

VOICES – Hospice

Phyllis Tuckwell Hospice Care



Phyllis
Tuckwell
Hospice Care

...because every
day is precious

REPORT

Reporting period May 15 – Sept 15

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SUMMARY

Key findings

- ❖ The PTHC VOICES – HOSPICE Survey 2015 achieved a response rate of 62%.
- ❖ The care across the In-Patient unit and the Community was rated as exceptional or excellent by 89 % of respondents.
- ❖ For those who had discussed and expressed a preference with their relative/carer, two thirds (66 %) said they would like to die at home with 28% saying the hospice.
- ❖ The most commonly recorded place of death was the patient's home/family member's home (51%)
- ❖ Pain was relieved well but slightly more effectively in the hospice setting than in the community/at home.

Summary - findings

Phyllis Tuckwell Hospice Care (PTHC) is committed to the delivery of high quality care and to a process of continuous service improvement. Seeking the views of people that use the service is vital in achieving this. Within the setting of palliative care, response rates are often low – however expectations were exceeded achieving a response rate of 62% (an increase of 29% on last year). Only one respondent expressed the view that they would rather have not received it. Three surveys were returned uncompleted.

When asked about the support the patient received with financial, spiritual and family matters many reported that it was not needed. The vast majority of those that did require support thought that there was enough available. More felt that emotional support was a need and this was generally reported as being met.

The relatives/carers were asked about the information and support that they had received. The vast majority said that they were always or usually kept informed. Emotional support was also an area of high satisfaction.

In reference to the Inpatient unit - respondents were asked if there had been enough nursing care and help available - 94% agreed. The care received from both doctors and nurses was rated very highly with 90% in the exceptional or excellent category. The high rating continued in a following question with 87% reporting that the patient was always treated with dignity and respect.

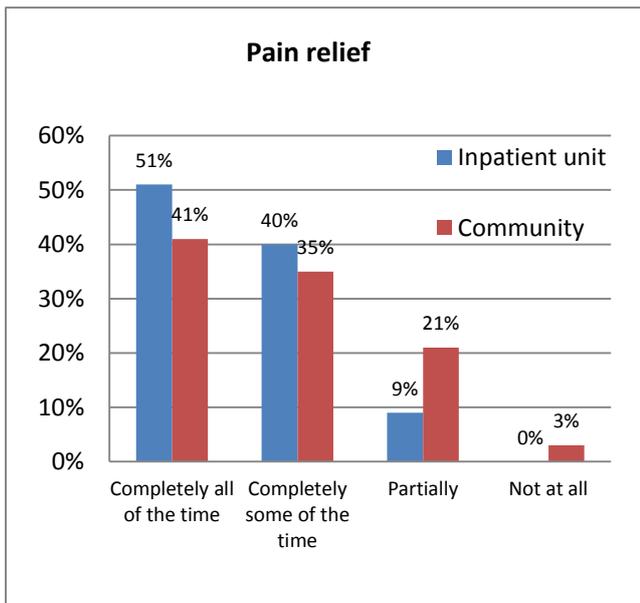
In the community most respondents felt that the patient saw the nurse as often as needed, with 85% saying that this was always the case. When asked specifically about support with urgent help in the evenings and at night most said that this was available with only 8% disagreeing.

The care the patient received from PTHC community nurses was rated very highly with 88% in the exceptional or excellent category.

When respondents were asked, overall had they and their family got enough help and support, 84% agreed that this was the case.

Support with symptoms and pain relief

Respondents reported that patients received good support with symptoms other than pain. Pain was also reported as being controlled to varying degrees. Both were managed slightly better in the inpatient setting (fig 1 & 2).



The graphs use the responses where this was relevant i.e. excluded 'does not apply' and 'don't know' responses.

Figure 1

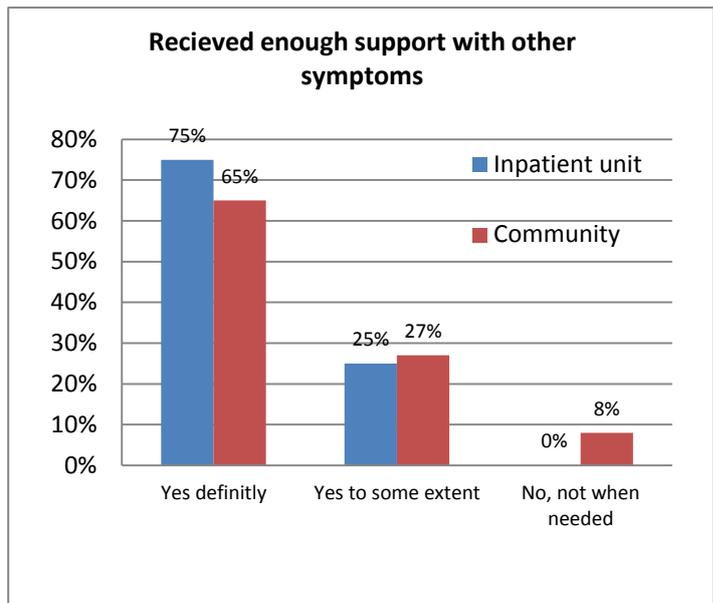


Figure 2

Circumstances surrounding death

Almost three quarters of patients had expressed a preference about where they would like to die, two thirds wanted to die at home.

The survey also provided information on where the patient died - almost half (49%) of patients (total sample 121) died in their home or the home of a relative, 36% died in PTH. The proportion of people dying at home has increased considerably (a percentage increase of 65%) from last year. Another positive is that the vast majority of respondents thought that 'on balance' the patient had died in the right place.

Almost half of the respondents said that they didn't want to talk about their feelings surrounding the patient's death. Those that did talked to a bereavement counsellor or nurse. Most respondents, who received the literature produced by PTH about bereavement services found the information helpful.

Summary – implementation

The voices survey was run over a four month period with 214 initial and 124 repeat surveys sent. The response rate was good - and better than other hospices have reported. This may be due to the time spent ensuring the survey was sent to most appropriate person. In terms of responses it was worth sending follow up surveys to those who had not initially replied. Only one expressed concern at receiving a second survey. The data was collated and entered on to a database, it was then interpreted and a report was written. The whole process was completed by the project lead. In terms of feedback the quantitative and qualitative data provides PTHC with a good sense of how its services are meeting the needs of the community. The data will also feed into service improvement and development.

The project has demonstrated that the VOICES –HOSPICE survey provides a validated method of measuring the impact and outcomes of hospice care. It is being used by a number of hospices and so there may also be an opportunity for bench marking.

SECTION 1

Introduction

This report presents the findings of the VOICES - HOSPICE survey conducted at PTHC over a four month period at the end of 2015. (The survey is a validated service evaluation and quality assurance tool for use in hospices). Its aim is to evaluate what bereaved relatives think about the quality of care provided by a hospice to patients and families before the patient's death, and to themselves in bereavement.

The central domains of measurement include:

- Inpatient care
- Care in the community
- Day Hospice care
- Care provided at end of life
- Bereavement care
- Demographics

The VOICES survey was conducted for the first time last year and provided valuable information about the service patients and carers receive - both quantitative and qualitative. This was reviewed by the clinical teams and used in the continuous improvement and development of services. The Senior Clinical Team reviewed the use of the tool itself and the data it generated and agreed to incorporate it as a regular tool in the governance and performance measurement structure.

The survey was developed jointly between the Southampton University School of Health Sciences and St Christopher's Hospice, London. It is based on the National Bereavement Survey – Voices conducted by the National Office of statistics.

Method

Surveys were sent to 214 bereaved relatives of patients cared for by Phyllis Tuckwell Hospice Care over a four month (eighteen weeks) period.

Patients

The list of deceased patients was taken from the PTHC electronic patient system. All patients known to PTHC that died in the set period were collated. To be included in the final sample patients needed to have been receiving care and/or support by PTH in the four months before their death and will have had more than one episode of contact.

Relatives

The notes of the deceased patients were examined and a survey sent to the next of kin or main carer (often one and the same). For the next of kin or carers to be included they needed to be over the age of 18 and have the ability to complete the survey. Care was also taken to avoid sending surveys to relatives where the family dynamics were sensitive. The survey was sent twelve weeks post bereavement.

The surveys were formatted in A4 colour booklet style and sent with a covering letter and with a freepost stamp address envelope included.

SECTION 2

Response rate

In all there were 383 deceased patients, known to PTHC, in the set period (215 in 2014). The final patient sample i.e. those meeting the criteria, was 231.

After examining the notes the final recipient sample (those relatives sent a survey) was 214 (149 in 2014 – an increase of 44%)

Reponses rate for initial survey sent = 39%

Reponses rate for follow up survey sent = 39%

214 surveys were sent out, 132 were returned = 62%

(129 completed)

Completion

There were various levels of completion with some questions unanswered - some more commonly than others.

Three surveys were returned uncompleted, others had whole sections unanswered – this happened most frequently with the community and the circumstances surrounding death sections. This may have been due to uncertainty as to who they had seen in the community and from which provider and the quite searching questions in the circumstances surrounding death section.

NB As the reporter had numbered the surveys they were aware of which services had been accessed by whom.

Nine respondents did not complete age and ethnicity.

For further information on response rates and completion - see appendix one.

Respondents

Patient's gender was fairly evenly split with slightly more men; however respondents were twice as likely to be women.

This section gives a little information about those who took part in the survey, both those completing surveys and the person who had died. (We asked respondents a few questions about themselves and about the person who had died). Of the 129 completed surveys 6 did not provide the requested demographic information.

Age, ethnicity, and gender

71% of respondents who returned and completed the survey were female, 29% male.

The deceased person to whom the respondents were referring in their answers were slightly more likely to be male rather than female (53% male and 47% female) and aged most commonly between the ages of 60 - 89.

Eight of the respondents described themselves ethnically as anything other than white British, this was true for 10 of the patients.

Most commonly respondents were the spouse of the person that had died (66%), followed by daughter and son respectively.

For further detail of age, ethnicity, and gender - see appendix one.

SECTION 3: Findings – In-Patient Care

Of the total 129 respondents who completed the survey - 55 stated the patient had been an In-Patient at PTH at some time before their death. The true figure was 56 (48 in last year's survey) but the section had not been completed by one person, the respondent stating it had only been for one day. This equates to 43% of the patients having been on the In - Patient Unit.

The following information will refer to the information obtained from the 55 completed.

Of the 55, 26 had also been cared for in the community, 1 had attended the Day Hospice and 9 had accessed all 3 areas.

Of those who had been on the In-Patient Unit just under half (49%) had stayed between 24 hrs and two weeks. Of the others, 26% had stayed 2-4 weeks, 7% up to 24 hours and 18% had stayed over four weeks.

NB Percentages in the following sections are based on the questions completed. Some free text comments are included.

Help and support available

Respondents were asked to consider the amount of personal and nursing care available and the adequacy of the general environment and bed area in providing privacy. With reference to personal and nursing care 75% 'strongly agreed' and 19% 'agreed' that there was enough personal and nursing care available, 2% neither agreed nor disagreed with the remainder 4% 'disagreeing'. In terms of the privacy provided, again 69% 'strongly agreed' with a further 24% saying that they 'agreed', 2% neither agreed nor disagreed, 2% disagreed.

Respondents were asked to consider the amount of support that was available. When asked if there was enough emotional support 67% said 'Yes definitely', 15% 'yes to some extent', 9% said that 'this type of help was not needed', 2% said 'no not when needed' 5% didn't know.

For religious and spiritual support 44% said that this was not needed, 37% said 'yes definitely', 6% 'to some extent', only 2% said 'No not when needed', 11% 'didn't know'.

Support dealing with financial matters was reported as not needed by 61% of respondents, 22% said there was 'definitely' enough support, 8% stating 'to some extent', 2% said 'No not when needed', the remainder didn't know.

In reference to support dealing with family concerns 38% said that this type support was not required, 38% felt that the patient definitely received enough support, with 16% stating 'to some extent', 2% said 'No not when needed', the remainder didn't know.

"The Nurses and Doctors were very attentive and nothing was too much trouble for them. Very kind, special people"

"The Doctor we saw gave fantastic support and advice"

"She was very well looked after. Everyone was so caring, she even made friends with people in her final days"

Care and Treatment

When asked about whether they received enough support in the relief of symptoms, other than pain, all of the respondents for which the question was relevant answered positively.

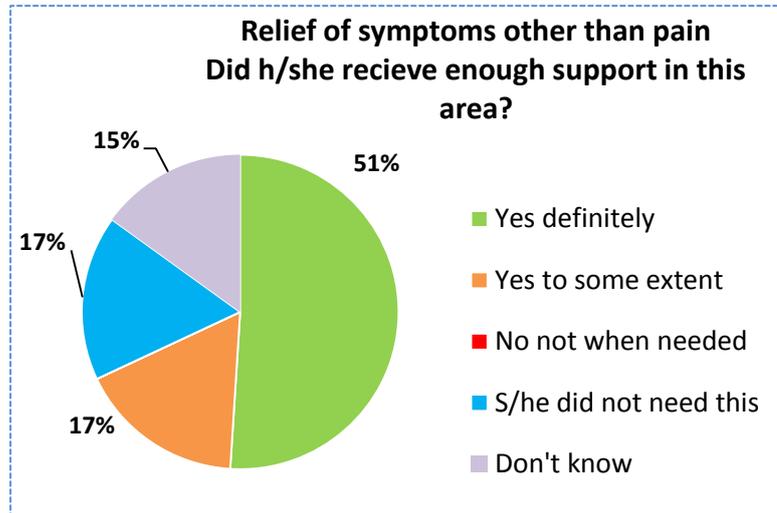
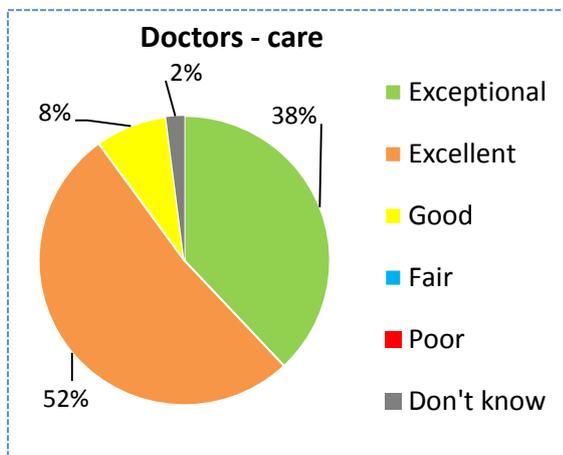
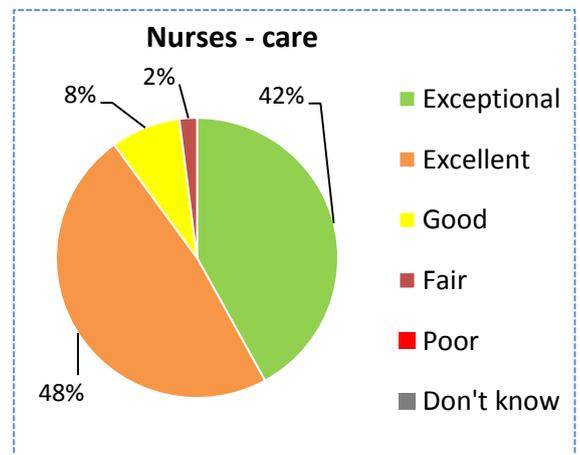


Figure 3

In reference to the care they received from both nurses and doctors the results were very good.



Figures 4 a & b



“All the staff (including housekeepers) were helpful, supportive and compassionate. My daughter was heavily pregnant and she received a great support”

When asked “How much of the time was s/he treated with respect and dignity by doctors and nurses?” The results were again very positive:

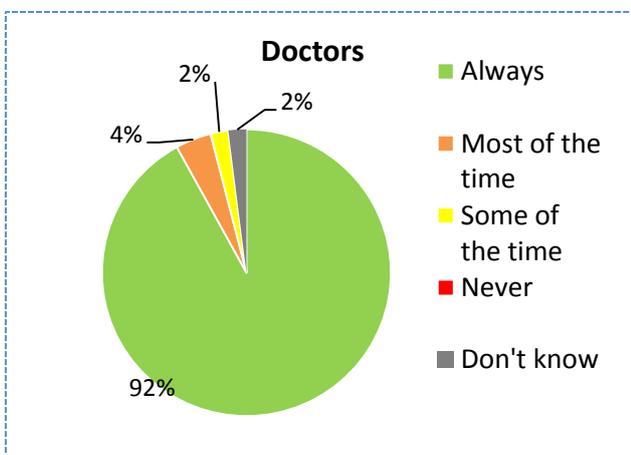


Figure 5 a

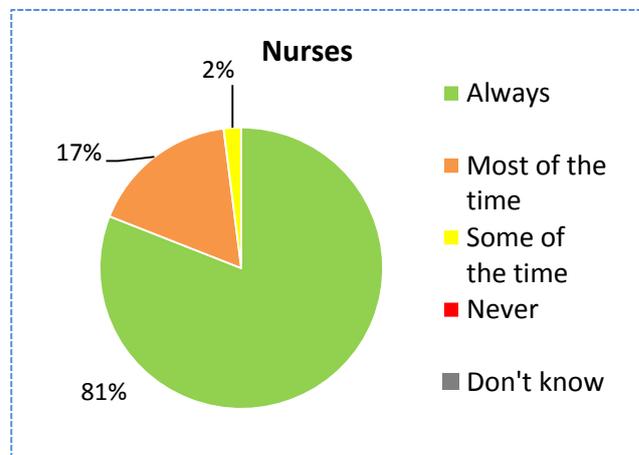


Figure 5 b

“My wife could not have had any better care anywhere in the world. Thank you”

Respondents were asked how well the patient’s pain was relieved. The results were generally positive:-

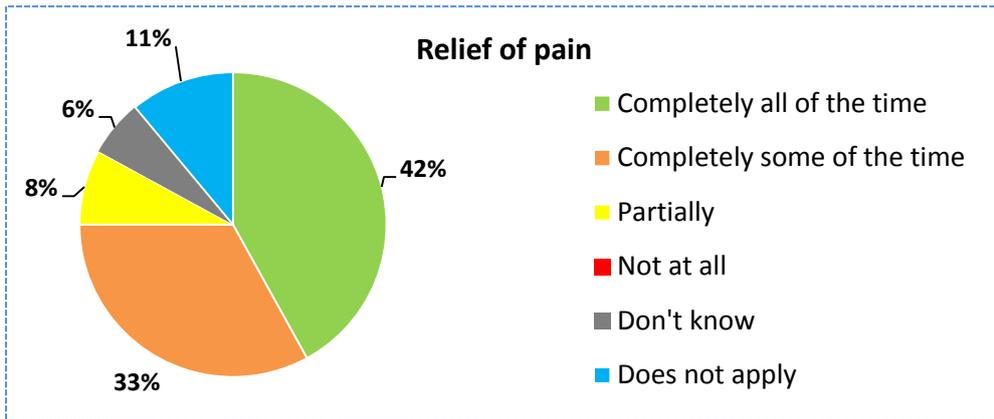


Figure 6

Communication and involvement

When asked the rather difficult question of “were there any decisions made about his/her care or treatment that s/he would not have wanted” the vast majority 84% answered positively with a ‘no’, 8% didn’t know and 8% thought that this did happen.

In reference to whether the Hospice worked well with other the patient’s GP and other outside services most thought that this was the case with 46% saying ‘definitely’, 15% saying ‘to some extent’, 8% said ‘no’, the remainder didn’t know.

“My husband was always consulted about his care”

Food and comfort

92% of respondents rated the food given to their relative as ‘exceptional’, ‘excellent’ or ‘good’ with the remainder saying either ‘fair’.

Question about the comfort and pleasantness of different areas the Hospice were answered as follows:

Room	Excellent 55%	Good 43%	Fair 2%	
Bathroom	Excellent 55%	Good 31%		Poor 2% Don't Know 12%
Communal areas	Excellent 62%	Good 34%	Fair 2%	Don't Know 2%
Coffee Lounge	Excellent 50%	Good 37%	Fair 5%	Don't Know 8%
The Garden	Excellent 73%	Good 21%		Don't Know 6%

“My husband was a fussy eater ... he thought he was staying in a 5* hotel when he was admitted to the Hospice”

Support and communication (direct question to relatives/carers)

When asked if the explanations about treatment and tests were easy or difficult to understand those that answered as relevant were positive with 71% saying ‘very easy’ and 29% ‘fairly easy’.

They were also asked if they and/or other family members were kept informed about the patient’s condition, 90% said ‘always’ or ‘usually’, 8% reporting ‘sometimes’ and 2% said ‘never’.

When asked about whether they themselves received enough emotional support from the hospice team there was a very positive response, with 85% saying yes, 4% said ‘no not when they needed it’ the remainder reporting that they hadn’t need it.

42% of respondents had stayed in the Hospice over night with all of them finding it useful. A few people said that they would have liked to but did not give any details as to why they didn’t. The remainder didn’t stay out of choice.

“Staying over- This was essential, she was very stressed about not being at home - with me staying she thought she was - priceless. Thank you”

“Stayed with Mum until she passed away”

“I was made to feel very welcome and offered food and drink”

SECTION 4: Findings – Community Care (defined for the purposes of the survey as Community Nurse Specialists and the Hospice Care at Home team)

Of the 129 respondents who completed all or part of the survey 96 stated that the patient received care from the PTHC community team. The true figure was in fact 112 (48 in last year’s survey) as 16 more had also received care in the community, but had not been completed the section. This equates to 87% of the patients having been supported in the community.

When comparing the VOICES data in 2014 and 2015 - looking at patients supported in the community, the figure has increased by 57% (2014 (48), 2015 (112)).

The following information will refer to the information obtained from the 96 completed surveys.

Of the 96, 18 had also been on the Inpatient unit, 2 had attended the Day Hospice and 7 had accessed all 3 areas.

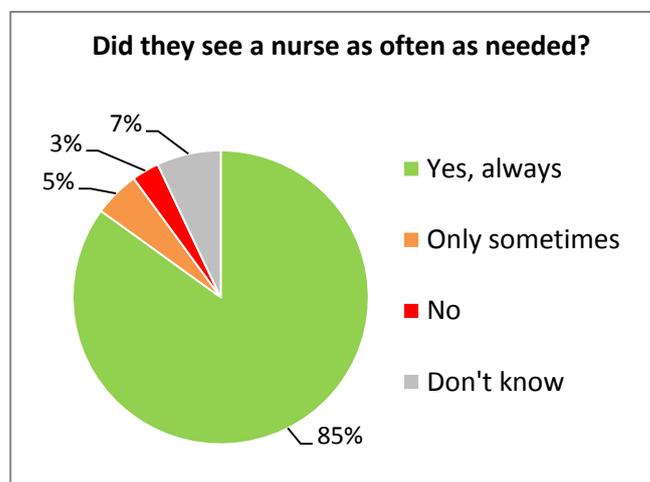
NB Percentages in the following sections are based on the questions completed. Some free text comments are included.

Help and support available

Respondents were asked “Whilst receiving care from the PTHC Community Service, did s/he see the nurse as often as it was needed?”

The majority thought that their relative did see a nurse as often as needed. With only 8% stating that this did not always happen.

Figure 7



When asked if they had received enough support. In terms of emotional support - 53% said 'Yes definitely', 21% 'yes to some extent', 14% said that 'this type of help was not needed', 4% said 'No' with 8% stating 'don't know'.

"I would like to say we had amazing care and help from all the nurses that attended my mother. Thank you so much for all your help"

For religious and spiritual support 67% said that this was not needed, 21% agreed that there was support, 4% said 'no not when needed' the rest didn't know. The results were similar when asked about support with financial matters, with 58%, 36%, 3% and 3% respectively.

With family concerns 45% said that this type of help was not required, 28% felt that the patient definitely received enough support, 15% stated 'yes to some extent', 4% said 'no', with the remainder answering that they didn't know.

"The ladies who visited my husband were so patience, caring and lovely. Truly exceptional and very much appreciated"

When asked about receiving help with urgent problems in the evening and at night many reported that this had not been required, 33% & 37% respectively. Regarding the evening time 52% said 'yes', 7% said 'no not when they needed' and 8% didn't know. For night time 44% said 'yes', 9% said 'no not when they needed' and 10% didn't know. Drilling down into the results in a bit more detail the responses saying 'no not when needed' equate to 12% and 17% respectively if only looking at cases where help was needed i.e. excluding 'not needed' and 'don't know'. However the results do indicate that patients' needs are being meet more successfully than last year with an increase in positive responses – this particularly apparent for the night time.

"The Hospice care team arranged night sitters when we needed them. They were all friendly and made both of us feel at ease. My husband's dignity was always preserved"

"Mainly had the night support and they were fantastic. Enabled me to get good nights sleep and also answered lots of questions I had"

In terms of relief of symptoms, other than pain - 92% of respondents, that reported this as a need, answered positively.

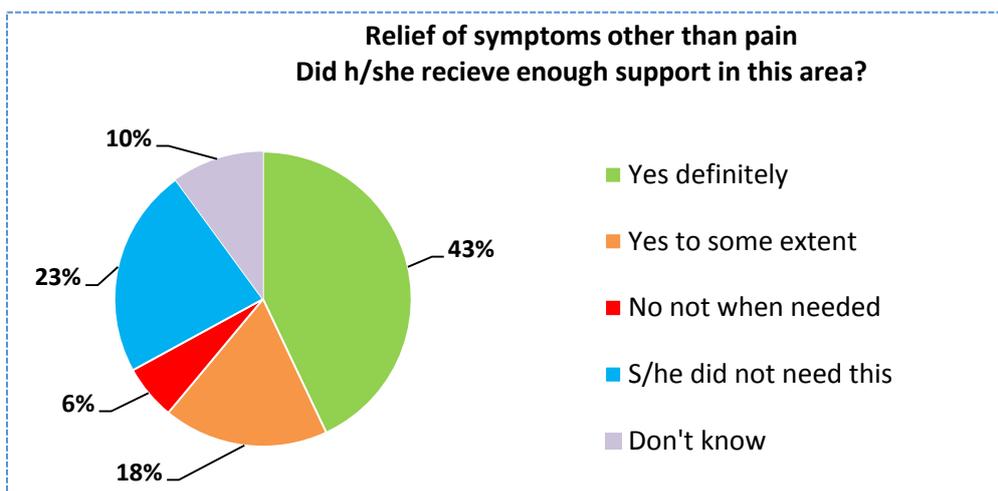
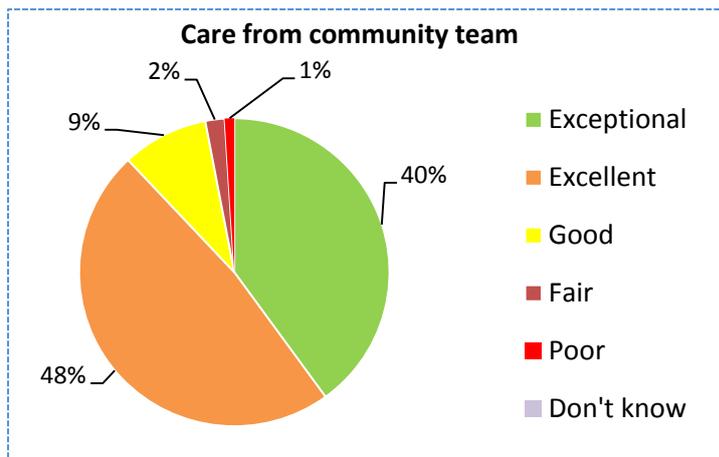


Figure 8

When relatives/carers were asked what they thought about the care the patient received - the results were extremely good with 88% saying it was exceptional or excellent:-



"We were amazed at the care we were given and felt gratitude. It helped with our shock and sorrow"

"The home care team we saw were unfailingly cheerful, caring, sensitive and supportive - I really don't think we could have managed without them"

Figure 9

Respondents were asked how well the patient's pain was relieved:-

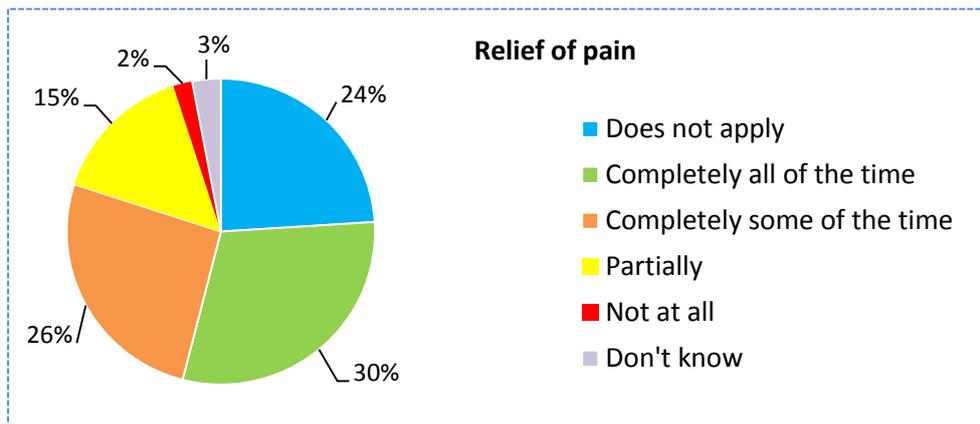


Figure 10

These results for how well pain was relieved were not quite as positive as in the Inpatient unit; however they are significantly better than the results from the annual National Bereavement Survey - Voices conducted by the National Office of Statistics (NOS) 2014:-

The 2015 NOS VOICES reported responses from its national survey (pain relived at home) as; 19% for 'completely all of the time', 30% for 'completely some of the time', 43% for 'partially' and 8% for 'not at all'

This PTHC VOICES HOSPICE Survey (reporting period 2015) reports: - 41% for 'completely all of the time', 35% for 'completely some of the time', 21% for 'partially' and 3% for 'not at all'. NB the 'does not apply' and 'don't know' responses are discounted the percentage responses.

Support and communication (direct question to relatives/carers)

When asked if the explanations about treatment and tests were easy or difficult to understand responses were positive with 60% saying 'very easy' and 32% 'Fairly easy', only 1% said it was 'fairly difficult'. The remainder said that they hadn't had an explanation or hadn't spoken with a nurse or doctor; however it wasn't clear as to whether this had been their choice.

All said that staff had had time to listen and discuss things. With 94% saying that they had been involved as much as they liked in discussions regarding care and treatment.

Finally relatives/carers were asked - "Overall, when caring for him/her, do you think you and your family got as much help and support from the PTH Community team as you needed?"

The Hospice Care at Home Team were wonderful - they came every day during the last week of my husband's life and were so kind and gentle with him. Our clinical nurse specialist was excellent and very supportive. I don't know how I would have coped without her to give me advice and answers to our questions, from her first visit until after his death.

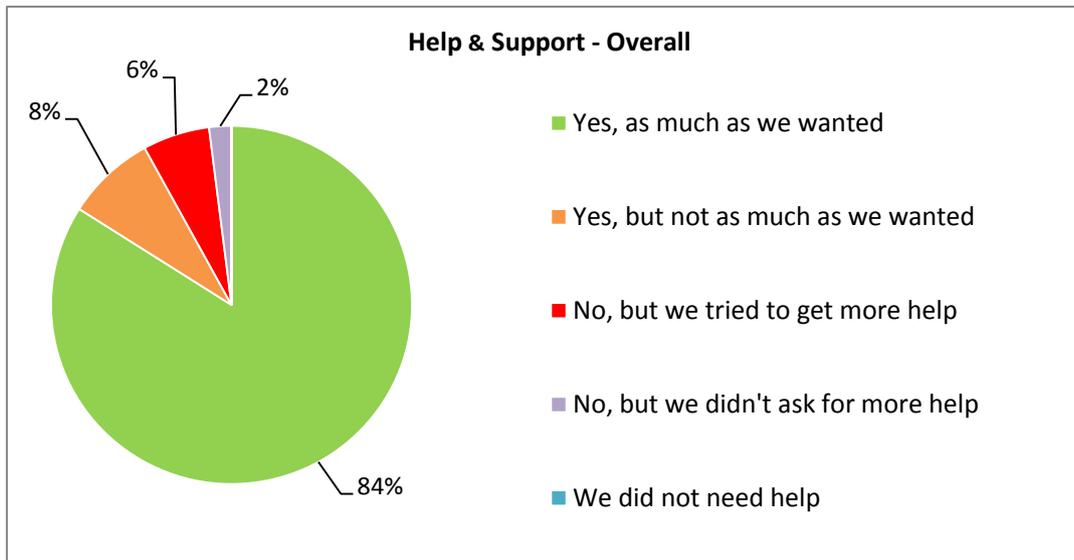


Figure 11

SECTION 5: Findings – Day Hospice

Of the total 129 respondents 13 stated the patient had attended the Day Hospice at some time before their death, it was in fact 14 (9 in last year's survey) but the section had not been completed by one person. This equates to 10% of the patients having attended Day Hospice.

The following information will refer to the information obtained from the 13 completed.

Of these - 4 had received care in the community and 9 had accessed all 3 areas.

The relatives/carers were asked whether their loved one had benefited from attending sessions in Day Hospice. 67% said always, 25% usually, 8% didn't know.

SECTION 6: Circumstances surrounding his/her death

This chapter presents responses in a section of the survey concerned with seeking views about a range of aspects concerning the patient's death. All respondents are asked to complete it.

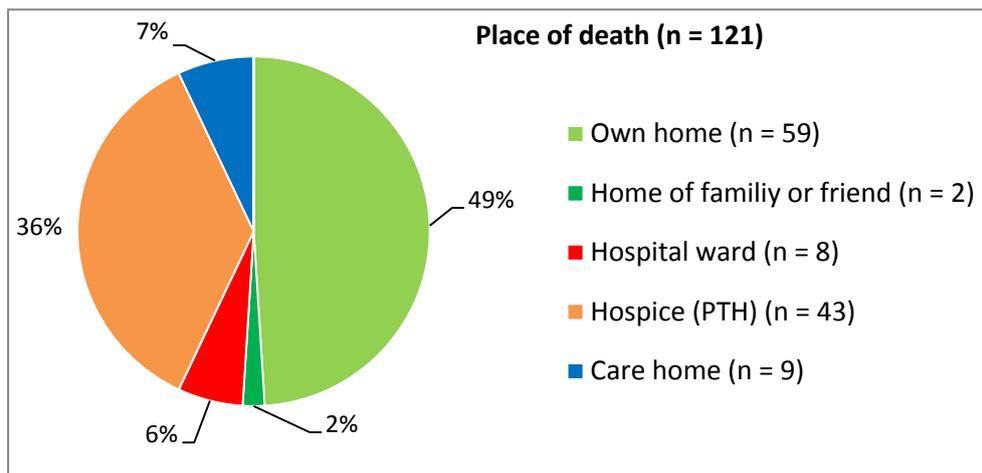
Of the total 129 respondents 121 completed all or part of this section.

The following information will refer to the information obtained from the 121 completed.

NB Percentages in the following sections are based on the questions completed. Some free text comments are included.

Place of death

The first question in this section asked respondents where the patient died:-



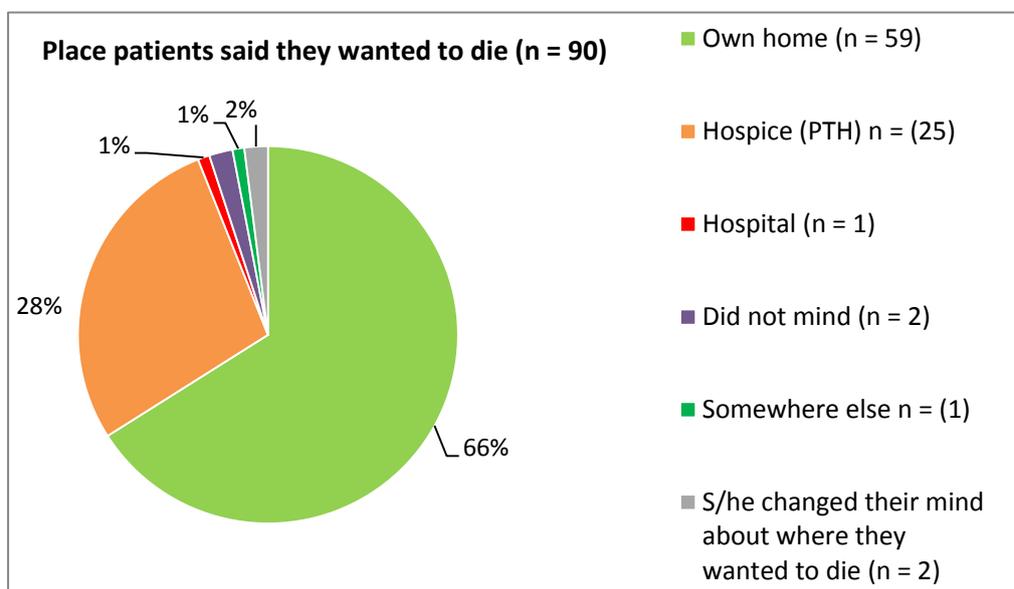
Graph also show numbers of responses

Figure 12

51% of patients had died in their own home or the home of a relative; the figure in last year's survey was 31%, an increase of 20% (a percentage increase of 65%).

Respondents were asked if the patient had ever said where they would like to die, 60% of them stated that they had. The next question asked where the patient actually said they wanted to die – interestingly 74% responded (unclear as to the reason for the discrepancy other than either; a misunderstanding of the questions or relatives imposing their views on where they think their loved one wanted to die). Two thirds (66%) stated the patient had wanted to die at home with just over a quarter (28%) saying in a hospice.

The number of responses (90/121) also demonstrates that people are still not always talking and sharing their thoughts about dying and where they would like this to be.



Graph also show numbers of responses

Figure 13

When comparing the percentage results between the two questions regarding where patients wanted to die and where they actually died (figures 12 & 13) it shows that less patients died at home than wanted to and more patients died in the hospice than had originally wanted to, however the deficit is less than last year. Also, only 90 respondents answered the question about where they wanted to die and it maybe that some of the patients that didn't express a particular preference may have been happy to die in the hospice.

This may be supported by the responses of the following two questions:

- “Do you think s/he had enough choice about where s/he died?” In which 83% answered ‘yes’, 10% were ‘not sure’ and only 7% said ‘no’.
- “On balance do you think s/he died in the right place?” In which 94 % answered ‘yes’, 3% were ‘not sure’ and only 3% said ‘no’.

“At the end my husband died quite suddenly. My daughters and I felt very supported by the overnight help that was arranged at short notice”

” She was so poorly and in pain at the end she wouldn't of made it home”

“Arrangements were made to get her home but she died before they were complete”

“We were very lucky- not everyone gets the choice & her cancer not being diagnosed in time (4 weeks prior to death) she would have died in hospital which she would have hated”

“I was so grateful that after receiving excellent care in the Hospice she was enabled to go home for 3 weeks before her passing, with an excellent support package from community nursing arranged by the Hospice”

Death on the Phyllis Tuckwell In-Patient unit

As stated previously 36% of patients died on the inpatient unit. The relatives/carers were asked if they're received enough support at the time of the death. All said yes.

“He was very well cared for”

“In her last days the hospice was so helpful and very caring”

Support in bereavement

Respondents were asked if they had talked to anyone at Phyllis Tuckwell Hospice Care about their feelings surrounding the illness and death. All respondents are asked to complete it.

Of the total 129 respondents 120 completed all or part of this section.

The majority (48%) said they hadn't but this had been their choice. 34% had spoken to someone and 13% said they would have liked to.

“For personal reasons I felt I should learn to cope with my daughter's death by myself. I have nothing but total respect for Phyllis Tuckwell Hospice. Superb place with first class staff”

Of those that had spoken with someone from PTHC - most reported to have spoken to a bereavement counsellor (42%), followed by a nurse (38%), others included bereavement service volunteer (5%), social worker (5%), doctor (5%) and complementary therapist (2%). They were also asked if this happened as quickly as they had wanted, 77% said yes, 7% would have liked to speak to someone sooner and 16% were unsure.

“Myself and my son have received so much help and support from the Hospice which is ongoing. Counselling for us both has been invaluable - Phyllis Tuckwell Hospice is a very special place”

Bereavement information

PTHC offer bereavement support to all bereaved relatives and friends. This comes in a number of forms, including leaflets and booklets. This section asked all respondents whether they received information of this kind.

Firstly they were asked about a leaflet giving information about what to do after a patient’s death. This is given to relatives/carers by the inpatient staff if the patient has died on the ward and the community team nurses (usually HC@H) if the patient has died at home. Most of respondents (80%) said that they had received the leaflet. Of these 99% found it helpful, 1% didn’t find it helpful.

Secondly they were asked if they had received a booklet called ‘Breaking through the clouds’. This is sent to the relatives/carer listed on the bereavement data base generated from the bereavement referral window completed after death (*there is an option to not receive bereavement support information). Again, most said that they had received this, although slightly less at 74% (this may be due to the above*). Of these again 96% found it helpful.

There were many comments from the respondents about having loving and supporting families and not requiring help, they all seemed to appreciate the offer and availability.

SECTION 7: Conclusions and recommendations

Conclusion

In general, the feedback received from the 129 surveys reflects a high level of regard for the work of Phyllis Tuckwell Hospice Care, with the majority of carers very satisfied with the support provided to them and their loved one.

The 214 surveys sent indicate that the number of patients accessing PTHC services has increased in the last year (since the last VOICES). The data from the responses also shows changes in the services patients are accessing – with a considerable increase in patients receiving care in the community – this mirrors organisational data and affirms PTHCs commitment to caring for people in their own homes.

An area of for improvement identified in the last survey was the provision of support for patients and carers in their own homes when circumstances change quickly, particularly during the evenings and at night. This is a difficult area as our teams work with numerous primary health care staff with varying levels of involvement. However increases to the both the CNS and Hospice Care at Home teams, as well as continued collaboration with our community colleagues, has resulted in higher satisfaction in this area.

Although, as already stated, the vast majority of comments were positive we cannot get things right all of the time and if the organisation is to be responsive to the changing needs of patients and their families it is important that the more constructive comments are considered. Discussion around this feedback can result in improvements and drive change. All comments are recorded in a spreadsheet and are discussed at Clinical Governance and the Senior Clinical team meeting (both have representation from all clinical services/areas). Where necessary there will be an action plan which will be discussed, disseminated and followed up by the relevant team/service lead.

Final note

Phyllis Tuckwell Hospice Care aims: - 'To care compassionately for people with a terminal illness, and those closest to them, so that they live their life to the full and their ending is peaceful' (mission statement). The results of this survey i.e. care across the In-Patient unit and the Community being rated as exceptional or excellent by 89 % of respondents is a testament to the hard work and commitment shown by all the PTHC staff and volunteers.

Recommendations

VOICES HOSPICE is now established as an ongoing data collection method at PTHC. The planned cycle of a four monthly data collection period annually is providing quality feedback whilst remaining manageable in terms of resources. It is therefore recommended that the VOICES HOSPICE Survey continues on the same basis. However as any new methods or emerging tools for measuring quality are developed they will be discussed and considered by both the Clinical Audit and Research Group and the Senior Clinical Team.

Currently the surveys are collected and read in real-time, with any serious concerns being flagged to the relevant service lead. However the general comments/feedback spread sheet is not reviewed until the end of the data collection and after the report is written. It is proposed that all comments of concern are discussed within a suitable timeframe of receipt (two weeks) with the relevant service lead and a plan as to how to move forward recorded and actioned. How and when to respond to individual comments and feedback also needs to be reviewed. The survey currently asks the respondent if they are willing to be contacted about comments they have made and requires them to leave a telephone number. Many provided a number but it is not really clear as to whether they want or expect to be contacted. Therefore it is proposed that we add an additional question 'would you like to be contacted in regard to any comments you have made'. The Quality and Audit lead would contact them herself to gain more information enabling her to refer to the relevant service lead. Alternatively she may refer directly to the relevant clinical lead in the first instance. This approach constitutes good practice and demonstrates the organisation's commitment to patient experience and user engagement.

Changes to survey

See above paragraph regarding contacting the respondents.

Within the IPU section of the survey, participants are asked how much of the time the patient was treated with respect and dignity. However, this is not an option for Community section of the survey. This will be a useful addition to the survey.

The hospice is currently asking the Friends and Family Question in various feedback cards and documents. Therefore it would be beneficial to include this within the PTHC VOICES survey.

The full data and surveys including all individual comments will be made available to the clinical leads. The patient associated with the survey can be identified and thus crosscare records examined allowing individual circumstances to be scrutinised.

APPENDIX ONE

Response rate

In all there were 383 deceased patients, known to PTHC, in set period. The patient sample meeting the criteria was 231.

Criteria

Relatives of patients that had been seen (more than once) by a PTH service within 4 months of death. They can have accessed several services – so complete relevant sections on survey

NB the information regarding the NOK and carer was not always readily available in the designated fields in the crosscare system.

After examining the notes the final recipient sample (those relatives sent a survey) was 214.

Method

The surveys were sent 12 weeks post bereavement. They were sent with a personally addressed letter. If a response had not been received within 3 weeks follow up survey and letter was sent.

Reponses rate for initial survey sent = 39%

Reponses rate for follow up survey sent = 39%

In terms of responses it was worth sending follow up surveys to those who had not initially replied.

214 surveys were sent out, 132 were returned = 62%
(129 were completed)

Age, ethnicity, and gender

Respondents

There were more female than male respondents 91/38

	18-19	0
	20-29	3
	30-39	2
	40-49	15
F	50-59	15
	60-69	19
	70-79	23
	80-89	6
	90-99	3
	unknown	5

	18-19	0
	20-29	0
	30-39	1
	40-49	3
M	50-59	7
	60-69	11
	70-79	10
	80-89	5
	90-99	0
	unknown	1

56 were wives, 29 were daughters
There was also a daughter-in-law,
2 sisters and 2 friends

29 were husbands, 7 were sons.
There were also 2 fathers and a
partner

Patients

More of the deceased were male - 69/60

	18-19	0		18-19	0
	20-29	0		20-29	0
	30-39	0		30-39	0
	40-49	2		40-49	3
M	50-59	7	F	50-59	6
	60-69	9		60-69	15
	70-79	28		70-79	13
	80-89	20		80-89	19
	90-99	3		90-99	4

The vast majority of patients were white British 119 (92%).

The others were:

White Irish (4), White other (2), Indian (1), Pakistani (1), Asian other (1), and Caribbean (1)

Completion

Respondents were asked to complete the sections relating to the services the patient had accessed (In-Patient Unit, Community and Day Hospice); both the circumstances surrounding death and the bereavement sections were to be completed by all. The collator of the survey had information detailing which services accessed by the patient and was therefore able to establish which sections were not completed when they could have been. This was most commonly the community and the circumstances surrounding death sections. This may have been due to uncertainty as to who they had seen in the community and from which provider and the quite searching questions in the circumstances surrounding death section.

Inpatient unit

One respondent did not complete the inpatient section when applicable. There was no apparent reason for this. Most questions were completed well

Community

Sixteen respondents did not complete the community section when applicable. This may be due many different health care professionals including those from PTH contacting or visiting the home. The respondent may also not have lived at the patients home and may not have always seen or known who was visiting. Most questions were completed well.

Day Hospice

One respondent did not complete the Day Hospice section when applicable.

Circumstances surrounding death

Eight respondents did not complete this section (applicable to all). It was the most poorly answered section with 2 questions answered particularly poorly:-

Question 29:- 'Where did s/he say that s/he would like to die?' Only 74% answered. NB there was not a 'don't know' option.

Question 30:- 'Do you think they had enough choice about where s/he died?' Only 74% of respondents answered this question.

Implementation

Estimated costs

The cost of printing paper and envelopes = 17p. Postage = 35p per survey. Total cost of 52p per survey sent (52p x 306 = £159)

The project was implemented by the Quality and Audit Lead and as an estimate all the different elements equated to 4-6 weeks of work time = 104-156 hours.

It consisted of administrative and analytical work.