

# “What She Told Us Made the World of Difference”: Carers' perspectives on a hospice at home service

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**Abstract /** This paper explores the expectations and needs of current and bereaved carers whose relatives received care at home from a palliative care team. **Aim:** A hospice at home service was established in 2006 to provide patients with care in their own homes. We examined whether this model of care was helpful in mitigating carers' burden and in enabling terminally ill patients to be cared for and die at home. **Methods:** This study utilized a survey and interviews. Participants were carers in the midwest of Ireland. Survey responses from 122 carers were analyzed using SPSS 18.0 (SPSS Inc., 2009); interviews with 15 carers were also conducted. **Results:** Carers' expectations of the service were often exceeded, and quality of care dimensions were rated highly. Future improvements could include facilitating discussions on place of death and offering bereavement support. **Conclusion:** The service is supporting carers in facilitating their relatives' choice to die at home.

**Résumé /** Cette étude explore les attentes et les besoins des soignants endeuillés, ou sur le point de l'être, dont les proches étaient soignés à domicile par une équipe de soins palliatifs. **But :** En Irlande en 2006, on a mis sur pied une équipe de soins palliatifs à domicile afin de pouvoir soigner les malades à la maison. Nous avons choisi ce modèle de soins pour tenter de savoir si cette formule diminuait le fardeau des soignants et si elle permettait à leurs proches de choisir d'être soignés à la maison et de pouvoir y mourir. **Méthode :** Nous avons conduit notre recherche sous la forme d'une enquête et d'interviews. Les participants étaient des soignants qui habitaient la partie ouest de l'Irlande. Suite à notre enquête nous avons analysé les réponses de 122 participants à l'aide du logiciel IBM SPSS. De plus, nous avons eu des rencontres individuelles auprès de 15 de ces soignants. **Résultats :** La qualité des services dépassait souvent les attentes des aidants, et la qualité des soins était hautement appréciée. Nos résultats indiquent qu'on pourrait améliorer certaines dimensions et favoriser les discussions quant à l'endroit de la mort et les services

offerts aux endeuillés. **Conclusion :** Le service de soins palliatifs à domicile apporte un support moral aux soignants et facilite le choix de leurs proches de pouvoir mourir à la maison.

## INTRODUCTION

Carers are integral to the delivery of hospice at home (HaH) services, which support individuals who wish to be cared for and to die at home. Their role is complex: carers give medications, engage in symptom management and coordination of care, and provide everyday personal and social care. Given the centrality of this role, it is essential that we solicit caregivers' views and take them into account when evaluating services and when planning and designing future service provision (1).

A service in the midwest of Ireland provides comprehensive services for palliative care patients, including a 24-hour HaH service — the first of its kind in Ireland. A multidisciplinary team of specialist nursing, medical, social work, physiotherapy, occupational therapy, and pastoral staff provides the services. This affords patients and their carers/family members access to professional help in assessing and managing the physical, emotional, psychosocial, and spiritual dimensions of the patients' illness. Through their collaboration with primary care and acute care hospital specialists, members of the multidisciplinary team also provide education and information to carers/family members.

## LITERATURE REVIEW

Previous studies have been concerned with carers' experiences in general palliative care (2) and in planned respite care (3); they have also sought to determine carers' support requirements (4) and investigated carers' experiences of HaH services

(5-8). Carers generally reported that their main need was for the support that would enable them to provide patient care at home (5). They required access to support — specifically, access to general practitioners and district nurses, to equipment, to support for themselves, and to information about the patient's illness and symptom control. The inability to access out-of-hours care in crisis situations or specialist staff was a concern for carers (6).

Research conducted in Northern Ireland (7) explored bereaved carers' experiences with HaH and found among these carers a general lack of awareness of the service. These carers identified having access to nursing care and medical support, and making it possible for patients to choose their place of death as their most important concerns, as did carers in another study (8). Carers in an Australian study emphasized the importance of palliative care services in controlling symptoms and providing pain relief; they also reported that they valued the social contact afforded them by the palliative care team (9).

Research on the experiences of informal current carers and on the impact that caring has on these carers is limited. Carers have reported their need for information and advice, in-home respite care, help with household tasks, and financial support. Their low mental health scores point to their need for support in order to maintain their sense of well-being (10).

Three reviews have examined aspects of palliative care services. Docherty and colleagues (11) noted caregivers' multiple concerns, highlighting caregivers' need for communication with, and knowledge from health professionals. The authors stressed the lack of research incorporating the perspectives of patients, service providers, and caregivers. Bee, Barnes, and Luker (12) identified a lack of practical support related to the inadequate exchange of information; they also noted the need for skills training and the need to involve carers in the design and development of new education interventions. Shepperd, Wee, and Straus (13) supported the use of end-of-life care programs to facilitate patients' wish to die at home and called for an evaluation of the effects such programs have on patients' families and informal carers.

Researchers have concurred that the needs of bereaved carers/family members are not being met (14, 15). One study conducted in an Irish hospice setting examined the nature and use of bereavement services and identified areas for improvement (15).

Over the past decade, researchers have examined issues related to hospice-based services, evaluated the needs and support requirements of informal carers, and highlighted the importance of

ensuring such support. Carers have identified their most significant concerns — these include having access to professional support, adequate knowledge, practical nursing skills, out-of-hours services, and education and bereavement support.

This study therefore aimed to determine whether the HaH model of care was helpful in mitigating current and bereaved carers' burden and in enabling terminally ill patients to be cared for and die at home.

## METHODS

To evaluate the HaH service from the carer's perspective, we employed a mixed design that included a postal survey and interviews. The survey questionnaire was based on validated survey tools (16-18). Two versions were created — one for current carers and one for bereaved carers. These were piloted and revised. They took 20 minutes to complete, and the topics they covered included: carers' early experience; usefulness and timeliness of the HaH service; and communication between the HaH team and patients and carers, quality of patient care, and support for carers. Bereaved carers were also asked about the last week of the patient's life, the place of death, and bereavement support. The interviews were semistructured and the topics addressed were designed to relate to the care journey in order to enrich the depth of information. Interviews ranged from 15 to 45 minutes and were digitally recorded.

The research was approved by the local ethics committee.

### Study Population

The data were collected between January 2009 and August 2011. Employing a sampling strategy tailored to achieve similar group sizes, we invited 240 carers who were at least six months into bereavement and 215 current carers to participate (for a total of 455 carers). Of these, 51 current carers and 17 bereaved carers declined, so 387 questionnaires were distributed; 122 questionnaires were returned, 41 from current carers and 81 from bereaved carers (for a response rate of 32 percent). A total of 29 carers agreed to participate in interviews.

### Analysis

The questionnaire data were analyzed using SPSS 18.0 (SPSS Inc., 2009), and the qualitative responses were coded and thematically analyzed. The similarity of the questions for bereaved carers and those for current carers permitted us to combine the responses for some parts of the analysis.

**Table 1 / Overview of Respondents**

	Number	%
<b>Age</b>		
25-34	2	2
35-44	25	20
45-54	31	25
55-64	23	19
65-74	26	21
75-84	14	11
85+	1	1
<b>Relationship to patient</b>		
Spouse/partner	58	47
Parent	44	36
Child	10	8
Sibling	4	3
Other relative	4	3
Friend	2	2
Other	4	3

## RESULTS

### Questionnaire Findings

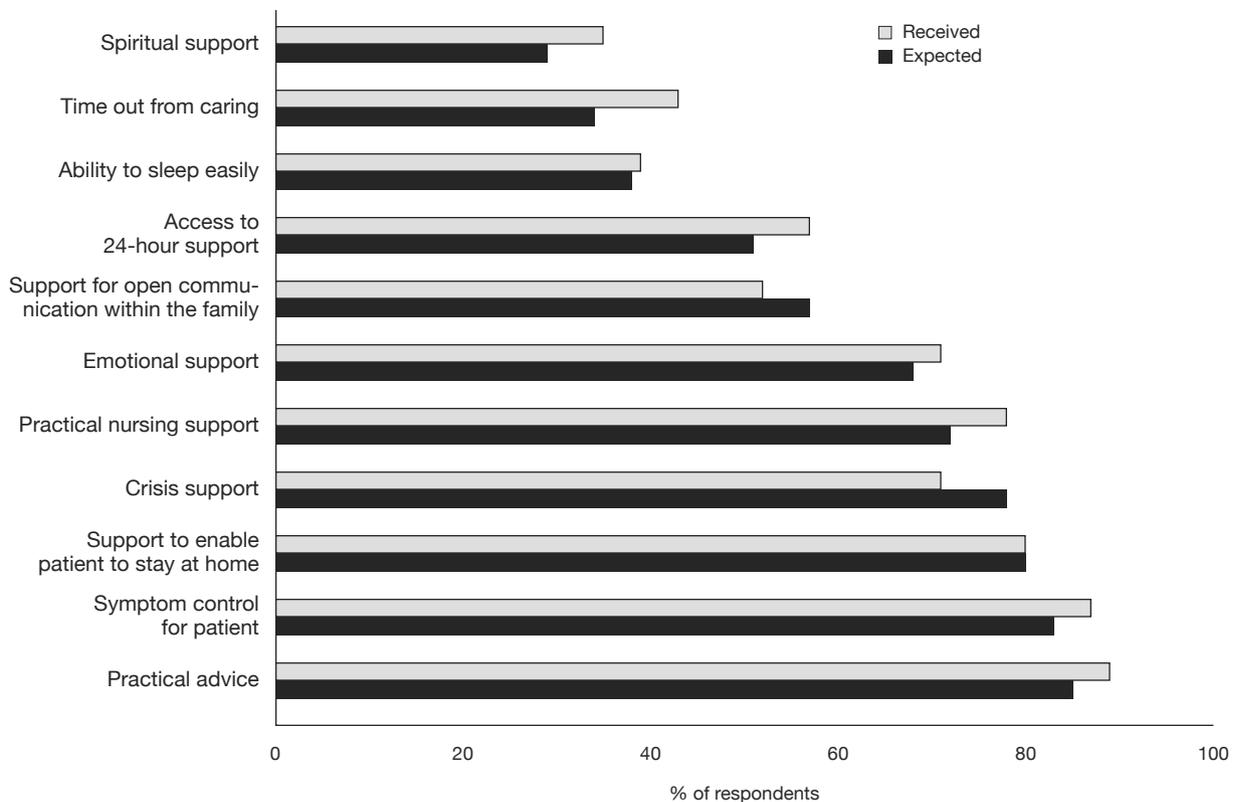
We present the questionnaire findings first. Not all questions were answered, so the range of responses differed across items. An overview of the respondents is shown in Table 1. In all, 96 percent of respondents (117 of 122) reported that referral to the HaH service had happened at the right time, and 98 percent (120 of 122) indicated that the first visit from a HaH team member also came at an appropriate time. The information provided at this visit was satisfactory to 91

percent of respondents (111 of 122). Figure 1 illustrates how the service equalled or exceeded respondents' expectations in all but two areas: access to 24-hour support, and support for open communication within the family.

Almost 98 percent of respondents (120 of 122) indicated that they were satisfied that the service allowed terminally ill patients to remain at home. On out-of-hours service, crisis support, and respite care, the number of responses was generally low, but the responses there were reflected a high level of satisfaction. Respondents found both nighttime visits and 24-hour availability of support highly valuable and very useful.

Among carers who benefited from respite care, 85 percent (35 of 41) found it very useful; and of those who received a shorter break from caring responsibilities, 60 percent (32 of 53) thought it very useful. Of those who used the nighttime visits service, 74 percent (35 of 47) found it very useful as it allowed them to sleep well, and 74 percent (35 of 47) were satisfied with the services available in a crisis situation.

The facilitation of open communication within the family was considered very useful by 68 percent of respondents (43 of 63). The level of satisfaction with spiritual support was lower than that for other support, with 56 percent (24 of 43) stating that it was very useful and 14 percent (6 of

**Figure 1 / Respondents' Expectations of Services Compared with Received Services (n=122)**

43) reporting that it was not useful. Overall, 84 percent (72 of 86) reported that the service was useful or very useful. Similar levels of satisfaction were reported for the daytime call service — 86 percent (82 of 95) found it very useful. However, the nighttime call service was used by a small number of carers.

Responses indicated that there were significant variations in the contact patients had with different types of professionals on the HaH team; however, there were different numbers of health personnel representing each profession, and their availability varied. A majority of the carers (77 percent, 86 of 112) reported that they were always able to reach the team when necessary.

General perceptions of the quality of the team's communication about the patient's illness and continuing care were very good for 75 percent (66 of 88) of patients and 69 percent (74 of 107) of carers (the question asked for the carers' views on how the team communicated with the patient as well as how the carers found the team's communication). Carers were always or usually satisfied with several aspects of communication: whether they were dealt with sensitively during telephone contact, whether they were permitted sufficient time to explain their concerns, and whether they received appropriate answers to their questions.

While 52 percent (62 of 119) of the carers stated that place of death had not been discussed with the patient, 57 percent (42 of 74) said that such a discussion would not have been beneficial. There was a statistically significant association between whether or not discussion had occurred with the family regarding place of death and where the patient died (analysis done using crosstabs with a chi-squared statistic;  $p < 0.05$ ). Specifically, when carers had discussed the preferred place of death with the HaH team, 66 percent of the patients they cared for died at home; whereas with respect to the patients who died elsewhere, only 23 percent of their carers had discussed the preferred place of death with the HaH team.

No team member had raised the issue of place of death with 55 percent of the carers (59 of 107). Of these, only 19 percent (11 of 59) were confident that it would have been beneficial; 56 percent (33 of 59) were confident that it would not have been beneficial. Discussions about continuing care and place of death were significantly more likely to occur with the patients' family members/carers than with the patients themselves, which highlights issues related to disclosure of diagnosis, patient versus carer control, and the individual's right to know.

The HaH service helped patients to spend their time as they chose: with their spouses or partners

(with whom 100 percent of patients wanted to spend most or all of their time), children (98 percent, most or all of their time), and other family members or friends (97 percent, most or all of their time).

Most respondents (97 percent, 112 of 115) were satisfied with the quality of care received and reported that the patient's dignity was maintained most or all of the time; 81 percent (87 of 107) considered the service to be very good at caring for the patient in accordance with his or her wishes. In terms of symptom control, 80 percent (90 of 112) said that the service was successful in ensuring that the patient's symptoms were controlled to a level that was acceptable to the patient. When it came to emotional support, 86 percent of the carers (95 of 110) reported that the service was very good or good at providing it.

Overall, 84 percent of carers (97 of 116) stated that the quality of care received was very good for the patient, and 80 percent (90 of 112) said it was very good for themselves; this rate was higher for patients than for carers (Wilcoxon signed-rank test:  $p = .001$ , test statistic = 3.5).

#### Additional Responses of Bereaved Carers

Of the bereaved carers, 84 percent (65 of 77) reported that the HaH service could have done nothing more for patients during their last week of life. Most of the patients — 57 percent (46 of 81) — who received care from the service died at home; 32 percent (26 of 81) died in hospital, 4 percent (3 of 81) died in a nursing home, and 6 percent (5 of 81) died in a hospice. A majority of carers — 72 percent (58 of 81) — stated that their loved ones had died in their preferred place, but 19 percent (15 of 81) said that they had not. Patients had been able to say goodbye to their loved ones, claimed 49 percent (40 of 81) of carers. However, the duration of the care received from the HaH service was significantly affected by place of death (comparison of independent samples using the Kruskal-Wallis test;  $p < .05$ ). Those who died at home had, on average, received care for 2.6 months, as compared with 4.7 months for those who died in hospital, and 16 months for those who died in hospice. There was a significant relationship between place of death and relationship to carer: all child patients died at home ( $n = 6$ , 100 percent); and 71 percent of carers' parents died at home (analysis done using crosstabs with a chi-squared statistic;  $p < .05$ ).

With regard to bereavement support, 72 percent of bereaved carers (57 of 79) had contact with an HaH team member after the patient's death, and 11 percent (9 of 81) attended a bereavement support evening. A total of 10 carers used

bereavement support and the counselling service, and their responses were generally positive. However, 28 percent of the bereaved carers (22 of 79) were unaware of the existence of the bereavement support program.

In relation to education, 53 percent (39 of 74) said that they would like to undertake a program that would help them to optimize their caring skills. They identified four subjects that such a program should include: understanding the illness process; giving practical support; accessing communication and support; and caring for others and maintaining their own well-being. However, some added that to attend such a program they would require additional support, as the patients they were caring for would need assistance in their absence.

### Interview Findings

Findings are reported under four themes: professional care, information and communication, symptom management, and access to the HaH service and choice of care. Table 2 summarizes the interviewed carers' profiles.

#### Professional care

When the nurse or the care assistant was the primary professional involved, interviewees expressed satisfaction with the input. All but two highlighted the staff's exceptional and professional interpersonal skills and the sensitivity shown to the carer.

*"[The care assistants] gave such great support to [the patient] and to me, and it's based on caring and listening."* (Carer 5)

Carers reported that the staff provided support to the patient, the carer, and other family members. They appreciated the range of support offered, which included counselling, advice, and practical help. It was clear that assessments had been undertaken to ensure that support levels matched individual needs. Carers valued the informal and friendly approach adopted by some professionals; they also appreciated the more formal and authoritative approach adopted by others when it was appropriate to the situation. Designating a key professional for the patient was considered beneficial and reflective of best practice.

Carers stressed that it was important for them to be made to feel that they were equal partners in care delivery. They valued the ability to make decisions without being undermined by health professionals, highlighting the importance of being listened to by a nonjudgemental person. Carers appreciated that team members and additional services were accessible, if required.

### Information and communication

Carers reported that they had been provided with a range of information during the first team-patient-carer meetings. Although much of that information had been difficult to comprehend initially, team members readily repeated it as questions arose. The HaH service promoted an ethos of service-user participation in decision making, ensuring that carers had the information they needed to make the right decisions for their loved ones. Most carers were also satisfied with the way in which information was communicated. One carer made this representative comment:

*"I appreciated the nurse's clearheadedness. I was all emotional and very distressed, but she was just calm and clear."* (Carer 5)

One carer, however, did not benefit from the information, because she had severe literacy problems. Another felt ill informed about the availability of additional supports, and consequently she believed that her decision to have the patient admitted to hospice had been a mistake.

While overall there were few criticisms related to information and communication, some carers were unaware of the existence of services, and the longer these carers were involved with the HaH team, the more likely it was that team members would assume that the carers knew more about services than they actually did.

#### Symptom management

Carers voiced their fear of being unable to relieve patients' pain and manage their symptoms. Many elaborated on the complexity of patients' needs and the range of interventions required to ensure that their distress was minimized and their pain controlled.

*"I had to learn all about the medicines which she had to have...They made out a chart for me, the numbers I had to give for the days...and that was a nightmare to me at the beginning."* (Carer 4)

In all cases, there were reports of how well staff dealt with sensitive and demanding situations, from their substantial involvement in daily clinical care to their weekly monitoring calls.

*"They were in every time you called and said 'He is in pain, and we can't get on top of the pain.' And it was, 'Don't worry...we have the means, we have the facilities'...and they were at the door within 20 minutes, and the pain was under control then in no time."* (Carer 13)

#### Access to the HaH service and choice of care

The majority of carers (14 of 15) felt that the patient's referral to the service had come at the

appropriate time. Only one thought that it had come too early. Carers felt supported in undertaking their role, and most were satisfied that the patient had remained at home in conditions that maximized his or her well-being. Home was the preferred place of care, although five carers said that they had never discussed this preference with the patient either because the topic was too sensitive, or because the patient's preference was already well known.

Most carers (13 of 15) cited instances in which psychosocial support was provided and said that this had been of significant help to them in continuing with their caregiving role. Examples of this support included: addressing worries, offering pastoral care, giving general support, bolstering confidence, and assisting with practical tasks.

*"[The staff member] had come out to us and did a tape [recording] with [the patient]. She taped one for me and one for the kids. And she helped [the patient] to do letters...she copied them all, and she had pictures for everyone...We would only get them when he died. They were, and still are, so important to us."* (Carer 9)

Some carers felt that in their bereavement there was little the team could do to help them. Two carers reported having follow-up contact with the team after the patient's death, but after this, the contact ended.

*"I felt [the team] listened to everything...I found them very helpful...but I didn't really have contact afterwards."* (Carer 11)

In summary, carers agreed that the service had made an important and positive contribution to their experience as informal carers. Most indicated that caring for their loved one was a role they had accepted willingly out of a desire to ensure that the patient's preference to die at home was fulfilled. However, caring also compromised carers' physical and psychological well-being. They worried about how they might cope with the stress of trying to help the patient deal with pain, given that they lacked the confidence and expertise to manage medications and symptoms effectively. Some were exhausted due to the multiple demands placed upon them — providing nighttime patient care, looking after other family members, and/or dealing with financial problems.

## DISCUSSION

### Meeting Carers' Expectations and Needs

The HaH service exceeded carers' expectations. These were: to receive the practical advice and assistance required to keep the patient at home, to be assured of symptom control, to have good

communication with the HaH team, and to be given crisis and bereavement support. These expectations have been reported in the literature (5, 7, 12).

Respondents were satisfied with the multidisciplinary service and found the input of different types of professionals to be useful. They highly valued access to nighttime care and 24-hour care. However, they still required additional, ongoing support — including practical nursing assistance — as reflected in previous studies (5, 8, 10). The HaH service helped make it possible for most patients to be cared for at home, as McLaughlin, Sullivan, and Hasson concurred (7). However, carers' need for psychoeducational support, information, and practical skills training remains to be addressed (3, 12). Mastel-Smith and Stanley-Hermanns (19) examined the greatest learning needs of caregivers and recommended a model that is cognizant of carers' learning preferences and congruent with their situation.

Carers reported that the team provided very good symptom management, and this reflected the findings of Sekelja, Butow, and Tatersall (9). In a crisis, they found the HaH service to be very useful; this represents an improvement on the findings of Exley and Tyrer (6), who reported that carers were concerned about accessing out-of-hours or crisis services. Most carers judged the overall quality of patient care to be good to very good; this aligns with the findings of McLaughlin, Sullivan, and Hasson (7).

Effective communication improves service-user care (20). Carers were mostly very positive about the quality of communication, which is paramount in palliative care services (4, 11). However, carers also reported their need for ongoing information and advice during the care period (4, 7, 10). Of particular concern is how information is conveyed to people with literacy problems; in light of this, there is perhaps a need for information to be made available in different formats and at different points in the care trajectory.

The need for psychosocial support is great in palliative care, but effective, evidence-based approaches to supporting carers are still in their infancy (1, 21). The HaH service supported carers in fulfilling their responsibilities and in coping with their loss and their grief. New practice guidelines could prove useful in further developing this service (21).

### Place of Death and Bereavement Support

The bereaved carers indicated that the majority of patients who received care from the HaH service died at home. Other research supports this finding. Sekelja, Butow, and Tatersall (9) reported

that 51 percent of care recipients died at home; Lucas and colleagues (8) found that 87 percent of patients died at home. Murray (22) stressed that the comprehensive palliative care service in the midwest of Ireland stood out nationally as a good example and helped more people to be cared for at home. Most of the carers in our study reported that their loved ones had died where they had wanted to die; this reflected earlier findings (7, 8). Referral to the HaH service would seem to facilitate death at home as opposed to death in hospice or hospital. The combined factors of timely referral and shorter duration of care for the terminally ill may emphasize that the service is targeted well.

Some specific aspects of communication require further consideration. Importantly, carers reported that discussions about preferred place of death, disclosure of diagnosis, and advance care planning frequently did not occur; this has also been reported in earlier studies (8, 9, 23). Ways of dealing with such sensitive topics have been examined elsewhere (24), as has the onus on professionals to initiate the discussion (11, 13).

Jansma, Schure, and Meyboom de Jong (4) highlighted carers' need for bereavement support. Our finding that carers had only a limited need for bereavement support was interesting; we attribute this to carers' having extensive support from family and friends, which other researchers have reported as well (25, 26). However, the reasons that carers did not access bereavement services in larger numbers may also include carer uncertainty and lack of information. It is difficult to ascertain whether carers did not make use of bereavement counselling because they were unaware of its existence or because they thought it was unnecessary. Of those who used bereavement support services, 70 percent found the experience quite useful, a finding supported by a previous study (15). Hegarty and colleagues (27) recommended that information be made available to, or discussed with the family both before and after the death of the patient, and that the wider community be informed about available bereavement services. Milberg and colleagues (28) found bereavement follow-up to be valuable as it creates an opportunity for health professionals to offer support to bereaved family members and to draw their relationship with the family to a positive conclusion.

But bereavement support may not be appropriate in every case — in fact, some studies have indicated that it may be harmful if not properly targeted (29, 30). A synthesis of bereavement services literature (25) showed that a only minority of individuals sought formal bereavement support because a majority preferred the support of their

own social networks; and an Irish study reported that family and friends were the most important source of support (26).

## LIMITATIONS

Our main challenge was to maximize the number of participants in our study. Potential reasons for the study's small sample size are the sensitive and emotional nature of its subject and time demands on current carers (10). Due to the sample size, the generalizability of the interview findings is limited.

## CONCLUSION

This study found that the HaH service was successful in supporting carers looking after their loved ones at home and in alleviating the impact of illness and loss. Many aspects of the service met carers' needs and were rated highly by the carers, who judged the overall quality of care delivered by the service to be very good. In accord with best international practice, the service's user-centred approach offered carers the opportunity to become involved in improving the quality of the HaH service. This study highlighted recurring issues in the literature related to the important role that informal carers play in supporting terminally ill patients at home (12, 17, 21). It also focused on specific issues encountered by the HaH team in addressing the needs and support requirements of these informal carers. This study contributes to the evolving body of research on palliative care as perceived by the carer, and it identifies some of the deficits within the existing literature.

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