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Time, timing, talking and training: findings from an exploratory action research study to improve quality of end of life care for minority ethnic kidney patients

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Abstract

Background. With an ageing and increasingly diverse population at risk from rising levels of obesity, diabetes and cardiovascular disease, including kidney complications, there is a need to provide quality care at all stages in the care pathway including at the end of life and to all patients.

Aim. This study purposively explored South Asian patients' experiences of kidney end of life care to understand how services can be delivered in a way that meets diverse patient needs.

Methods. Within an action research design 14 focus groups (45 care providers) of kidney care providers discussed the recruitment and analysis of individual interviews with 16 South Asian kidney patients (eight men, eight women). Emergent themes from the focus groups were analysed thematically.

The research took place at four UK centres providing kidney care to diverse populations: West London, Luton, Leicester and Bradford.

Results. Key themes related to time and the timing of discussions about end of life care and the factors that place limitations on patients and providers in talking about end of life care. Lack of time and confidence of nurses in areas of kidney care, individual attitudes and workforce composition influence whether and how patients have access to end of life care through kidney services.

Conclusion. Training, team work and time to discuss overarching issues (including timing and communication about end of life) with colleagues could support service providers to facilitate access and delivery of end of life care to this group of patients.

Key words: culturally competent, diversity, ethnicity

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Introduction

Inequalities in outcomes and access to services have been documented as common experiences for minority ethnic groups in the UK [1]. South Asian communities have a higher prevalence of type 2 diabetes-related end-stage kidney failure (ESKF) and a relative risk of acceptance rate to kidney replacement therapy of 5.8 compared with the White European population [2]. These problems are compounded in the kidney setting by the longer waiting times that South Asians experience for suitable donor organs [3] and the disproportionately higher number of South Asians experiencing ESKF and cardiovascular disease complications [4] contributing to a demand for end of life care.

Much of the research about patient experience of care to date has been conducted with English-speaking patients, which is a limitation [5] and means there is little evidence for professionals to guide culturally competent end of life care for minority ethnic patients. This project purposively focused on South Asian (those originating from India, Pakistan and Bangladesh) patients, their experience and that of their care providers to inform delivery of care across diverse patient populations.

This study explored end of life care for South Asian patients across haemodialysis, peritoneal dialysis (PD) and conservative care pathways, to identify where there are inequalities in access and experience of end of life care. An action research approach was used as this would support the emergent testing of what was understood about inequalities in end of life kidney care at the outset, which was that: generalizable lessons could be drawn from existing practice; communication and engagement underpins culturally competent end of life care; and integration of culturally competent end of life care is associated with perceptions of quality, skills and resources.

Materials and Methods

Four kidney services were recruited to take part in the study via one of their consultants who acted as principal investigator (PI) for their site. These were West London, Luton, Leicester and Bradford, and had been selected as they all provided specialist kidney care to a diverse patient population that included South Asian communities and together included the predominant South Asian groups in the UK. Each site was a case study in an action research process [6] described in Figure 1 [7].

The site PI recruited patients who fulfilled the inclusion criteria—South Asian patients over 18 years old receiving end of life care or

aware that they will soon be receiving end of life care—to take part in a single interview; and service providers who fulfilled the inclusion criteria—involved with planning, developing or providing end of life care to renal patients—to take part in up to three focus groups. Both interviews and focus groups lasted up to 1 h in duration and patient interviews were conducted in the participant's preferred spoken language and at their choice of location, which was usually their home.

A team of research interviewers, the majority of whom were bilingual in the main South Asian languages spoken in the UK, conducted the patient interviews and the lead researcher (E.W.) conducted two of the interviews and facilitated the focus groups at each site. The research was approved by an NRES ethical committee (ref no. 09/H0301/62) and informed consent using approved project information was taken from participants prior to each interview and focus group. These were audio recorded, translated as required and transcribed verbatim into Word documents for analysis.

Transcripts were checked for accuracy by members of the research team at the Institute for Health Research, University of Bedfordshire before being analysed thematically [8]. Emerging themes from patient interview data were fed into subsequent focus group discussion and themes from the latter analysed in the same way (Figure 1). This action research process enabled focus group discussions that included clarification, interpretation and disagreement so that the themes reported had been through an iterative process of critical reflection.

Data analysis was carried out by the lead researcher who is experienced in action research and qualitative research analysis, specifically thematic analysis [9]. The chief investigator for the research provided oversight for the data analysis and the rest of the authorship team were involved in the discussion of findings and dissemination of findings including for this publication. This article reports on the analysis of all the service provider focus groups and results are organized under the overarching themes—time, timing, talking and training—that were present in the data from all groups as described below. Tables 1–6 contain extracts from data which illustrate these themes.

Ethical approval for this project was given by Essex 1 Research Ethics Committee, ref. no. 09/H0301/62.

Results

Time

Service providers felt that the time to talk to patients and their families was important. Clinicians working in the community

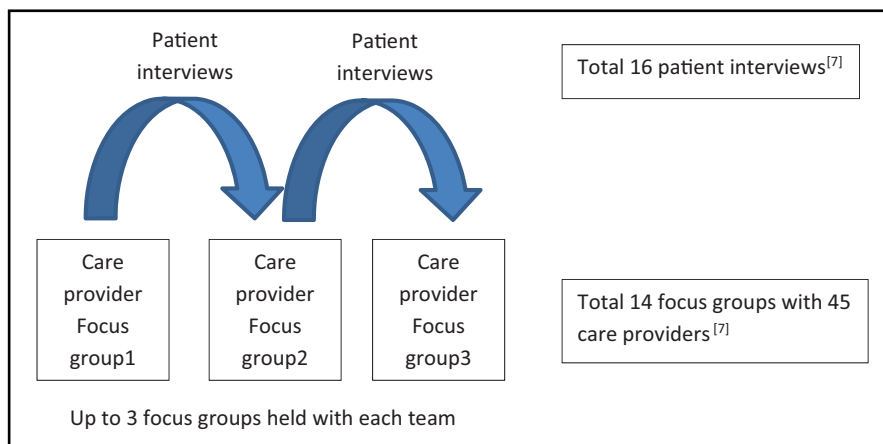


Fig. 1. Emergent analysis discussed in focus groups.

Table 1.

'I've heard nurses say that they try their best not to talk to patients in much detail because they know that if they do that for ten minutes then that delays their next job by ten minutes, which is awful but, you know, you can see it from their side, their point of view, that means somebody else is ten minutes late going on and that patient would be really annoyed with them because they'd been an extra ten minutes in the waiting room. And you can just imagine that if it was a conversation that was – they knew was going to be difficult and time consuming, they wanted to give that patient the time, that it might just be easier to delay that because they've got so many other things to do.'

(Care provider 6 FGA3)

Table 2.

'That's where I think we have the problem, if you feel that these conversations have to end in an "end of life" discussion, then, of course, you're going to avoid them. But actually the conversations don't need to end like that, they can just identify what the issues are and you can still say to the patient "OK, I'm hearing what you are saying and I think we really need to give this more time and give you a chance to talk about this with Dr X, sister X", you know ... and that's what you need to tell the nurses. They should be encouraging the conversations but they don't need to take them to a full "oh, so let me", they don't have to go through the options at that point.'

(Care provider 2 FGF2)

Table 3.

'It can make it more difficult when they hit a crisis and, you know, we haven't had that discussion and, you know, and particularly if they're under a different care team in an acute situation rather than the PD team. They come in out-of-hours, maybe at the weekend, it's an entirely different set of doctors that maybe, that don't have the relationship we have with the patient, maybe have a different set of beliefs to the way we run things within PD and then the management plan could completely change and you could find someone who you thought was on a palliative care sort of pathway leaning towards that sort of end of life stage in their, you know, stretch of their illness, you come in and find they've got a line and they're on haemo and it's completely gone against what we thought we were planning.'

(Care provider 2 FGE2)

Table 4.

'It can be fairly complicated because mother has never made any decisions for herself, why should she all of a sudden, us telling her you are person in your own right and should have a say about this; she is quite happy not voting, you know, ... voluntarily, she got the right to vote ... it's too much of a change for them to have a voice or an opinion on matters which concerns their care.'

(Care provider 3 FGD1)

and in outpatient clinics were more able to give more time than colleagues working in the acute and dialysis setting. Follow-up visits helped to provide information in a staged manner and at a pace that allowed patients time to understand, clarify and make decisions about their care during the end of life phase.

Table 5.

'If we go back to basics it's about exploring our own feelings first before we can deliver it to anybody else and if you never feel comfortable with it you'll never get on top of that. So the first thing to address is to actually understand how we feel personally about that because you'll always try to make it okay for the patients ... and that's actually not being helpful. And so you're also not perhaps able to set the scene properly for them as to what they can expect and what the people around you can expect.'

(Care provider 2 FGB2)

Table 6.

'I think it's a lot to do with the confidence of those nurses though and perhaps lack of wider experience. I think quite often nurses who work on the dialysis unit they may go there – correct me if I'm wrong – quite often there are people with a broader experience of working lots of specialities and some have to go in there relatively early in their careers, so they've not maybe got a wider, you know, experience. Our dialysis unit is half staffed by people from overseas, you know ... who – there might be some reverse cultural barriers.'

(Care provider 1 FGA3)

Nurses working in dialysis units, in contrast, were perceived not to have time to identify and talk to patients about end of life issues that might surface, because of the need to keep to schedule and to get through the practical tasks of dialysis. Furthermore, participating haemodialysis nurses felt that it was not an appropriate time, while patients were attending the dialysis unit, to discuss end of life care issues and rather that these should only be discussed during clinic appointments with the patient's consultant who was the patient's lead clinician (Table 1).

If South Asian patients required interpreters for communicating with service providers this took up additional time in encounters. Again this was more possible within scheduled outpatient or community appointments but not always possible in acute, dialysis or emergency scenarios. Providers of care on a haemodialysis unit explained that talking to family members by telephone, encouraging patients to bring family members with them to clinic appointments and, if necessary, increasing the frequency of appointments, were means of compensating for communication barriers that exist for non-English speaking South Asian patients, as well as being part of good care for all patients who may need an advocate.

Involvement of patients' family members and rapport built through repeat contacts helped to facilitate communication and end of life decision-making with patients on peritoneal dialysis. The importance of an on-going and gradual approach over time (where possible) was echoed in other focus groups. Participants described the need for time to revisit and continue dialogue when patients and their families found it difficult to accept that there was no more medical intervention that would change the prognosis, and for decision-making about palliative care to take place through several iterative conversations, often with different members of the care team, allowing time for other issues, such as depression, to be addressed and patients' preferences revisited.

The increase in size of dialysis units was thought to have affected the time and direct contact that senior nurses had had in the past to develop communication and a depth of knowledge about individual patients that would have enabled easier

conversations about end of life care to progress when appropriate. Lack of time and staff meant less time available to talk to patients as well as colleagues over and above the more practical hand-over process. Not having time to talk through the generalities of care with colleagues, such as how to handle conversations about end of life care, was raised as an issue where emotional support was seen as an important element of care and part of the haemodialysis team's responsibility as the patient's main care provider (Table 2).

Timing

The point at which patients are considered by clinicians to be entering the end of life care phase varied across the different participating teams and was reflected in the patient sample that included a number of patients on a conservative care pathway who were early on in the end of life phase as well as other patients who were nearer dying, and some were on dialysis.

Service providers articulated the difficulty in identifying when patients are reaching the end of life phase as patients were described as the 'survivors' of their cohort and as 'bouncing back' and having 'nine lives'. They were not surprised that some patients did not consider themselves at the end of life stage if they were still dialysing and had not transitioned in their minds from active 'hopeful' to palliative 'hopeless' type of care. This dichotomy and language was challenged by other clinicians as being 'unfortunate and disappointing' if it reflected a perception that patients might have.

Some of the teams were at different stages in developing a 'cause for concern', or similarly named, register for identifying and monitoring change in a patient's health that might prompt a change in their care. Whether identification of a patient as 'cause for concern' always triggered conversations with patients, in line with the principles of informed consent and disclosure, was unclear because care providers reported that there was a range of different attitudes and opinions held by colleagues about the benefits or not of discussing end of life and advance care planning early on with patients.

End of life care planning was included from the outset in the annual reviews conducted by one participating consultant in order for there to be an on-going opportunity to revisit the issues and patient concerns, but such an explicit approach was not reported by other teams. Even with timely discussion, however, and the advance care planning that took place with some patients and families, participants reported examples of when patient wishes to die peacefully at home were not achieved. This happened when the family felt unable to cope at 'crises' points during the patients' last phases of life resulting in emergency assessment and admission to a hospital where they either died or were put on haemodialysis that prolonged the dying phase (Table 3).

Talking

It was suggested by some participants that South Asian patients were less likely to have thought through their wishes concerning end of life care compared with White Europeans. Others thought that the timing and willingness to discuss end of life was linked to gendered and generational attitudes towards discussion and autonomy in healthcare encounters, which was supported by patients' descriptions of their involvement in decision-making with clinicians (Table 4).

Services providers described the different ways in which communication with patients about end of life care usually took

place. In the PD setting, this evolved through the on-going contact that members of the clinical care team have with patients and their families. Groups of clinicians from dialysis units reported that the conversations about end of life care took place mainly with the patient's renal consultant or with palliative care specialists if referred.

Having a diverse renal care workforce also meant that at several of the sites there were bilingual members of staff whose language skills were drawn on to facilitate communication with patients where appropriate and if available. Other ways that talking with patient's about end of life needs and preferences were facilitated were by clinicians in supportive care roles, for example, renal counsellor, renal social worker or clinical psychologist with allocated time for renal patients. At one site, an ethnic minority support worker who spoke multiple languages was a member of the renal team and participating patients there reported that they had had full discussion and planning about their end of life care through her.

Training

Participants who were dialysis nurses felt it was difficult for them in their role, especially if they were inexperienced, to have discussions with patients about end of life care without training. However, they also thought it was important to engage and communicate with patients to assess and support patients with both their physical and emotional needs. This, they said, would include conversations that might lead to discussions about end of life care that would take place with other members of the dialysis team in a clinic appointment.

A team approach to discussing and helping patients to make decisions and plan their care as they progressed towards and through the end of life phase underpinned patient access to end of life care and promoted care provider confidence. A combination of formal training, peer support and leadership was described in one focus group as helping to engage with patients and their families. This was accompanied by satisfaction in the delivery of appropriate and timely support because it was meeting the needs of patients at a critical time in their lives.

In other focus groups where the team approach was less to the fore because of the size of the unit or the setting (acute rather community or homecare), participants identified different aspects of professional development and competencies that might help them deliver end of life care. These were, for example, how to manage a Do Not Resuscitate directive on a haemodialysis unit or how to engage with patients on the dialysis unit about concerns without feeling it would need to end in an 'end of life' discussion. Some specific elements it was thought could be trained for through in service training while others, because they related more directly to individual, personal and cultural attitudes, were less tangible, requiring reflective practice and action as a team (Table 5).

The team's educative role in providing end of life care to patients was described in relation to: the opportunities for providing information through on-going contact with patients and families; the explanation of the concepts of palliative care and supportive care and their meaning in practical terms; and the need to be proactive in providing timely information. It was suggested that some patients and their families (and more in the SA community), may not have thought about end of life care issues and with the likelihood of acute situations in the future patients might find it easier if they had been able to think through and pre-plan in advance.

Changing patterns in the kidney population as well as the workforce was also something that care provider participants raised and felt the system needed to plan for, including a shift in attitude for some clinicians to become more familiar with a palliative approach (Table 6).

Discussion

As end of life care aims to address the total care of a person with advanced and incurable disease to help them live as well as possible until they die [10, 11], investigating how this gets delivered by non-palliative care teams and to patients with a range of cultural backgrounds is important to understanding equity of access. The chronic nature of kidney disease and availability of renal replacement technology in the UK make kidney care a complex area for predicting and delivering end of life care. However, as the numbers of people with ESKF [12] and those from ethnic minority groups are set to increase in the future [13] a better understanding of how to deliver quality end of life care in this context will be valuable for commissioners, providers of services, patients and their families.

Studies from Canada and the UK suggest that patients wish to plan for the end of their lives and look to their clinicians to initiate discussions at the appropriate time [14, 15]. Most of the patient experience research, however, has excluded non-English speakers and we know little of whether the same is true for people with different cultural backgrounds or about the delivery of their care. This exploratory study with a focus on care provided to South Asian kidney patients at end of life, therefore, goes some way to filling that gap.

The action research methodology employed in this study supported a sustained analysis process with feedback and discussion of emerging themes from both patient and focus group data. In this way, the themes reported here are a distillation of the data analysis from all the focus groups with care providers in a variety of roles and at different locations [16] over a period of critical reflection.

Despite limitations of the study—small patient sample, exploratory nature with an inclusion criteria requiring patient awareness and knowledge and service provider motivation to be involved in the research process—this thematic data analysis from 14 focus groups has produced a rich descriptive account of some of the key issues and challenges for care providers in providing access to and quality end of life care for South Asian kidney patients in the UK.

This has highlighted that the time required to discuss end of life care issues with patients is greater for South Asian patients where there are cultural or language barriers to direct communication with the patient. In addition, the assumption that all patients expect or wish to take an active part in decision-making about their end of life care during the end of life phase may not be a valid or a culturally competent one.

The timing of discussions about end of life care in the kidney setting appears to be influenced by a number of factors: treatment modality and setting; consultant's approach; care provider role and confidence; and patient preference. Without open discussion early on to provide information and discover patient preferences, then following up over time to revisit these, it may not be possible for service providers to be confident that the care is being delivered in culturally sensitive and, therefore, patient-centred way.

There is limited communication between haemodialysis staff and patients about end of life because of lack of staff time,

issues of privacy, staff confidence and cultural barriers for both patients and care providers. Good communication between patients and providers was seen as the key process enabling access to quality end of life care that meets both the emotional and physical needs of patients under the care of kidney services. The ideal picture of good practice was one of the gradual conversations and rapport built up over time to enable a comprehensive and timely understanding of patient needs and wishes.

Other researchers have described some of the challenges of disclosing end of life prognosis [17] and a need for an individualized approach to discussing end of life care that is culturally competent [18]. In-service training together with reflective practice and a team approach were suggested as ways to achieve this.

Conclusions

With population predictions and increasing rates of type 2 diabetes, it is likely that the number of South Asian patients with ESKF will grow in the future and will benefit from greater understanding of end of life kidney care.

Kidney care providers require time to engage with South Asian patients and their families to understand and meet their emotional as well as physical needs as they approach and progress through the end of life care pathway.

More exploratory research is required to investigate South Asian patients' experiences later on and as they progress through the kidney end of life care pathway. This could be achieved through further research with informal carers and care providers, and comparisons across different patient groups.

In-service training and a team approach are ways to improve understanding of the issues and increase the confidence of all providers who need to engage with patients about end of life care.

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Authors' contributions

E.W. and G.R. conceived the study, designed the study and led the writing of the article; E.B., M.D.S.G., J.S., G.W., T.M., R.M., S.S. and K.F. all led the data collection at each of the study sites and contributed to the writing of the article.

Conflict of interest statement

None declared. The results presented in this article have not been published previously in whole or part.

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