Patient attitudes towards the arteriovenous fistula: a qualitative study on vascular access decision making

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Abstract

Background. The use of arteriovenous fistulas (AVFs) among hemodialysis (HD) patients has been consistently associated with lower rates of morbidity and mortality; however, up to 30% of eligible patients refuse the creation or cannulation of an AVF. We aimed to understand the attitudes, beliefs, preferences and values of patients who refused creation or use of an AVF.

Methods. With qualitative methodology, we conducted semi-structured interviews with 13 HD patients (Canada,
Introduction

As of 2007, ~50% of Canadian hemodialysis (HD) patients and 47% of American HD patients had an arteriovenous fistula (AVF) for vascular access (VA) [1]. In comparison with arteriovenous grafts and central venous catheters (CVCs), the use of AVFs are consistently associated with lower rates of morbidity and mortality [2–7]. However, recent studies demonstrate a marked decline in the prevalence of AVFs and an increase in CVCs within Canada, Australia and countries throughout Europe [1, 8, 9]. The decline in use of AVFs can be attributed to patient, facility and health care system factors [10]. In our recent study, 80% of the nephrologists indicated that patient refusal is a major barrier to creating a mature AVF [11].

The research on decision making among patients with end-stage renal disease (ESRD) focuses on patient refusal for dialysis, withdrawal from dialysis or choice of dialysis modality [12–14]. To our knowledge, there are no studies on the patients’ decision-making process in choosing a form of VA.

Informed decision making is an important pillar in patient care. Patients who show greater understanding of chronic kidney disease from educational classes are more likely to choose dialysis with a fistula [15]. Patient factors can also influence decision making, as patients >65 years old with fistulas are more likely to be bothered by pain, bleeding, bruising, swelling and appearance of their fistula [16].

To explore the decision-making process, we conducted a series of 13 in-depth interviews with HD patients who had previously refused an AVF. We sought to understand how their attitudes, beliefs, preferences and values influenced their choice of VA.

Materials and methods

We used a qualitative methodology with a phenomenological approach to explore patient attitudes, preferences, beliefs and values when deciding on VA choices for patients on chronic conventional HD. Patient recruitment

We recruited patients from a tertiary care HD unit in London, Canada, between June and August of 2009. Patients dialyzing with a catheter, who were deemed eligible for an AVF by their nephrologist, but refused creation or cannulation of the AVF were eligible for the study. We excluded patients who did not have the capacity to provide informed consent, could not speak English well enough for an open-ended interview or were on the waiting list for a kidney transplant.

From eligible patients, a purposeful selection was carried out to sample for maximum variation with respect to age, gender, length of dialysis, previous failed AVFs, cause of renal failure and previous use of peritoneal dialysis. Our sampling strategy was chosen to maximize the diversity of patient experiences [17].

Data collection

We created an interview guide based on a literature review of VA. The guiding questions and potential probes kept the interview focused on patient experiences, preferences and beliefs. The guide was modified as interviews and data analysis progressed to include new questions and themes derived from initial interviews.

An independent interviewer (W.X.), not involved in direct patient care, conducted all the interviews using the iterative approach. Semi-structured interviews were tape-recorded and transcribed verbatim. Field notes were taken on patient appearance, behavior, speech and mood, as well as any nonverbal behavior and interviewer reflections. Interviews lasted between 15 and 45 min.

Analysis

Transcripts were analyzed independently by three reviewers (L.M.M., L.H. and W.X.) through line-by-line coding. A series of common themes were determined after three interviews. This was reviewed again with realignment of the themes after 10 interviews. Saturation was reached when no new themes were identified after a total of 13 interviews. Exemplar quotes were extracted based on the thematic analysis with filler words deleted when they have been agreed upon to have no impact on the statement.

Trustworthiness and credibility

We purposefully sampled patients of different ages, genders, previous fistula use, time on dialysis, cause of renal disease and previous use of alternative dialysis modalities to enhance the spectrum patient experiences. Sample size estimation was arrived at by first by consulting other qualitative studies of similar design, which provided an initial range. The guide was modified as interviews and data collection progressed to include new themes and questions derived from initial interviews. An independent analyst familiar with the experience of renal patients and renal disease determined that the themes were credible in the perspective of these patients. We used a qualitative methodology with a phenomenological approach to explore patient attitudes, preferences, beliefs and values when deciding on VA choices for patients on chronic conventional HD.

Results

The sample was selected from a population comprised of 147 patients receiving chronic HD using a catheter, of which 48 (33%) patients were eligible for a fistula. Of those
identified, 32 (68%) patients refused creation of a new fistula or cannulation of an existing fistula. We interviewed 13 patients, 7 males and 6 females (Table 1). Six patients had a previous AVF.

We observed three major themes surrounding the decision to refuse a fistula: negative personal or vicarious experiences with the fistula, knowledge transfer and informed decision making and acceptance of status quo (Table 2).

Impact of previous personal or vicarious experiences with a fistula

Six of thirteen patients in our study had at least one previous fistula. Other patients learned about the fistula through talking with or seeing other patients with a fistula. We identified four common experiences that influenced the participants’ decision to reject a fistula: failure to mature, difficulty with cannulation and pain, bleeding from the

Table 1. Participant characteristics (N = 13)*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
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<tbody>
<tr>
<td>Mean age, years (SD)</td>
<td>69 (12)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7 (54)</td>
</tr>
<tr>
<td>Female</td>
<td>6 (46)</td>
</tr>
<tr>
<td>Mean time on dialysis, months (SD)</td>
<td>47 (28)</td>
</tr>
<tr>
<td>Previous use of PD</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Previous transplant</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Previous AVF use</td>
<td>6 (46)</td>
</tr>
<tr>
<td>Previous AVG use</td>
<td>2 (15)</td>
</tr>
<tr>
<td>Previous CVC use</td>
<td>6 (46)</td>
</tr>
</tbody>
</table>

*Participants’ diagnosis causing renal disease included diabetes, hypertension, IgA nephropathy, vasculitis, malignancy, renovascular disease and familial disease. AVG, arteriovenous graft; PD, peritoneal dialysis; SD, standard deviation.

Table 2. Themes surrounding VA decision making

<table>
<thead>
<tr>
<th>Theme</th>
<th>Comment</th>
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| I. Impact of previous personal or vicarious experiences | Failure to mature
| ’I’ve seen that they don’t work and they can’t get them to work and
I just wasn’t interested in [the fistula].’ |
| Cannulation                                | ’I don’t want somebody poking at my arm every time I come here . . .
I’ve seen one nurse will take forever to try and the next thing
you know she’s got somebody else there trying so they’re poking
at your arm.’ |
| Bleeding                                   | ’. . . by the time I got home the coat I had on was loaded with blood.’ |
| Body image                                 | ’Her arm was just swelled up. And after that I seen another who had
an awful arm and they had to go back to [a catheter].’ |
| II. Knowledge transfer and informed decision making | Healthcare professionals
| ’I was told that [the fistula] was the best way to go. And that dialysis
would work better if I had a fistula. So that basically made up my mind.
Yeah OK. I’ll get the fistula. And if I ever do have to go on dialysis,
it’s already there and waiting.’ |
| Dialysis-patient peers                     | ’They said they’ve had more than one [fistula]. They’ve had several.
And they’ve had problems with it so they’ve had to get new ones.
And it all takes time . . .’ |
| Perceived lack of knowledge                | ’My doctor actually sent me to the hospital but he didn’t tell me why
or anything. While I was in there, they put the [catheter] access in
and started me on dialysis. I didn’t know anything about it.’ |
| III. Patient acceptance of status quo      | Lifestyle limitations
| ’I’ve been in a pool a few times, I just cover [the catheter] all up with
plastic and tape it over.’ |
| Lack of actual complications or concern for complications | ’I’ve had this [catheter] for two years and I was running with two
catheters and as long as you pay attention and clean yourself
properly and watch for infection, you won’t get any.’ |
| Complications of fistula creation          | ’Most of the people that have been here have passed on because
they keep fooling around with . . . putting [the fistula] in your arm,
then they take it out.’ |
| Focus on the present, day-to-day living    | ’. . . nobody can predict what your health is going to be in the future
I don’t think. I feel pretty good right now, but you live from day to day’.
fistula after needle withdrawal and consequent time commitment and appearance of the fistula (Table 2).

Patients mentioned that previous experiences of failure to mature were major deterrents to obtaining another fistula.

‘I was hoping that [my fistula] would develop to the point where it would be more successful but that didn’t happen. And I followed all the rules. I did all the exercises, but that wasn’t enough.’

Cannulation pain and discomfort due to needles was common.

‘That’s a pretty big needle and it’s uncomfortable. And then, when you’re lying here, you can’t move, at all, because it used to interfere with it. I tried to put the cream on to desensitize. That really didn’t do very much.’

The rate of successful cannulation was another patient concern given the low prevalence of fistula use in this unit, though none of the participants refused cannulation permanently.

‘[Nurses] don’t have experience with fistula. They have experience with the line . . . it’s maybe a good idea that if you have fistula you get the same person to poke your arm . . . maybe just teach the patient how to do it.’

Persistent bleeding and consequent time commitment was an issue.

‘After dialysis, sometimes I have to stay longer, you know? Because the bleeding didn’t stop. And sometimes I just come back because of bleeding. It’s a different story every time.’

Body image was also important to a few patients, as one patient stated about her vicarious experiences,

‘she had [the fistula] in all her life and she had big welts, big bumps, all in her arm. And then at that time, they were going to change it to the other arm. She had a lot of problems. Her arm was just swelled up.’

Knowledge transfer and informed decision making

We explored how patients obtained and processed information and how this influenced their decision on type of VA. Patients reported obtaining information from health care professionals, other dialysis patients and the Internet. Meanwhile, some patients perceived a lack of information (Table 2).

Patients with ESRD within the London Health Sciences Centre system receive information in many forms: meeting with a nephrologist, receiving written material, attending instructional courses, receiving teaching from the VA nurse and planned and impromptu interactions with other health care professionals. The information provided greatly influenced patients’ decision either for or against the fistula.

‘The paperwork that the [VA nurse] gave me was very well done . . . I sat down and looked at it a few times and decided to [go for the fistula].’

Interactions with health care professionals were important.

‘I was told that [the fistula] was the best way to go. And that dialysis would work better if I had a fistula. So that basically made up my mind . . . and if I ever do have to go on dialysis, it’s already there and waiting.’

In deciding to forego another fistula after a failed one, health care professionals were also a key influence.

‘[The doctor] only gave me a thirty percent chance that it would work again. And that’s when I decided well I’m not going to go through all that again if I’ve only got a thirty percent chance. So I use the catheter . . . I think if he’d given me a fifty-fifty chance, I probably would have had it again.’

Patient-to-patient knowledge transfer also played an important role. One patient with a positive perception of the fistula stated

‘most of the information came by word of mouth. To me, I’m one of these guys, I want to see before I do. Two or three people I associate with, they all had [the fistula]. They didn’t seem to be complaining about it.’

However, most patients used other patients’ experiences as a deterrent to having a fistula.

‘Two or three guys that had [the fistula], they really had a lot of problems with their entire arm and all over . . . two that I know that went back to up here [pointing to catheter site] have had it for quite a while. The arm thing just didn’t seem to work.’

Several patients perceived they did not have enough information about different VAs to make an informed choice.

‘My doctor actually sent me to the hospital but he didn’t tell me why or anything. While I was in there, they put the access in and started me on dialysis. I didn’t know anything about it.’

Some patients had gaps in their knowledge about the fistula.

‘I misunderstood what a fistula really does. I thought it was something that they stuck in your arm and then there was an access to that where they just plugged it in or something. I didn’t realize that they stuck needles in your arm.’

Patient acceptance of status quo

Patients identified the following as justification for use of the catheter: acceptance of catheter limitations on lifestyle, lack of actual catheter complications, lack of concern for potential catheter complication, fear of potential complications with fistula creation and attitudes about longevity and preference to focus on the present including living for today (Table 2).

Patients emphasized overall satisfaction with their current catheter despite awareness of the lifestyle limitations of their catheter.
‘it would make my quality of life a little better using a fistula rather than the catheter . . . . I’d be able to shower and be able to go swimming, but I’ve pretty much resigned myself that the catheter is the only way for me to go so I don’t shower. I take a bath.’

Patients minimized chances and occurrences of complications. One patient mentioned that they are using the catheter because ‘the catheter has been successful and has done the job.’ Another patient mentioned that ‘I haven’t had an infection in this one yet’ There appeared to be a mentality that despite a previous infection, the current one has been functional and uncomplicated, with several patients using similar phrases to ‘ever since then it’s been all right’, referring to their newly placed catheter.

Patients were aware that ‘the fistula was considered to be a little safer, a little less chance of getting an infection.’ Despite the awareness, infectious complications were minimized.

‘I’ve seen two or three that had a bad infection. From what the doctor told me, as long as you keep [your catheter] good and clean you wouldn’t have an infection . . . . The first time I ever had [an infection], I didn’t know what might happen. [The doctor] said “don’t worry about it, we’ll just pull that one out and put another one in and give you some antibiotics and it should be okay.”’

Patients also did not want the hassle and complications of undergoing fistula placement. One patient commented on her preference not to have a surgery, ‘I’ve had 37 operations. I don’t want any more’. Another patient believed other patients’ death was related to a lack of success of the fistula.

‘most of the people that have been here have passed on because they keep fooling around with . . . putting [the fistula] in your arm, then they take it out.’

Patients’ future outlook was important.

‘it’s a big step [to get a fistula] . . . . I look at it from a different perspective than most people. I’m 69-years of age in December of this year and I’ve got to keep asking myself ‘how much does my body take,’ because every time I change something my body reacts accordingly and I don’t know how much it will take.’

Another patient who had considered stopping dialysis altogether was strongly against the fistula stating that ‘if they wanted to move [my catheter] from this spot to my arm, I wouldn’t take dialysis.’ Patients also reflected on hopes for alternatives to dialysis. Despite being ineligible for a transplant, one patient stated ‘I’m hoping they’ll put me on the [transplant] list again. I’m young’.

In contrast, and to reinforce the importance of outlook on life, one patient who actually decided to obtain a fistula through the course of the study mentioned the long-term benefits of the fistula.

‘over time the fistula will outlast and outwork your catheter because the catheter eventually has to be cleaned out, repositioned. If the fistula is working properly, you won’t have that problem. It’ll last for years . . . in the long run that supercedes anything else . . . . I would rather look at the green grass, than the roots of the grass. . . . You have to keep your attitude up. If you lose your attitude, you will just go down and down. So, it’s another day and another way of living.’

Many patients, despite their preferences for dialysis with a catheter, claimed that they would tell other patients that ‘they had to make up their own mind’ regarding choosing an access for dialysis. Patients also recommended that you have to ‘have a reason and do a lot of research’. One patient who had a previously failed fistula stated ‘I guess I would tell them to try the fistula’.

Discussion

Our study explored patients’ decision-making process with regard to refusal of a fistula. We elicited three major themes: (i) previous personal or vicarious experiences with a fistula, (ii) knowledge transfer and informed decision making and (iii) patient acceptance of the status quo. Our findings support dialysis patients’ preferences for a shared decision-making process between the health care team and patient, one of the major pillars in the patient-centered health care model [19]. While a fistula may be recommended, a patient can turn down a fistula for several reasons, and a study recently published by our group showed that 80% of nephrologists consider patient refusal to be a major barrier for fistula creation [11]. In our study, the patients we interviewed were experiencing a wide spectrum of symptoms and altered quality of life from their dialysis and comorbidities. Frustration with their disease and value of current health can impact decision making and health outcomes [20, 21]. For example, two patients who perceived their doctor’s reassurance of a guarantee of a successful procedure ended up with complications. These patients may be less inclined for further interaction within the health care system.

Patients made decisions using their own or vicarious experiences with the fistula. The spectrum varied from patients who would consider a fistula again if chances of success were higher to patients who would stop dialysis if they had to obtain a fistula. Many patients reported poor overall outcome, including failure to mature and inability to cannulate, as a major deterrent to having a first or repeat fistula. Studies report a failure to mature rate of up to 65%, likely due to creating fistulas in patients who are less likely to have successful maturation [22]. By establishing eligibility criteria for fistula creation, we can seek to decrease the failure to mature rate and expose fewer patients to negative vicarious experiences with the fistula. Our study also found that patients were concerned with the lack of experience nurses had with cannulating a fistula. At our center, the high prevalence of catheter use and nursing staff logistics reduces the experience of successful cannulation. Although there were no patients who refused cannulation permanently, poor experience with previous cannulations or lack of knowledge of what cannulation involved were
cited as potential reasons against a patient consenting to cannulation. Patients in our study also reported pain as a result of needles, appearance, bleeding and increased time commitment as dissatisfactions, which is consistent with previous literature [16].

Knowledge transfer and informed decision making was an important theme. Influence from peers was important, consistent with literature regarding patient decision making in ESRD [12, 13]. For patients in our study, peer influence was often as important as influence by health care professionals. Patients expressed camaraderie such as ‘the three musketeers’ with other dialysis patients. Family members of patients did not appear to be influential in decision making, contrasting studies of dialysis withdrawal where burden to family was a theme [14]. Information from health care professionals is provided at our center through paper-based and verbal teaching, either within groups or individually. Patients gravitated towards one or more forms of information, and no patients were discouraged from any particular form of teaching. During seminar teaching, patients see examples of fistulas, grafts and catheters in patients who have been on dialysis for a while. At our center, we emphasize the fistula as the optimal VA. Nurse and physician preference within a specific center has been shown to influence the prevalence of VA modalities in centers that prefer grafts [23].

Timing of information is important for patients [12, 24]. Several patients in our study had sudden starts to their dialysis. Patients may forget or misunderstand information about VA if given at a time when they are overwhelmed with information regarding their health or by their personal reactions to disease. Even given at a good time, some information may prove to be difficult to absorb [25]. Misunderstanding of information played an important role in some patients, including one patient who was unaware needles were involved with the fistula. Patients who show a greater understanding about CKD have increased use of a fistula [15, 26].

Previous literature suggests that many patients perceive a lack of choice in dialysis modality because of medical contraindication or health care professional preference [12, 27]. Given eligibility for a fistula, a patient is always given a choice between the fistula and catheter. This availability of choice may influence individuals to make a choice independently without physician influence compared to dialysis modality choice that may be more dictated by the physician. However, nephrologists should emphasize to fistula-eligible patients that the catheter is only a temporary solution until a fistula is established [28].

Once patients begin dialyzing with an access that appears to work, consideration of other options becomes less likely. This is especially true when lack of complications couple with good patient adaptations to catheter restrictions, including inability to shower or swim. Previous literature suggests that once a treatment plan is established, alterations tend to be resisted by the patient [12, 29, 30]. These findings reinforce the importance of starting dialysis with a fistula, but also early referral and frequent nephrologist visits, which are associated with increased fistula use at the start of dialysis [31–34]. Physicians should be cognizant that recommending a fistula may be interpreted by a patient as a change in the status quo and a sign of disease progression, which a patient may not be willing to accept [13].

Though taken seriously by health care professionals, infection of catheters was downplayed by patients. If a catheter was to be infected, patients also believed it would be easy although painful to be provided another one. In previous studies, only 3% of patients believed infection was a major concern [16].

Our study had some limitations. This dialysis unit had a high prevalence of catheter use, and patient attitudes in this unit may not be reflective as those from a unit with a lower rate of catheter use. There are no major financial barriers to fistula creation in Canada because hospital-related costs do not require out-of-pocket payment from the patient. However, patients often have to travel long distances (>200 km) to come for an access procedure or creation, and this cost is born by the patient and the family. Patients’ recollection of education regarding VA may omit forgotten knowledge used during their actual period of decision making.

Our study elicited the reasoning process patients use to make an informed decision regarding a fistula versus a catheter. A health care professional must build a trusting relationship explaining all different options of care with the help of multiple educational resources that should not only be received but understood by the patient. Fistula eligibility criteria should be studied to reduce the failure to mature rate and decrease negative vicarious experiences with the fistula. Although nephrologists consider the fistula to be the optimal VA, patients do not think in the same terms of reducing infection rates, but rather place greater emphasis on the practical day-to-day use of their VA and its influence on their quality of life and future outlook.

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