Table 2: Summary of studies included in review

Author	**Year**	**Country**	**Aim**	**Methods**	**Summary of Findings**
Andershed	2006	Various	Systematically review research focusing on the relatives' situation and needs in end-of-life care	Literature Review: 94 papers analysed, 59 qualitative and 35 quantitative	Good patient care, communication, information and the attitude of the professional are of decisive importance
Anderson, *et al.*	2008	Australia	Present family carers' experiences of administering medications for pain management in the home	Qualitative: Semi-structured interviews with family carers (n=14)	Family carers willingly assumed responsibility of medication administration They could provide immediate symptom relief, which was of utmost importance.
Appelin, *et al.*	2005	Sweden	Identify a comprehensive picture of palliative care in the home, as experienced by the people involved	Secondary analysis of three phenomenological studies: including 6 cancer patients, 6 next of kin and 6 district nurses	Advantages of palliative care at home; striving for normal life Disadvantages: commitment, composed of adaptation and extra work, and demands, composed of frustration and uncertainty
Armes, *et al.*	2003	UK	Explore the reasons why patients were admitted for inpatient care from the home	Qualitative: Semi-structured interviews with main family carer and health professionals involved in care of 10 patients	Family carers reported difficulties in knowing what to monitor, how to interpret symptoms accurately and when to inform a professional
Bee, *et al*.	2009	Various	Examine the practical information needs of family carers providing home-based palliative and end-of-life care to people with advanced cancer	Systematic review: 26 articles	Research consistently highlights lack of practical support, often related to inadequate information exchange Typically manifest in relatives adopting a 'trial and error' approach to palliative care
Brazil, *et al.*	2012	Canada	Evaluate patient centredness of community palliative care from the perspective of family members who were responsible for the care of a terminally ill family member	Quantitative: survey (n=111) (46.0% response rate)	Care was perceived as largely accessible and responsive to patients' changing needs. Respondents tended to provide more negative ratings concerning practical arrangements and the organisation of care: who was coming, how often and when
Brazil, et al.	2010	Canada	Examine how the comprehensive	Cochrane Review (11	There is evidence that supportive interventions

			nature of the Stress Process Model could elucidate on the stressors associated with caring for a palliative cancer patient	randomised controlled trials included)	may help reduce family carers' psychological distress. Findings suggest that practitioners should enquire about the concerns of caregivers and should consider that they may benefit from additional support
Carlander, *et al.*	2011	Sweden	Explore situations in daily life that challenge family carers' self-image when caring for a dying family member at home	Qualitative: bereaved family carers' (n=10)	Situations that challenged the family carers' self-image were connected to experiences such as 'forbidden thoughts', intimacy and decreasing personal space
Fisker, *et al.*	2007	Sweden	To illuminate the experiences of surviving relatives in connection with their care at home of terminally ill, dying spouses	Qualitative: interviews with surviving relatives (n=8)	Themes: 1) the loving promise to the terminally ill and dying spouse 2) surviving spouse became altruistic, neglecting his or her own primary needs 3) surviving spouse grieved in lonely isolation characterised by stress and an ethical dilemma in connection with breaching the promise
Funk, *et al.*	2010	Various	Review qualitative research on home-based family caregiving at the end of life	Literature review: qualitative research (105 articles included)	Lack of definitional clarity; a reliance on interview methods and descriptive, thematic analyses, and a relative lack of diversity of patient conditions
Grande, *et al.*	2009	UK	Give an overview of the current state of carer research, its gaps and weaknesses, and outline future priorities	Review of the carer literature and a consensus meeting by experts in the field	Family carers' needs and adverse effects of caregiving have been extensively researched In contrast, there is a lack of both empirical longitudinal research and conceptual models to establish how adverse effects may be prevented through appropriate support A reactive, "repair" approach predominates
Harding, *et al.*	2012	UK	Explore the perceived needs and challenges of family carers' in home cancer palliative care To generate evidence to inform a	Qualitative: interviews with family carers' of home cancer palliative care (n=20)	Family carers reported the need to be prepared for their caring role, to be visible to professionals, to receive clear and specific information about the patient's condition, and

			subsequent appropriate intervention based on family carers' experiences		to be emotionally supported They described challenges as uncertainty, distress at witnessing disease progression and the daily struggle with financial issues, personal time, own health and sleep problems
Hunstad, *et al.*	2011	Norway	Explore family carers' views of what determines the quality of home care at the end of life	Qualitative study: (n=7)	1) None of the participants had planned to give or receive palliative care in the home However, they did not regret that the home had been the place of care 2) Factors deemed important to achieving the best possible home-based palliative care included around-the-clock help, holistic care, and affirmation of the significance of the carer's role
Ishii, *et al.*	2012	Japan	Investigate circumstances, difficulties, and correlated factors for family carers, who provided care at home for a family member with terminal cancer	Quantitative. Survey (n=306) (response rate: 81%)	it is important for home care providers to introduce services to reduce care burden A thorough explanation of the patient's symptoms and condition is necessary to reduce distress and anxiety for family caregivers
Linderholm, *et al.*	2010	Sweden	Explore how the family carers' of a dying relative in palliative home care experienced their caring role, and support, during the patient's final illness and after death	Qualitative: interviews with family members (n=14)	Being a family carers' was natural when a relative became seriously ill. More or less voluntarily, the family member took on a caring role of control and responsibility The family carers' felt left out and had feelings of powerlessness when they did not manage to establish a relationship with the healthcare professionals
McNamara, *et al.*	2010	Australia	Identify family carers' beliefs around health service support, and the influence on the carer's health following the death of a family member	Qualitative: interviews with carers (n=1071) Triangulation with healthcare records	Family carers' were less likely to be coping if they were aged 60 years or less, female, had lost a spouse/partner and the deceased family member did not die in the family carer's preferred place
Milberg, *et*	2007	Sweden	Develop a theoretical framework of	Qualitative: Interviews with	The secondary analysis generated three

al.			family members' experience of palliative home care staff, based on a secondary analysis of four previous studies	family members of mainly cancer patients (n=469)	theoretical blocks: (1) general components of staff input (2) specific interactions with staff (3) emotional and existential consequences of staff support
Milberg, *et al.*	2003	Sweden	Describe and interpret the construct of meaningfulness in next of kin of cancer patients who are in advanced palliative home care	Qualitative: Interviews with next of kin (n=19)	Elements that facilitated meaningfulness included; comfort, retaining everyday life, action, commitment, and hope
Milberg, *et al.*	2003	Sweden	Describe what aspects are important when next-of-kin evaluate advanced palliative home care (APHC)	Qualitative: Interviews with next of kin (n=217)	Service aspects and comfort emerged as main categories The staff's competence, attitude and communication, accessibility, and spectrum of services were valued service aspects The actual place of care (i.e., being at home) added to the perceived comfort
Phillips, *et al.*	2009	US	Better understand family carers' perspectives of providing end-of-life (EOL) care to elders facing expected deaths from life limiting, chronic illnesses	Qualitative: Interviews with family carers' of elders (n=28)	Family carers' of elders with life-limiting illnesses needed nursing guidance about EOL care earlier than it is usually provided All nurses providing care to elders in any setting should be ready to offer early education in the practical, technical, and emotional dimensions of end-of-life caregiving
Proot, *et al.*	2003	Netherlands	Explore the experiences of family carers, their needs for home care, and which health services they receive	Qualitative: Interviews with family carers (n=13)	Continuing previous activities, hope, keeping control, satisfaction and good support are factors which may decrease the caregiver's vulnerability, and may protect against fatigue and burnout Support from family carers' and professional caregivers was not sufficient
Rollison, *et al.*	2002	Sweden	Evaluate how next of-kin experienced information provided, care, symptom relief, and care-giving burden	Quantitative: Survey with next of kin carers (n=75)	Next-of-kin were generally more satisfied with emotional support and care than with information provided Symptom relief was sufficient in most cases Next-of-kin's experiences of burden were: 45%

					felt homebound, 26% felt isolated at home and 51% reported a sleep deficit Women felt homebound to a higher degree than men
Schulz, *et al.*	2003	US	Study the impact of end-of-life care on family carers', who are family members of persons with dementia, and the family carers' responses to the death of the patient	Quantitative: Survey (n=217)	End-of-life care for patients with dementia was extremely demanding of family carers. When death was preceded by a protracted and stressful period of caregiving, family carers' reported considerable relief at the death itself
Somerville	2001	UK	Investigate the experiences of Bangladeshi family carers living in the UK, associated with caring for a dying relative.	Qualitative: Interviews with family carers (n=7)	In addition to the demands and stresses caused by their relative's symptoms and the knowledge that they were dying, the Bangladeshi family carers experienced communication barriers, isolation and anxieties regarding visas and housing, yet all were uncomplaining about their situation
Stajduhar	2003	Canada	Explore the social context of home-based palliative caregiving	Ethnographic study	Home-based palliative caregiving resulted in life-enriching experiences for many caregivers, however assumptions about dying at home and healthcare reforms resulted in some caregivers feeling 'pressured' to provide home care and then they felt their obligations to care were exploited by the health care system Home and family relationships change when home becomes the site for health care provision Most notably, family carers' were distressed by the numbers of different healthcare professionals coming into their home
Stajduhar, *et al.*	2005	Canada	Describe the variations in, and factors influencing, family member's decisions to provide home-based palliative care	Qualitative: Interviews with family members (n=13) family members (n=47) and health care providers (n=25)	Decisions were influenced by three factors: fulfilling a promise to the patient to be cared for at home, desiring to maintain a 'normal family life' and having previous negative encounters with institutional care

					Findings suggest interventions are needed to better prepare family carers’ for their role and enhance family carers’ choice in the decision-making process
Wong, *et al.*	2009	Australia	Explore the positive meanings constructed and ascribed to the experience of providing palliative care at home by bereaved family carers’	Mixed method study: including qualitative interviews (n=22)	Bereaved family carers gave accounts that accentuated the benefit and satisfaction derived from providing direct palliative care at home, including a sense of reward for doing something good, meeting the expressed needs of the patient, continuing with normal life as much as possible, improving the conditions of the relationship and meeting cultural expectations of the right thing to do