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Dying at Home of Cancer: whose needs are being met? The experience of family carers and healthcare professionals (a multiperspective qualitative study)

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Title of the article

Dying at Home of Cancer: whose needs are being met? The experience of family carers and healthcare professionals (a multiperspective qualitative study)

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Up to five **keywords** relevant to the content of your manuscript. This will enable us to identify the most suitable reviewers for your manuscript

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Abstract

(250 words)

Objectives

Supporting patients to die in the place of their choosing is an important aspect of end of life care. Our study set out to answer the question: 'How does the home environment influence perceptions of quality of death, and the experience of caring for the dying at home, for family carers and healthcare professionals (HCPs)?

Methods

A qualitative approach, using multiperspective interviews with bereaved family carers (n=15) and a nominated HCP (n=13) ensured depth of insight gained on supporting a home death. The semi-structured interviews were audio-recorded, transcribed verbatim, and analysed using Framework.

Results

We found that the home environment enabled normality, a sense of control and individualised care which family carers often perceived as contributing towards a good death. However, the home environment created challenges for both family carers and HCPs, due to the differing and at times conflicting needs of the dying person and their family carers.

Conclusion

We have shed light on the complexity of balancing the demands and the satisfaction of caring for someone dying at home. The ability to manage these conflicting needs influenced whether carers perceived the home setting as the best place for the person to have received care in their last days of life.

INTRODUCTION

Supporting patients to have choice about where they die is an important aspect of end of life care. In the UK in recent years, the focus has often been on supporting patients to die at home, as this is where most people prefer to die.(1-3) More recently, there has been a move towards exploring the quality of death in different settings and identifying other outcomes people value at the end of life.(4-6)

Although home is where many people say they would prefer to die there is limited evidence on which specific aspects of the home environment are regarded as positive, and its contribution towards a 'good death', necessitating further study of the meaning of home. (7)The role of family carers to support patients to die at home is critical and a home death is extremely unlikely to be achieved without this.(8-10) There is a growing body of evidence on what dying at home means to those supporting it to happen.(11,12)

The number of UK deaths is predicted to increase to more than 620 000 per year by 2030.(13) Many people, especially older people living alone, might not be able to be supported to die at home. It is therefore timely and important to clearly understand which aspects of dying at home, in addition to it being the preferred place of death, are regarded as contributing to a quality experience.(14) These aspects should be maintained for those that are cared for at home in their last days of life, but, equally important, and where a home death cannot be achieved, other care settings should consider if they can replicate some or all of these aspects.(6,15)

There is extensive literature on what constitutes a 'good death',(16-19) with the National End of life Care strategy describing a 'good death' as 'being treated as an individual, with dignity and respect, being without pain and other symptoms, being in familiar surroundings and being in the company of close family and or friends.(1) Having a 'good death' is linked to having high quality palliative care that include decision making focused on the dying person, addressing physical comfort, respecting dignity and proximity of family and emotional support to family during periods of change.(5)

Our study set out to answer the question: 'How does the home environment influence perceptions of quality of death, and the experience of caring for the dying at home, for family carers and HCPs?' In order to achieve this, we aimed:

- To explore the experience of caring for someone who wished to die at home in North Wales and did so;
- To explore the contribution of the home environment to the overall quality death, and
- To identify the impact of the home environment on family carers and HCPs as they provided support to enable dying at home.

METHODS

A qualitative approach, consisting of multiperspective interviews of bereaved family carers and a nominated HCP was taken in order to gain depth and richness of insight.(20) Ethical approval was obtained from the North Wales Research and Ethics Committee (13/WA/0246).

Sampling and recruitment

The study took place in North Wales, where the Betsi Cadwaladr University Health Board provides services for around 678,000 people. There is access to a full range of multi-disciplinary specialist palliative care inpatient and community services, including 24/7 medical advice. Other support services include night sitting, rapid response and Hospice at Home. 18.5% of the resident population of the region is aged 65 and over. This is predicted to change over the next 20-30 years with a large growth in the number of older people. The population is scattered between large concentrations of people in and around the region's key urban centres, coastal resorts and rural market towns and smaller concentrations in and around rural villages, hamlets and settlements. Due to a relatively poorly developed road infrastructure, travel time to hospitals can be an issue for remote rural communities. Tackling health inequalities is a key issue, with almost one fifth of the population living within the most deprived wards.

Purposive sampling was used to ensure a range of characteristics and experiences of relevance to the research question. Patient sampling criteria included age, duration of illness due to primary diagnosis and geographical and urban/rural differences. Cancer/non-cancer diagnosis had also been intended as a purposive sampling criterion, but only family carers of patients who had died from a cancer diagnosis could be recruited. HCP sampling criterion was professional role.

Participants were approached through specialist palliative care teams (SPCTs). Bereaved main family carers were identified from records of patients who were under the care of the SPCT and who had died approximately six months prior to the expected interview dates. (21) Family carers of adult patients who wished to die at home and did so, who were known to the local SPCT and had two face-to-face visits by this team were invited if they:

- Had no serious psychological distress as determined by SPCT clinician
- Were not involved in further investigative procedures such as an inquest or a complaints procedure
- Were aged 18 or over.

The Carer Information Sheet acknowledged the potential to cause distress by discussing this topic and explained available support mechanisms. It detailed the interview process, including how informed consent will be recorded, and introduced the interviewer as an experienced palliative care clinician.

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5 The family carers nominated two HCPs that had been involved in supporting their relative to
6 stay at home. One HCP per carer was approached based on purposive sampling principles
7 and to preserve HCP anonymity.
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10 **Data collection methods**

11 Topic guides were developed with participation of all team members. Between November
12 2013 and May 2014 JP conducted face-to-face semi-structured interviews with 15 family
13 carers in their own homes (60-90 minutes), and telephone interviews (up to 30 minutes)
14 with 13 HCPs.
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19 In three of the 15 family carer interviews other relatives were present at the interview and in
20 two cases they contributed to the discussion (see participants C10 and C14 in Table 1). Five
21 female and ten male patients were cared for by these carers. All patients had a primary
22 cancer diagnosis and the duration of their illness due to their primary diagnosis varied from
23 two to 84 months (mean = 14.27, median = 12 months).
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28 Four of the HCPs were SPC clinicians, and the others were primary care clinicians,
29 mostly district nurses (n=6) No doctors were interviewed. (Table 1).
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Table 1: Study participants: demographic information

Carer information		Patient characteristics				HCP selected for interview	Additional information
Carer code	Relationship of carer to patient	Duration of illness due				to primary diagnosis	
		Gender	Age	Primary diagnosis			
C1	Husband	Female	80+	Liver cancer	6 months	SPC nurse working in the community	
C2	Daughter	Male	89	Stomach cancer	12 months	District Nurse	Moved into daughter's house for duration of illness
C3	Daughter	Female	90	Glioblastoma	6 months	SPC Occupational Therapist	Lived with daughter prior to illness
C4	Wife	Male	73	Lung cancer	9 months	District Nurse	
C5	Wife	Male	80+	Oesophagus cancer	7 years	SPC nurse working in the acute hospital	
C6	Wife	Male	70	Melanoma	14 months	District Nurse	
C7	Husband	Female	65	Lung cancer	12+ months	District Nurse	
C8	Husband	Female	62	Pancreas cancer	17 months	District Nurse	
C9	Wife	Male	65	Bowel cancer	4 months	Hospice at Home Support Worker	
C10	Wife and sister	Male	60	Bowel cancer	3 months	District Nurse	
C11	Daughter	Female	90	Lung cancer	3 months	GP (Not available for interview)	Lived with daughter prior to illness
C12	Daughter	Male	88	Bowel cancer	12 months	SPC nurse working in the community	Moved into daughter's house for duration of illness
C13	Wife	Male	80	Bowel cancer	18 months	SPC doctor: (Not available for	
C14	Wife and daughter	Male	80	Pancreas cancer	2 months	Marie Curie nurse	Moved into daughter's house for duration of illness
						interview)	
C15	Wife	Male	70	Bowel cancer	12 months	Pharmacist	

Analysis

Data were analysed using Framework,(22) a systematic, five-stage matrix based system which facilitates analysis both by theme and by case.(23-26) Framework was chosen as it is well suited to policy relevant research such as this and is particularly convenient for purposes of transparency and clarity.(27) The codes were obtained inductively from an initial analysis of the data (JP and JH). JP constructed a code index and applied the codes consistently for all interviews. All coded transcripts were reviewed and new codes were identified or merged together into broader categories. Interpretation of the themes derived from the data was conducted by JP with involvement of JH, and a data interpretation workshop involving all authors.

Research team and reflexivity

The research team was multidisciplinary, comprising a SPC occupational therapist (JP), an academic palliative care consultant (MP), an academic general practitioner (RN) and a medical sociologist/ qualitative methodologist (JH). JP conducted the interviews. Study participants were informed that JP was an HCP and in this context working as a researcher.

RESULTS

In this paper we argue that the home environment enabled normality, a sense of control and individualised care which family carers often perceived as contributing towards a good death. However, the home environment created challenges for both family carers and HCPs, due to the differing and at times conflicting needs of the dying person and their family carers. It shed light on the complexity of balancing the demands and the satisfaction of caring for someone dying at home. The ability to manage these conflicting needs influenced whether carers perceived the home setting as the best place for the person to have received care in their last days of life.

Three main themes emerged from the data.

Theme one: A 'sense of home' contributed to family carers' perception of a good death being achieved

According to family carers' accounts, a 'good death' related closely to the dying person remaining in an environment that had a sense of 'home'. This was created through the maintenance of normality, control and individualised care.

One family carer described moving the dying person's bed so that a familiar view could be seen at all times, another described a dying person who appreciated being able to continue a long-held routine of completing a crossword in their garden. Physical objects within certain rooms were also valued, such as being surrounded by a life-long collection of clocks, being able to sleep in the marital bed or to have pets on the bed or under the armchair. The familiarity of certain rooms provided comfort and often fond memories and probably as a consequence of this, changes made in the home were often reported as very unpopular with dying people.

Being at home gave opportunities for peace and quiet and also for the informality of friends and family calling in, creating a sense of normality of life.

"It seems to me that when you are in hospital that conversation dries up, but when you are at home things seem more relaxed and normal."[Carer 12]

In contrast to patients' experience (as reported by carers), the normality of home environment had changed drastically for many family carers. Descriptions of changes to layouts of bedrooms, lounges and sleeping arrangements with provision of commodes, stair lifts and special armchairs were all cited as changing the normal arrangement of the home and thus their own experience of the home. Family carers' own patterns of daily life had also changed, with jobs, family routines and children's schooling being adapted to enable family carers to continue caring.

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3 So, while the sense of home and normality of family life was highly prized by the dying
4 people in their last weeks of life, that same sense of the normality of home had been lost
5 for the family carers who sought to make the home and their daily routines support the
6 needs of their dying relative.
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10 *“When he was in the room the curtains were always shut and the fan on ... it felt*
11 *sad.”*[Carer 9]
12
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15 At the same time, the home environment gave family carers satisfaction through
16 enabling their dying relative to remain in control. This was demonstrated through the
17 ability to remain actively involved until the very end in pastimes such as putting make
18 up on, bathing in their own bath and sharing a bed.
19
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22 *“When DN [District Nurse] first came in they said what they would do ... and he said*
23 *‘I will decide’ and to be fair they listened to him.”*[Carer 15]
24
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27 HCPs viewed the home environment as a place where both the dying person and their
28 family carer(s) were in control and could direct the work of the HCPs. One family carer
29 described insisting that visiting HCPs removed their shoes upon entering their house as
30 he knew his wife would have wanted this.
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34 Being at home enabled family carers to focus on their dying relatives’ needs and provide
35 them with the individualised care that they wanted them to have. It provided the
36 opportunity for family to come together. One participant described having a dinner party
37 with a deteriorating relative sitting with all family and listening to family ‘chatter’. This type
38 of experience led to family carers reflecting positively on their experience and viewing their
39 ability to provide care as rewarding and contributing to a ‘good death’.
40
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42
43 *“so that night we all sat down as a family, with Dad in his bed, he was there but he wasn’t*
44 *if you know what I mean and we were watching TV when he slipped away.”*[Carer 2]
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48 **Theme two: Coexistence of differing and at times conflicting needs of dying people and** 49 **family carers**

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51 The home environment is both the dying person and their family member(s)’ space - but
52 their views and needs appeared to differ and conflict at times. Family carers expressed that
53 caring for loved ones in the home setting could be both immensely satisfying and
54 challenging for them. Two particular areas, information needs and provision of practical
55 support, were highlighted that can result in a difference of opinion between patients and
56 their carers. In both these areas the dying person’s views often took precedent over the
57 carer’s, and therefore risked carer views or needs not being acknowledged. Different
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3 information needs of involved parties are a well-known phenomenon and are not
4 dissimilar to other care settings,(28-31)so, for the purposes of this paper, we will focus
5 on the provision of practical support in the home environment.
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9 The reluctance of some dying people to accept the provision of practical support from paid
10 carers or of adaptive equipment created difficulties. Many family carers described that they
11 needed more hands-on help at an earlier stage, or the acceptance of the use of adaptive
12 equipment to facilitate practical care. However, many dying people were reluctant to accept
13 these and family carers described getting exhausted or requiring other family members to
14 insist on acceptance of practical care or equipment. The fact that the dying person had such a
15 limited prognosis resulted in carers viewing the home as the dying persons' area of control
16 and this, at times, contradicted the family carer's needs in trying to support them.
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22 *"he was getting heavier and insisted on walking – the District nurse insisted that he*
23 *had a commode but he would not use it when they were not around"*[Carer 6]
24

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26 *"my husband wouldn't take his medication but when he did he was much calmer ...*
27 *and I needed help but he wouldn't have it"*[Carer 9]
28
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30
31 Aspects of the home environment created extra demands on family carers which other care
32 environments (e.g. hospital or hospice) would not. In other care settings practical support
33 could be instigated at an earlier stage which suggests that the home results in patients
34 retaining control even if it is in opposition to family carers' needs. It also suggests that at
35 times the home environment could be detrimental to family carers' physical and emotional
36 needs and continues to highlight the importance of identifying the family carers' needs
37 separately from the dying person.
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42 *"My mum could be stubborn and say 'I don't want to go to the toilet', so I would say it*
43 *will take two of us, but she would say 'well, I don't want to go'. So then the carer*
44 *would leave and then she would say I will go now (laughs) but I managed."*[Carer 11]
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48 Many family carers spoke openly about exhaustion, the juggling of different roles and the
49 drastic impact on their lives. This appeared to be intensified when family carers were unable
50 to take a break from their caring role. In spite of this, family carers still derived immense
51 satisfaction by having supported their dying relative at home, reporting that they had gained
52 new skills such as assertiveness (for example when getting General Practitioners to visit their
53 dying relatives), and reflecting on the satisfaction of the intimacy and closeness of providing
54 personal care. Care activities allowed opportunities to share laughter and memories
55 enriching the relationships both between the carer and the dying person and between
56 family carers.
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3 **Theme three: The challenge for HCPs of providing support for differing needs of both**
4 **dying people and family carers**

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6 HCPs commonly described immense satisfaction from the close involvement with
7 dying people and their family members during the care period, knowing they had
8 supported a wish to die at home.
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11 *“They were so thankful but it was a pleasure to really get to know them all”* [DN
12 – Carer 2]
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16 *“...when we are told thank you for bringing him home... without the families*
17 *doing this we cannot do this – we have to work as a team “* [DN - Carer 8]
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21 They also described challenges.

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23 HCPs identified communication skills as critical in supporting both parties. Consistency and
24 regular contact was also described by both family carers and HCPs as critical in enabling the
25 development of a trusting relationship and anticipation of needs to be met. Many family
26 carers commented on the value added by honest and sensitive communication by skilled
27 staff of all levels including communication about expected deterioration. Some family carers
28 stated their needs were insufficiently acknowledged even though their nominated HCP
29 reported being content with the quality of communication and felt that the carer had
30 appeared satisfied too.
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36 The home environment can be a challenging place for HCPs to effectively provide support.
37 HCPs described frustration at their inability at times to address the differing needs of the
38 dying person and their family carer(s) due to resource constraints (e.g. lack of time or
39 availability of night time cover), often in the context of poor information transfer from
40 previous settings of care (e.g. hospital discharges). They highlighted the conflict created by
41 guidance (e.g. moving and handling) that protects paid carers but could leave family carers
42 in a position to complete such tasks in an unsafe manner. HCPs acknowledged that they
43 often needed more emotional support themselves to cope with the demands of supporting
44 home deaths.
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51 *“We could see what was needed to help and wife was struggling but had to be led*
52 *by the patient ... was frustrating at times”* [DN – Carer 2]
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55 *“We insisted he used the commode but it left us feeling uncomfortable as we knew*
56 *it was harder for the wife to”* [SPC nurse – Carer 12]
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DISCUSSION

The importance of this paper lies in the portrayal of the tension created for family carers in balancing the burden of care and the satisfaction of having supported a wish to die at home. It emphasises the necessity for HCPs of recognising these potentially different needs in order to optimally support a home death. Our study contributes to the growing body of evidence on what dying at home means to those supporting it to happen, and, uniquely, triangulates between carer and HCP views.

Family carers: needed, burdened yet satisfied

The potentially different or conflicting needs of dying people and their family carers are described in the literature,(7,32) but our study develops this theme, adding important detail to aid crucial understanding of how the home as a setting contributes to conflicting emotions. The satisfaction of the perception of having supported a 'good death' appeared to be key in enabling many of the family carers to tolerate significant changes to their own routines and environment whilst striving to maintain normality for the dying person. In spite of the clearly described burden of care, most family carers felt that the fulfilment of their dying relative's wishes and needs were their overwhelming priority. This, in turn, led to them reflecting on the experience with a level of satisfaction that, for many, significantly outweighed any concerns about their own needs at that time. Understanding this is central in planning and managing a home death.

In addition, our study findings reinforce current literature showing that:

- Home is more than a building: The home can be described as multi-layered,(6,7) with the physical location or building being just one aspect. Other aspects which are valued are familiarity, comfort and closeness of family and friends and empowerment of the dying person and family carers to live, with a semblance of normality in a less-medicalised environment, until the very end.(19,33)
- Place, people and dignity contribute to a 'good death': Having a home death is perceived by many family carers as contributing positively towards a 'good death'. They often associate being cared for in the home environment with dignity in dying. Our findings echo the descriptions of a good death in the literature.(1,5,16-19)

Strengths and limitations

We conducted in-depth qualitative interviews with a rich and varied purposive sample of family carers and HCPs. The research team was multidisciplinary (palliative and primary care physicians, occupational therapist and medical sociologist).

The objectives of the study necessitated the sample to be drawn from one, albeit large, Health Board. The family carers interviewed had lived with the dying person for this period

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3 of care. All patients had a primary cancer diagnosis. HCP recruitment was challenging.
4 Despite trying to get views from a range of professions, none of the nominated doctors
5 were available for interview in the study period.
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11 **CONCLUSION**

12 Our study provides information on the experiences of caring for the dying at home in North
13 Wales, and the contribution the home environment is perceived to make towards a 'good
14 death'. It provides insight into how family carers reflect on the balance between the
15 significant demands of the caring role and satisfaction derived from successfully discharging
16 this role. It highlights for HCPs that the dying person and family carers might have differing
17 needs and that that this fact needs to be acknowledged in their clinical practice. There seems
18 to be synergy of evolving understanding of the complexities underlying dying at home policies which
19 are emerging from our study and other recent or synchronous work.(11,12) Our study adds to and
20 strengthens this growing consensus, importantly demonstrating how similar understandings and
21 concerns are prevalent in areas of the UK with very different geographical and demographic
22 composition and using different methods and sample.
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30 The home environment is unique in creating an environment where differing needs
31 have to co-exist. The challenge for HCPs remains in providing support for differing needs
32 of both dying people and family carers within this home environment.
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CONTRIBUTORS

All authors were responsible for the overall study conception and study design. JP conducted the interviews and analysed the data. JH supported JP in data interpretation, in preparation of a data interpretation workshop attended by all authors. JP was responsible for drafting the manuscript and all authors approved the final manuscript.

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COMPETING INTERESTS

None declared.

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Semi-structured Interview Topic Guides

Carers' topic guide

Home as a place of death:

- How decision made about where [patient name] should be cared for as condition deteriorated
- Choices felt to have
- Extent of preparation had
- Importance of home as a place for [patient name]
- Topics which were difficult to discuss / whether being at home make this better or worse

Support available

- Type/who/when/how involved
- Timing of support offered
- Interaction of different support teams
- Process of being informed of condition/how information was shared

Support/interventions received/experienced

- Physical/psychological/emotional/practical/social/information

A good death

- Views on whether [patient name] had a good death
- Most helpful support / intervention
- Least helpful support / intervention

Difficulties in staying at home

- Whether risk of hospital admission
- What helped/did not help

Carers' role:

- Most rewarding aspect
- Most challenging
- Advice for anyone else who wants to support someone to die at home

Healthcare professionals' topic guide

Referral

- How became involved in this case
-
- Appropriateness of timing

Type of support offered

- Support offered
- List all specific interventions that offered as possible

Dying

- Preparation
- Whether discussion about dying at home
- Awareness of the importance of the home to patient/ family
- What a good death means to you
- Whether felt that a good death was achieved

Impact of the home:

- Were there any aspects of support at home that were more challenging
- Were there any aspects of support at home that were more rewarding

Team work

- Who was involved
- How communicated
- Views on role of a key worker

Views on dying in different settings

- Challenges and rewards of dying in different settings
- Recommendations for improving services to support dying at home