

Improving clinical skills to support the emotional and psychological wellbeing of patients with ESRD: a qualitative evaluation of two interventions

Taylor, Francesca; Combes, Gill; Hare, Jennifer

DOI:
[10.1093/ckj/sfw017](https://doi.org/10.1093/ckj/sfw017)

License:
Creative Commons: Attribution-NonCommercial (CC BY-NC)

Document Version
Publisher's PDF, also known as Version of record

Citation for published version (Harvard):
Taylor, F, Combes, G & Hare, J 2016, 'Improving clinical skills to support the emotional and psychological wellbeing of patients with ESRD: a qualitative evaluation of two interventions', *Clinical Kidney Journal*, vol. 9, no. 3, pp. 516-524. <https://doi.org/10.1093/ckj/sfw017>

[Link to publication on Research at Birmingham portal](#)

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.



ORIGINAL ARTICLE

Improving clinical skills to support the emotional and psychological well-being of patients with end-stage renal disease: a qualitative evaluation of two interventions

Francesca Taylor¹, Gill Combes¹ and Jennifer Hare²¹Institute of Applied Health, University of Birmingham, Birmingham, UK and ²Royal Wolverhampton NHS Trust, Renal Psychology Service, New Cross Hospital, Wolverhampton, UKCorrespondence and offprint requests to: Francesca Taylor; E-mail: f.taylor@bham.ac.uk

Abstract

Background: Many patients with end-stage renal disease (ESRD) need and want improved emotional and psychological support. Explicit attention to patients' emotional issues during consultations can help, yet renal consultants rarely address emotional problems. This qualitative study aimed to evaluate whether two different low-cost interventions could individually enable consultants to talk with patients about their emotional concerns during routine outpatient consultations.

Method: One intervention involved patients using a Patient Issues Sheet to identify two to three issues they would like to talk about in their consultation and the second involved consultants asking patients a direct question about their emotional feelings. Consultants were trained to handle any emotional issues raised. Semi-structured interviews were conducted with five consultants and 36 ESRD patients from two UK renal units. Interviews were transcribed verbatim and analysed using the constant comparative method.

Results: Although consultants and patients tended to use the two interventions in different ways, they expressed generally positive views about how helpful the interventions were in promoting discussion of emotional issues. Consultants appreciated the training for facilitating empathetic handling of patients' emotional disclosures and containment of discussion. Most patients who raised emotional concerns were satisfied with their consultant's responses, while others were dissuaded from more explicit discussion by their consultant's concentration on physical considerations.

Conclusions: These qualitative study findings suggest that both interventions are feasible and acceptable and have the potential to help consultants improve emotional and psychological patient care, providing cognitive and behavioural tools to enable discussion of emotional issues during routine outpatient consultations.

Key words: clinician-patient communication, emotional, end-stage renal disease, psychological, qualitative research

Received: December 4, 2015. Accepted: February 25, 2016

© The Author 2016. Published by Oxford University Press on behalf of ERA-EDTA.

This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact journals.permissions@oup.com

Introduction

Dialysis and renal transplantation are life-saving treatments, but they are also demanding and impact appreciably on the everyday lives of end-stage renal disease (ESRD) patients, often negatively affecting emotional and psychological well-being. Many patients find the transition to dialysis frightening and traumatic [1–3]. They can continue to experience periods of distress throughout their time on dialysis due to the stress of treatment, loss of sexual function, altered body image and decreased physical and cognitive functioning, as well as consequent effects on employment, relationships and lifestyle [4–7]. Transplant patients experience many of the same stresses, along with fear of transplant failure and significant distress if a transplant does fail [8].

The prevalence of depression or anxiety in the ESRD population is around four times higher than in the general adult population [9–11]. No robust data exist on the prevalence of lower-level emotional and psychological problems, defined as difficulties in coping effectively with the diagnosis, physical symptoms and treatment, which result in distress, poor emotional adjustment and reduced quality of life [12, 13]. Nonetheless, a recent study found that more than a third of dialysis patients experienced emotional difficulties, particularly during the transition to dialysis and early months on dialysis [3]. Furthermore, untreated psychosocial problems are associated with withdrawal from dialysis [14, 15], poor medication and diet compliance [16–18] and reduced ability to engage in pre-renal replacement therapy education and treatment choice [3, 19, 20].

Despite this evidence, management of patients' emotional and psychological difficulties, particularly at the lower level, remains suboptimal. Access to support is often restricted to patients with higher-level needs requiring psychiatric or psychological intervention. Patients want improved lower-level support, particularly in the areas of adjustment and coping, yet their needs tend to be ignored and frequently remain untreated [19, 21–23].

The reasons for clinicians' insufficient response are complex. There is some evidence that renal staff find it hard to recognize patients' distress [21, 24, 25], while cancer studies suggest that patients tend not to spontaneously express emotional concerns [26–30]. Additionally, doctors can be reluctant to address emotional issues during consultations: although talking about emotional concerns appears to improve patients' well-being [31–33], doctors prefer to focus on biomedical issues [34, 35]. Discussions with local renal consultants identified further barriers, including worries about lengthening consultation times, being unable to deal with the issues raised by patients and added costs. Notably, though, there is relevant research conducted in other long-term conditions to indicate that clinicians can be trained, particularly through motivational interviewing, to facilitate patient engagement during time-constrained consultations [36, 37].

The aim of this qualitative study was to evaluate whether two different low-cost interventions designed to adjust consultant–patient communication could feasibly be used individually during routine outpatient consultations to enable consultants to talk explicitly with patients about their emotional concerns.

Materials and methods

Ethical approval was received from a local committee of the National Research Ethics Service (13/LO/0443). The study was also approved by the Research Governance office of each Trust. All patient participants gave written informed consent. Guidance provided by Bristowe *et al.* [38] for ensuring quality when

undertaking qualitative research in renal medicine was used to assess reliability and validity in developing the study aims, designing an appropriate methodological approach and appropriate and rigorous data analysis and interpretation.

Design and setting

A qualitative design was employed to enable an in-depth understanding of the context in which the interventions were used, as well as the experience of those providing and receiving the interventions [38–40]. Patients and consultants were recruited to the study from two NHS Hospital Trusts.

Interventions

Patient participants received one of two interventions while attending a routine outpatient consultation. The first intervention involved the use of a Patient Issues Sheet (Figure 1), on which patients were asked to indicate the two to three issues that they would most like to talk about during their consultation. Shown on the sheet were the main physical and emotional ESRD-related patient concerns [24, 25], with blank circles where patients could insert additional issues. A study researcher gave patients a sheet to complete while they waited in the Renal Unit and then to take to their consultation. Consultants were informed which patients had received a sheet prior to the consultation.

The second intervention entailed consultants asking patients a specific question adapted from one included in the Patient Health Questionnaire (PHQ-9) [41] and recommended by the National Institute for Health and Clinical Excellence [42]. The question wording agreed upon by consultants participating in the study was 'During the last few weeks have you been feeling down or miserable at all?'

The consultants engaged in a 90-min interactive training session led by a renal psychologist that covered patient engagement using motivational interviewing, open questions, affirmation and reflection [43]; employing a three-stage model of counselling to ask patients about their feelings [44, 45]; and handling emotional issues raised by patients. Each consultant then used the 'patient question' in two to three consultations, observed by the psychologist, who provided feedback on how they managed patients' responses.

Recruitment

Eligible patients were adults >18–90 years of age with ESRD who attended a routine renal outpatient clinical consultation during the study period. The study population was also restricted to patients on dialysis for no more than 12 months; there being evidence identifying emotional difficulties as particularly prevalent among recent dialysis starters [3]. Patients were excluded if they were cognitively impaired or currently accessing psychological support. Purposive patient sampling was planned to provide maximum diversity of age, gender, ethnicity, position along the ESRD pathway and dialysis treatment type. However, because patient numbers were smaller than expected in both study sites, all eligible patients were included in the potential sample—34 patients in one site and 41 patients in the other. A week before their outpatient appointment, patients were sent a consent form and study information sheet. A study researcher explained the purpose and nature of the study to patients in the Renal Unit prior to their consultation and consenting patients were allocated in sequential order to one of

Below are some issues that other people with your illness have said they wanted to talk about with their renal clinicians.

*Please mark the 2 or 3 issues you would **most** like to talk about with your clinician during your consultation today. There is space for you to add any other issues you would like to talk about.*

The form consists of 25 ovals arranged in a grid-like pattern. The ovals contain the following text:

- Sleeping
- Diet
- Hope
- Sadness
- Enjoying life
- Coping
- Side effects of treatment
- Nervous
- Kidney function
- Worry about the future
- Energy levels
- Sex life
- Tiredness
- Condition worsening
- Adjustment to dialysis
- Relationships
- Acceptance
- Medicines
- Maintaining control
- Pain
- Feeling down
- (Empty oval)
- (Empty oval)
- (Empty oval)

Please have this sheet with you during your consultation

Fig. 1. Patient issues sheet.

the two interventions. Thirty-six patients (48% of those eligible) agreed to participate: 27 patients from site 1 (79%) and 9 from site 2 (22%). Reasons for non-consent were not collected.

All eligible consultants in the two study sites were invited to participate. Eligible consultants were those who held regular

outpatient consultations with dialysis patients and were willing to be trained by a renal psychologist and then use two different interventions in routine consultations with eligible patients. Five consultants expressed interest, three from site 1 and two from site 2, and were sent a consent form and study information

Table 1. Exemplar patient interview question and question prompts

Question: Did you use the sheet at all during your consultation?
Question prompts: How did you use it? When did you use it? What did you say? What did your consultant do? What did your consultant say? Was this helpful or not helpful?
Exploratory prompts: Why do you feel that way? Can you tell me a little more about that? Why is that? Anything else you can think of?

sheet. They all agreed to participate. All access and consent processes for patients and consultants complied with ethical principles [46].

Data collection

Interviews were conducted between June and November 2013. Patients were interviewed by telephone to accommodate the significant time constraints created by their treatment. The interviews took place 7–14 days after they had received an intervention. Consultants were interviewed face-to-face in their Renal Unit and at the end of the study. Patient interviews lasted 10–50 min (median 32) and consultant interviews 35–70 min (median 48). The interviews were semi-structured (Table 1) to allow the key areas of research interest to be explored without being overly prescriptive in terms of content and direction [47, 48]. In each patient interview, participants were read the patient question and asked if their consultant had used this question during their last consultation. All interviews were digitally recorded and professionally transcribed in full, with transcripts checked against recordings.

Analysis

A framework approach was used to code and categorize the research data [49]. Patient and consultant data were analysed separately and two individual frameworks developed from the analyses. Transcripts from the first third of patient interviews and first two consultant interviews were read and reread by one researcher. Data were broken down using line-by-line coding; the codes were clustered manually to identify preliminary categories based on issues and themes. Initial frameworks were developed from the emerging codes and categories after scrutiny and discussion with a second researcher, who had also read the transcripts. Together the researchers asked questions of the data to assist identification of category properties. Verbatim patient and consultant responses were then entered onto separate spreadsheets.

Constant comparison was utilized, with each data collection from further interviews compared with every other for similarities, differences and connections [50, 51]. Categories included in the two frameworks were refined and enhanced, some combined and others condensed or removed. This process was undertaken independently by one researcher and was supplemented by continuous collaborative discussion with the second researcher to reach consensus and confirm categories.

Results

Participants

The mean age of participants was 61 years. Most participants were male (67%) and white British (69%) and had been on dialysis for ≤6 months (58%). Two patients were recruited in error, each having been on dialysis for longer than the 12-month inclusion

Table 2. Characteristics of patient participants (n = 36)

Characteristic	n (%)
Mean age, years	61
Age	
18–49 years	9 (25)
50–64 years	10 (28)
≥65	17 (47)
Gender	
Male	24 (67)
Female	12 (33)
Race/ethnicity	
White British	25 (69)
Asian British	9 (25)
Black British	2 (6)
Current dialysis therapy	
Peritoneal dialysis	21 (58)
Haemodialysis	15 (42)
Time on dialysis therapy	
>3 months	13 (36)
3–6 months	8 (22)
7–9 months	6 (17)
10–12 months	7 (19)
>12 months	2 (6)
Received patient issues sheet	
Yes	21 (58)
No	15 (42)

criteria. They were nevertheless included in the results, since the additional time period was only 1 month. A total of 58% of participants were on peritoneal dialysis (PD) and 42% on haemodialysis (HD) (Table 2).

Twenty-one patients (58% of participants) were given a patient issues sheet. Nineteen of these patients said they completed the sheet and 16 said they used the sheet during their consultation. Twenty patients (56% of participants) said they had been asked the patient question, while two patients could not remember.

Four consultant participants were male and one was female; three were Asian British and two white British.

Qualitative interview findings

Following analysis, five categories were identified: (i) interventions adapted for personal use (consultants and patients), (ii) patients enabled to raise emotional issues (patients), (iii) consultants facilitated to explore emotional issues (consultants), (iv) handling discussion (patients) and (v) training valued (consultants). Supporting quotations are provided in Table 3.

Interventions adapted for personal use

Each consultant had their own way of using the patient question, adjusting the intervention to suit their personal consultation style. One consultant used an accompanying explanation, as they felt it was awkward to ask a direct question alone. They explained to patients how it was normal to have emotional concerns and that talking about these feelings would enable appropriate support to be offered to them (Quote 1).

A targeted approach was used by another consultant, who chose which patients to ask the question according to whether or not they perceived the patient to be distressed. This consultant worried that patients who appeared to have no emotional

Table 3. Supporting quotations by category

Theme	Quotations
Interventions adapted for personal use	<p>Quote 1: I've stressed to them, 'Well, it's entirely correct that you are allowed to feel upset about a life-changing event. It's normal to feel depressed. It does happen. So it's important that we talk about it to help you in all its – you know, to deal with all its aspects'. Consultant 3</p> <p>Quote 2: I didn't really want to use those questions with those patients because they were just going to look at me funny and it was going to reflect on me and how I interacted with the patient. Consultant 4</p> <p>Quote 3: Everything is going quite well there's a sudden change of direction. . .And that's the problem I have with the intervention in the sense that if everything is going swimmingly, how do you say it without feeling uncomfortable? Consultant 2</p> <p>Quote 4: What I normally do is to, I just put them (the Patient Issues Sheet) aside first and then I go through what I would normally do, you know in a clinic setting, and then come to, towards the latter part of the consultation I will ask 'is there anything in the yellow sheets that you want to discuss?' That's how I start with that. I mean they will just look at the sheets and say these are the areas that I circled or indicated. . .I just go through the sheets with them. Consultant 1</p> <p>Quote 5: S/he took the sheet off me and s/he said you know, 'What would you like to talk about on here?' Patient 16</p> <p>Quote 6: Now I might have misunderstood it, but I thought s/he was going to ask me for that at some point. S/he never made any reference to it at all. . .I walked out of there carrying it still folded up in my hand. Patient 13</p> <p>Quote 7: I felt uncomfortable because the patients weren't bringing it to the fore. . .They've got the piece of paper that they're asked to bring in and they've not put it in front of me and they've got it to one side. I just felt because it happened so often, I was surprised. Consultant 2</p>
Patients enabled to raise emotional issues	<p>Quote 8: 'I mean, I think if you start going on how you're actually feeling or if I go in and say, "well look, I'm feeling a bit depressed" and you're wondering whether you're encroaching on their time. . .I know they haven't got a lot of time but, I mean, you might feel as though yes you are taking up extra time and they really perhaps don't want to be bothered so you perhaps don't talk about it with them.' Patient 35</p> <p>Quote 9: It shows that somebody cares. Patient 36</p> <p>Quote 10: The sheet helped me because I'd got those three rings round the items I was interested in. I knew what I was going to say and what I was going to ask. Patient 1</p> <p>Quote 11: It prompted me to ask the questions. Had I not had that form, I might not have asked the questions. Patient 18</p> <p>Quote 12: I think probably without the yellow sheet, I probably wouldn't have had that conversation about the prognosis. Patient 16</p>
Consultants facilitated to explore emotional issues	<p>Quote 13: As doctors perhaps we haven't helped them because we haven't actually thought about how they're managing. . .So by asking these obvious questions outright, overtly, has helped to explore those issues. Consultant 3</p> <p>Quote 14: If it has a structure there's more of a pathway and you know how to proceed, like A, B, C. . .So it's just a way of how to make it part of your normal working way of practice as opposed to being a bit erratic and haphazard. Consultant 5</p> <p>Quote 15: I just happened to ask that question and it just opened up the flood gates of issues the patient is facing. . .I just kept quiet and just let her talk and just use words like, 'I see, I understand', sort of reaffirm her emotion and her display and trying to reassure her that, you know, it's a safe environment for her to talk about it. And it's been very positive. Consultant 1</p> <p>Quote 16: Well, you just talked about it, you know, sort of if there was a problem then yes, you know, what support they had, who was at home, you know, a lot of the time they're elderly and yeah, they don't get out much and they feel all they do is come for dialysis and go home again. So it's relating to sort of, you know, is there any way you can improve that? But then often its multi-factorial isn't it? There's no easy answer. Consultant 5</p>
Handling discussion	<p>Quote 17: She/he kind of reassured me, basically put my mind at ease, that it's kind of OK. . .The answer was, well it was sufficient basically. I don't really know what else the consultant could have done. Patient 6</p> <p>Quote 18: She/he was empathetic. . .Just in, you know, her/his eye contact, her/his tone of voice etcetera. Things like that. But also giving me the time to ventilate, you know, what I was thinking, what I was feeling, and listening to what I was saying. Patient 16</p> <p>Quote 19: I don't know whether she/he actually was pushed for time or something but I got the feeling that s/he didn't really want to go into discussions about things. . .when I said about the feeling tired and lack of energy s/he accepted that but didn't want to go into detail about it. . .I felt there could have been a bit more time to discuss perhaps the things that I might have wanted to talk about rather than feeling pushed to the idea that s/he wanted to carry on their way and that was it. Patient 32</p>
Training valued	<p>Quote 20: I'm capable of handling sort of a mild display of emotion, but when the patient is crying and really upset I find it sort of out of my depth. But it was good that we had some training with us and so what I've done is I just kept quiet and I just let her talk. And I find that the most useful strategy actually. Consultant 1</p> <p>Quote 21: I will say, 'well on our next visit we'll talk about whatever is unresolved. Consultant 3</p> <p>Quote 22: The most useful thing, actually, was having somebody say, 'These are the services that seem to be available round here that you may wish to try'. . .Having that knowledge of 'these are the services available' was the most important thing, from my point of view. Consultant 4</p>

difficulties would consider the question inappropriate, impacting negatively on the consultant–patient relationship (Quote 2).

For one consultant, the question was too direct and downbeat, discordant with the positive mood and tempo they liked to maintain in consultations, especially if all the patient's physical indicators were good (Quote 3). This consultant preferred to ask a more open-ended question, such as 'How have you been feeling?'

Additionally, the timing of the question varied. Some consultants said they asked the question at the beginning of the consultation, while others recalled using it after they had covered clinical issues (Quote 4).

The patient issues sheet was also used in different ways. Several patients reported that their consultant had directly asked what they had marked on the sheet. Some patients said they had responded by reading out the issues, while others mentioned showing or handing the sheet to their consultant (Quote 5). A number of patients said they had never exposed their sheet, but instead recalled the issues marked. Few patients talked about taking the initiative by referring to the sheet or handing it to their consultant without prompting.

Three patients recollected making no use of their completed sheet. For one patient, this was because the issues came up spontaneously, whereas for the others, there was a perception that the consultant had not encouraged use of the sheet (Quote 6).

Similarly, consultants described diverse approaches to using the patient issues sheet. In particular, there was a notable contrast in terms of whether or not they encouraged their patients to talk about what was marked on the sheet. For example, one consultant recounted how they liked to look at the sheet together with the patient and then discuss what was indicated. Perceiving the sheet as a patient-led intervention, another consultant said he/she preferred not to stimulate or direct its use in any way (Quote 7).

Patients enabled to raise emotional issues

Both interventions prompted favourable patient reactions, primarily because patients felt enabled to mention emotional concerns. Patients appreciated the patient question because it encouraged expression of personal worries, giving them the opportunity to speak about their feelings. For example, one patient said the intervention had 'allowed' them to use their consultant's restricted time to discuss emotional issues (Quote 8). The question also made patients feel more cared for by their consultant (Quote 9).

A minority of patients disliked the question and chose not to discuss their emotional needs; they presupposed that an admission of feeling down or miserable would imply being depressed, and feared the associated stigma. There were also some patients who felt the question was not relevant to their current mood. Nonetheless, all patients thought that consultants should continue using the intervention, except for one participant, who thought it was better for patients to sort out their own problems.

The patient issues sheet was valued for being a helpful aide-memoire, enabling patients to recall during their consultation the issues they wanted to discuss (Quote 10). Patients also appreciated the sheet for the information it offered about the type and scope of issues experienced by other renal patients, and for providing useful guidance on what they could ask their consultant about. Several patients mentioned that the sheet gave them 'permission to engage' by sanctioning them to raise personal concerns for discussion (Quotes 11–12).

Consultants facilitated to explore emotional issues

Consultants expressed mostly positive opinions about the effectiveness of the interventions in enabling exploration of patients'

emotional difficulties. The interventions were thought to help identify those patients experiencing emotional problems, 'opening the door' to discussion and a better understanding of their well-being. Some consultants said this helped to improve care (Quote 13). Consultants also valued having a structured way to recognize and respond to patients' concerns, since this facilitated the incorporation of emotional discussions into routine consultations (Quote 14). However, one consultant was surprised that fewer patients than expected had raised emotional issues.

Some consultants appeared comfortable with patients' emotional release and listening to their concerns. Others seemed to want to question further or to find solutions. For example, one consultant described the perceived positive effects of listening and being empathetic on a patient's well-being (Quote 15). Another explained how they would work with their patients to identify the cause of any emotional difficulties and then try to solve the problem, although they acknowledged that this could be difficult given the many stressors often involved (Quote 16).

Handling discussion

Patients were generally satisfied with how their consultant conducted discussion about any emotional issues they had disclosed in response to an intervention (Quote 17). Expressions of empathy were particularly appreciated and seemed helpful in encouraging patients to explain more about their feelings (Quote 18). There were also patients whose consultant was said to have adopted a more practical and problem-solving response, often focusing solely on the physical symptoms that might be causing the issue raised. While some of these patients were content their consultant had discussed the issue, there were others for whom a practical response, without consideration of emotional aspects, appeared to have constrained discussion and support.

A few patients expressed dissatisfaction because they thought their consultant had prevented or closed down discussion, and seemingly preferred to keep to their normal consultation agenda (Quote 19).

Training valued

The training was found to be very helpful, particularly by those consultants who described themselves as feeling less comfortable managing patients' emotional responses. It was seen as having provided a useful menu of ways to respond empathetically and supportively to patients' expressions of emotion (Quote 20).

Consultants also valued learning strategies to structure and contain discussion of emotional issues; for example, agreeing with the patient to continue discussion into the next consultation (Quote 21) or suggesting referral to local support services (Quote 22). As a result of using these approaches, several consultants said they had been able to support patients without lengthening the consultation.

Discussion

This qualitative study found that both interventions, the patient question and the patient issues sheet, were helpful in enabling consultants to talk with patients about emotional issues during routine outpatient consultations. The results indicate that the form, manner and context in which each intervention was used tended to determine how effective it was in adjusting consultant–patient communication and encouraging explicit discussion about emotional concerns. Our study suggests several elements that could be facilitative, and these are summarized in Table 4.

Table 4. Suggested intervention features to facilitate consultant–patient discussion of emotional issues

- Direct questioning about a patient's emotional well-being, adapted to individual consultant style (appropriate timing and context)
 - provides an enabling prompt for patients to speak out
 - communicates that emotional disclosure is acceptable
 - helps patients feel cared for
 - helps consultants identify patients with emotional problems
- Provision of information for patients, pre-consultation, about issues (emotional and physical) they can discuss with their consultant
 - offers patients permission to engage
 - gives useful guidance on what patients can ask about
 - can be used as an aide-memoire during the consultation
- Consultant endorsement of any intervention feature made available to patients to raise emotional issues
 - signifies consultant encouragement
 - helps patients feel more comfortable and confident about its use
- Clear demonstration of consultant empathy in response to emotional issues raised by patients
 - patients appreciate their consultant listening
 - acknowledgement of distress can encourage discussion and further disclosure
 - patients can feel less supported if a practical, problem-solving approach is used without attention to emotional factors
- Use of strategies by consultant to manage and contain discussion
 - for example, agreeing with the patient to continue discussion into the next consultation; suggesting patient referral to local support services
 - enables provision of emotional support without lengthening consultation

The patient issues sheet seemed to work best when patients were actively encouraged by their consultant to talk about what they had marked. There was limited spontaneous patient use of the sheet, which may be because this involved a change to the expected consultant-led consultation structure. It suggests that consultant prompting and overt attention to issues raised are important in influencing effective intervention use. Interestingly, Brown *et al.* [33, 52] reported that cancer patients given a question prompt sheet were only comfortable about asking more questions in consultations when there was oncologist endorsement of the sheet.

There were two aspects of the patient question that appeared to encourage emotional disclosure and discussion. First was the question helped to make patients feel more cared for emotionally. Through simply asking the question, consultants conveyed that support was available and disclosure acceptable. The importance of perceived care and empathy in encouraging emotional response is well-documented in cancer studies [26, 28, 30, 53]. Second, the question provided an enabling prompt for patients. While some consultants were uncomfortable using a direct and specific question, most patients supported its use. Patients felt they were being given an opportunity and the support of their consultant to speak about their emotional feelings. This is in line with existing evidence that clinician use of leading questions facilitates discussion of psychosocial issues [29]. However, direct questions have been shown to have differential effects dependent on the general style of the consultation; asked in an appropriate situation they can result in disclosure, but they may have the opposite effect when inserted out of context [28]. Adaptation of the intervention to individual style, as practiced by consultants in this study, may therefore be apposite.

Our findings showed that both interventions were appreciated by patients and there appeared to be no negative reactions. Most patients who raised emotional concerns were satisfied with how these were handled. Several patients seemed to have experienced a sense of empathy, and this subsequently encouraged more disclosure about feelings. The training for consultants appears to have had an important role in helping them handle patients' emotional responses effectively, as well as containing discussion so that consultations were not felt to have been lengthened. However, a few patients reported that their consultant had concentrated

only on the physical aspects of issues mentioned and not the emotional, which in some cases seems to have restricted discussion. This supports earlier findings that patients tend to provide more information about psychosocial issues to clinicians who openly acknowledge their distress [28, 54].

A major strength of this study is that the qualitative design enabled exploration of the feasibility, acceptability and appropriateness of the two different interventions [38] and an understanding of consultant and patient responses to the interventions. However, the study has limitations. As our sample included only patients on dialysis for ≤ 12 months, the findings may not be generalizable to all ESRD patients. Further, we did not directly observe consultant–patient interactions and therefore cannot verify the reported responses. Although the study endeavoured to employ a purposive patient sample to provide maximum diversity, this was not possible. As a result, none of the recruited sample was on home HD and females were under-represented. Notably though, there were no identifiable gender differences in patients' responses to the interventions, despite evidence indicating that females are more likely to express emotional issues [55, 56]. For this qualitative study, the interventions were not placed within a theoretical framework. Any future research, however, would benefit from the explicit incorporation of a theoretical framework to measure and describe mechanisms of change: patient–clinician communication theory [57, 58] or communication constructs integrated with theories of self-efficacy [59] and enablement [60] appear relevant.

Nonetheless, the findings from this qualitative evaluation suggest that both interventions can feasibly be used individually during routine outpatient consultations, with the potential to equip consultants with the cognitive and behavioural tools to discuss emotional issues and help improve their support of ESRD patients' emotional and psychological well-being. Consultants in the two study sites have continued to use one or both interventions. The interventions therefore show promise, but future research with larger samples is needed to measure the impact of the interventions on patients' emotional well-being.

Acknowledgements

This article presents independent research funded by the National Institute for Health Research (NIHR) Collaboration for Leadership

in Applied Health Research and Care (CLAHRC) Birmingham and the Black Country and the NIHR CLAHRC West Midlands initiative. The views expressed in this article are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. We thank Dr Johann Nicholas and Dr Kerry Tomlinson for their contributions to setting up the study and Dawn Child, Susan McGuire, Zoë Hancock and Pamela Nayyar for their assistance throughout the study.

Conflict of interest statement

The authors declare no conflicts of interest. The results presented in this article have not been published previously in whole or part, except in abstract format.

References

- Gregory DM, Way CY, Hutchinson TA et al. Patients' perceptions of their experiences with ESRD and hemodialysis treatment. *Qual Health Res* 1998; 8: 764–783
- Hutchinson TA. Transitions in the lives of patients with End Stage Renal Disease: a cause of suffering and an opportunity for healing. *Palliat Med* 2005; 19: 270–223
- Combes G, Allen K, Sein K et al. Taking hospital treatments home: a mixed methods case study looking at the barriers and success factors for home dialysis treatment and the influence of a target on uptake rates. *Implement Sci* 2015; 10: 148
- Kimmel PL. Psychosocial factors in dialysis patients. *Kidney Int* 2001; 59: 1599–1613
- Kimmel PL. Depression in patients with chronic renal disease. What we know and what we need to know. *J Psychosom Res* 2002; 53: 951–956
- Hooper J, Cohen LM. Psychological and psychiatric considerations in patients with advanced kidney disease. In: Chambers EJ, Germain M, Brown E (eds). *Supportive Care for the Renal Patient*. Oxford, UK: Oxford University Press, 2004, 155–176
- Kimmel PL, Peterson RA. Depression in end-stage renal disease patients treated with hemodialysis: tools, correlates, outcomes and needs. *Semin Dial* 2005; 18: 91–97
- Chilcot J, Spencer BW, Maple H et al. Depression and kidney transplantation. *Transplantation* 2014; 97: 717–721
- Murtagh FEM, Addington-Hall J, Higginson IJ. The prevalence of symptoms in end-stage renal disease: a systematic review. *Adv Chronic Kidney Dis* 2007; 14: 82–99
- Hedayati SS, Yalamanchili V, Finkelstein FO. A practical approach to the treatment of depression in patients with chronic kidney disease and end-stage renal disease. *Kidney Int* 2012; 81: 247–255
- Palmer S, Vecchio M, Craig JC et al. Prevalence of depression in chronic kidney disease: systematic review and meta-analysis of observational studies. *Kidney Int* 2013; 84: 179–191
- British Renal Society. The Renal Team. A multi-professional renal workforce plan for adults and children with renal disease. Recommendations of the National Renal Workforce Planning Group, British Renal Society, 2002, pp. 44–47. http://www.britishrenal.org/getattachment/Workforce-Planning/WFP_Renal_Book1.pdf.aspx (2 November 2015, date last accessed)
- Trigwell P, Taylor JP, Ismail K et al. The provision of psychological support and care for people with diabetes in the UK. London, UK: Diabetes UK, 2008, p. 72. Available at: http://www.diabetes.org.uk/Documents/Reports/Minding_the_Gap_psychological_report.pdf (2 November 2015, date last accessed)
- Cohen LM, Dobscha SK, Hails KC et al. Depression and suicidal ideation in patients who discontinue the life-support treatment of dialysis. *Psychosom Med* 2002; 64: 889–896
- McDade-Montez EA, Christensen AJ, Cvengros JA et al. The role of depression symptoms in dialysis withdrawal. *Health Psychol* 2006; 25: 198–204
- Jindel RM, Joseph JT, Morris MC et al. Noncompliance after kidney transplantation: a systematic review. *Transplant Proc* 2003; 35: 2868–2872
- Cukor D, Rosenthal DS, Jindal RM et al. Depression is an important contributor to low medication adherence in hemodialysed patients and transplant recipients. *Kidney Int* 2009; 75: 1223–1229
- Clark S, Farrington K, Chilcot J. Nonadherence in dialysis patients: prevalence, measurement, outcome and psychological determinants. *Semin Dial* 2014; 27: 42–49
- Tong A, Sainsbury P, Chadblan S et al. Patients' experiences and perspectives of living with CKD. *Am J Kidney Dis* 2009; 53: 689–700
- Morton RL, Tong A, Howard K et al. The views of patients and carers in treatment decision making for chronic kidney disease; systematic review and thematic synthesis of qualitative studies. *BMJ* 2010; 340: c112
- Schell JO, Patel UD, Steinhilber PD et al. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *Am J Kidney Dis* 2012; 59: 495–503
- Gill P, Lowes L. Renal transplant failure and disenfranchised grief: participants' experiences in the first year post-graft failure—a qualitative longitudinal study. *Int J Nurs Stud* 2014; 51: 1271–1280
- Bristowe K, Horsley HL, Shepherd K et al. Thinking ahead—the need for early Advance Care Planning for people with haemodialysis: a qualitative interview study. *Palliat Med* 2015; 29: 443–450
- Bass EB, Jenckes MW, Fink NE et al. Use of focus groups to identify concerns about dialysis. *Med Decis Making* 1999; 19: 287–295
- Weisbord SD, Fried LF, Mor MK et al. Renal provider recognition of symptoms in patients on maintenance hemodialysis. *Clin J Am Soc Nephrol* 2007; 2: 960–967
- Maguire P, Faulkner A, Booth K et al. Helping cancer patients disclose their concerns. *Eur J Cancer* 1996; 32: 78–81
- Butow PN, Brown RF, Cogar S et al. Oncologists' reactions to cancer patients' verbal cues. *Psychooncology* 2002; 11: 47–58
- Ryan H, Schofield P, Cockburn J et al. How to recognize and manage psychological distress in cancer patients. *Eur J Cancer Care* 2005; 14: 7–15
- Pollack KI, Arnold RM, Jeffreys AS et al. Oncologist communication about emotion during visits with patients with advanced cancer. *J Clin Oncol* 2007; 25: 5748–5752
- Anderson WG, Alexander SC, Rodriguez KL et al. 'What concerns me is . . .' Expression of emotion by advanced cancer patients during outpatient visits. *Support Care Cancer* 2008; 16: 803–811
- Greenfield S, Kaplan SH, Ware JE et al. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *J Gen Intern Med* 1988; 3: 448–457
- Butow PN, Dunn SM, Tattersall MHN et al. Patient participation in the cancer consultation: evaluation of a question prompt sheet. *Ann Oncol* 1994; 5: 199–204

33. Brown RF, Butow PN, Dunn SM et al. Promoting patient participation and shortening cancer consultations: a randomised trial. *Br J Cancer* 2001; 85: 1273–1279
34. Vail L, Sandhu H, Fisher J et al. Hospital consultants breaking bad news with simulated patients: an analysis of communication using the Roter Interaction Analysis System. *Patient Educ Couns* 2011; 83: 185–194
35. Hack TF, Ruether JD, Pickles T et al. Behind closed doors II: systematic analysis of prostate cancer patients' primary treatment consultations with radiation oncologists and predictors of satisfaction with communication. *Psychooncology* 2012; 21: 809–817
36. Rollnick S, Butler CC, Kinnersley P et al. Motivational interviewing. *BMJ* 2010; 340: c1900
37. Lundahl B, Moleni T, Burke BL et al. Motivational interviewing in medical care settings: a systematic review and meta-analysis of randomised controlled trials. *Patient Educ Couns* 2013; 93: 157–168
38. Bristowe K, Selman L, Murtagh FEM. Qualitative research methods in renal medicine: an introduction. *Nephrol Dial Transplant* 2015; 30: 1424–1431
39. Green JC. Understanding social programs through evaluation. In: Denzin NK, Lincoln YS (eds). *Handbook of Qualitative Research*, 2nd edn. Thousand Oaks, CA: Sage, 2000, pp. 981–1000
40. Pope C, Mays N. Qualitative methods in health research. In: Pope C, Mays N (eds). *Qualitative Research in Health Care*, 3rd edn. Malden, MA: Blackwell Publishing, 2006, pp. 1–11
41. Spitzer RL, Kroenke K, Williams JB, Patient Health Questionnaire Primary Care Study Group. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. *JAMA* 1999; 282: 1737–1744
42. National Institute for Health and Clinical Excellence. The treatment and management of depression in adults with chronic physical health problems: CG91 Depression with a chronic physical health problem. Manchester: National Institute for Health and Clinical Excellence, 2009. <http://guidance.nice.org.uk/CG91> (2 November 2015, date last accessed)
43. Miller WR, Rollnick S. *Motivational Interviewing: Helping People Change*, 3rd edn. New York, NY: Guildford Press, 2012
44. Carkhuff RR. *The Art of Helping*, 6th edn. Amherst, MA: Human Resource Development Press, 1987
45. Egan G. *The Skilled Helper: A Problem-Management and Opportunity-Developing Approach to Helping*, 7th edn. Belmont, CA: Brooks/Cole, 2002
46. Christians CG. Ethics and politics in qualitative research. In: Denzin NK, Lincoln YS. (eds). *Handbook of Qualitative Research*. London, UK: Sage Publications, 2000, pp. 133–155
47. Sidani S, Broden CJ. *Design, Evaluation and Translation of Nursing Interventions*. Chichester, UK: Wiley & Sons, 2011
48. Holloway I, Wheeler S. *Qualitative Research in Nursing and Health Care*, 3rd edn. Chichester, UK: Wiley & Sons, 2010
49. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *BMJ* 2000; 320: 14–116
50. Bryant A, Chamaz K. Introduction. Grounded theory research: methods and practices. In: Bryant A, Chamaz K (eds). *The Sage Handbook of Grounded Theory*, Paperback Edition. London: Sage, 2007, pp. 1–28
51. Corbin J, Strauss A. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. New York, NY: Sage, 2008
52. Brown R, Butow PN, Boyer MJ et al. Promoting patient participation in the cancer consultation: evaluation of a prompt sheet and coaching in question-asking. *Br J Cancer* 1999; 80: 242–248
53. Suchman AL, Markakis K, Beckman HB et al. A model of empathetic communication in medical interview. *JAMA* 1997; 277: 678–682
54. Del Piccolo L, Saltini A, Zimmerman C et al. Differences in verbal behaviours of patients with and without emotional distress during primary care consultations. *Psychol Med* 2000; 30: 629–643
55. King AM, Gordon AH. Sex differences in emotion: expression, experience and physiology. *J Pers Soc Psychol* 1998; 3: 686–703
56. Jansz J. Masculine identity and restrictive emotionality. In: Fischer AH (ed). *Gender and Emotion: Social Psychological Perspectives*. New York, NY: Cambridge University Press, 2000, pp. 166–186
57. Cegala DJ, Broz SL. Physician communication skills training; a review of theoretical backgrounds, objectives and skills. *Med Educ* 2002; 36: 1004–1016
58. Ruben BD. Communication theory and health communication practice: the more things change, the more they stay the same. *Health Commun* 2016; 31: 1–11
59. Bandura A. Self-efficacy: toward a unifying theory of behaviour change. *Psychol Rev* 1977; 84: 191–215
60. Howie JGR, Heaney DJ, Maxwell M et al. A comparison of a Patient Enablement Instrument (PEI) against two established satisfaction scales as an outcome measure of primary care consultations. *Fam Pract* 1998; 15: 165–171