

Data Supplement – Detailed Search Strategies

1. ELECTRONIC SEARCH STRATEGIES

Medline (1946 to August Week 3 2013)

1. home.mp. or Home Nursing/ or Home Care Services/
2. Palliative Care/ or palliat*.mp.
3. Terminal Care/ or terminal*.mp.
4. hospice\$.mp. or Hospices/
5. end of life.mp.
6. Terminally Ill.mp. or Terminally Ill/
7. Qualitative Research/ or qualitative*.mp.
8. Focus Groups/ or focus group*.mp.
9. Interview/ or interview*.mp.
10. Experienc*.mp.
11. view*.mp.
12. opinion*.mp.
13. Attitude/
14. Perspectiv*.mp.
15. 2 OR 3 OR 4 OR 5 OR 6 OR 7
16. 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14
17. 1 AND 15 AND 16

Psycinfo (1806 to August Week 4 2013)

1. home.mp.
2. Home Care/
3. Palliative Care/ or palliat*.mp.
4. Terminally Ill Patients/ or Terminal Cancer/ or terminal*.mp.
5. hospice\$.mp. or Hospice/
6. end-of-life.mp.
7. end of life.mp.
8. focus group*.mp.
9. interview*.mp.
10. Experienc*.mp.
11. view*.mp.
12. Attitudes/ or opinion*.mp.
13. Qualitative Research/ or Qualitative*.mp.
14. Life Experiences/ or Perspectiv*.mp.
15. 1 OR 2
16. 3 OR 4 OR 5 OR 6 OR 7
17. 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14
18. 12 AND 13 AND 16

BNI (from 1993 to 2013-07-02)

home AND (terminal\$ OR Palliat\$ OR (end of life) OR end-of-life OR hospice\$) AND (qualitative OR experience OR view OR perspectiv OR opinion OR interview OR focus group

Embase (1974 to 2013 Week 35)

1. home.mp. or home/ or home care/
2. palliative therapy/ or palliat*.mp.
3. terminal care/ or terminal*.mp.
4. hospice\$.mp. or hospice care/ or hospice/ or hospice nursing/
5. end of life.mp.
6. end-of-life.mp.
7. focus group*.mp.
8. interview*.mp. or interview/
9. experience/ or Experienc*.mp.
10. view*.mp.
11. attitude/ or opinion*.mp.
12. Qualitative*.mp. or qualitative research/
13. Perspectiv*.mp. or perception/
14. 2 OR 3 OR 4 OR 5 OR 6
15. 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13
16. 1 AND 14 AND 15

CINAHL (retrieved on the 3rd Sept 2013)

- S16. S1 AND S14 AND S15
- S15. S2 OR S3 OR S4 OR S5 OR S6
- S14. S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13
- S13. (MH "Qualitative Studies") OR "qualitative\$"
- S12. "perspectiv\$"
- S11. "opinion\$"
- S10. "view\$"
- S9. "experienc\$"
- S8. (MH "Interviews") OR "interview\$"
- S7. (MH "Focus Groups") OR "focus group\$"
- S6. (MH "Terminally Ill Patients") OR (MH "Terminal Care") OR "terminal\$"
- S5. (MH "Hospices") OR (MH "Hospice Care") OR "hospice\$"
- S4. "end-of-life"
- S3. "end of life"
- S2. (MH "Palliative Care") OR (MH "Hospice and Palliative Nursing") OR "palliat\$" OR (MH "Hospice Care")
- S1. (MH "Home Health Care") OR "home"

2. NON-ELECTRONIC SEARCH STRATEGIES

a) Reference checking from key primary studies, systematic reviews, the studies included in the Cochrane review (to identify qualitative studies associated or conducted alongside the evaluative studies) and the studies included in this review.

b) Citation search of the included studies using the 'Cited by' option on Web of Science, Google Scholar and Scopus, and the 'Related articles' option on PubMed and Web of Science

c) Hand-searching: all issues of the Journal of Palliative Care to ascertain the completeness of the search strategy; of the Palliative Medicine from 1987 to 1993; International Journal of Palliative Nursing (1995 and 1966) and Journal of Palliative Medicine (1998 and 1999) because these issues are not indexed in the databases (18).

d) Contacts with experts and identification of grey literature in relevant text books, conference abstracts and dissertations

Data Supplement – Reciprocal Translation Table

Study	Overall meaning	Components	Experiences	Supporting quote
<p>1. Sweden, 2007 (2 papers, one describing patients results, other with carers)</p> <p>Face-to-face interviews Phenomenological-hermeneutic interpretation</p> <p>4 chronic heart failure (CHF NYHA III/IV) patients 3 current carers</p> <p>Dedicated MDT; hands-on tailored care, 24h access to nurses, level of training not given</p>	<p>Patients: struggling with uncertainty of disease progression, symptoms (weight, pain, breathlessness, fatigue) and loneliness; PAHC provides care that facilitates life at home → team is an adjustable and trustable 'safety belt'</p> <p>Carers: struggle with being always on call to manage uncertainty (ease the downs and support the ups) and try to maintain everyday life normal - getting help from team provides security by sharing responsibility and trusting their ability to help</p>	<p>Shared-decision making (patients problems taken seriously, they can influence treatment); tailored-made care (carers manage to take care at home)</p>	<p>Getting help to maintain everyday life at home Security</p>	<p>'He (the doctor) is not up on his high horse, he chats with you like an ordinary person' (patient) 'He gets such good care and we are really happy. I also think the feeling of security makes us feel more free so we//can go places we haven't been able to visit for years' (carer)</p>
		<p>Team available 24/7, easy to contact with quick response</p>	<p>Patients feel welcomed by the team ; alternative to calling an ambulance</p>	<p>'I should say it's the best thing I have had, yes absolutely, absolutely the best // to have someone to see every day if you phone, they answer right away'; (patient) 'This care is incredible//I don't even know if he'd still be alive, I don't think he would be if he would have had to be going in and out of hospital because he didn't want to go... however bad a time he was having, you know it went too far, he was retaining too much water and he felt so bad with it.' (Carer)</p>
		<p>Competence in alleviating suffering</p>	<p>Patients trust in ability of team to relieve suffering; SECURITY Patients are technically and pharmacologically well adapted, enabling everyday life with better health; Carers trust in team ability to care for medical and technical devices</p>	<p>'I think they're so kind and they do what they can to help. . . nothing is too hard and they are very competent in what they do' 'I don't understand some people, they have these problems but they just don't seem to want to . . . I think they think it is hard if they have to take Furix. You have to run to the bathroom so often and you have to accept that. Like the doctor said either you're in pain or you get help''</p>
		<p>Home visits</p>	<p>Carers relieved from responsibility and feeling to be taken care of</p>	<p>'When they (the team) are here it's such a relief, I don't feel like crying all the time, at least that's how I feel'; 'Imagine, if I'd been in bed I'd also get taken care of. Often I think, if I'm feeling a bit down, that if they're here anyway can't they check my blood pressure.'</p>
<p>2. Sweden, 2007</p> <p>Longitudinal face-to-face interviews analysed with phenomenological-hermeneutic approach</p> <p>1 CHF patient (NYHA IV) and his carer (wife)</p> <p>PAHC: dedicated MDT; hands-on tailored care, 24h access to nurses level of training not given</p>	<p>Living ups and downs, aware of failing heart (patient), always available to support and provide security at home (carer). Unpredictable illness is integrated in everyday life with the support of the PAHC team, by providing a 'safety belt' that adapts to needs of the family, allowing to find meaning in togetherness (maintain relationships and family life). Home care acceptable to patient whilst not living alone and not being bedbound (physical burden on wife).</p>	<p>Competence to help when disease worsens (associated with 24/7 contact and quick response)</p>	<p>Ability to recognise worsening of disease and trust that team will be able to help allows for managing the situation at home better</p>	<p>'Pt: It's difficult to lie there - it's as if someone's got me around the neck and is holding me so that I can't lie back - as if someone's got their hands round my throat and is holding on, not letting go. Interview: Does it scare you when you feel like that? Pt: I don't know really; I'm so used to it now - if I hadn't had home care visits then it would have been bad, but now I know that if I phone they come in 5-10min, half an hour - it depends on where they are, and then I get help.'</p>
		<p>Being informed about disease and its monitoring, being provided with needed technical devices and medical treatment and information/teaching on how to manage these</p>	<p>Treatment causes suffering but if patient knows how to assess disease he may feel mastery of situation with increased chances for influencing decisions; sharing responsibility to monitor treatment is a burden for carer but it facilitates life at home and outside</p>	<p>'I've got a little cooling bag that I have the injection in... Those are the sort of things you have to remember to take with you; it's easy now - we've had it so long, so now you know what you need to take with you so that things will be okay.'</p>
		<p>Home visits with practical help</p>	<p>Carer feels consoled when PAHC takes care of patient, she feels the need of having some time to be listened by team</p>	<p>"When he is fairly all right I don't bother so much; we talk about things in general because I want him to have... as it were, to have that part... I can't really phone either if there is something special without him hearing, and I don't really want to either. It certainly happens that there have been times when I've thought... I'd like to talk to them without him hearing."</p>

Data Supplement – Reciprocal Translation Table

<p>3. UK, 2013</p> <p>Focus groups and telephone interviews analysed with thematic analysis</p> <p>75 bereaved carers (70 caring for cancer patients)</p> <p>Hospice at home team (training not specified, author confirmed it is intermediate / specialist)</p>	<p>Carers felt greatly responsible for ensuring appropriate care to patient and carrying out many aspects of caring themselves; reluctant in discussing their own care needs despite caregiving had great impact on many aspects of their lives.</p>	24/7 possible contact	Knowing it was possible was reassuring (even if not used)	
		Named support contact	Facilitated coordination and continuity of care, access to advice, information and support services	
		Being informed about disease progression, symptom control, OOH help, anticipatory guidance (including closeness to death), learn to manage devices and medications, financial support	Avoid unwanted hospitalisations, maintain normality and manageability of situation, deal with uncertainty and anticipate events	
		Being listened to and included in decision-making	Maintain sense of contribution, acknowledgement of role as carer but also as recipient of care	
		Home visits with practical care ('hands-on' care), including in time of death	Mainly when patient deteriorated and mobility became a problem, relief of burden without being excluded; keep situation controlled after death	
		Respite (mainly overnight)	Allowed some sleep during late stages, important to manage situation when patient needed intense care; preferably by nurse if managing devices was needed; it might allow carer to maintain professional life or do house chores	
<p>4. UK 2005</p> <p>Face-to-face interview, cross-sectional, framework approach</p> <p>12 bereaved carers of cancer patients</p> <p>H@H team: one leading nurse with advanced training (not clear if there was MDT existed or nurses only), technical devices (hospital bed, syringe drivers), no 24h care (OOH and weekends by voluntary nurses)</p>	<p>Choice of caring at home to grant last wish and avoid 'cold and impersonal' hospital environment despite some uncertainty regarding this preference (i.e. it could be difficult to manage at home). H@H service valued due to quality of care, support and carer respite, facilitating death at home, personal relationships with nurses who were highly committed; Service shortcomings: no OOH provision, delay in supplying and removing specialist equipment</p>	Home visits with hands-on care, follow-up adapted to needs	Decreased burden by providing respite – carers would have opportunity to sleep or leave the house; being taken care of, accompanied (presence)	'She rang up it would be about half-past five and asked me if it would be possible for her to come in earlier. She said "I have time on my hands" she said "and I don't want to intrude but would it be possible for me to come in earlier?" I said "Yes you can come in when you like". So she came in a good 2 hours before she should have done. As he deteriorated during the night she stopped, although she should have finished her shift and gone home, she was still here at 10 the next morning. She really was a godsend...' (carer 8)
		Contact available only during routine hours on weekdays	Abandonment and vulnerability when unable to access OOH in emergencies; difficulties in managing syringe driver despite training received	'...until about half-past 10 he was in real pain and they promised us when he came home that it wouldn't hurt and we were getting quite cross and he was getting cross wasn't he? Because he hated pain, he was a bit of a wimp anyway wasn't he?' (carer 3); 'There was just one that was a bit off hand with me because I said about doing the syringe at night. I said "Can't the Marie Curie...?" "No. She is not allowed to..." She said "You can fill it and you can give it to him..." She was really nasty with me so I did complain about that and got an apology. I said well "look I am not a nurse; I have never used a syringe in my life' (carer 9)
		Competence – delays with supplying and removing specialist equipment	Delays in going home from hospital (frustration); distress	'Getting the equipment together was a process that could have been done quicker and I would have had her home there and then if they had delivered the bed and the service was available. I would have had her home sooner but I didn't know it was going to be 9 days' (carer 7); '...I think the worst thing was it took a while for the Red Cross to come and fetch everything back. That was the worst. I couldn't come in here until they'd been because I couldn't stand looking at an empty bed. That was the worst I think' (carer 10)

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<p>5. Denmark, 2006 1 Face-to-face interview 2-4w after beginning of home PC, analysis by template framework</p> <p>6 cancer patients 5 current carers</p> <p>SPECIALIST: palliative home care MDT hospital-based, with doctors and nurses with advanced training, visits during day and evening, telephone advice at night; consultant role - care provided by GP and DN</p>	<p>Patients and carers value same aspects of palliative care. Most important issue was to receive care from specialist knowledgeable palliative care that allowed for relief of symptoms; second most important issue was sense of security, provided by being able to contact specialists who knew them 24/7 and knowing patient could be admitted in hospital if needed; cooperation between home care team and GP/DN worked well; expectation that team should offer respite to carers</p>	<p>Competent care</p>	<p>Specialised knowledge allowed for decrease symptom severity, flexibility in treatment, feeling listened to, wishes taken into account → SECURITY</p>	
		<p>Availability 24/7 and attachment to team, no visits overnight, patients could be admitted to hospital if needed</p>	<p>Security of having 24/7 contact and option for patient to be admitted</p>	<p>'Now I feel safe if something happens. I know I can turn to you.' (Patient 7) 'I've found security by coming here [inpatient ward], which was what I needed. And there are also people here who are very nice and take their time to talk about everything. So this is very good. But the conversation and the security, well, you could have the conversation at home if someone came by sort of regularly. But the security, well, that might just slip a bit. Because the staff couldn't be there everyday.' (Patient 3)</p>
		<p>Hands-on care provided by DN</p>	<p>Uncertainty regarding ability to deal with syringe driver (one patient only)</p>	<p>I shouldn't have been involved at all. I feel, well, I would have felt more secure if I hadn't heard some of the conversations; for example, "Is this supposed to be here?", "Are you sure this is right?", "Could you just come, I wrote something wrong on the pump". "Don't start doubting about anything, because what's in it is right". Why should I be involved in that? I don't understand it. If it had been a situation where experience showed that something could happen, which I could manage myself, then I could have been given information about what to do. (Patient 4)</p>
		<p>Knowing family and decision-making</p>	<p>Home conference held one week after admission to team was acceptable, too many people</p>	
<p>6. UK, 2001 1 face-to-face interview, grounded theory</p> <p>14 bereaved carers 4 current carers (16 caring for cancer patients)</p> <p>Home Palliative Care: clinical nurse specialist (don't know about team composition), 24h access to advice and support</p>	<p>Carers experience ambivalence in how they feel about support and what they do to support patients – explored in 5 concepts identified → design of carers support interventions should be focused on improving caregivers role (work with lack of identification, provide safe and legitimate time and space, be time limited and be respectful of coping mechanisms), offered on different formats and short</p>	<p>Support to caregivers</p>	<p>Hampered by lack of identification of caregivers as such; caregiving at cost of missing other opportunities and postponing needs</p>	<p>"It's like limbo looking after someone, and this is your life and you have to get on with your life, but all the time it's in the back of your mind that's it's like you're waiting to really start your life, but that sounds really awful.... but that's not what I mean, but you are sort of waiting to start living."</p>
		<p>Home visits and competent care</p>	<p>Relief of responsibility by listening, providing advice and taking care of patient</p>	<p>"When I can't cope with his tears or his nightmares they can just come in and counsel him and look after him, and that's where they succeed, not when I have my own fears and nightmares. I think there just has to be a distinct separate team because otherwise there are conflicts."</p>
		<p>Respite service</p>	<p>May not be appropriate because carers may not want to leave patient, ambivalence because they feel they need some time away</p>	<p>"People say go out take a break and I say no, I don't want to go anywhere... I'm not interested.... I feel my duties are here: my duty is to work for my husband. And I want to do as much as I can." "I think the carer should have a little freedom sometimes: going out at least once in a week or once in a month. I could go for a nice long journey all on my own, just to sort of clear my mind. You know, carers have got it in their mind: I have to go back home, I must hurry up."</p>

Data Supplement – Reciprocal Translation Table

<p>7. UK, 2012 (2 papers, one about perceived needs and challenges of caregiving, other about coping and support)</p> <p>1 Face-to-face interview, thematic analysis</p> <p>20 current carers of cancer patients</p> <p>SPECIALIST: Hospital-based community palliative care team: gives specialist support</p>	<p>Caregivers need to be informed about available support services, disease progression, symptoms management, death; they need time from professionals to learn about these issues. Lack of information may cause uncertainty, distress, difficulties in managing care at home and helplessness. Caregivers support intervention should be educational, include information about available realistic services and reinforce use of social networks and individualised assessment for respite need. They should also enable coping strategies, such as finding benefit in caregiving, acknowledging importance of individual to fulfil the role and identify sources of informal support</p>	Being informed about disease progression, symptom management, death and its practicalities, support services	Care at home more manageable, more security in what to do, better able to deal with uncertainty (watching patient deterioration is difficult an distress increases when there are treatment side effects or uncontrolled symptoms)	'I am more concerned about his symptoms the illness presents. Like for 3 weeks now he has been unable to talk...so we can't have normal conversation like husband and wife...'; 'Tips and advice on how to deal with common problems and symptoms would all be useful I am sure. People are thrown into these situations they do not ask for it...'; '...how to make him more comfortable and help him with the pain...I can't help with the physical stuff'; 'If he dies I know the procedure...but I just don't know how to get it there and how it works when someone dies in this country'; 'I asked the nurses and they tell you certain amount but they don't say how much time he's got...nobody can tell you how long somebody has got but they can give you some sort of idea...nobody told me that he would die that quickly'; 'Basically what is his condition now if he is deteriorating what are the signs what I need to look for what could be the problems what would happen?'; 'First time they were giving him injection...we don't know whether it is a good idea or not. We just carry on'; 'The radiotherapy, they stopped the treatment after 2 to 3 sessions. What is going on? We have no idea'
		Being listened to and acknowledged	Opportunity for emotional relief, it decreases loneliness	"At least I will have some time to share my views with the nurse and know they have time for me..."; "I think the interview is good because it gives the caregiver the chance to say their views and how they feel"; "I just felt quite alone and if there was someone that you could just talk to...if there was someone that you felt or knew that you could phone up...?"
		Day respite	Have some personal time (decreases isolation) but unable to live patient for long	"If someone came for some time to look after the patient and give the caregiver a rest, if they could stay there for a day and the caregiver can go out, go shopping, just to get out then, that could give them a real break..."; "Is so different, I feel I am isolated, I feel I don't have a life."; "If I had a day off I will have a day off but I am still worried about her and I want to get home. So I can't go for long because I can't leave her too long..."
		Night respite	Decrease sleep deprivation	"I don't get proper sleep because he wakes up during the night to get to the toilet."; "It's like having a small child. You are aware what is going on even if you are unconscious. And obviously do not sleep very well."
		Home visits by nurses	Relief	'Our palliative nurse tries to do her best. Her encouragement is fantastic. She is such a nice lady to us so we are happy. Whenever she comes we are happy.' (Ca 15); '... but having someone wanting to help him feel better in himself, talk with him and spend some time with him has made a huge difference.' (Ca 10)
		Financial support	Scarce, increased anxiety	"I get caregivers allowance, I get £8 per week which is very little and my husband gets assistance allowance which is £60 per week and that is something, sometimes we manage but we do not have a great income"

Data Supplement – Reciprocal Translation Table

<p>8. US, 2009</p> <p>Face-to-face interview analysed by thematic analysis¹³ bereaved caregivers (majority of a larger groups with dementia 12/22)</p> <p>INTERMEDIATE: Palliative care access through care at home - home based geriatric PC program: 24h phone access to team, hands-on</p>	<p>Team provided EoLC at home for those unable to come to clinic and those preferring care at home. Accessible and expert practitioners helped ease the transition between acute hospital care and home-based EoLC. Improvements needed: earlier referral, less transitions home-hospital before referral, continuation of care when patient admitted to long-term care</p>	<p>Competence</p> <p>Patients assisted to stay at home by having assessment of home needs; relief and decreased uncertainty by trusting expertise of professionals Communication: team was a consistent place to turn to despite multiple sites of healthcare → team able give anticipatory guidance and help make transitions toward EoLC more smoothly → earlier referral could have avoided multiple transitions</p>	<p>‘In fact, had it not been for programs like [PATCH], it would have been impossible. Because when you get into situations where someone’s in extreme pain, and they’re unable to go to visit the doctor, there’s nothing you can do. You certainly don’t want to watch them suffer.’ (Caregiver ID #7); ‘The only thing is that what we really needed was an expert geriatrician who knows a lot about the medicines.’ (Caregiver ID #18); ‘In talking with [the PATCH physician], we found out that actually there was a two-pronged care; there was hospice and then palliative care. Initially my mother did not require hospice, so it was palliative care . . . and that worked very well until her health deteriorated further, and then she went into the hospice program.’ (Caregiver ID #7)</p>
		<p>Availability (with competence)</p> <p>Team was an alternative to calling an ambulance – avoid unwanted institutionalisations</p>	
		<p>Home visits</p> <p>Comforted by having a physician at home</p>	<p>‘When [the doctor] came out to the house to see her, I really think that made her feel better, and I know it made me feel better.’ (Caregiver ID #5)</p>
<p>9. Sweden, 2006</p> <p>Case study, stepwise content analysis of caregivers’ (mother) diary</p> <p>One caregiver of a patient with cancer</p> <p>Palliative home care team with specialist nurses (not sure if MDT)</p>	<p>Hope, denial, belief and control are significant concepts in the communication between mother and son. When PC team came in, son was in denial and mother felt relieved by being able to share her concerns and being acknowledged. Team maintained son’s coping mechanism but when treatment was being +harmful than beneficial, team invited family conference to explain situation and introduce EoL talk. Shared decision of stopping treatment was made</p>	<p>Competence in evaluating situation, listening, communicating and doing a timely family conference</p> <p>Acknowledge mother’s concerns about death proximity whilst respecting son’s denial, recognise death proximity (treatment + harmful than beneficial); enable shared decision-making and acceptance of death → feelings shared by family (sorrow, despair), hope may be fostered by sharing realistic motive (e.g. time in family), preparation for dignified death with some possible control over the process (express preferences)</p>	<p>My daughter-in-law still hopes that the new chemotherapy will have some effect and so does my son. But I do not believe in them. I think my son is far too ill; And I he fights I it hurts seeing. He is very, very ill. I wish he had some peace. We are so helpless. (October 1, 2003); I wonder if the picture of my son’s despair will ever go away. He was sitting on his legs in the bathtub, showering his stomies. He looked at his arms: Mammy, there is nothing left. I hugged him and said: No. There is not very much left. No use to train any more. No, no use to train. My son’s head bent down drooped, his chin was shivering, he pursed his lips, he slowly turned his head from one side to the other. Despair! Such a despair you cannot comfort, not even share. It is doubled when I see it. My hugs cannot comfort it, my tears cannot make it less. Dear dear son. This was not meant to be! (October 30, 2003, 3:30 AM)</p>
		<p>Competence in adapting care to family life, respecting spaces at home and involving and acknowledging whole family (especially important for the child to adapt to situation and for the patient and wife to be acknowledged as couple)</p> <p>Adapting medication schedules to allow for family time – team encouraged all family life possible in waiting for death; team available to listen and talk privately to family members</p>	<p>Even if my son could not digest any food he was told that he could sit by the dinner table. His wife cooked his favourite meals and he sat by the table together with the rest of the family. Even if he just took some food into his mouth, smelled it, tasted it, and then put it back on his dinner plate, there still was a family dinner the day before he died; My son and daughter-in-law felt very miserable as the value of spending some time physically close was of great importance for both of them. The nurses observed the dilemma. After some thoughts, they managed to “rebuild” the new madras so both sides of the bed had the same level; The kitchen was a place for talks. As the infusions, given at least twice a day in the beginning and more often as the illness proceeded, took about an hour, there was time for talks. In the kitchen over a cup of coffee, we all had the opportunity to ask questions in private, articulate our fear, be acknowledged and comforted. There were times and opportunities for tears and hugs.</p>

Data Supplement – Reciprocal Translation Table

		<p>Competence in escalating treatment and share the responsibility with caregivers if needed and wanted</p>	<p>Allowed for infusions of blood, liquid nutrition and pain relief to be done at home, routines were established → only possible because nurses would visit at home and trusted families</p>	<p>In a very obvious way the nurses asked for a place in the fridge and cupboard in the kitchen where they could store the medicine. They made themselves at home; When my son's pain was escalating and the analgesic pump was not enough the nurses taught me to and my daughter-in-law to use an injection pen containing additive doses. In complete trust the nurses placed morphine ampoules in the cupboard in the kitchen. Even if the team came on request it could take some 20 minutes before they arrived. And these 20 minutes would have been very long for my son without the possibility for us to reduce pain.</p>
		<p>Home visits</p>	<p>Feeling of presence, helps in adapting care to family life Opportunity for team to introduce and to get to know family – important to respect family 'ways' and give signs of continuity (e.g. medication box provided safety by signalling presence of nurses at home even if not physically there – help available at any time); Very important in time of death and afterwards</p>	<p>The healthcare team supports, gives him intravenous drip and the nurses are there for us!; The nurse asked for a place in the bathroom to put the equipment box, a big black carrier that was locked. It got its own place in the bathroom upstairs, beside my son's bedroom; They helped out shifting the bedclothes, found the most comfortable position for my son, wet his lips, and checked on the analgesic. By then my son was still conscious but had difficulties speaking. One of the nurses stayed by my son [...] The presence of the nurse was a relief to me; The nurses made the examinations that are legally required to declare death. Then they and the family all gathered in the kitchen. There was time to tell about the last hours, there were opportunities to weep, to share hugs. [...] The nurses took charge of the practicalities. They arranged for the last transportation. And they stayed as long as the family members wanted them to.</p>
		<p>Coordination of care between settings and for different needs</p>	<p>Contacting pharmacy, arranging transport and hospital appointments – team worked like a shield, surrounding family in their contacts with different organisations; Physician facilitated access to expert care</p>	<p>The nurses had prepared the pharmacy prior to my visit there. It was arranged for me to pick up all the things at the back entrance of the pharmacy, where I could bring my car. And for sure it was needed. The big boxes containing nutrition and infusion for a week were heavy. I did not have to explain anything. The nurses had prepared it all; A bed was available at the oncology clinic, where my son could rest after the nephrostomy was in place. Dr V visited my son at the ward to see that he was all right. After a couple of hours he could leave the ward by ambulance...</p>
<p>10. Australia, 2004 Face-to-face interview analyse by thematic analysis Current carers (47/54) of cancer patients participating in an RCT of psycho-education</p>	<p>Caregivers confront a variety of challenges that may be buffered by the ability to identify positive aspects from caregiving → caregiving is not inherently negative and interventions should be targeted to caregivers that cannot identify any positive aspects. Key home PC aspects that appear to decrease sequelae: continuity, role definition, respite information, access</p>	<p>Lack of time to talk to caregiver, no acknowledgement of role and needs</p>	<p>Uncertainty, distress; caregivers only disclosed challenges when talked face-to-face and privately</p>	<p>'What's palliative care going to do? They stand at the door and ask my mother-in-law questions for five minutes, ask when the GP's next visiting and then they go'; 'When the palliative care nurses come, I feel as though they come to see my husband and I'm in the background. I don't want to interrupt and take their time away from him'; 'I've had three visits from the palliative care service and three different nurses have come, how can they know what I really need'; 'I don't know the difference between the volunteer and the nurses and how can nurses expect to understand my circumstances in a half-hour visit'; 'The doctors and nurses don't seem to communicate properly to one another. I'm not sure who's in control of my wife's care'</p>

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<p>intervention for carers</p> <p>Metropolitan community PC (MDT, 24/7, training not specified)</p>	<p>to resources, symptom management education, time to talk personally</p>	<p>No access to respite, poor family support</p>	<p>Increased burden, no ability to do other chores and care for other family members (e.g. children) or themselves</p>	<p>'I've got a 3-year old son, I'm 5 months pregnant, my mother's dying, my father's a pig of a man. My husband won't let me put our son into crèche one day a week. My husband rang me the other day on the way to work to say that his car had broken down and he wasn't sure what to do'; The only time I get to myself is when I go to bed'; 'I haven't had time to go to doctors for myself'; 'I don't feel as though I can leave the home'; 'In three weeks I've had two and a half hours out of this flat. I've never felt so trapped in my life'; 'I have no time to think about myself'; 'There is free time but it only comes in snippets, e.g. 30 mins here, 30 mins there,; but not enough time to do anything of substance'</p>
<p>11. US, 1989-1993</p> <p>3 longitudinal face-to-face interviews analysed by constant comparison (last interview 3m after death)</p> <p>14 current caregivers of 10 different families. All patients with cancer</p> <p>Home care of oncology hospice program: hospice team (probably advanced training nurses) with home care, inpatient unit and respite unit</p>	<p>Sources of stress: Patients symptoms (mental changes and physical deterioration), interactions with others (including personal care aides), concerns for self. These were dealt with:</p> <p>Coping strategies: with overall experience of caregiving, with uncertainty and social support. Related to Lazarus theory: change environment – being relieved from caregiving - and change meaning. Social support included: Support from hospice nurses: 24h availability and accessibility, effective communication skills, accepting and non-judgmental attitudes, competence as practitioners</p>	<p>Accessible and available services: 24/7 easy access to known professionals, with low threshold for contact and prompt response with timely helpful suggestions or changes of treatment, home visit available if needed</p>	<p>Nurses encourage contact for any issue by phone and a decision to visit was either immediate (by talking to nurse) or within first 20 min. Nurses called back for follow-up → crucial for caregivers to deal with arising problems</p>	<p>"And every time I called the hospice, I always got an answer. They took my phone number, and their call came a few minutes later. They answered, you know? And if I needed them, if something was wrong with my husband, I used to call them, and they were right down." (75 yo wife); "As soon as you call, you've got somebody. Within 20min we had an answer when I called about the pain med. I said that my aunt was having pain, and the Percodan wasn't getting it. the nurse said, "OK. That's OK because we can do something about that." I really think it's a plus if there's somebody there all the time, because even if you don't need something, I know that it's there and that makes a big difference. If I hadn't known there was somebody there, I might have panicked. Just knowing that was a real big help. She called all the time asking if we needed this or needed that. I definitely needed that kind of support." (40 yo niece); "now I hesitated to call at 11 o'clock at night, 2 o'clock in the morning, but they keep telling me, "If you're scared, if you're worried, if you've got a problem, if something's not right, call." And I have. The longest I had to wait for somebody to call back was 20min." (64 yo daughter)</p>
		<p>Competence: effective communication skills</p>	<p>Nurses are available to listen and offer reassurance, with accepting and non-judgmental attitude, answer questions honestly, explain current changes and give anticipatory guidance, either in home visits or telephone contacts. Calm and unhurried attitude, spending the time needed for caregivers to feel comfortable with their responsibilities</p>	<p>"The nurses take time to talk to you, to reassure you. They'll talk to you just as long as you need to have them talk to you, to reassure you, or to advise you. They were relaxed and make you feel... I mean, here you are all nervous and upset, and you're calling up and you feel bad because its the middle of the night and you're disturbing somebody, and they make you feel like it's the middle of the day, and they don't have anything else to do. And they calm you down and make you feel better. You just don't feel so all alone. Then they'll call back and see how things are going. They follow up so that you know they really care." (64 yo daughter); "Emotionally, like when things happen, the nurses let you know what's going on and what to expect, too. That's the thing. Like the one time - this was Christmas Eve - he had bloated up, and she had told me on the phone that he could vomit, and I was so glad she told me because at least this way we knew what was coming, and it didn't throw me." (49 yo wife); "It is dawning on me how critical it is for the nurses to be positive and upbeat and never let on that you're putting them out, or that they are having a bad day, too. They do it so well. They are never in a hurry and they are never upset about anything, and you need that. So it's due to their attitudes and how they interact with us that we are able to hang in there and do as well as we do." (49 yo daughter)</p>

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		Competence as practitioners	Nurses well informed, medically knowledgeable and competent, with professional autonomy and problem-solving skills	"Knowing that they know what they're doing, I have confidence in the way they handle problems. I'm comfortable. You can trust them with having the medical part of it competently too. I can tell from the way they express themselves, the kinds of things that they are saying. They tell you the point of what they're doing." (40 yo niece);
		Access to respite: few uninterrupted hours at home or away provided by family members, hospice volunteers or home health aides; unit could provide 5d/month respite (long-term)	Allowed for creating windows of time (coping mechanism): allowed caregivers to pursue hobbies, maintain contact with friends and accomplish goals Personal care aides: helped to relieve caregiver from responsibility but could become a source of stress when aides were not dependable or when they represented strange presence at home Long-term respite: 4 families used monthly, 2 used for last moments, 4 never used it due to fearing feeling of abandoning patients or because they did not need.	"First hospice suggested I should get somebody during the night. So then the first night they sent an aide and it was 3:00 in the morning and I didn't sleep yet because, you know, there's a stranger in the house." (78 yo wife); a) "I call them "windows of time". You've got an hour here or two hours there, so when one of my daughters is here, or somebody's here. I'll run out and do some running around. I'll grab that time to run. You have to be kind of flexible. You can't be real strict [about your routine]. You have to kind of flow with the punches and jump on the opportunity. Or sometimes he'll sleep part of the time so you can break away without feeling like you're being neglectful." (49 yo wife); "My life isn't as exciting as I'd like. It's kind of a boring life, and it's kind of a grind, but I make up for it. I enjoy myself. I do things like go out for a breakfast. I like doing that. I only do that a couple of times a week. Even if there's nobody to go with, I'll just read the paper, have a few cups of coffee, and relax." (26 yo son); "I usually stay up for a couple of hours after she goes to bed at night. It works out pretty well like that. It gives me some time at night alone. I need that time." (40 yo niece)
12. Sweden,2008 Narrative interviews analysed with interpretive content analysis (hermeneutics) 8 patients with metastatic cancer SPECIALIST - Palliative homecare teams (PHT) - 5d/w hospital-based consultant MDT with 7 nurses + 2 physicians with PC advanced training	Patients find themselves living with intense suffering, due to physical unpredictable deterioration (which causes uncertainty) and the physical (homebound) and existential (components of experiences not sharable with family/professionals) loneliness. Patients need to have some "breathing space" in suffering, i.e. to be relieved from their suffering and regain hope, in order to have the opportunity to prepare. Being at home enabled independence and sense of well-being and it was possible due to secure confidence of having significant others as family caregivers and the PC team at hand, providing whole package of social support at home	Competence in effectively controlling symptoms (mainly pain, insomnia, loss of appetite)	Patients have respite from distress which allows for regaining hope (patients more calm and peaceful), having increased strength to participate in daily life with higher sense of usefulness to others. Inner peace that enhanced QoL. Patients feel more hopeful because they can appreciate life and have a sense of living well. The respite from suffering gives patients the opportunity to prepare (not possible if going through intense suffering). This involved having time to reflect about the selves and let go of life → feeling of safety and courage to revalue life enabled patients to come to an insight and communicate difficult feelings	"During the entire autumn I just didn't seem to notice how time passed. I felt so depressed for some reason or other. And it's only now that I am beginning to feel a little better and I am able to grasp what's happening. I really felt like life was over. Well—every week brought something else. Now I am pleased to note that things are much better. My body seems to be holding together.; "Then I don't think things are so difficult for me at all. It's much more difficult for those who will be left behind, who have to fix everything for me. It will most surely take a year or more for them to get over this."; "To be able to recognize scents, see my own things and smell my own towels and bed linen—the feeling of being at home is positive. I have always felt safe and secure in hospital but then again I have never felt insecure at home. Yes, I must say things are as good as I could possibly expect in this situation. The good life is not always necessarily a healthy life."
		Easy contact with prompt response, care needs quickly fulfilled	PC team crucial for feeling of security at home – patients relieved to entrust physical and psychological deterioration to PC team	"When I feel that I can't hang on I become sad. But then someone has always comes along and says "No, no, we need to do something about this. This won't do." And then I become hopeful again. Hope won't help me to live longer—it's not a condition— but I want to live well and feel good the days that I have left to live."
		Competent communication	Also crucial to provide security, facilitate autonomy and increase potential for	"I can make my own decisions—I am able to decide over things in an entirely different way than in hospital. If I decide I want them to come later than 8

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			experiencing optimal QoL – it involves being listened to, being able to participate in decision-making and feeling that care provided is affirmative	o'clock in the morning—even although we have agreed to that time—I can just phone and change the time to 9 or 10. And if I want to skip my drip like I did before . . . at least one day last week, I just phone them and we agree on this."
<p>13. Sweden, 2012</p> <p>Face-to-face interviews analysed through directed content analysis using secure-base (attachment theory) as exploratory concept</p> <p>12 patients and 14 caregivers (9 cancer, 3 non-cancer)</p> <p>SPECIALIST - 3 Advanced palliative home care (APHC) teams (MDT advanced training, 24h) and 5 primary care-based teams (MDT advanced training)</p>	<p>Perceiving a sense of security during palliative home care was important to all participants because death and dying were constant threats that contributed to vulnerability and loneliness. The team helped patients and families to feel secure by being available and reliable, providing professional symptom management and support to family members at home, welcoming patients and families to contact and preparing for what was to come. Participants trusted themselves and/or team to handle any threats that might appear, i.e. in control (situation is manageable) and at peace (possible to relax) enabling participants to be themselves, living life and maintain hope despite threatening situation. It meant feeling secure enough to maintain everyday life activities (living a changed life but with similar core components) and meeting friends despite the risk of breakthrough symptoms (i.e. focus should be on living instead of death threat)</p>	Available 24/7 easy contact via telephone with prompt and reliable response	Participants have access to competence in relieving patients' symptoms, communicating, nursing, caring and providing aids and staff members acted as agreed. These characteristics, alongside continuity in staff contacts and support for family members enhanced participants trust in team. Important to feel welcomed to contact the team when in need of help.	"I know that I can get help. When something happens, pain or something, it's only a call and then they [palliative staff] come after fifteen or thirty minutes at most. ... It really gives you a feeling of security... I compare that to the year I had to go to the emergency department...This is heaven... It is like being rich... " (35 yo man with generalised malignancy); "I have had anxiety during the nights ... I knew that if I could not manage in the night, I could phone the palliative home care team. ... Even when I was completely stressed out ... I could convince myself "They are there, you know that" ...I have thought many times that I should not phone and disturb them, but they have told me that they are there for me, and not I for them ... This makes me understand that I can contact them without bothering them..." (66 yo woman with generalised malignancy with unknown origin); "When I just sat and said "I do not want to die, I do not want to die", I got such intense death anxiety. Then it was so good to know that I could phone the palliative home care team, they would come here... and my husband could rest a little. That is security, it is peace, inside me. That they are there, if nothing else is to be found, they are there" (66 yo woman with advanced cancer of unknown origin); Interviewer: "Could you describe what it is like to feel secure?" Patient: "Life with the disease does not take over everything.... I know that if something is not working, I only have to make a phone call [to the palliative home care team] to get help. This makes you focus on other things. When I come home I do not think about it [the illness] at all ... I do other things. ... and that is the best praise I can give ... that I do not think about it.'" (35 yo man with generalised malignancy);
		Competent management of suffering (physical, psychological, social or existential)	Important to patients and family caregivers to be comfortable, which in turn enables security.	"Six weeks ago, when I had difficulty breathing, I felt ... the end is approaching... I just lay in bed and thought "I hope death will come soon"... I had lots of thoughts like that over several days. ... But then I got morphine [prescribed by the palliative home care doctor] ...It has taken away these thoughts ... and now I feel calm again, in mind and body, and secure" (62yo woman with gynaecological cancer); "You get angry when you do not manage by yourself. ... It is really depressing when I cannot get out of bed by myself. ... The morphine injection...It has worked very well ... I can do it myself. If I had not had that, I would not be able to put on my trousers and socks by myself ... It has given me a lot of security (62 yo man, prostate Ca);
		Home visits	Relieved of burden of responsibility when caregivers get help from team for tasks that represented too much of a burden (e.g. medication, dressing wounds, assessments of patient) → facilitated perception of team as a secure base	Interviewer: "How important is security when a family member has a severe disease?" Family member: "It is very important. Because sometimes you are very worried ... and then it is good to have someone who can come... and see if I'm doing things right, so we don't wait too long before going in to the hospital, or maybe we could wait a bit longer" (55 yo woman, husband with advanced neurological disease); "... you don't know when it's coming close [husband's death]... And that gives you a feeling of insecurity. And you worry a bit... most unsure if you can cope or not...if something happens...so you lose control of it

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				<p>all. But you know people [staff members] will come. Yes like this morning, when he had such a bad turn [husband had epileptic fits]. It was really relaxed because they [staff members] were here" (65 yo wife, husband with brain tumour).</p>
<p>14. Sweden, 2004, 2011</p> <p>Cross-section survey w/ open-ended questions on powerlessness and helplessness analysed with qualitative and quantitative content analysis</p> <p>233 Next-of-Kin (NoK) or family members (134 bereaved) of cancer patients, defined as the person identified by patient as being the primary carer at home</p> <p>SPECIALIST: APHC (MDT with nurses and doctors with advanced training, 24h telephone support)</p>	<p>Powerlessness and helplessness of caregivers are common and triggered by patients suffering (physically, psychosocial and existential), perception of patient decline (bodily functions and individuality), feelings of insufficiency (caregivers wanted to act in relation to situation and concerned lack of resources and dependence of external resources). Reactions to powerlessness and helplessness included physical and psychological symptoms, loneliness, anger and guilt. Protective aspects: condition stable and patient coping well, trusting relationship with patient and support from extended social network, accessibility to PC expertise providing individual support and information, being listened, doing good for patient, opportunity for distraction, acceptance, meaning and hope and security</p>	<p>Competence in communicating and providing individualised care</p>	<p>Being known by staff, either disease and life history, being visited by the same staff or updated members (continuity) contributed to sense of security. Being informed about disease progression, situation management, support that the team can provide</p>	<p>"I feel a bit insecure when it is not the same staff members coming... I have good contact with the two assigned nurses. It is not the same with the others... The two assigned nurses sit down and talk to me...not only about me being sick ... but about what I have done in my life, what I have been able to do ... it is more personal" (62yo man with prostate cancer).; "I had such a great feeling of security when I left [the doctor's office at the palliative care in-patient ward]]. I thought 'Okay, I am going to die here, then I have to make the best of it. ... That talk helped a lot. ... I understood... 'This is the way it is'" (35 yo man with generalised malignancy).</p>
		<p>Competence in maintaining condition stable and managing symptoms</p>	<p>Good symptom control and retaining everyday function was perceived by caregivers as relief from suffering which enabled comfort and was protective for powerlessness and helplessness</p>	<p>"[I never experienced powerlessness and/or helplessness during the palliative home care period because]. . .he was able to take care of his personal hygiene, although it took a lot of time. . . and the staff members of the palliative care team helped him with painkillers" (73 yo wife, husband with sarcoma).</p>
		<p>Availability 24/7 easy contact</p>	<p>It relieved family members of burdensome responsibility of caregiving, decreased perception of loneliness in that situation and contributed with hope (e.g. in team's skills for symptom management). It also allowed for security (recurring emotional state protecting against powerlessness and helplessness)</p>	<p>"I felt and knew all the time that it was serious. . .[but]. . . my partner and I received all the help we needed from APHC. To me that was a great support [and this eluded me from experiencing powerlessness and helplessness during the palliative home care period]. ..We could phone whenever we wanted and get help. The final period would have been difficult without APHC. (41 yo man, partner with cancer in lung and back); It makes you feel secure knowing that the doctors are available, that a nurse can come soon, and to get help, prescriptions, medication, information and that they can come if needed. I have called many times to doctors, before the referral when my husband has been in need of help, and it has been difficult getting in contact with someone and I have been queuing in the telephone time after time, and then I have felt powerlessness and anger. (63 yo wife, husband with sarcoma, occasionally experienced powerlessness and/or helplessness during the palliative home care period).</p>
		<p>Competence in listening, informing, and acknowledging caregiver</p>	<p>Encounters with staff experienced as respectful, committed, hopeful and kind, unhurried and centred in both patient and family members as individuals. Caregiver acknowledged as a person with important knowledge about patient condition. Information given on how patient is coping and medical aspects (disease progression, treatments and side effects). Being listened (e.g. by staff) was also helpful because it facilitated manageability of their situation (practically and existentially)</p>	<p>"[It was helpful for me with informative] Talks with doctors and nurses at APHC at my pace. The staff had a supportive attitude that gave me a feeling of being one of the team, that was going to make life as comfortable as possible for my husband." (70 yo woman, husband with brain tumor, never experienced powerlessness or helplessness during the palliative home care period); "Throughout the whole period of my husband's illness, I tried to be with him as much as possible. I understood what was happening thanks to APHC. Especially during the last days they were very skilled in preparing us what was going to happen, step by step. I really felt secure and felt their deep human qualities!" (49 yo woman, husband with lymphoma; experienced powerlessness and/or helplessness occasionally during the palliative home care period).</p>

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<p>15. Sweden, 2003, 2004</p> <p>Longitudinal face-to-face interviews analysed with hermeneutic-meaning interpretation with Antonovski Salutogenic Framework of sense of coherence</p> <p>19 current caregivers of cancer patients</p> <p>SPECIALIST: advanced Pall hospital-based home care (HBHC) - 24h hands-on availability, MDT with advanced training, back-up ward</p>	<p>Findings were analysed to look for caregivers' comprehensibility, manageability and meaningfulness.</p> <p>Comprehensibility: shaped by open-information, symbols and previous knowledge. Enable caregiver to build a 'congruent inner reality' when incorporating congruent information</p> <p>Manageability: shaped by power, competence, accessibility and support. Caregivers felt isolated with responsibility of taking care of patient despite lack of competence (existential isolation) → togetherness with patient and staff (i.e. trust in resources, shared responsibility and being a resourceful contributing part) reduces feeling of isolation</p> <p>Meaningfulness: enabled by comfort, retaining everyday life, action, commitment and hope (something to look forward to, e.g. comfort)</p>	<p>Competence in communicating</p>	<p>It enabled a congruent inner reality, i.e. non-contradiction between sources of comprehensibility (open-information, symbols, basic life assumptions and previous knowledge) vs chaos when contradiction was present. Professionals should therefore look for enough knowledge about individual basic life' assumptions, previous knowledge and inner reality to be able to balance information giving (open and symbolic)</p> <p>Also influences manageability (through emotional support, i.e. positive attitude, listening, individualised, caring, open)</p>	<p>"Informant: It is very clear to me what is going on, the deterioration. I talk very openly with doctor X about that and mother takes part in these discussions too. We discuss these issues very well, I think, so it is clear to me what is going on and that we are approaching the terminal stage, rather soon, I think.</p> <p>Interviewer: Why do you think so at this point? Informant: I think so because of her blood tests, they have discovered new mets, she feels sick, has little appetite and her condition is deteriorating."</p>
		<p>Competence in relieving patient and caregiver suffering</p>	<p>Main areas: medicine, nursing and communication, included emotional support– increased manageability</p> <p>Increased manageability</p>	<p>"My husband was going to be discharged from the hospital [with a PEG], but I said I can't take care of such things. But they said it was very easy to learn how to use it. 'No', I said. 'I can't take that responsibility'. . . Then the dietician came 'It is so easy', she said. I felt I was going to be ill, because I could not do this. (Sighs) And later on that afternoon I had diarrhoea. And was not feeling well and was terribly worried. . . . Then the palliative doctor came, and he was almost like an angel. He presented all the things the palliative home care team could offer. And then I felt that this was a support for us'."</p>
<p>16. Sweden, 2003</p> <p>Cross-sectional survey with 2 open-ended questions analysed through qualitative content analysis</p> <p>217 bereaved caregivers (189 of cancer patients)</p> <p>SPECIALIST: APHC (MDT with nurses and doctors with advanced training, 24h telephone support)</p>	<p>Imported aspects of NoKs' evaluation of home PC service relate to the service (staff, accessibility and spectrum) and to comfort (feeling secure, being in the centre, sharing caring and being at home). Positive experiences of sharing caring and receiving undivided attention are related to trusting relationships and patient centeredness → NoK evaluated service by expressing aspects of interaction with staff.</p>	<p>Competence in symptom control (including continuity and reliability)</p>	<p>Positive aspect of staff: enabled trust in team and contributed to feeling of security and comfort</p>	<p>"Bad contact with the doctors, the whole family reacted, even the patient. Three doctor visits, three different doctors, and they told the patient different things, which made him worried. They seemed negligent . . . The patient was upset after these visits"</p>
		<p>Competence in communicating (listening, answering, unhurried and calm, empathetic, helpful)</p>	<p>Aspects that enabled trust in team and feeling of being in centre → comfort. Being in centre meant receiving undivided attention, being acknowledged by team, having wishes met</p>	<p>"He was the focus of everyone's consideration, and was treated with dignity and professional skill. We the family were treated with a great deal of consideration"; "I'd had total responsibility for my sick relative for four months, and for me, APHC was an enormous relief. For the first time in a very long time I was incredibly relieved just to have someone that I could talk to sometimes."</p>
		<p>Availability 24/7 and easy to contact with prompt response</p>	<p>Team could be contacted by phone at any time, available to visit at short notice (waiting time could be too long) or regularly: positively valued and contributed to security</p>	<p>"My husband could remain at home during the whole disease process, sleep in his own bed, spend time with the children, grandchildren, and friends (as long as he still had the strength), knowing all the while that doctors and other staff members were accessible 24 hours a day. This gave us security, and it was a privilege to have this arrangement during a difficult time"</p>
		<p>Home visits with help and advanced technical support (e.g. blood transfusions)</p>	<p>Feeling of sharing caring with staff</p>	<p>"If there was a problem like pain, shortness of breath, or if some aid were needed to facilitate the care, the team arranged things: a morphine pump, an oxygen tank, a commode, and so on." ; "Their positive mood and helpfulness gave us a feeling of security and relief during the visits. Easy to get in contact with and quick to come."</p>

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<p>17. Sweden, 2007</p> <p>Secondary analysis of datasets 14, 15, 16 to identify health-disease continuums and generalised resistance resources in PC</p> <p>469 family members: 118 current and 351 bereaved (441 caring for patients with cancer)</p> <p>SPECIALIST: All settings: MDT with nurses and doctors with advanced training, 24h support</p>	<p>General components of staff input that facilitated movement of caregivers to health end of the continuum – if positively loaded then existential and emotional well-being increased: competence, support, spectrum of services, continuity, accessibility;</p> <p>Specific interactions with staff could also facilitate this movement: being in the centre and sharing caring.</p> <p>Security identified as a potential relevant parameter to monitor</p>	<p>Competent communication (being listened, informed and acknowledged)</p>	<p>Contributed to feelings of being in the centre by staff having time to listen, acknowledge and meet wishes.</p> <p>Acknowledging caregiving and welcoming participation in care enabled togetherness and decreased isolation</p>	<p>"He was the focus of everyone's consideration, and was treated with dignity and professional skill. We, the family, were treated with a great deal of consideration." (Informant 170); "My husband was going to be discharged from the hospital [with a PEG], but I said I can't take care of such things. But they said it was very easy to learn how to use it. 'No', I said. 'I can't take that responsibility'. . . Then the dietician came 'It is so easy', she said. I felt I was going to be ill, because I could not do this. (Sighs) And later on that afternoon I had diarrhoea. And was not feeling well and was terribly worried. . . . Then the palliative doctor came, and he was almost like an angel. He presented all the things the palliative home care team could offer. And then I felt that this was a support for us. (61 yo wife)</p>
		<p>Home visits with practical help and advanced support</p>	<p>Important to sharing caring and sense of self-transcendence</p>	<p>2) ". . . It's good that someone outside the family also talked about the need to move [to another place of living], so it's not only the children who address this question. . . . I think it is good for the person that has cancer to get an assessment also by a medically trained person. . . . It relieves me, when a medically trained person talks to mother, if it is done in a good way. (53 yo daughter, mother with breast cancer)</p>
		<p>Availability 24/7 easy to contact</p>	<p>Security, Hope</p>	<p>"My husband could remain at home during the whole disease process, sleep in his own bed, spend time with his children, grandchildren and friends (as long as he still had the strength), knowing all the while that doctors and other staff members were accessible 24 hours a day. This gave us security, and it was a privilege to have this arrangement during a difficult time." (Informant 60)</p>
		<p>Competence in relieving suffering</p>	<p>Hope</p>	<p>"One does not want them to continue to suffer, that is so undignified. I feel it is better that they pass away and before that receive all the help that is needed with treatment of pain and things like that. They [the patients] will get that, I hope and believe. According to my experience with the palliative home care service, I'm convinced that we will get help with that. (53 yo daughter, mother with breast cancer)</p>
<p>18. Sweden, 2000</p> <p>Cross-sectional survey with open-ended questions analysed with qualitative content analysis</p> <p>72 bereaved NoK of mainly cancer patients</p> <p>SPECIALIST: 3 advanced home care teams (HBHC): 24h hands-on availability, MDT with advanced training, back-up ward</p>	<p>Caregivers with highly positive attitude regarding PC team. Security identified as cornerstone for successful home care and was especially shaped by: competence of staff, 24/7 availability, respite for caregiver. Mental stress and physical exhaustion also described and important areas for support would be improved communication, staff continuity, time out and bereavement visits</p>	<p>Availability 24/7 easy contact with prompt response</p>	<p>Caregivers confident because they knew who to turn to when help was needed - Feeling secure</p>	<p>'They came home to us as soon as we asked for it. We always had someone to turn to.'</p>
		<p>Competence in symptom management and communication</p>	<p>Contributed to security</p>	
		<p>Home visits with practical aid</p>	<p>Increased manageability of situation at home (possible for patient to stay at home)</p>	

Data Supplement – Reciprocal Translation Table

<p>19. Sweden, 2013</p> <p>Face-to-face interview focused on patients descriptions of participation in home care, analysed by qualitative content analysis</p> <p>19 HF patients NYHA III/IV</p> <p>INTERMEDIATE: MDT with no specialist training in home PC, 24h accessibility, hands-on (2xd-1xm)</p>	<p>HF patients experiences of receiving home care were in correspondence with preferences; home visits facilitated participation and patients experiences of home care differed from previous experiences with care; Patients participation in care in line with HF at home model: care was planned in consultation with patient; patients conducted self-care but also collaborated with professionals, performance of self-care linked to previous experiences but also linked to receiving home care (model emphasises patient education with focus on self-care where optimisation of treatment also includes follow-up monitoring of self-care).</p>	Home visits with practical help	Good moment for communication to happen – team open to need for information and with time to provide it - allowed patient to participate in care	"No, you can talk with them. It is easier than if you have to call the doctor and talk, then you always have to hurry, it is not really the same// but they are never in a hurry in that way, they know, they are never stressed really but they can sit there and have a minute of peace and quiet. Yes if there is something else I want to ask about" (P5); "We discuss medicines and things like that many times, back and forth; which one is good, which one isn't good and which one works quickly (P12); "That they talked to me // That they ask me what I want and do not want. Not just saying things (like) "this is the way it will be", that I have not been part of and decided, that maybe I do not want" (P4). "I have felt good with this thing about letting others... they examine me and they contact a doctor and they make their evaluation on the basis of the information they have received from me. Of course, I tell them how I feel and about those things but I do not get in the way and have not done that during all of the time that ...// ... no for me they can decide" (P1).
		Competent communication	Listening and providing care-related information, allowing for shared decisions and planning of future visits; allowing for patient to participate in care – enables safety and individualised care (only possible if continuity in care)	"Yes, first give information to the patient, that is the alpha and omega, that is my opinion, so you know what you have and what you are dealing with" (P7); "I can feel when it begins to take hold, then I take those extra things (diuretics) and then I know that it will let up..., I have been living with this so long that I know my body" (P6);
		Competence in relieving suffering	Patients trusted in health professionals to recognise deterioration and manage it	"It is when you are to have a checkup visit, that is when they come here, the visiting nurses, it is once a week just now when they check my weight and if I am gaining too much fluid, it is then that I get injections, right then. So I never have to wait for until I get really bad. They help me and they keep an eye on me" (P2); "Yes, I mean that I have always relied on the doctors and all that. That is really what I have done, and I, I do not know in what context, I would question them, I do not have any knowledge about some things" (P11).
		Availability and easy welcomed contact	Patients feel that it is feasible to initiate visit	"Yes, if I am beginning to feel really bad, even more than the usual, and then as I said, then I get in touch with them, the staff that is, and then they get in touch with her (the visiting nurse), and then she (the nurse) calls me // I think that is good, for quite often you have your doubts about doing this if you know you contact them and all they say is yes, you can come in, yes // That is the way it used to be //and that really did not help, and I would say I really felt so bad that I just couldn't(make it). (P18)."

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Data Supplement - Main Changes to the Protocol

Phase of study	Change to the protocol	Major justification for change
Screening	Studies reporting experiences with services other than specialist or intermediate services were excluded	Comparability with Cochrane review Time constraints, limit the number of studies for meta-ethnographic synthesis
	Studies in German, Chinese and Japanese were excluded	Time and resources constraints
	Studies on bereavement services only were excluded	Bereavement services were considered a specific component of the home palliative care services
	Screening audit was replaced by discussions with the team about inclusion decisions	Resources constraints and high number of studies included for full-text screening
Quality appraisal	The quality appraisal was not audited	Resources and time constraints