

Non-dialysis management of end-stage renal failure

There are several issues pertinent to adopting a palliative care approach to end-stage renal failure (ESRF), when conservative management is

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considered. These include the importance of creating a voice for the voiceless; of considering the cultural constructs of health, illness and appropriate care; the fluidity of family—healthcare professional boundaries

and the potential psychological implications of this work for all healthcare professionals.

This article draws on systemic theory in considering the application of a Palliative care approach to conservative management of ESRF. Family care is commonly seen as core to sustaining people at the end of life. However, feedback suggests that many family members feel alone and talk of how, in going to hospital, the person they have known and loved becomes a patient and not a person — both in their eyes and in the eyes of professionals.'

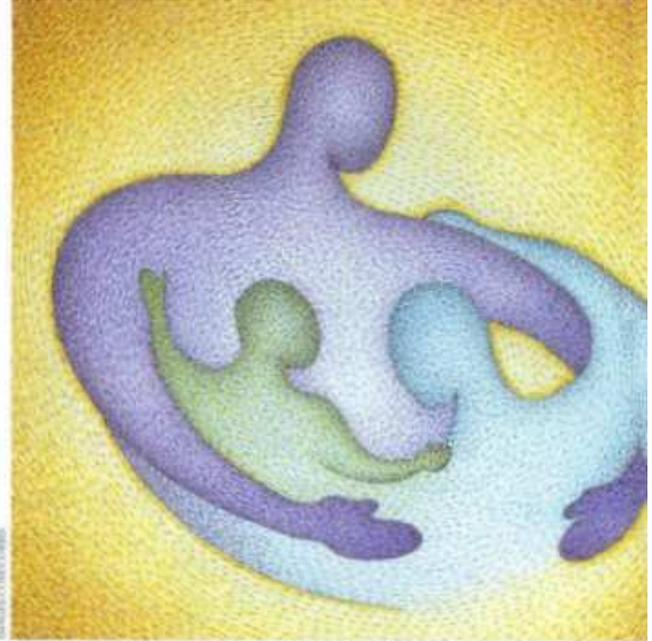
The word 'family' is used here to refer to those who matter most to the ill person, but it is also important to recognise that for many, the term is empty of meaning and does not invoke a sense of help and support.

Although there tends to be the assumption that family members draw together at times of illness and other crises, this is not always the case. As such, members of the renal care team will inevitably be required to help families negotiate their differences while dealing with the enormous practical and emotional demands of the illness.

Dialysis withdrawal or non-initiation

Despite the media's interest in opposition to withdrawing life-sustaining support, in both the UK and USA, one seldom hears of opposition with respect to dialysis. Instead, discussions centre on the circumstances and manner in which withdrawal should take place.²⁻⁶ Growing numbers of patients die following withdrawal or the non-initiation of dialysis.

There are many reasons for this. For example, advanced age and co-morbidity are no longer contraindications to initiating treatment, so advanced renal failure may be only one of many extremely disabling afflictions the patient experiences. Withdrawal then offers patients a chance of taking control over their final weeks and months. In most cases, death will not be sudden and, where the ill person has not experienced cognitive deficit, there is time to close



Good end-of-life care means that the setting allows for resolution and reconciliation

affairs and say goodbye - an opportunity unavailable to most people.

Nonetheless, any decision not to treat is always complex. To reach such decisions, patients and their families need space for careful discussion and non-intrusive, non-judgemental support.⁷ However, such decisions are difficult for professionals as well. Despite the need for discussion, both staff and families tend to find this extremely stressful and tensions can escalate. Compounding this is the fact that the boundary between professionals and family members tends to be most ambiguous at such stages of life.^{8,9}

When anyone becomes seriously ill, the boundary of the family changes; of necessity, it becomes more permeable as professionals play an increasingly active role in the practical and emotional lives of the ill person. This may shift once the initial crisis abates and the condition becomes more chronic.

Several factors probably account for this. In addition to the practical demands of the condition, family members often feel incompetent; they are operating in a world for which few of us have had training and they do not automatically know how to support their loved one. It, therefore, falls to professionals to share what has been learned and to help families 'catch up' on this process. Moreover, as their experience will be so different to that of others in the community, people tend to feel isolated, heightening the importance of being able to relate to healthcare professionals who are aware of what they are experiencing. This is possibly more

important for people who have migrated and therefore cannot access family support. In such cases, we may be expected to almost 'stand in' as a replacement family.¹⁰

However, stepping in too close when someone is dying may actually push other family members out,¹¹ so one needs to reflect on whether interventions are most organised around the needs and beliefs of the ill person and family, or the needs of the professional.

Palliative care

Several renal units in the UK have begun to recognise the need to move from a concept of care based on treatment and cure, to that of palliative care.

The WHO defines palliative care as, 'an approach that improves the quality of life (QoL) of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'¹²

Palliative care stresses user consultation and collaboration, listening to how people feel, what their attitudes are and how they experience services and care¹³. In so doing, it places emphasis on the QoL, the quality of care and, of course, the quality of death.

In many ways, palliative care is about creating a voice for the voiceless. It is about recognising that when someone is ill and dying, they may be unable to voice what they really want and need, for fear of adding to the burden their families and the medical team already face. This includes understanding that some thoughts may be easy to share, but others may feel too frightening or shameful and tend to be hidden or referred to indirectly. However, as one palliative care user writes, 'Please watch out for these subterfuges'¹⁴. That which is most important, is probably still too hard to say.

What tends to be most needed at these times is supportive, non-intrusive listening.¹⁵ As professionals, this means accepting and tolerating that tears can be helpful; our task is not about blocking sadness and anger, but helping people to face powerful feelings and grieve. For some, too much has been left painfully unresolved for far too long and it is these families who may require, but may not always accept, additional psychosocial input.

In the USA, it has been suggested that GPs explore what all healthy older adults might want in the event of becoming ill, for instance:¹⁶

- Whether they would want to know the name and all the details of any condition they are diagnosed with.
- Who they would want informed to help them to reach decisions about their illness and treatment.
- Whether they would want the doctors to do everything to keep them alive, or just ensure they are made comfortable.

While these ideas were developed as a response to cancer, the principles of palliative care are equally relevant to renal settings, where families face ongoing uncertainty and have to find a way of making sense of living with an increasingly disabled family member, while also anticipating their death.

It is worth mentioning that there tends to be a distinction between the palliative care delivered by all professionals (for example, symptom control and holistic attention to the QoL, as defined by the patient) and that provided by specialist palliative care teams. Their role is to educate and support other healthcare professionals, and to take direct referrals where symptom control, psychosocial and spiritual care are particularly challenging. Palliative care teams offer a holistic framework. In some centres, they work closely with renal units. However, regardless of whether the work takes place at home, in a hospice or in hospital, the emphasis is on palliative and renal teams working together.

Protocol guidelines

In responding to these new challenges, a growing number of clinicians have suggested useful guidelines on conducting discussions, when the patient is either able or unable to participate.^{2,3,5,17} Overall, the literature prioritises the establishment of:

- Legal clarity concerning the ability to reach an informed choice
- Pathways of care for the dying that are preset, but flexible
- Planning advanced care early in the relationship with patients
- Regular mechanisms for feedback from families on the quality of end-of-life care.

While definitions of good end-of-life care vary somewhat, the term generally means that the following is assured:

- Physical comfort and emotional support
- Shared decision-making
- The dying person is treated with respect
- Information and emotional support is provided to family members
- The end-of-life setting allows for resolution and reconciliation
- There is a co-ordination of care across settings
- An absence of avoidable suffering, consistent with clinical, ethical and cultural standards.

Inevitably, the needs of families in this context are likely to vary. Tensions can easily arise as the anticipation of death evokes feelings that relate to prior separations and loss. For example, loss of an older family member may represent the loss of the very person who held the family together. For transnational or bicultural families, a death may also represent a split from their culture of origin.¹⁸

Moreover, all families will be engaged in a process in which some, but not all, aspects of their experience are shared. Despite the image of pulling together,

desperation to resolve issues unrelated to illness may surface. Guilt, regret, shame and blame may become so pervasive that they dominate the chance family members have to make sense of their lives and say goodbye.

While there is undoubtedly some need for direct information and advice, it is one's role as a facilitator that is most likely to help families to begin to share what they both want to say but find difficult to begin. For example, in cases where a person is too ill to comment it may help to ask open-ended or even

Tensions can easily arise as the anticipation of death evokes feelings

hypothetical questions like: 'If your father were able to speak, what do you think his wishes would be?' In some cases, rather than offering prescriptive advice, it may be worth drawing on what others have found helpful.

It is worth noting that underlying some of the confusion at such times is often a positively intended commitment to protection. Although there may be a need to talk, conversations about death may be taboo. Conversations about dying or settling affairs could be brushed off with humour. While this may minimise distress in the short term, when joking becomes the only frame of talk, it blocks conversations about more serious issues, paralysing decision-making.

Indeed, Leichtentritt and Rettig argue that beliefs about protection tend to be based on morality and human rights.¹⁹ For example, they suggest that the notion of one's right to know and decide tends to be more of an issue between partners, while the notion of duty tends to dominate for adult children, who see protection against knowing as a fulfilment of the Judeo-Christian commandment to 'honour thy mother and thy father'.

The cultural context of care

No individual can be separated from the context in which she or he lives, be it the family, medical or wider cultural context. Therefore, ideas about withdrawal or non-initiation of treatment need to be placed firmly within the cultural context of care. In the UK, for example, the interest of the patient is seen as paramount; the wish of a patient who is able to make an informed choice takes precedence over all other considerations.

The concepts of patient's autonomy and rights are relatively new and are based primarily on a culture of individualism. However, we do not operate in isolation. We all make sense of ourselves in relation to others; in many ways, it is the relational aspects of dying that contradict the principles of individual autonomy.

This means that practices based on the individual right to choose may be particularly antithetical to cultures that value life over a more comfortable death or place family connectedness over individual autonomy.¹⁹⁻²³

This does not mean working according to cultural stereotypes. Indeed, avoiding stereotyping means avoiding assuming that families from cultures with close traditional structures will automatically wish to

care for their own. Ethically, medical professionals need to recognise that ideas about healthcare are inevitably constructed by the dominant cultural belief systems and that operating according to those beliefs can unwittingly undermine the experience of people whose beliefs are different.

This is particularly relevant, as there are indications that minority ethnic groups are over-represented among patients with ESRF in the UK. No one factor is likely to account for this. There may be important lessons to be learned about encouraging all people to seek care earlier, and about what might contribute to medical interventions being experienced as racist. In cross-cultural work, one way of familiarising oneself is to ask the family about their beliefs and practices. However, Firth argues that when working much of the time with seriously ill people from cultures that are different to one's own, this is not enough.¹⁸ One needs to find out more about the family's cultural context before embarking on the work, to avoid burdening families with the additional role of cultural interpreters. For example, there may be very different ideas about life and death; the expression of pain, suffering and grief; the cause of the condition; the value of disclosure and truth-telling; acceptance of outside authority; expectations of family responsibility and gender.

This means one might be faced with beliefs that conflict with ideas one holds dear, and having to temper one's own views to ensure we meet the needs of those entrusted to our care. Laying aside one's own assumptions and entering the world of others involves taking informed risks and engaging in a continual process of self-reflection.

Personal—professional connections

Finally, any application of a palliative care framework to the renal setting requires some reflection on personal-professional connections and how this contributes to finding sustenance and meaning in the work. As with families, concern about 'getting it right' can be paralysing. Anxiety about how to pace what is said may mean that one moves too fast or holds back for fear of intruding.

In palliative care, professional roles overlap. This is both its strength and its downfall; it is the overlapping and multidisciplinary nature of the work that enables holistic care to take place. However, it also means difficulties arise that relate to lack of clarity about who is doing what.

This means that staff need a strong sense of their own professional identity to allow others to share aspects of their work without being threatened. This is an incredibly important issue and needs to be considered at recruitment.

It is impossible to fully separate one's personal and professional thoughts. However, from time to time, it is worth exploring whether holding back reflects our own inhibitions or those of the people we are working with.

Jung coined the term the 'wounded healer' to depict how we seek to help ourselves in helping others. In working with people at this end stage of life, relationships are continually being established with people preparing for death. As noted earlier, to some extent this is inevitable and may be extremely important to some families. However, in other cases, healthcare professionals need to guard against becoming too central in the family's life. It is also worth acknowledging that the intimacy that evolves in such contexts can become tremendously important to the professionals as well. Helpful though this may be, Firth argues that to rely too heavily on this intimacy means that professionals are endlessly being drawn into powerful experiences that end abruptly.²⁴

Although the dominant ethos might be about treatment, the job may also feel like a relentless process of being faced with death. Perhaps the most useful message from the palliative care literature is the value of helping the helpers, protecting staff from what has been variously called 'burnout', 'compassion fatigue' and 'secondary stress' - the proliferation of terminology no doubt reflecting the enormity of the issue.

This is incredibly important and meaningful work. In helping families to negotiate the dual processes of holding on and letting go to the person and life they once knew, renal professionals are entrusted with a task that has far-reaching consequences across the generations.

This article, therefore, ends with a plea for more research, training and consultation to find the language to address some of the complex and distressing, but stimulating, issues related to this work.

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Key Points

- User involvement and feedback is an important part of palliative care.
- The 'right to choose' is founded on culturally based notions of individual autonomy and might conflict with ideas from cultures that prioritise family involvement.
- Beliefs about access to care might influence individual and family decision-making.
- It is important to address the emotional implications for healthcare staff of working with people who are dying.