

ORIGINAL RESEARCH

Waiting for a kidney transplant: patients' experiences of haemodialysis therapy

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Abstract

Aim. This paper is a report of an exploration of the experiences of patients with end-stage kidney disease who were having haemodialysis.

Background. The losses and lifestyle disruptions caused by end-stage kidney disease are a fundamental source of suffering for people. The hope of a transplant is an important factor in people's ability to cope with end-stage kidney disease and dialysis.

Method. A Heideggerian phenomenological methodology was used. A purposive sample was selected of 16 patients with end-stage kidney disease having hospital-based haemodialysis therapy in the Republic of Ireland. Qualitative interviews were conducted in 2006–2007. Data were analysed using qualitative interpretive analysis.

Findings. The overarching pattern identified was 'Waiting for a kidney transplant'. This pattern consisted of three themes: living in hope, uncertainty and being on hold. Participants described their experiences of living in hope while they waited for a kidney transplant. However, as the waiting time continued indefinitely, participants became uncertain, and this meant that they were unable to contemplate opportunities in the future. Moreover, the restrictions of haemodialysis therapy prevented them from performing many of the activities they had taken for granted in the past. Consequently, they described their experiences of being on hold while they waited for a kidney transplant.

Conclusion. Nurses should engage in open and honest discussions with patients in relation to kidney transplantation so that they are able to recognize and address their concerns about kidney transplantation.

Keywords: end-stage kidney disease, haemodialysis, kidney transplant, nursing, patients' experiences, phenomenology

Introduction

End-stage kidney disease (ESKD) is a chronic and debilitating condition. Haemodialysis is one modality of renal replacement therapy for ESKD. People having hospital-based

haemodialysis have to adhere to a strict regimen of dialysis, dietary and fluid restrictions, and medications (Al-Arabi 2006, Krueger 2009).

According to the literature, people with a long-term illness such as ESKD experience many losses, which culminate in

suffering (Morse 2001, Ohman *et al.* 2003). Morse's (2001) model of suffering is a particularly useful framework against which to describe people's experiences of ESKD.

Background

The international literature indicates that the losses incurred as a result of long-term illness are a fundamental source of suffering (Morse 2001, Ohman *et al.* 2003, Chesla 2005). For example, there are a number of losses and lifestyle disruptions experienced by people with ESKD which may culminate in suffering (Hagren *et al.* 2001, Hutchinson 2005). The restrictive nature of ESKD and dialysis affects the patient's ability to perform normal everyday activities, such as working, socializing and travelling (Al-Arabi 2006, Kaba *et al.* 2007). Consequently, people experience distressing emotional responses, such as uncertainty, hopelessness and depression (Baines & Jindal 2003, Asti *et al.* 2006, Krueger 2009). In particular, qualitative research exploring experiences of ESKD illustrates that these people oscillate between the release and suppression of distressing emotions. We suggest that these oscillatory characteristics are reflected in the model of suffering, advanced by Morse (2001).

According to Morse (2001), suffering consists of two states: 'emotional suffering' and 'enduring'. Emotional suffering is a distressed state where emotions are released. Therefore, people protect themselves from psychological distress by suppressing these unpleasant emotions. Morse (2001) describes this strategy as enduring. It is a strategy that enables people to get through an unbearable situation. People who are enduring focus on the present, and this allows them to get through each moment of the adverse event. By focusing on the present, they cognitively block out the past and future (Morse 2001).

We suggest that the oscillation between the release and suppression of unpleasant emotions depicted in Morse's model mirrors people's experiences of ESKD presented in the international literature. For instance, participants in a study by de Guzman *et al.* (2009) indicated that they coped with the distress of having haemodialysis by blocking out thoughts of their illness and treatment. By viewing haemodialysis as an obstacle they needed to get through, they were able to retain the will to live.

Hagren *et al.* (2005) illustrated the existential struggle experienced by patients having haemodialysis therapy. The participants in the study indicated that the dialysis machine served as a constant reminder that they were living on borrowed time. To overcome the distress of dialysis, they strove to get through each day as autonomously as possible. The ability to maintain mental distance from thoughts and

feelings about the illness and treatment helped to minimize distress.

Similarly, participants having haemodialysis in a study by Calvin (2004) described their experience of uncertainty due to declining health. To cope with uncertainty, they moved into a phase of personal preservation where they blocked distressing thoughts and feelings out of their mind.

Molzahn *et al.* (2008) suggested that dialysis therapy represented a fine line between life and death for patients with ESKD. Therefore, in order to cope, some participants adapted a present day perspective. Correspondingly, a study by Curtin *et al.* (2002) illustrated that patients having haemodialysis tolerated uncertainty by predominantly concentrating on the present. Other studies also highlighted people's efforts to suppress distressing emotions and focus on the present, in an effort to cope with ESKD and dialysis (King *et al.* 2002, Kierans 2005, Tanyi & Werner 2008).

According to Morse (2001), people move back and forth between the suppression and release of distressing emotions before they move beyond suffering. Hope plays a central role in this process (Morse 2001). The hope of a kidney transplant is an important factor in people's ability to cope with ESKD and dialysis therapy (Krueger 2009, Mitchell *et al.* 2009). However, the hope of a transplant is often undermined by feelings of uncertainty and anxiety in relation to the potential complications of the procedure (Polaschek 2000, Pradel *et al.* 2009).

Thus, the model of suffering described by Morse (2001) provides a useful framework to describe the patients' experiences of ESKD portrayed in the literature.

The study

Aim

The aim of the study was to explore the experiences of patients with end-stage kidney disease who were having haemodialysis.

Methodology

The philosophical perspective

Hermeneutical phenomenology is a qualitative research methodology used to enhance understanding of the experiences of people in their everyday lives (Diekelmann & Ironside 1998). The approach to hermeneutical phenomenology used for this study was informed by the philosophy of Martin Heidegger (1889–1976). Heidegger's (1962) notion of time is central to his phenomenological philosophy.

According to Heidegger (1962), time does not signify our common understanding of time as clock time. Instead, time is *originary temporality* and is a basic structure of our existence or being (Heidegger 1962). In originary temporality, the present incorporates the past and the future as a unified whole (Dostal 1993).

The originary future relates to the way in which people press ahead or project themselves forward into some way of life or some possibility of being in the future (Mulhall 1996). Our ability to progress forward into possibilities in the originary future provides the originary past and present with projective or future-directed characteristics.

The originary past is composed of the important set of relationships, practices and language that we have by virtue of being born into a particular world (Heidegger 1962). These background or contextual features set up the possibilities for our future existence.

We perform every action in the originary present in-order-to project forward into some goal or possibility in the originary future. Therefore, the originary present is the time that contains the tasks and activities we perform on an everyday basis. We act in the present, based on the contextual features from our past, to project forward into possibilities in the originary future (Blattner 1992). Consequently, the originary present highlights the connection in the threefold structure of originary temporality (Blattner 1992).

Heidegger (1962) uses the term 'ordinary time' to describe clock time. He indicates that we normally use clock time to structure the everyday activities we perform in the originary present (Blattner 2005). Therefore, ordinary time is embedded in originary temporality via the originary present.

Participants

A purposive sample of 16 patients participated in the study. Prior to conducting this study, the primary author (AM) had completed another qualitative study to explore the experience of ESKD for 16 patients in the Republic of Ireland. This sample size yielded substantial data and was deemed an appropriate sample size for the current study. The sample included seven women and nine men. Patients were considered for inclusion in the study if they were aged 18 years or over, were able to converse in English, and were having hospital-based haemodialysis therapy for ESKD.

Data collection

Two qualitative interviews were conducted with each participant during 2006–2007. Participants were given the choice to have the interview in the dialysis unit or in their own

homes. Two requested to be interviewed in their homes and the others were interviewed during dialysis therapy. The follow-up interview occurred approximately 1 year after the initial interview. In the first interview, one opening question was used: 'What is it like to have haemodialysis therapy?' After the initial question, probing questions were used, such as 'What was that like?' and 'Can you tell me more about that?' The focus of follow-up interviews was determined by the themes identified during the analysis of data from the initial interviews. The interviews were audio-recorded and transcribed verbatim.

Ethical considerations

Approval to conduct the study was given by the Research Ethics Committee at the study hospital. A counselling service was available to provide follow-up support in the event of a participant becoming upset during an interview. However, this service was not required as no participants were distressed during or after the interviews.

Data analysis

Data were analysed using a qualitative interpretive approach proposed by Diekmann *et al.* (1989). Transcripts were read and interpretive summaries of each interview were written up. A list of categories was created from each interview, and the categories were compared and contrasted among the interview texts from all participants. This allowed shared or similar categories to be identified and developed into themes. A database created in *Microsoft Access* was used to code, synthesize and store data. As the themes were developed and refined, a pattern that linked the themes was created.

Rigour

Data were collected and analysed by the primary author (AM), who had previously worked as a renal nurse. Consequently, it was acknowledged that pre-understandings of the research topic would potentially influence the interpretations made throughout the study. To prevent these pre-understandings from overly influencing the findings, various strategies were used to enhance rigour.

For instance, the format of the first interviews was open-ended. This ensured that participants' responses were not constrained by the perspective of the researcher. A diary of critical reflection was completed throughout the study. The aim of the diary was not to 'bracket' pre-understandings about the topic, but to heighten awareness of these understandings in an effort to prevent them from influencing

interpretation of the data. The written accounts maintained in the diary also provided a record of decisions made throughout the study, which is an element of rigour (Molzahn & Shields 1997).

The primary author developed the initial categories and themes from the data. In addition, the other members of the research team read all the interview transcripts and discussed and debated the categories and themes in detail. This process allowed interpretations to be challenged, clarified and extended, thus enhancing the rigour of the study.

Findings

The participants ranged in age from 30 to 65 years and had been having haemodialysis for from 1 month to 5 years. The experience of waiting for a kidney transplant was identified as a constitutive or overarching pattern in the study. This pattern consisted of three themes: (1) Living in Hope; (2) Uncertainty; and (3) Being on Hold. In the follow-up interviews, participants highlighted how their experiences had changed over time.

Living in hope

Several participants described their experiences of living in hope while they waited for a kidney transplant. Embedded in their accounts was their predominant focus on clock and calendar time. This focus allowed them to get through the days, weeks, months, and years until the waiting was finally over.

For instance, the hope of receiving a transplant allowed a 32-year-old man who had been having dialysis for a year to believe that this was a temporary treatment:

[The doctor] came down and said that they [medical team] would work me up for a transplant as quick as possible... So I got a line fitted and I was on dialysis... I don't really mind dialysis because I know it's going to be short-term... I dealt with it pretty quickly, because [the doctor] said I would get a transplant quickly.

A 31-year-old man having dialysis for 1 year also confirmed how the hope of a transplant enabled him to view haemodialysis as a short-term problem:

I'd met people who had transplants and I realized it's [dialysis] actually not as bad as I thought it was. I met one guy who had a transplant 25 years ago and it's still working fine... it's [dialysis] a bit uncomfortable for maybe a year or two but after that, if I look after myself and if luck is on my side, it [kidney transplantation] can go well.

Like the other participants, a 55-year-old man highlighted his hope of getting on the waiting list for a kidney transplant. He

had been having dialysis for 2 years since his previous kidney transplant failed:

This week I'll be having my stress test and I should be getting on it [transplant waiting list] within the next month or so... that's providing that I'll pass the stress test, but hopefully I will... I'm absolutely delighted... If you're on the list there's hope, there's light at the end of the tunnel.

Other participants used this analogy of light at the end of the tunnel to characterize their experiences of hope. For example, a 44-year-old woman having dialysis for almost 3 years stated:

Hopefully I'll get a kidney soon and that'll be the end of it [dialysis], you always live in hope... there's light at the end of the tunnel.

A 59-year-old man having dialysis for 1 year illustrated how the perspective of clock and calendar time was ingrained in his experience of living in hope:

You're living in hope [of getting a transplant], you just feel like it could be tomorrow, it could be a year from tomorrow... it could be any day... It will happen, but you have to wait.

Follow-up interviews with some participants highlighted how their experiences of living in hope changed to uncertainty over time:

Uncertainty

Participants described the experience of uncertainty while they waited for a kidney transplant. It seemed that they interpreted the 'average' waiting time to mean the 'actual' waiting time. The average waiting time for a kidney transplant is merely an estimate, and many people wait well beyond this. However, when participants exceeded the 'expected' date for a kidney transplant, their hope turned to uncertainty.

For instance, one man's experience of living in hope changed as the wait for a transplant continued. He believed that he would receive a transplant in a short duration of time. However, at the time of the follow-up interview, he had been waiting almost 2 years and was becoming increasingly uncertain about his future:

Well, in the beginning, I was told that the average waiting list [for a transplant] was around 12 to 18 months, so when I started on dialysis I had two years left out in my head for it all to be over... but I'm nearly two years on dialysis now, so you just don't know... it's waiting all the time.

By the time of the follow-up interview one man had failed the medical assessment to gain entry to the transplant waiting list

on two occasions. When confronted with uncertainty, he was concerned about his future:

I've been to [the transplant unit] twice... they [medical team] say I'm overweight... I'm really trying so hard, but it's impossible to get the weight down... the longer it [waiting for a transplant] goes on, the worse you feel about it... at the beginning, you have no knowledge of what's happening at all... but after being on dialysis for two years, I feel I'm going to be stuck here and that's it.

Some participants described their experiences of uncertainty at the initial interviews. These people had already exceeded the average waiting time for a kidney transplant at this point. For example, a 43-year-old woman emphasized how the uncertainty of waiting indefinitely for a transplant had turned her hope to despair. She had been having haemodialysis for 4 years since her previous kidney transplant had failed:

The doctors said I'd be waiting for a year and a bit to get the transplant... then it became two years and a bit, three years and a bit, and now it's four years... people shouldn't listen to this! Because you think, 'OK, I can do a year or two years on dialysis', but then it's devastating when you pass the two years.

In the initial interview, a 40-year-old man who had been having haemodialysis for 18 months confirmed that he was becoming increasingly uncertain as the time spent waiting for a transplant continued indefinitely:

If somebody said to me I would have to wait another year [for a transplant], it would be like a nightmare... I think they [healthcare team] should tell us straight and I hope they are.

A 49-year-old man had been having dialysis for 1 year and 7 months. He also described the uncertainty he experienced when he exceeded his expected wait for a transplant:

Before I started dialysis, I'd ask [the healthcare team] what was the average [waiting time for a transplant], and it was 18 months to two years, but I've heard of people having transplants just after a few months, and then there's people that have been waiting five to six years... It's hard not to think, 'Well, why not me?' Sometimes I think I'm going to be waiting a long time, I better just get used to the idea.

Being on hold

As a result of their experiences of uncertainty, participants were unable to contemplate opportunities in the future. Moreover, the restrictions imposed by haemodialysis prevented them from performing many of the everyday activities they had taken for granted in the past. Consequently, they described their experiences as being on hold while they waited for a kidney transplant. Moods of

sadness, depression, and despair were palpable throughout their accounts.

For instance, one man said:

My life is on hold... because I worked in construction and some jobs can be physical... I don't know what employer will employ me if I'm taking every second day off... I see a future if I get a transplant. It's mainly about work... how am I going to survive and pay bills... I have to come in here three times a week for four and a half hours... it's continuous, until I get a transplant.

A woman also expressed her experience of being on hold while she waited for a kidney transplant. She indicated that her life was engulfed by the restrictions of haemodialysis therapy. Therefore, her ability to contemplate opportunities for the future was diminished:

I look at life as if it's on hold until I get a transplant... because you're not doing what you want to do... it [dialysis] gets in the way of work, it gets in the way of a normal routine... it's like I'm bonded to it [dialysis]... and when you do get the transplant, it's like the shackles are gone.

The absence of a definite end to the wait for a transplant restricted another man's outlook for the future, and in the follow-up interview he said:

I feel on hold... There's times when I get down in the dumps... I'm waiting and I think it's [the transplant] never going to happen... I get a bit depressed at times... and I've got to a stage where I say, 'Why am I trying so hard to get on this thing [transplant list]?' There's no hope for me getting on it... I just feel, 'Is my day ever going to come?'

In another follow-up interview a man emphasized how his life centred on the 'waiting game' for a kidney transplant. Therefore, he was on hold until he eventually received the call for transplantation:

I'm on hold... it's just a big waiting game now... waiting for that call [for a transplant]... I never leave the phone, I have the phone with me 24/7... Every Tuesday, Thursday, Sunday for the past 23 months I've been just planning to go to dialysis... I'm watching everything I eat, everything I drink... After getting the transplant, I think I'd get my life back...it [life] wouldn't be on hold then.

Another man also described his experience of waiting for a transplant as being on hold. He had given up work to ensure that he would not miss the phone call for a kidney transplant:

My life is on hold... very, very much so... I can't plan anything, can't go anywhere... I'm waiting for the phone to ring... I might get a days work but what happens if the phone rings... I could earn a bit more money but there's always the chance I might be called for a transplant.

Discussion

Study limitations

Our findings offer interesting insights into patients' experiences of ESKD and haemodialysis therapy. However, the limitations of the study include the small purposive sample and the qualitative methodology. These elements preclude generalization of the findings to the larger population of patients having haemodialysis therapy. However, the primary aim of the study was not to generalize the findings, but to develop an in-depth account of participants' experiences of haemodialysis therapy.

Experiences while having dialysis

Like the findings of our study, the literature highlights the feelings of hope and uncertainty experienced by patients with ESKD while they wait for a kidney transplant (e.g. Polaschek 2000, Krueger 2009). However, the experience of being on hold has not previously been identified as an important feature for these patients. We suggest that the concept of 'enduring' described in the model of suffering by Morse (2001) characterizes certain features of participants' experiences of being on hold while they wait for a kidney transplant.

As mentioned previously, Morse (2001) contends that people who are enduring suppress their emotional responses and focus on the present in an effort to get through an unbearable situation. When people focus on the present, they block out the past and future. These qualities of enduring correspond with the disruption in time identified in our participants' experiences of being on hold. However, we suggest that it is Heidegger's (1962) account of originary temporality that is embedded in participants' experiences of waiting for a kidney transplant. Moreover, the experience of waiting indefinitely for a transplant resulted in the suspension of originary temporality, which is characteristic of the description of profound boredom depicted by Heidegger (1995).

Information received from the healthcare team in relation to the average waiting time for a kidney transplant led participants to assume that they would receive a transplant in a definite period of time. We suggest that this assumption encouraged them to focus on clock time up until they exceeded this timeframe. Indeed, their accounts of living in hope illustrate their predominant focus on clock and calendar time. In this way, they are able to get through the days, weeks and months until the wait for a transplant is finally over.

Heidegger (1962) indicates that we normally understand ordinary or clock time in relation to the activities we perform

in the originary present. Therefore, ordinary time is based on the originary present and subsequently originates from originary temporality. However, Heidegger indicates that if we merely focus on the seconds, minutes and hours of ordinary time, this contextual background remains hidden (Blattner 1999). We suggest that, while participants focused on clock and calendar time, the threefold structure of originary temporality embedded within their experience of waiting for a transplant remained concealed.

When participants exceeded the 'expected' waiting time for a kidney transplant, they experienced uncertainty. They began to realize that haemodialysis was not the short-term problem they had initially anticipated. We propose that their perspective on time changed at this point. They were no longer merely focusing on getting through ordinary or clock time while they waited for a transplant. Instead, the uncertainty of waiting for a transplant hindered their ability to project forward into possibilities in the originary future. Hence, they described their experiences of being on hold while they persistently waited for a kidney transplant.

We suggest that participants' experiences of being on hold represented a suspension in the threefold structure of originary temporality. The three dimensions of originary temporality form a unified whole, with a projective or future-directed character based on the originary future. Participants' descriptions of being on hold suggested they were unable to project forward into possibilities in the future. Without the projective characteristics of the originary future, the unified structure of originary temporality is suspended or stopped (Heidegger 1995). Moreover, as a result of being on hold, participants were unable to perform their everyday activities in the originary present, and this contributed to the suspension of originary temporality.

The suspension of originary temporality represented in participants' experiences of being on hold is reminiscent of Heidegger's (1995) description of profound boredom.

In this state we are 'held in limbo' by the suspension of originary temporality (Heidegger 1995). We are held back from our possibilities in life, and consequently from our past and future (Haar 1999). Because of the projective characteristics of the originary future, death is one possibility that lies before us throughout our existence (Mulhall 2005).

According to Heidegger, when originary temporality is suspended in profound boredom, this paradoxically illuminates the threefold structure of originary temporality to us (Hoffman 2005). By illuminating the unified structure of originary temporality, boredom discloses death as one possibility of our existence (Hoffman 2005). Therefore, boredom is a fundamental existential mood (Heidegger 1995). When profound boredom confronts us with the finitude of existence,

What is already known about this topic

- Patients with end-stage kidney disease undergoing hospital-based haemodialysis therapy have to adhere to a strict regimen of dialysis, dietary and fluid restrictions, and medications.
- The losses and lifestyle disruptions caused by end-stage kidney disease and dialysis culminates in suffering.
- The hope of a transplant is an important factor in patients' ability to cope with end-stage kidney disease and dialysis.

What this paper adds

- The experience of waiting for a kidney transplant is important for patients on hospital-based haemodialysis therapy.
- Patients' experiences of waiting for a transplant change over time from being hopeful, to being uncertain, to being on hold.
- Waiting for a kidney transplant causes disruption in time for patients and initiates distressing moods.

Implications for practice and/or policy

- Nurses should engage in open and honest discussions with patients in relation to kidney transplantation so that they are able to recognize and address their concerns about kidney transplantation.
- Further research is needed to explore the experience of being 'on hold' in greater depth with other groups of patients with end-stage kidney disease.

it causes us to experience distressing moods (Hoffman 2005). Participants' accounts of being on hold highlighted distressing moods such as sadness, hopelessness and despair.

We propose that the suspension in temporality and the distressing moods illustrated by participants' experiences of being on hold mirror specific features of the concept of enduring advanced by Morse (2001). However, there is a need to expand the concept of enduring in order to make it a more appropriate framework to describe these experiences of being on hold while waiting for a transplant. We suggest that incorporating characteristics of Heidegger's perspective of mood and temporality with Morse's (2001) concept of enduring allows a more appropriate description of the experience of being on hold to be formulated (see Figure 1).

Morse (2001) believes that people who are enduring suppress emotions and focus on the present in order to get through an unbearable situation. However, when they focus

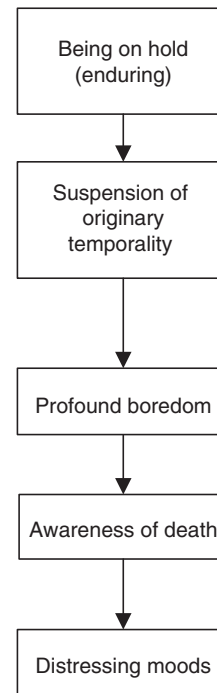


Figure 1 Expanded conceptualization of enduring.

on the present, they essentially block out the past and future (Morse 2001). These qualities of enduring correspond with the suspension of temporality identified in our participants' experiences of being on hold while they waited for a kidney transplant.

By expanding the concept of enduring, we can illustrate how the experience of being on hold as enduring causes the suspension of originary temporality and culminates in profound boredom. Profound boredom confronted participants with the finitude of their existence and initiated distressing moods. Morse (2001) indicates that while people are enduring, emotional distress can increase in intensity. However, the intensification of distress in Morse's concept of enduring refers to emotional distress. In order to make Morse's concept of enduring a more accurate depiction of our participants' experiences of being on hold, we need to replace the term 'emotion' with Heidegger's term 'mood'. By viewing emotion as mood within the concept of enduring, we are able to illustrate how the suspension of temporality caused by the experience of being on hold (enduring) culminates in profound boredom. Profound boredom highlights the possibility of death to the participants and creates distressing moods.

Conclusion

Heidegger's perspectives of time and boredom have not previously been identified as key features of people's expe-

riences of ESKD and dialysis. Consequently, our findings offer a new perspective on the experience of ESKD and dialysis which can inform the nursing care of these patients.

Our participants believed that ESKD and haemodialysis therapy were short-term problems which would be alleviated by a transplant. We suggest that there is a need for nurses to engage in open and honest discussions with patients in relation to kidney transplantation. This would allow them to assist patients to meet the criteria for the transplant waiting list, address their concerns about transplantation, and discuss the possibilities for live donor transplantation.

The experience of being on hold has not previously been identified as an important feature of people's experiences of waiting for a kidney transplant. We recommend that further research be carried out with other groups of patients with ESKD to explore the experience of being on hold in greater detail. Further research is also recommended to evaluate the robustness of the new conceptualization of enduring proposed in this paper.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

AM was responsible for the study conception and design. AM performed the data collection. AM, PAS and PD performed the data analysis. AM, PAS and PD were responsible for the drafting of the manuscript. AM, PAS and PD made critical revisions to the paper for important intellectual content. AM and PAS obtained funding. PAS and PD supervised the study.

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