Exploring symptoms in patients managed without dialysis: a qualitative research study.


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EXPLORING SYMPTOMS IN PATIENTS MANAGED WITHOUT DIALYSIS:
A QUALITATIVE RESEARCH STUDY

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SUMMARY
Little is known about the prevalence and burden of symptoms in patients managed without dialysis. This study was the result of a larger study exploring the experiences of 30 such patients and their trajectories to death, data were analysed relating to symptoms once the patients had been referred to a Renal Supportive Care Service based in the East End of London, UK. A high symptom prevalence was found with 30 different symptoms reported at first consultation. Widely reported symptoms impacting on daily living included breathlessness, oedema, pruritus, nausea and vomiting and pain. Findings indicate that as symptoms escalate and death approaches, some symptoms, such as fluid overload and lethargy become difficult to treat indicating that death is close. This new knowledge can help staff as they attempt to determine when the end of life is approaching in order to support and care for patients appropriately. This paper highlights a need for effective identification and management of symptoms as they arise and further exploration of the effects of these symptoms on daily living.

KEY WORDS Nursing • Palliative Care • Psychosocial • Research

BACKGROUND
Although there is much evidence related to symptoms for those with cancer (Coyle 2004; Friedrichsen and Erichsen 2004; Lindqvist et al. 2004; Potter 2004; Souter 2005; Hopkinson et al. 2006), evidence concerning the prevalence and burden of specific symptoms of patients opting not to

BIO DATA
Helen Noble BSc, DMS, RGN has extensive research expertise in nephrology nursing particularly related to those who opt not to embark on dialysis. She is presently working as a lecturer in adult Nursing at the School of Community and Health Sciences, City University, London as she completes her doctoral studies. Her research interests lie in patient experience using a practitioner research approach. Her work has led to international interest and debate. She is a member of the European Dialysis and transplant Nurses Association, on the Editorial boards of the Journal of Renal Care, End of Life Journal, Turkish Journal of Nephrology Nursing and the British Journal of Nursing. Helen’s research constitutes a contribution to health care management for those coming towards the end of life in the field of nephrology. It also includes development in practitioner research methodologies. Recently she was nominated by the World Scientists Forum for ‘Eminent Scientist of the year 2009’ International Award in the field of Nephrology.

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have dialysis is limited (Noble and Rees 2006). There remains a need for effective identification and management of symptoms as they arise in this population alongside acknowledgement of the symptom burden faced by patients.

The palliative needs of those patients with stage 5 CKD managed without dialysis may be at least as great as for patients with cancer. Saini et al. (2006) explored the similarities, and aimed to highlight any differences in symptom burden between patients with stage 5 CKD not having dialysis, and those with advanced cancer. There was no significant difference between the two groups in the symptom profile overall.

More recently, Murtagh et al. (2007) have reported on symptoms in advanced renal disease in patients managed without dialysis and found that patients suffered a mean of 11.58 symptoms requiring symptom control similar to those with advanced cancer.

Given the paucity of literature in this area, these two studies are important. Although it is helpful to undertake quantitative studies of this nature, it is evident that answers gained by survey would be greatly enhanced if patients were allowed, through interview, to supplement their responses with rich qualitative data. This paper reports on this, which is such a study.

METHODS

The original study, of which this smaller study is the result, analysed the data of 30 patients and their experiences after the decision not to embark on dialysis had been made. The data relating to their symptoms were analysed once they had been referred to a Renal Supportive Care Service (RSCS) based in the East End of London, UK. The service has been described in the literature (See Noble et al. 2007). The study was exploratory, interviews and observation data were gathered during naturally occurring consultations (n = 73) with patients and/or carers who were seen in the nurse-led RSCS based in the East End of London, UK. All patients referred to the service were asked to participate in the study. Thirty were recruited from October 2006 to October 2007 and all consented to participate along with 17 carers. Each patient was referred with an eGFR below 15 or stage 5 CKD.

Ethical approval was obtained from the local ethics committee. Patients were seen three-monthly and interviews took place until death or study end in June 2008. Consultations with the researcher either took place in the nurse-led clinic or in the patient’s home if he/she was too unwell to attend the hospital. The naturally occurring clinical consultation served as the interview with patients and carers. The only difference at the consultation was that it was tape-recorded with the consent of those present. Sometimes carers were in attendance or, when a patient was unable, or did not wish to participate in the interview, the interview took place with a carer. Many patients or their carers were interviewed more on than one occasion. The total number of interviews completed equalled 75.

The clinical consultation was the primary means of data collection to explore in-depth, with patients and carers, their experiences and needs once they were managed within the RSCS. The consultation was based on an interview schedule developed for use in the service adapted from an interview schedule used by the Hospital Trust’s local Palliative Care Team. Although the schedule highlighted a number of questions to be asked, such as how the patient’s main worry had been dealt with since the last consultation, in reality the interview was open and driven by the patients’ or carers’ needs and preferences. This enabled a more person-centred approach to be taken and allowed for the identification of key problems and experiences as articulated by the participants. This was important as the staff were unaware of which issues required attention and had to work this out intuitively while caring for patients and listening to their concerns. A key feature of these consultations as a research method was their ability to provide an in-depth personalised perspective of the experience for study participants. They also allowed for an opportunity to clarify and further understand the research issues being studied (Ritchie 2003).

Written consent was taken and continuing consent checked at subsequent clinic or home visits. Participants were given reassurance that if they became uncomfortable about any information disclosed, it would not be used, once this had been requested. Apart from the one patient who withdrew from the study after his first interview, no requests to withdraw data were received. It was explained that findings would be anonymised. All interviews were taped and transcribed verbatim.

FINDINGS

THE SYMPTOMS

A high symptom prevalence was found in the patients in the study. Thirty different symptoms were reported at first consultation and included: altered taste, breathlessness, pruritus,
lack of energy, dizziness, pins and needles in legs, nausea, vomiting, diarrhoea, constipation, poor appetite, poor balance, trembling, pain, immobility, insomnia, depression, poor memory, sore mouth/tongue, confusion, aching body, cramps, poor vision, weight loss, weakness, incontinence, phantom pain, difficulty swallowing, dry skin and headaches. Common reported symptoms can be seen in Table 1. The symptoms most widely reported are now described.

Oedema
Oedema was a problem for all except one patient in the study. Patients presented with foot or leg oedema, initially treated successfully with small doses of diuretics (usually 40 mg furosemide), which could be increased if the oedema did not resolve or returned (up to a maximum dose of 250 mg). Once oedema became difficult to treat with oral diuretics, the only option was admission to hospital for intravenous diuretics. Associated breathlessness as the fluid accumulated was often also noted. Mary, prior to her last admission to hospital had considerable problems with fluid overload and oedema, which affected her ability to remain at home and be cared for. Agnes, her carer, described her last days:

*Agnes*: And then she [Mary] had a fall in the bathroom and we picked her up and it was kind of downhill from there. And the main problem was the fluid on the legs, which made her more and more immobile, ... so I think the fluid was gradually coming up ... And by the weekend [she died] she was quite chesty and breathless

Pain
Different types of pain were widely reported by 27 patients and included pain due to arthritis, a fractured hip, leg ulcers and cancer. No patient had pain due to renal disease specifically. A multitude of conditions could cause pain. Diane had pain due to an unknown cause and had to undergo tests in order to determine a diagnosis that would explain it:

*Diane*: I just went up for a test because at the time, I was getting awful bad pain, underneath my rib, ... they wanted to find out what was causing it, and they went through all these different things, like x-rays ... and they took me down and give me a thing down the throat, a camera down the throat, and he told me it was lung cancer.

Nausea and vomiting
Nausea and vomiting were suffered by 27 patients. Whatever the initial cause, anti-emetics were prescribed and seemed to help. Occasionally nausea and vomiting were short-lived and well managed with ‘as required’ medication.

Mary: I still have the symptoms that I always have had with this [the kidney disease], but I have the cure for each of the ones, you know ... The thing for sickness and this that and the other. I don’t get sick as much as I used to.

Mary’s nausea was related to uraemia but some patients presented with nausea and vomiting related to other problems. At one consultation John clearly had a chest infection, causing him nausea and Raymond had constipation, which he attributed to his feelings of nausea. Often it was difficult to decide if the nausea was attributed to the uraemia or another problem, although an antiemetic was usually offered in either case.

Immobility
Immobility and problems with walking, standing and the ability to be active and self-caring were problems for 20 patients in the study. Patients complained of ‘feeling trembly’ in their legs, having a fear of falling, painful knee and hip joints that made walking difficult and general dizziness and poor vision that could hamper the ability to be independently mobile. Often it was difficult to determine why patients were immobile and the cause was put down to old age or other diseases that might limit the ability to mobilise freely.

Bowel and bladder problems
Difficulties related to incontinence and altered bowel habits were alluded to by 16 patients in the study. Medications such

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Oedema</th>
<th>Pain</th>
<th>Nausea/vomiting</th>
<th>Immobility</th>
<th>Bowel and bladder problems</th>
<th>Lethargy</th>
<th>Breathlessness/dyspnoea</th>
<th>Pruritus</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>96</td>
<td>90</td>
<td>90</td>
<td>60</td>
<td>53</td>
<td>53</td>
<td>50</td>
<td>47</td>
<td>37</td>
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Table 1: Commonly reported symptoms.
Breathlessness

Breathlessness was suffered by 21 patients in the study at some point in their trajectory to death. Sometimes it was due to fluid overload caused by renal disease and/or associated anaemia. Occasionally, other diseases caused this problem. Arnold suffered from COPD and had been breathless for some time. Noble et al.

Lethargy and insomnia

Feeling tired with concurrent lethargy was common, with 26 patients finding this debilitating and adding to the feeling that life was not as it previously had been, where daily chores, tasks or social needs had been attended to with ease. Fatigue could be due to a number of reasons, including the inability to sleep well at night, depression, anaemia, poor nutrition, medication and possibly uraemia. Determining its cause was difficult. Samuel complained of feeling 'Tired, tired, tired'. Gillian attributed her tiredness to her heart failure. Lethargy, especially that associated with the approaching end of life, was distressing for patients and staff alike.

Pruritus

Pruritus was problematical for 21 patients at some time in their illness trajectory. In the study, pruritus was often persistent and something that some patients lived with. Occasionally it led to other problems:

Raymond: But then I had an itch like you do, and scratched it just like that, without any notice, and I noticed that I had made it bleed. It then wasn’t bleeding but a great big ulcer came up, a great big thing it was. It burst and it’s in a right state now, I just hope that it doesn’t get any worse.

Raymond ended up with an ulcer that required regular dressing by a district nurse and this became another nuisance that he had to contend with alongside other troublesome symptoms.

Depression

Depression was reported by 11 patients in the study. Often the depression was attributed to an inability to do the things that patients had previously been able to do with ease, but others were depressed due to the decision not to have dialysis. Alfred initially felt ‘right down’ when he was told that he would not be a suitable candidate for dialysis and Abdul, although he refused dialysis as he did not want to attend hospital three times a week for treatment, became depressed after overhearing a doctor say ‘the possibility is that he will die’.

Identifying symptoms indicating that death was near

Of the 30 patients recruited, 17 died during the study. Many suffered symptoms that indicated kidney function had deteriorated to such a point that life could no longer be sustained. Symptoms included extreme tiredness and lethargy, where patients felt unable to get out of bed, and oedema that had become difficult to manage with diuretics. Appetite was often reduced to such a point that little sustenance was ingested and was associated with nausea and vomiting in those following a uraemic trajectory to death. Although several patients in the study received acute medical intervention when close to death, quite a few showed signs that death was approaching as their kidney function decreased. Abdull’s daughters talked about his last days of life and how he reached the stage where he could not leave his bed. Weakness and lethargy were described, which eventually led to an inability to communicate:

Salma: But still he would be talking to us normally, everything was fine, and then he got to a stage where he couldn’t get out of bed and he got too weak then he was too tired even to come to the next room. ... And then slowly, slowly what happened he started not talking to us, he went a bit mute ... Like we would talk to him he wouldn’t reply back and we just have to make his mind up for him and then after that he started deteriorating really fast, didn’t he?
Often there was pruritus, sometimes incontinence and regularly oedema. When oedema became difficult to treat, the end of life could often be predicted.

For some reason not readily understood, pain often became a problem towards the end of life. Sometimes it was due to the underlying condition causing the original pain. For example, Raymond’s arthritic pain greatly increased and Akbar’s cancer pain required very strong analgesia. Others, such as Ada, had suffered pain much of her later life but this increased in her last days of life, as explained by her son, for reasons that were not quite clear:

**Jack:** She was in considerable pain, I think, that is why when I spoke to that doctor that she [the doctor] actually phoned me to ask my permission to give her the painkiller. She explained you know, the fact that there was nothing else that she could do, and my mother was in so much pain, and she really felt that...She was always in some form of pain but I think that she was screaming out with it so the pain was considerable.

**Helen:** Do you know what that pain was caused by?

**Jack:** I think, I may have been told, I am not absolutely certain I know. I am not absolutely certain (ES).

In many cases patients deteriorated rapidly in the last few weeks of life, having been relatively stable for many months or even years. Many of the patients had a period of time when it could be identified that they had deteriorated before they finally died. It was inevitable for these people that the end of life was approaching, sometimes this was relatively well managed, especially if the patient suffered a uraemic death, as did Raymond who was cared for at the local hospice, his uraemic symptoms promptly identified and treated effectively. Other patients had been in and out of hospital on several occasions over a period of years, but there was ultimately a clear identifiable swift path to death, as in Ada and Sana’s case. Sana’s last weeks included several renal symptoms, including nausea, vomiting and oedema, all of which were well managed as described by a Clinical Nurse specialist (CNS) (working within the RSCS):

The symptoms she got were nausea and vomiting and the pain, other than that she was fine. She only became oedematous recently, on her last week. She had enough support from the district nurses. We had Macmillan night time sitters ... The family was really happy she was comfortable and she coped (CNS).

The symptoms expected from those dying a renal death were very similar to those withdrawing from dialysis, so generally they could be planned for. However, in some cases patients who deteriorated did not die as expected. This unanticipated phenomenon demonstrates that predicting that someone was in the process of dying is not always reliable.

**DISCUSSION**

The patients in the study suffered a number of problematic symptoms causing distress. This paper highlights a need for effective identification and management of symptoms as they arise and further exploration of the effects of symptoms on daily living. Importantly it throws light on some symptoms that presented indicating that the end of life was approaching. No other work has explored symptoms in a qualitative manner.

Only one study, which is quantitative in nature, of symptom prevalence in patients managed without dialysis, has been carried out (Murtagh 2008) since the present study finished. The majority of symptoms uncovered in the present study have also been identified in Murtagh’s (2008) work and therefore add credibility to findings from this study. Symptoms uncovered in the present study, not reported in Murtagh’s work, include: trembling, poor vision and phantom pain, indicating that different methodologies may uncover varying symptoms (Murtagh used quantitative methods), but the number of symptoms uncovered with each research method was high. Some symptoms were reported due to specific problems, such as phantom pain in a lady who had undergone a limb amputation, demonstrating that the symptoms reported might vary depending on other comorbidities suffered by the patient.

Murtagh’s (2008) study focused on symptom data collected at baseline and a month before death, whereas the present study took note of symptoms at any point in the disease trajectory, whenever they were identified by patients as problematic, therefore this study collected information on symptoms that could have been present at any point in the patient journey through the service. The present study allowed patients to use their own words to discuss the symptoms causing them concern, encouraging them to report what was of most
importance to them. It is possible that this has led to a more accurate picture of the symptom burden in this population. Alternatively, some symptoms that patients were experiencing may not have been reported and explored, as the more serious issues took precedence at consultation with the researcher. The qualitative approach also allowed illustration of the impact of symptoms on people’s lives, which is less easy to gauge with quantitative tools. Clearly there are strengths and limitations to each methodological approach.

Symptoms in those managed without dialysis can be compared to those with cancer. Work by the Symptom Prevalence Group (Vainio and Auvinen 1996) identified common symptoms in 1,640 patients with cancer. Findings can be viewed in Table 2.

Although there are some difficulties in comparing previous work with the present study, as not all symptoms can be compared like for like, it can be seen that renal patients who are managed without dialysis, experience problems such as pain (90% vs. 57%), nausea (90% vs. 21%), dyspnoea or breathlessness (50% vs. 19%) and bowel problems (53% vs. 23%) more often than do cancer patients. They also suffer more symptoms than those reported in the cancer population (9 vs. 6 symptoms).

Specific symptom management has not been fully explored in this population, although it is presumed that some symptoms can be managed successfully using knowledge and evidence from those managed with dialysis. For example: pain might be treated with haloperidol (Germain and McCarthy 2004) and insomnia with temazepam (Germain and McCarthy 2004). Whatever the treatment, a full assessment will be required to determine the severity of symptoms prior to treatment (Noble 2009).

Although this study has explored the symptom burden, considerable gaps remain in understanding the symptoms that patients, managed without dialysis, experience (Noble and Chesser 2009). Research into the incidence and prevalence of symptoms in these patients, the causes of symptoms and interventions that can relieve them is urgently required (Murtagh 2007). Research needs to be directed toward the symptoms that patients and carers report as being most problematic and as this study demonstrates, may include breathlessness, pruritus, lethargy, insomnia, nausea and vomiting and pain. Little is yet known about the relative impact on patients of specific symptoms such as those listed that may seriously compromise function or cause alarm. It may also be that palliating symptoms will decrease anxiety in patients, for example, managing breathlessness may relieve the fear this causes if experienced. Evaluation of treatments designed to offer palliation in those managed without dialysis is required and a range of symptoms assessed and monitored before it can be claimed that treatments are effective. Knowledge of symptom profiles and patterns of change in patients may help practitioners prevent them as well as relieve distress, and ultimately provide optimum palliative care.

In order to explore changes in symptoms over time, more longitudinal studies are needed following the patient until death. Identifying troublesome symptoms and knowing how best they are managed through the disease process as the end of life approaches will help ensure that symptoms are managed and quality of life is improved even until the end of life.

CONCLUSION

The findings presented in this paper are of immense importance and uncover many of the difficulties created by symptoms that are encountered by renal patients not treated with

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Pain</th>
<th>Anorexia</th>
<th>Constipation</th>
<th>Nausea</th>
<th>Dyspnoea</th>
<th>Insomnia</th>
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<tbody>
<tr>
<td>Percent</td>
<td>57</td>
<td>30</td>
<td>23</td>
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<td>19</td>
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Table 2: Reported prevalence of symptoms in patients with cancer (n = 1,640).
EXPLORING SYMPTOMS IN PATIENTS MANAGED WITHOUT DIALYSIS: A QUALITATIVE RESEARCH STUDY

dialysis. The findings focus on a population with a high symptom burden requiring symptom control. Distressing symptoms suffered included breathlessness, pruritus, lethargy, insomnia, nausea and vomiting and pain. Assessment needs to be focused on identifying these symptoms in particular, with targeted interventions to alleviate them once identified. Symptoms may also have psychological and social consequences that need consideration. Assessment and intervention should not purely focus on pharmacological interventions but include appropriate psychological and practical support. For example, in this study, massage was identified as beneficial in relief of pain. Symptoms are often under-recognised and under-treated but staff require specific training with the knowledge of symptom assessment incorporated into routine clinical practice. Findings from the present study also indicate that as symptoms escalate and death approaches, some symptoms, such as fluid overload, pruritus and lethargy, become difficult to treat indicating that death is close. This new knowledge can help staff as they attempt to determine when the end of life is approaching in order to offer appropriate support and care for patients and carers.

ACKNOWLEDGEMENTS

The author Helen Noble has no conflict of interest.

REFERENCES


Author Queries

Q1  Wiley-Blackwell: Please check the style of citation of conflict of interest in ‘Acknowledgement’ section.
Q2  Author: Please provide the name and location of the publisher for reference Noble (2009).