**Experiences and needs of older people with end stage renal disease: bereaved carers perspective**

**Pungchompoo W. Richardson A. and Brindle L.**

**Abstract**

**Background:** There is a growing population of older patients with End Stage Renal Disease (ESRD) managed without dialysis in Thailand, and services have yet to be developed to specifically respond to the needs of this group. As a consequence this population are likely to have unmet needs with respect to health care, and suffer from symptoms that could be better managed.

**Objective:** This qualitative study explored experiences and health care needs during the last year of life among older people with ESRD managed without dialysis from the perspective of bereaved carers.

**Methods:** A retrospective post-bereavement approach to collect qualitative interview data was adopted. Purposive sampling was used to select 12 bereaved relatives of older patients with ESRD managed without dialysis who had died in the previous 5-10 months. Semi-structured interviews were conducted. Data were digitally recorded, transcribed and analysed through framework analysis.

**Results:** Four main themes were identified: symptom experiences, impacts of being managed without dialysis, symptom managements, and health care needs and utilization of services.

**Conclusions:** Findings confirmed patients’ needs were not being met and identified the need to develop approaches to symptom management (pain and breathlessness) at home, health education, and psychological and spiritual support at the end of life.

**Key words:** End stage renal disease (ESRD), Age care, Symptom management, Bereaved carer

**Introduction**

ESRD is progressive, and people can develop a variety of physical, psychological and social problems at any point during the illness (Zalai *et al.* 2012). The National Kidney Foundation practice guidelines for chronic kidney disease recommend that ESRD patients should be started on dialysis when they reach stage 4 or when uraemic symptoms are severe (Levey 2003; Ansell *et al.* 2007). However, the management of ESRD in Thailand is costly, and more than half of patients cannot access dialysis because the cost is prohibitive. Furthermore, access to this form of management is limited since it is only available in specialist institutions (Narenpitak & Narenpitak 2008).Therefore, there are a large proportion of this population managed without dialysis in Thailand. The largest group of patients with ESRD is older people who may decline or discontinue dialysis or not be offered it in the first place, even though it might be clinically indicated, with an associated impact on their health-related quality of life (Munshi *et al.* 2001). From a European study, patients managed without dialysis suffer from symptoms including lack of energy or fatigue, pruritus, dyspnoea, leg oedema, drowsiness, pain, dry mouth, muscle cramps, difficulty concentrating, insomnia, constipation, dizziness nausea and muscle pain (Murtagh *et al.* 2007a). Depressive and anxiety disorders are also the most common mental health problems among this population (Zalai *et al.* 2012). Moreover, it has been argued patients managed without dialysis have been particularly neglected (Murtagh *et al.* 2009). The voice of patients managed without dialysis is generally silent in the literature (Noble *et al.* 2010). Therefore, using proxy accounts is easier to justify.

Holistic, integrated care pathways based on carer perspectives, including the identification of information needs related to the original diagnosis, associated comorbidities, treatment options, prognosis, and assistance in developing strategies to manage communication with patients as the end of life approaches are needed (Noble *et al.* 2012). Within the hospice model, palliative care is initially focused on the patient and their family (World Health Organization 2004). According to a study from UK about the issues associated with care delivered to patients who decide not to undergo dialysis, the key attributes of renal supportive care should include available from diagnosis to death, with an emphasis on prognosis and the impact of advanced disease, an interdisciplinary approach to care, restorative care including active disease management and palliative care in tandem, effective, lucid communication to ensure informed decision making, and family and carer support (Noble *et al.* 2007a). In Thailand, the involvement of family strongly impacts on the provision of end-of-life care, and they have a vital role in making decisions and providing care for the terminally ill in hospital or in the home (Kongsuwan & Locsin 2011).

There is a paucity of research directed at how patients manage without dialysis in Thailand in order to explore what their needs are and how they die. This is important because these patients are anticipated to have particular care needs, some of which relate to the fact that they are approaching the end of their lives. In order to develop palliative care aimed at improving the quality of life of these patients, knowledge is required about patients’ experiences, symptom burden and health care needs as the end of life approaches. There are difficulties in conducting research with dying patients such as older ESRD patients who have serious multiple comorbidities including ischemic heart disease, pulmonary oedema, and uraemia (Murtagh *et al.* 2007a). Proxy reports are an accepted way by which to access the views of patients at the end stage of their lives (Elkington *et al.* 2005a). In the study, the informants’ accounts were perspective of bereaved relatives therefore used as a proxy for the deceased person’s experience.

**Objective**

The purpose of this study was to explore symptom experiences and health care needs during the last year of life among older people with ESRD managed without dialysis from the perspective of bereaved carers. Furthermore, it was planned that the results would be used at a later date to inform the development of the VOICES (View of Informal Carers – Evaluation of Service) – ESRD/Thai questionnaire (not the subject of this paper).

**Methods**

**Design:**  This study reported here is the first phase of a mixed-method project that used an exploratory sequential design, to develop a culturally specific questionnaire (Creswell & Plano Clark 2011). This type of design is best suited to exploring a phenomenon and particularly useful when the researcher needs to develop and test an instrument(Creswell & Plano Clark 2011). This first phase used qualitative research methods, involving retrospective semi-structure interviews and proxy reports, to explore the experiences of older people with ESRD managed without dialysis from the perspective of bereaved carers.

**Setting/ Subjects:**

The participants for the study consisted of bereaved relatives of people aged 60 or above with ESRD managed without dialysis. Renal nurses were trained how to select participants by the researcher. Bereaved relatives were recruited from two renal units from two hospitals in Chiang Mai province, Thailand. Twenty five carers were approached but only 12 consented. All participants had been involved in caring for patient in the last three months of life, were willing and able to participate in the study; were capable of providing informed consent (not cognitively impaired), and experienced the death of family members with ESRD 5-10 months previously. The study was concerned with balancing accuracy of information and avoiding emotional distress to relatives. Thus, data collection took place between five and ten months after the death of the deceased person (Elkington *et al.* 2004; Elkington *et al.* 2005a; Elkington *et al.* 2005b).

**Ethics**

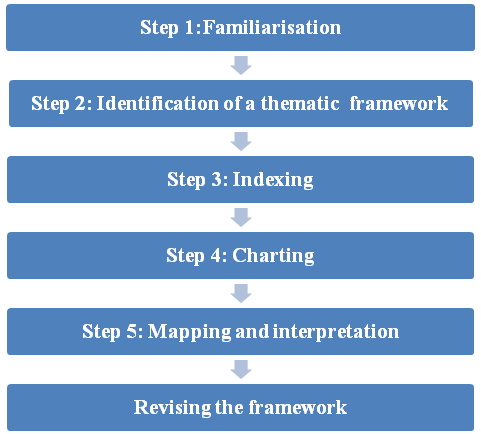
The study protocol was approved by the Research Ethics Committee at the Institutional Review Board of Faculty of Nursing (IRB), Chiang Mai University, Thailand and the Research Ethics Committee from two hospitals (Nakorn Ping hospital and Chiang Mai Ram hospital).

**Data collection**

Retrospective, exploratory data collection was employed (Elkington *et al.* 2004). Purposive sampling was used to select participants. Data were collected using semi-structured interviews to explore patients’ experiences of symptoms, symptom control, contact with health care services and information received. The form of these interviews was face-to-face and most of the interviews took place in the subjects’ homes. The interview topic guide was developed based on the VOICES questionnaire (View of Informal Carers-Evaluation of Service) which has been used to evaluate experiences and health care needs of patients with a range of chronic diseases in the last year of life (Addington-Hall2002). A topic guide was created to include questions in a logical sequence from general to the specific (Polit & Beck 2012). Then, the researcher encouraged participants (bereaved carers) to talk freely and to tell stories in their own words. If participants (bereaved carers) felt emotionally distressed during the interview, the researcher acknowledged their distress and provided information or telephone numbers for them to contact the renal nurse for support at the renal unit. If the researcher felt a participant (bereaved carers) was displaying severe distress and judged they might need treatment or care, the researcher (with the person’s permission) referred the participant directly to a general physician (GP) at the emergency department or alternatively discussed the issue with the renal nurse and the general physician who referred the participant for specific support. The interviews were digitally recorded and transcribed. Each interview was referenced by the researcher using a code number 01 being the first and 12 being the last. Transcriptions were translated into English by the researcher and proof read by an English proof reader. To validate the accuracy of the translation and ensure nothing was lost in translation, back translation was conducted in order to check content validity.

**Data analysis**

The interviews were analysed using a framework approach to ensure rigor and transparency. Framework analysis consists of five stages(Elkington *et al.* 2004; Adams *et al*. 2012; Hanratty *et al.* 2012): a) familiarization (immersion in the raw data); b) identifying a thematic framework (drawing on a priori issues and questions as well as issues which are raised by participants themselves, in order to examine and reference the data); c) indexing (applying the thematic framework to all the data); d) charting (grouping the data according to the part of the thematic framework to which they relate using distilled summaries linked to transcripts via page numbers or hyperlink) and e) mapping and interpretation (mapping the range of phenomena and, where appropriate, creating typologies and/or finding associations between themes with a view to providing and explaining). The final few interviews demonstrated no new information or insights and the research team agreed that data saturation had been reached. The procedures for data analysis are presented in Figure 1.



**Figure 1 Flowchart of the framework analysis process**

The initial framework progressed through the three key stages of framework analysis becoming more organized, increasingly specifying the important symptom experiences and health care needs (see Table 1).

**Table 1 Three key stages of framework analysis applied to the study data**

|  |  |  |
| --- | --- | --- |
| **Initial thematic framework** | **Revised thematic framework used in indexing** | **Themes and sub-themes used to map the range of views and experiences** |
| **1.Symptom experiences**  1.1 Physical symptoms & impacts  - Breathlessness  - Pain  - Oedema  - Weakness/fatigue  - Weight loss  - Dependency  1.2 Psychological symptoms & impacts  - Stress/worry  - Depression  - Anger/ Aggressive  1.3 Spiritual distress  1.4 Financial problem  **2. Symptom control**  2.1 Pharmacological managements  - Pain relief medicines  - Others medicines  2.2 Medical interventions  - Oxygen support  2.3 Alternative managements  - Massage  - Music therapy  - Pray to Lord Buddha  **3. Health service utilization**  3.1 The 30 Baht scheme  3.2 Possibility to received HD  3.3 Hospital based care  3.4 Home visiting  3.5 The end of life care  3.6 Information sources(doctor, nurse, anyone else)  **4. Unmet needs**  4.1 Health services for ESRD patients who managed without dialysis  - Need for effective referring system  - Need for home visiting before & after the death  4.2 The need to care by specialists  4.3 The information support  - Providing full information  - Need time to explain  - Need for good communication  4.4 The financial support  - Free for the treatment  - Free for the cost of transportation | **1.Symptom experiences**  1.1 Physical symptoms & impacts  - Breathlessness  - Pain  - Oedema  1.2 Psychological symptoms & impacts  - Stress/worry  - Depression  - Fear to die  1.3 Spiritual distress  1.4 Financial problem  **2. Symptom control**  2.1 Pharmacological management  - Pain relief medicines  - Others medicines  2.2 Medical interventions  - Oxygen support  2.3 Alternative managements  - Massage  - Music therapy  - Pray to Lord Buddha  **3. Health service utilization**  3.1 Hospital based care  3.2 Home visiting  3.3 Type of care  - Care from doctor  - Care from nurse  - Care from specialist  3.4 Information sources (doctor, nurse, anyone else)  **4. Unmet needs**  4.1 Need for end of life acre  - Need care by specialist  - Need for effective referring system  - Need for home visiting  4.2 The need to care by specialists  4.3 The information support  - Providing full information  - Need time to explain  - Need for good communication  4.4 The financial support  - Free for the cost of transportation | **1.Symptom experiences**  1.1 Physical symptoms  - Breathlessness  - Pain  - Oedema  1.2 Psychological symptoms  - Worry  - Low mood  1.3 Spiritual distress  **2. Impacts**  2.1. Breathlessness & its impact  2.2 Pain and its impact  2.3 Oedema & Its impact  2.4 Emotional impact  2.5 Spiritual impact  **3. Current symptom managements**  3.1. Breathlessness & its management  3.2 Pain and its management  3.3 Oedema & Its control  3.4 Psychological management  3.5 Spiritual support  **4. Health care needs and utilization**  4.1 Health service provision  4.2 Home visiting  4.3 Spiritual need  4.4 Financial support |

**Demographic characteristics**

**The informants**

Participants were aged between 35 and 67 years. Five of participants were aged between 60-69 years. Eleven of the participants were female. The relationship of participants to the deceased were: wife (4 cases); daughter (4 cases) daughter-in-law (2 cases); husband (1 case); and niece (1 case).

**The deceased**

Half of the deceased were aged between 60-65 years. Three deceased were aged between 66-70 years. Two deceased were aged between 71-75 years and one was aged over 75 years. Seven of the deceased were male, and five female. All informants reported that the deceased had lived at home while they were managed without dialysis. Half of the deceased died at home; the other half died in hospital. Five died within 12 months after the decision had been made to pursue management without dialysis. One died within one month of the start of management without dialysis (see Table 2).

Table 2 Characteristics of the deceased (n= 12)

|  |  |
| --- | --- |
| **Characteristic** | **N (%)** |
| **Age of the deceased**  60-65  66-70  71-75  75+ | 6(50)  3(25)  2(16.7)  1(8.3) |
| **Sex of the deceased**  Male  Female | 7(58.3)  5(41.7) |
| **Duration of being managing without dialysis**  1 month  3 months  6 months  12 months  24 months  36 months | 1(8.3)  3(25)  1(8.3)  5(41.7)  1(8.3)  1(8.3) |
| **Place of death**  Home  Hospitals | 6(50)  6(50) |

**Results**

**Symptom experiences**

* **Physical symptoms**

From the carers’ accounts, the physical symptoms that most affected patients in the year before death were breathlessness, pain and oedema. During the few months before death, carers explained that the intensity of those symptoms increased dramatically and reflected a rapid decline in a patient’s physical health (see Table 3).

**Table 3 Physical symptom experiences**

|  |  |  |
| --- | --- | --- |
| Symptom experiences | Impact | symptoms management |
| **Breathlessness**  *Breathlessness caused the most suffering to him during the last months. Breathlessness was the symptom that caused him to be readmitted to the hospital many times until he died (Carer No.**05).* | *His breathlessness was serious. In the last three days before he died, he felt really weak. He said “I feel really weak and I am unable to breathe properly, please take me to the hospital” (Carer No. 04).* | *The month before he died, the oxygen support was provided to him in the hospital but the physician in the hospital did not provide the oxygen equipment to take home. This caused him to die very quickly only 3-4 hours after back home (Carer No. 04).* |
| **Pain**  *…While he was being managed without dialysis, the back and hip pain caused suffering to him. During the 3 days before he died, he got pain around both legs and abdomen. Both legs felt very painful when he walked or moved (Carer No.**05).* | *He felt very painful when he had to walk since he got oedema around his body (Carer No. 12).* | *He had to receive pain relief medicines from the physician such as paracetamol at hospital. When he was readmitted to hospital with severe pain, the physician injected morphine to relieve his pain (Carer No. 01).* |
| **Oedema**  *2 months before she died, we could see that oedema was in every part of the patient’s body such as her legs, arms, hands, face and abdomen (Carer No****.*** *10).* | *Oedema meant he couldn’t walk and it caused him was in pain when he stood or started walking (Carer No. 03).* | *The patient got medicine to reduce oedema on her legs and medicine to excrete water out of her body. I think that the doctor or nurse should also provide information for caregivers how to control patients’ symptom such as oedema at home (Carer No. 02).* |

* **Psychological symptoms**

Management without dialysis affected patients’ psychological well-being. Psychological symptoms included worry and low mood. The impact and management of psychological symptoms are explained in more details below (see Table 4).

**Table 4 Psychological symptom experiences**

|  |  |  |
| --- | --- | --- |
| Symptom experiences | Impacts | Current symptoms management |
| **Worry**  *He was worried about his health problems such as breathing and oedema. This was because he thought his health problems made him unable to help himself and he became a burden for the family, which he didn’t want (Carer No. 01).* | *She was quite worried about her breathing problem as it got more severe and it caused her to be unable to do her daily activities by herself during that time. Sometimes, she felt like giving up and cried. She complained that* ***“I want to die. I look like a dead person.” (Carer No. 10****).* | *Sometimes I played the Dhamma song to make the patient feel relaxed and calm, which is quite good for controlling the patient’s emotional state (Carer No. 01).* |
| **Low mood**  *She looked really low mood after experiencing breathlessness and had to retain an ET tube with a respiratory machine. In the hospital, I saw her cry every day and every time the nurse came to provide the suction for her (Carer No. 06).* | *He didn’t want to say any word to us. He sometimes cried. During the week before he died, he was quite low mood and slept on the bed all day (Carer No. 01).* | *Sometimes I played the Dhamma song to make the patient feel relax and clam (Carer No. 01).* |

* **Spiritual distress**

Carers also described spiritual distress experienced by patients as a result of their illness, some carers mentioned that spiritual support might be considered as one of the most important aspects at the end of patients’ life (see Table5).

**Table 5 Spiritual distress**

|  |  |  |
| --- | --- | --- |
| Symptom experiences | Impacts | Current symptoms management |
| **Spiritual distress**  *Normally, he loved to go to the temples. He used to pray to the monks and receive blessing at each Buddhist event. When he got ill, he never went to the temple (Carer No. 01).* | *During his difficult time with ESRD, he couldn’t do it (Carer No. 03).* | *…she loved to put fresh flowers and a small portion of food in front of Lord Buddha’s image by herself at home. As you know, this indicates respect to put fresh flowers, water and food in front of Lord Buddha’s picture at home when you cannot go to pay respects to monks at the temple. This could also make her feel happy and released her tension in another way (Carer No. 02).* |

**Health care needs and utilization**

* **Health services provision**

Many carers suggested there was a need for more effective referral. Lack of specialist input and support for patients at the end of life had negative consequences (hopelessness and disappointment with service provision). Many carers stated that clear information related to symptoms of ESRD and their management should have been provided as early as possible and certainly when the patient was near the end of their life (see Table 6).

**Table 6 Health services provision**

| Needs | Impact | Suggestions |
| --- | --- | --- |
| **Need for an effective referral system**  *My husband had to wait at the district hospital for 3 days before he was referred to the provincial hospital. (Carer No. 03).* | *He then died 2 days later (Carer No. 03).* | *The district hospital should have a good referral system* ***(Carer No. 03).*** |
| **Need for specialists and support at the end of life**  *The doctor couldn’t help or didn’t do anything to help him when he was staying in the hospital. The physician and nurse also didn’t contact or provide any support to the patient when he went back home (Carer No. 12).* | *The patient complained that* ***“ I don’t want to see the doctor again.”*** *(Carer No. 12).* | *...the physician should provide effective investigation into the patient’s disease and get to know that the patient had ESRD and needed effective managements as early as possible (Carer No. 12).* |
| **The need to provide care with dignity**  *One time that my father was admitted to the hospital, the nurse blamed him very loudly. It was because he made dirty on the bed as he couldn’t help himself for going to the toilet (Carer No. 04).* | *The patient felt really ashamed before the other patients. (Carer No. 04).*  *I and the patient didn’t like to see the doctor if it was not necessary (Carer No. 03).* | *I think the doctor at the district hospital should provide a better way to treat patients (Carer No. 03).* |
| **Need for health education**  *The physician and nurse told us about ESRD and the treatment but they didn’t explain more how to control his oedema when he was managed without dialysis at home (Carer No. 07).* | *My relatives and I had to find out the information related to management with the patient’s symptoms by ourselves (Carer No. 02).* | *The doctor or nurse should provide clear information for patients and caregivers about the ESRD’s symptoms and management as early as possible before back home (Carer No. 02).* |

* **Home visiting**

In this study many carers mentioned that home visiting was not available for all patients. Ten of the twelve carers felt home visits before death were an important thing for renal nurses to do in order to assess a patient’s health problems at home; prepare and provide end of life care and help carers to deal with the situation (see Table 7).

**Table 7 Home visiting**

|  |  |  |
| --- | --- | --- |
| Needs | Impacts | Suggestions |
| **Need for regular home visits**  *During the time a patient is living at home, we need physicians or nurses to come to see the patient more often, not only 1-2 weeks before patient died (Carer No. 01).* | *Lacking of the regular home visiting, a patient’ s condition was severe, especially in regard to pain, breathlessness and oedema (carer No. 01 and 06)* | *…If physician and the nurse can assess the patient’s health problem at home. It will help the patient and the family prepares everything as early as possible (Carer No. 06).* |
| **Need for home oxygen support**  *…When he would like to go back home but he still needed the oxygen support as he couldn’t breathe without it.* *(Carer No. 04)* | *…Because of this he died very fast in 3-4 hours after he was taken home (Carer No. 04)* | *We would like the physician to support the patient with oxygen equipment at home. We need to borrow or rent it from the hospital (Carer No. 01).* |
| **Need for pain management at home**  *During last 3-5 months before he died, he always complained about the back and bone pain and asked for help.* ***“Please help me or do something for me to relieve these pains”.*** *(Carer No. 01).* | *The doctor or nurse didn’t come to see him at home. I had to take him to the hospital more often when he had severe pain (Carer No. 05).* | *…thought it would be better if the nurse or doctor could come to monitor patient’s symptoms and provide pain management at home. (Carer No. 05).* |

**Suggestions**

* **Spiritual needs**

The spiritual dimension of life was also described as an important aspect of support for ESRD patients in order to control their emotions, release tension and help patients feel peaceful and happy during the end of their lives. Therefore, some patients tried to perform their religious activities at home even though health problems were often a barrier (see Table 8).

**Table 8 Spiritual needs**

|  |  |  |
| --- | --- | --- |
| Need | Impacts | Suggestions |
| **Spiritual needs**  *When she was ill, she loved to put fresh flowers and small portion of food in front of Lord Buddha’s image by herself at home since she couldn't walk out of her room (Carer No. 02).*  *During the time he died, we invited monks to come to visit and give the blessings (Carer No. 04).* | *This would also make her feel happier and relieve her tension (Carer No. 02).*  *While he was dying, he wasn’t suffering and he died very peacefully (Carer No. 04).* | *We thought the receiving blessing from the monks would help patients fulfil his spiritual need, especially in the last hours (carer No. 4).* |

Need

* **Financial support**

This financial aspect was the leading cause of patients being unable to have regular health check-ups with the physicians, which resulted in patients being unable to maintain their physical health (see Table 9).

**Table 9 Financial need**

|  |  |  |
| --- | --- | --- |
| Need | Impacts | Suggestions |
| **Financial need**  *We were poor and the patient suffering with many symptoms. I had to take her to see a physician 1-2 times a month at the district or provincial hospitals when she got exacerbation with her breathing problem (Carer No. 02).* | *My patient couldn’t have health check-up regularly since we did not have enough money to pay for transportation to the hospital (Carer No. 02).* | *It will be better if the government could support the transportation cost for us (Carer No. 02).* |

**Discussion**

**Symptom experiences:**

* **Physical symptoms**

The intensity of symptoms increased dramatically during the last three months before death and reflected a rapid decline in patients’ physical health. Carers stated that breathlessness caused ***the most suffering***and created the greatest ***sense of difficulty for patients***. Breathlessness caused physical weaknesse, and impacted on patients’ sleep patterns and social isolation, forcing them to become dependent on carers for performing activities relating to daily living. Pain was described as ***“the main factor”*** whichmade patients feel uncomfortable. Oedema was described as ***“in everywhere”****,* and it resulted in patients experiencing ***“a lot of pain***” over a long period of time or for most of the time once they had oedema. Oedema limited patients’ mobility, and caused them to experience a lack of confidence in their body image. Symptoms affected patients’ daily living, and some symptoms such as breathlessness become difficult to treat with oedema becoming increasingly difficult to manage with diuretics when death was close (Noble *et al.* 2010). The intensity of symptoms such as pain has rarely been studied in patients who are managed without dialysis, perhaps because pain has not been thought to be problematic for renal patients (Murtagh *et al.* 2006).

A picture emerged of a heavy symptom burden experience among the Thai population which was extremely distressing for some, with symptoms such as pain, breathlessness and oedema appearing to be common. These results are consistent with studies in UK. For example, the functional status of patients with conservatively managed ESRD, measured using the Karnofsky Performance Scale (KPS) (Murtagh *et al.* 2011), remained stable during the last year of life but declined steeply in the last month of life of older person managed without dialysis in Thailand (Murtagh *et al.* 2011). Patients in stage 5 chronic kidney disease who were being managed without dialysis experienced fatigue and lack of energy (76%), pruritus (74%), dyspnoea (61%), oedema (58%), pain (53%), sleep disturbance (41%), restless legs (48%) and poor concentration (44%) (Murtagh *et al.* 2007b). Similar findings from another study in UK found the symptoms experienced by patients managed without dialysis were oedema (96%), pain (90%), immobility (60%), breathlessness (50%), pruritus (47%), lethargy and insomnia (53%) and depression (37%) (Noble *et al.* 2010).

The physical symptoms profile and revealed through the study are slightly different in comparison with previous studies in the UK. This might be because of limitations in the availability of specific symptom management at home such as oxygen support and pain control, which are currently not well managed in Thailand. In regard to the management of physical symptoms, oxygen support and other respiratory equipment (to manage breathlessness), pain relief medicines and diuretics (to manage oedema) were used, but these were only available in the hospital. Therefore, the effective identification and management of symptoms, a factor highlighted from the accounts of bereaved relatives in this study are important.

* **Psychological symptoms**

Little is known about the specific psychological and spiritual needs and relative impact of these aspects on patients. In particular, previous studies in the UK did not mention or explore the issue of worry and spiritual needs of older ESRD patients managed without dialysis. This omission was addressed in this study. Psychological symptoms including worry and low mood were perceived to be a crucial issue of concern. Worry caused patients to feel a ***“sense of being useless”*** because they were unable to help themselves to perform their daily activities. Worry appeared to impact on patients such that they were unable to control their emotions, especially when they suffered severe breathlessness during the last months of life; patients were reported to feel panic, and a fear of dying surfaced. The physical changes they experienced often interfered with their mental and social function (Tallis 2005). At the same time carers reported that low mood developed and increased in severity during the last few months before death. In previous research depression (27%) was found to be a psychological symptom of ESRD people managed without dialysis (Murtagh *et al.* 2006). In this study, carers reported that suffering with physical symptoms in the last few months before death resulted in the patients feeling depressed. Some patients appeared to experience depression or low mood as a result of the decision that they were not to receive dialysis, and some patients suffered with low mood after overhearing, from the doctor, that nothing more could be done for them (Noble *et al.* 2010). Findings suggest that low mood affected the patients, who became less interested in participating in activities with others. Similarly,low mood affected the patients’ management of ESRD, as they became unable to do things that they had previously been able to do with ease (Noble *et al.* 2010). Depression also appeared to change their personalities, caused them to manifest a lack of concern for themselves and give up their medical treatment. Patients with depression may not always clearly show the impact of their symptoms, but it could have been an important influence when considering the way some responded to treatment. According to these findings, psychological support is needed in order to improve patients’ quality of life during the end-of-life phase (Davison 2010).

* **Spiritual distress**

At the end of patients’ lives spiritual beliefs were shown to be an important factor especially, when patients were faced with uncertainty in their lives regarding symptoms burden and deterioration of their health condition. Religious and spiritual beliefs of Thai people became more so than before, the important part of their inherent belief system and daily lives (Davison 2010). Buddhism influences many parts of the Thai culture as well as health care beliefs and practice, as Thai Buddhists apply Buddhist Dhamma and supernatural beliefs to cope with various kinds of suffering including crises and illness. According to the carers, this coping strategy helped patients feel comfortable with and accepting of their health conditions (Yodchai *et al.* 2011). Praying to Lord Buddha was performed by both patients and their carers at home in order to help patients feel peaceful and fulfil their spiritual beliefs during the last stage of their lives. Thai patients with ESRD being managed with haemodialysis (HD) applied Dhamma (the Buddha’s teachings) to cope with the adverse effects of HD (Yodchai *et al.* 2011). However, patients’ ability to engage in spiritual/religious activities were limited by ESRD's complications at the end of life, causing distress for some. Hospice services are currently provided by several temples in Thailand, which are regarded as convenient places for dying patients, particularly patients with AIDS. Since, the majority of the Thai population (over 90%) are Buddhists, and the religion perspective is critical for Thai Buddhist which focus on promoting a peaceful death for persons who are dying (Kongsuwan & Locsin 2009). Therefore, the religion has a profound influence on end-of-life care in Thailand. In order to provide a holistic end-of-life approach to meet the spiritual needs of Thai people, understanding, respecting and planning interventions to facilitate patients’ spiritual and religious beliefs and practices is recommended.

* **Health care needs and service utilisation**

Physical, psychological and spiritual needs of patients developed during the last year of their lives, which often dramatically increased in severity in the last few months before death and were not addressed effectively by the health services available. Health service provision that includes a referral system, early investigation by a specialist, health education, support at the end of life and care with dignity (effective symptom and pain management, oxygen, psychological and spiritual support at home), are required to the best suit individual needs. Particularly, home visiting was identified by bereaved carers as the main service which should be provided regularly in order to monitor and control patients’ symptoms. Many carers explained that patients should have been provided with better quality health care when they were being managed without dialysis. Unfortunately, however, the lack of holistic care and proactive management by medical professionals when they were required to deal with patients’ physical, psychological, spiritual and financial issues at home caused the patients to feel that their needs had not been met. The health care needs which underline the need to address the fundamental care needs of ESRD older patients managed without dialysisParticularly, health services need to be able to rapidly respond to the steep functional decline of these patients in their last months of life. Also, it has been suggested that clinical staff should be required to undertake specific training on ESRD and end-of-life care (Noble *et al.* 2010). Similarly, emotional, social and spiritual support should be integrated with medical support (Davison 2010). Moreover, health care professionals need to define the role that various members of the multidisciplinary team will play in the provision of end-of-life care, such as symptom management and psychological and spiritual support (Davison 2010). Finally, the high quality holistic care delivered by specialised palliative care teams is an important element for improving the quality of life of patients and their carers (Hobson K *et al.* 2011)

**Limitations**

The proportion of carer informants who agreed to be interviewed in the first phase was less than 50% (12) of the total number of carers who were contacted (25). The reasons for declining to participate in the study, included the fact that many of them had to deal with flooding during the rainy season in Thailand, and some of them said that they had moved house from rural areas in Chiang Mai province to urban areas in Bangkok in order to get a job. A few said that they were busy as they had to work seven days a week and therefore would have no time available for interview. This refusal to engage in face-to-face interviews could have been reduced by offering telephone interviews for these participants.

**Conclusions**

Patients experienced a range of negative impacts whilst being managed without dialysis and that for some their suffering was severe, with uncontrolled symptoms and renal complications alongside physical symptoms (breathlessness, pain and oedema), psychological symptoms (worry and low mood) and spiritual distress during their last year at home. These findings reveal important information about the symptom experiences and health care needs and service utilization of this elderly population in Thailand. Through listening to carers’ accounts of their experiences, a mismatch between patients’ needs and services received has been demonstrated. Future research is required about carers’ perspectives, including their information needs associated with patients’ prognoses, treatment options, and appropriate communication to support patients at the end of life. Concurrently, more research is needed to explore and understand attitudes to the needs of this group among healthcare professionals and assess what education and training needs they have.

**Acknowledgements**

This study was supported by Chiang Mai University, Thailand and Faculty of Health Sciences, University of Southampton, United Kingdom. The authors whould like to give special thanks to their participants who graciously gave their time to take part in this study.

**References**

Adams E, Boulton M, Rose PW, Lund S, Richardson A, Wilson S and Watson EK (2012) A qualitative study exploring the experience of the partners of cancer survivors and their views on the role of primary care *Support Care Cancer*

Addington-Hall J (2002) Research sensitivities to palliative care patients. *European Journal of Cancer Care (England)* 11(3): 220-4

Ansell D, Fehally J, Feest TG and Al. E (2007) 10th annual report of the Renal Association. UK: UK Renal Registry, UK

Creswell JW and Plano Clark VL (2011) *Designing and conducting mixed methods research.* Sage Publication: Thousand Oaks, California.

Davison SN (2010) End of life care preferences and needs: Perceptions of patients with chronic kidney disease. *Clinical Jornal of America Society of Nephrology* 5: 195-204

Elkington H, White P and Addington-Hall J (2005a) The last year of life of chronic obstructive pulmonary disease: The carers' perspective. *Journal of Thorax* 60: Ii71-Ii71

Elkington H, White P, Addington-Hall J, Higgs R and Edmonds P (2005b) The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life. *Palliative Medicine* 19(6): 485-91

Elkington H, White P, Addington-Hall J, Higgs R and Pettinari C (2004) The last year of life of COPD: a qualitative study of symptoms and services. *Respiratoy Medicine* 98(5): 439-45

Hanratty B, Lowson E, Holmes L, Grande G, Addington-Hall J, Payne S and Seymour J (2012) Funding health and social services for older people - a qualitative study of care recipients in the last year of life. *Journal of the Royal Society of Medicine* 105(5): 201-7

Hobson K, Gomm S, Murtagh FE and Caress AL (2011) National survey of the current provision of specialist palliative care services for patients with end-stage renal disease. *Nephrology Dialysis Transplantation.* 26(4): 1275-1281

Kongsuwan W and Locsin R (2011) Thai nurses’ experience of caring for persons with life-sustaining technologies in intensive care settings: A phenomenological study. *Intensive and Critical care Nursing* 27(2): 102-110

Kongsuwan W and Locsin RC (2009) Promoting peaceful death in the intensive care unit in Thailand. *International Nursing Review* 56: 116-122

Levey SA, Et Al. (2003) National kidney foundation practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *Journal of American College of Physicians* 139: pp 137-147

Munshi SK, Vijayakumar N, Taub AN, Bhullar H, Lo NTC and Warwick G (2001) Outcome of renal replacement therapy in the very elderly. *Nephrology Dialysis Transplantation* 16: 128-133

Murtagh F, Addington-Hall J and Higginson IJ (2007a) The prevalence of symptoms in end-stage renal disease: a systematic review. *Advanced in Chronic Kidney Disease* 14(1): 82-99

Murtagh F, Addington-Hall JM, Donohoe P and Higginson IJ (2006) Symptom management in patients with established renal failure managed without dialysis. *Journal of Renal Care* 32(2): 93-8

Murtagh F, Addington-Hall JM, Edmonds PM, Donohoe P, Carey I, Jenkins K and Higginson IJ (2007b) Symptoms in advanced renal disease: A cross-sectional survey of symptom prevalence in stage 5 chronic kidney disease managed without dialysis. *Journal Palliative Medicine* 10(6): 1266-1276

Murtagh F, Sheerin NS, Addington-Hall J and Higginson IJ (2011) Trajectories of illness in stage 5 chronic kidney disease: a longitudinal study of patient symptoms and concerns in the last year of life. *Clinical Journal of the American Society of Nephrology* 6(7): 1580-90

Murtagh F, Spagnolo AG and Panocchia N (2009a) Conservative (non-dialytic) management of end-stage renal disease and withdrawal of dialysis. *Progress in Palliative Care Journal* 17(4): 179-186

Murtagh FEM, Spagnolo AG and Panocchia N (2009b) Conservative (non-dialytic) management of end-stage renal disease and withdrawal of dialysis. *Progress in Palliative Care Journal* 17(4): 179-186

Narenpitak S and Narenpitak A (2008) Prevalence of chronic kidney disease in type 2 diabetes in primary health care unit of UdonThani province, Thailand. *Journal of Medical Association Thai* 91(10): 1505-1513

Noble H, Kelly D and Hudson P (2012) Experiences of carers supporting dying renal patients managed without dialysis. *Journal of Advanced Nursing* 69(8): 1829-1839

Noble H, Kelly D, Rawlings-Anderson K and Meyer J (2007) A concept analysis of renal supportive care: the changing world of nephrology. *Journal of Advanced Nursing* 59(6): 644-653

Noble H, Meyer J, Bridges J, Johnson B and Kelly D (2010) Exploring symptoms in patients managed without dialysis: A qualitative research study. *Journal of Renal Care* 36(1): 9-15

Noble H, Meyer J, Bridges J, Kelly D and Johnson B (2008) Patient experience of dialysis refusal or withdrawal: A review of the literature. *Journal of Renal Care* 34(2): 94-100

Polit DF and Beck CT (2012) *Nursing research : generating and assessing evidence for nursing practice.* (9th Edition)Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins

Tallis K (2005) How to improve the quality of life in patients living with end stage renal failure. *Renal Society of Australia Journal* 1(1): 18-24

World Health Organization.(2004) *A community health approach to palliative care for HIV/AIDS and cancer patients in Sub-Saharan Africa.* Available from: <http://www.who.int/cancer/publications/community_health_approach/en/index.html> [Accessed 15/05/12]

Yodchai K, Dunning T, Hutchinson AH, Oumtanee A and Savage S (2011) How do Thai Pateints with End Stage Renal Disease Adapt to Being Dependent on Haemodialysis? A Pilot Study. *Journal of Renal Care* 37(4): 216-223

Zalai D, Szeifert L and Novak M (2012) Psychological distress and depression in patients with chronic kidney disease. *Seminars in Dialysis* 25(4): 428-438