facilitating discharge
7: Enable patients to stay in their own home
8: Connection with our service can be the first organisation involved
9: Working with other teams
10: Training, learnt so much
11: Seeing how far we have come in such a short time
12: Seeing confidence grow
13: using initiative
14: Supporting patients and families at difficult times
15: Avoid admissions

Claims, concerns and issue session 17th August 2020 for Hospice at Home Service

CONCERNS: WHAT HAS NOT WORKED SO WELL? WHAT AM I CONCERNED ABOUT?
1: Travel time
2: Travelling from house to house trying to keep to time
3: Being timed on the visit knowing that we are running late for the next visit
4: Having 1 hourly times and not getting to houses on time
5: Busy traffic
6: communication between coordinators can be tricky at times, could this be streamlined
7: Coordinators should be clearer on how long a visit should be and travel times between patients
8: Breaks, lunches, toilet breaks
9: Time to fit in lunch
10: Feel there is no need for daily catch up unless there has been a change or on new patients
11: Trak time
12: Trak documentation no responsible for others
13: Boundaries, not stepping on others toes
14: Looking after patient then they have gone to a POC and we no longer look after them, they soon pass away
15: It is not what I thought it would be
16: See more respite patients than EOLC
17: Have more respite patients
18: Sometimes feels you are chasing up people/hassling them (DNs, CPCT etc)
19: I thought we would have more EOLC patients
20: Recognising stress, taking on too much
21: Not feeling comfortable doing something and not questioning other colleagues when they feel it is okay
22: Continuity
23: On admission Criteria

ISSUES: WHAT QUESTIONS DO I HAVE? HOW CAN I HELP TO DEVELOP/WHAT DO WE NEED TO DO?
1: Factor in 1 hour in the day to cover lunch/breaks. Review after 2 week period
2: Organise the day by looking at patients in my area
3: Look at the placement of the patients and co-ordinate in staffs area
4: Improve communication by using SBAR digitally
5: Look at the travel in areas thinking of Local (walk to)and Outreach (drive to)
6: Try planning the day with no time slots. Coordinate the day as per requirement of patient need. Have more flexibility in the visits
7: Discussion on and deciding on whether the morning catch up is required. Can the team drive to their first visit and join the meeting from the car/
8: Discuss the use of SBAR as a means of communication for co-ordinators
9: For our respite patients can we think of using our Hospice friend service to aid in this