

Managing young adults with end-stage renal disease

New approaches are required to optimally manage young adult patients. Age-appropriate clinics held in youth-friendly environments can enable the development of positive peer support. Paul Harden explains how health professionals might approach managing young adult patients more effectively

■ young adult patients ■ peer support ■ end-stage renal disease ■ engagement ■ communication

Managing young adult patients with any chronic disease can be challenging, frustrating, infuriating and difficult, and many health professionals feel ill equipped to communicate effectively and engage young adult patients. There is a great deal to be gained or lost by delivering successful or unsuccessful health care to young adults who are at the point of launching their careers, relationships and families. Health professionals need to pay more attention to delivering personalised, consistent age-friendly care to the young adult to optimise outcomes.

Adolescence and young adulthood is a period of many changes to physique; social, educational and employment status; and is inherently destabilising and challenging. In addition, teenage and young adult patients with end-stage renal disease (ESRD) have to cope with the burden of a chronic disease and are frequently isolated both geographically and socially from peers in the same situation.

Transitioning transplant recipients from paediatric to adult care have had their health care largely supervised by their parents and may be ignorant of the cause of their kidney failure and have limited understanding of their medication regimen and the consequences of non-adherence (Watson, 2000; Dobbels, 2005). Young adults presenting in their late teens or early twenties with advanced renal failure frequently resort to denial of their underlying condition and struggle to come to terms with dialysis or transplantation. These factors coupled with adolescence and emerging adulthood lead to communication difficulties with the health-care team. The 'baseball hat phenomenon' where the young adult avoids eye contact and stares at the ground can result in poor interaction with health professionals.

This often results in the young adult rejecting consultations.

Effective communication

Communication with young adult patients needs to be carefully pitched to reflect developmental, cultural and dependence status. The majority of young adult patients want to be treated seriously like any other adult patient. It is almost always inappropriate to communicate in childish language to a 16 year old, as they will immediately lose respect for the clinician and are less likely to follow the advice delivered. It is most effective to use a non-directive approach featuring motivational interviewing principles and techniques (Pursey, 2013).

While several clinicians may need to interact with the young adult patient, there should be a lead clinician for the individual who may be a physician or nurse practitioner who should provide continuity of care and coordinate major therapeutic changes.

Trust may take a considerable time to develop within many patient-clinician relationships and is critical to achieving adherence (*Box 1*). Clinical consultations should not only focus on direct medical issues but be holistic and include education, employment and social development of the young adult patient. Use knowledge of specific interests of the patient to engage and reduce the patient-clinician barrier, such as recent success of a specific sports team, achievement at work, training in the gym, theatre or cinema visits.

A particular difficulty is to know how to best deal with supportive parents who may be overbearing and impede the patient-clinician interaction. It is important to take a firm hand and explain that health professionals need to see the patient individually for at least part of the consultation. Gradual weaning of the participation of the parent(s), while encouraging independence and self-management of the young adult patient, is a practical solution in most circumstances and is embraced by young adult patients who want to be treated independently.

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Parent(s) may need additional support during this transition phase, which may be effectively provided by a nurse practitioner. This is particularly important in young adult patients transferred from paediatric to adult care as the parents are likely to have maintained substantial involvement and control of their care.

Young adult clinics

Young adult transplant recipients have little in common with the average patient waiting in an adult transplant clinic. The average age gap is at least 30–40 years resulting in a substantial generational gap, with the result that the young adult patient rarely interacts with other patients in the waiting area. In most cases the young adult patient simply wants to be in and out of the clinic as quickly as possible, leaving minimal time for patient education or multidisciplinary input.

Adult hospitals and clinics create an aura of negativity with their focus on illness rather than health in the mind of the young adult, and coupled frequently with a negative reminiscence of dialysis or inpatient stays. A practical way to combat some of these barriers is to cohort young adult patients aged 16–30 into a dedicated, separate outpatient clinical service (Lane, 2007). Ideally, a support or youth worker can act as an ‘ice-breaker’ to facilitate direct peer interaction among the patients in the waiting area. The clinical location should be adjusted to provide a more ‘youth friendly’ environment such as a hospital coffee shop where young adults can socialise more naturally. This will lead to increased peer interaction and support through shared experiences complementing clinical care.

Learning from current practice

In a model run by the author, the clinic environment was felt to be very important and, as such, the clinic was taken outside the hospital setting into typical youth-friendly locations including a student common room of a local university, sports centre, chain coffee shop and a theme park (Harden, 2012). In these environments, the concept of ‘the all day clinic’ has been developed where recipients chat over a cappuccino, play a game of pool with each other, share the experience of a scary roller coaster ride and develop a close bond with others who have faced dialysis and the transplant experience. Peer support is instrumental in tackling low self-esteem of a chronic illness and to inspire participants to look after their transplants better and achieve more in education, employment and relationships.

Patients stay at the clinic for several hours with the medical consultation being only a small but important part of the process. New lasting friendships are fostered at these clinics and enhanced by social media interaction between clinic visits. A strong

Box 1. Tips for effective communication with young adult patients

- Communicate with young adult patients in a serious and professional manner exactly the same way that you would communicate with any adult patient
- Do not talk down, patronise or use inappropriate childish language
- Treat the young adult as an adult
- Familiarise yourself with important issues facing young adult patients
- Recognise the value of motivational interviewing techniques in communicating effectively with young adults

Box 2. How to establish a young adult clinic

- Recognise the need and potential benefit and convince key colleagues
- Identify all patients aged 16–30 who have chronic kidney disease (CKD) 5; dialysis or transplantation
- Establish a small multidisciplinary team to develop young adult service; physician, nurse specialist; youth worker (optimal), pharmacist and may be psychologist or counsellor
- Cohort all young adult patients into a new dedicated young adult clinic at a different time and in a different location to standard adult clinics

network of inter-patient support is generated by filling a gap that most health-care teams fail to offer.

Typical issues important to the young adult can be best addressed by other peers; examples might include: ‘How did you remember to take your medication at the right times when you first started at university away from home?’; ‘How do I tell a new partner that I’ve got a transplant and will it affect having sex?’; or ‘How did you cope having your ureteric stent removal?’. Young people want to know what other young people think and how they fit the transplant experience into their lifestyle; older patients and health professionals just ‘don’t get it and aren’t cool’. This powerful resource among young adult transplant populations should be used much more effectively.

It will take time to plan and establish a young adult clinic as change in culture is difficult and takes time within any clinical service. Other clinicians may not recognise an immediate benefit of a separate young adult service and only time and documented improvement in the patient experience and outcomes will convince them of the potential benefit (Box 2).

Young adult transplant community

The natural extension of a young adult clinic is to develop a young adult transplant community, which comprises a network of young adult patients who can share experiences jointly, easing the burden of their chronic illness. No one can really understand a disease process and the impact of its clinical

management more readily than someone who has experienced that process personally. Age-appropriate patient-to-patient mentoring can be encouraged to help new patients come to terms with the diagnosis of kidney failure, select the optimal renal replacement therapy to suit their personality and lifestyle, and prepare for the transplant operation and maintenance immunosuppression.

Peer mentoring is complementary to the roles of the clinical multidisciplinary team and can be facilitated and monitored by a youth or key worker. The bond and support between young adult patients can be further enhanced by a programme of regular social events throughout the year interspersed between young adult clinics. This is best organised by a youth worker who the patients connect with and is considered as one of them rather than one of the health professionals. Useful activities include bowling evenings, group restaurant meals, sporting events and theme park days. The British Transplant Games is an excellent opportunity to galvanise peer support among this age group and generate team spirit. Participation in sporting events can dramatically help to lift individual confidence and restore self-belief and set the young adult on course back into wider society (Wray, 2008).

Shared experience of transplants

The author has adapted the approach used in anti-natal clinics to provide direct joint peer support before, during and after live donor transplantation in young adult patients. Where feasible, planned live kidney transplant recipients have been paired together and introduced by the youth worker through the young adult service. The paired recipients are seen at pre-transplant preparation clinics and then proceed to be transplanted within 1–2 days of each other to allow a shared inpatient experience. Once discharged, they attend the post-transplantation outpatient clinics at the same time and in most cases have built a lasting bond and supportive relationship. The young adult clinic provides a valuable resource for peer support through the transplantation process.

Key points

- Use non-directive ways of communicating with young adult patients and be flexible with clinic timings, settings and develop a small multidisciplinary team
- Use text messaging and the internet to interact more effectively with young adults
- Utilise 'experienced' young adult patients as targeted mentors for new teenage and young adult patients in a unit
- Explore the role of shared experience by partnering young adult patients through the transplantation process

Simplification of medication regimens

In all age groups there is good evidence that adherence declines proportionally to the frequency of medication dosing (Reference?). This is a particular problem in young adults who frequently lead a very erratic and variable lifestyle, which is not conducive to multiple drug dosing regimens. The dosing regimen can be simplified to once daily in the morning, which is much more youth friendly and associated with higher adherence rates (Reference?).

Mobile phone alarms can be preset to remind the patient to take their daily medication, and daily dosette boxes can be prefilled if required (Miloh et al, 2009). Tablets in a dosette box are a clear visible reminder that the day's medication has yet to be taken, while sometimes it can be difficult to remember whether medication from traditional containers has been taken. Individual approaches should be explored to best fit in with the young adult's lifestyle, but peer advice can be valuable.

Conclusion

New approaches are required to optimally manage young adult patients with ESRD. Age-appropriate clinics held in a youth-friendly environment will enable the development of positive peer support. A small group of dedicated multidisciplinary clinicians should be trained to manage the young adult service and maintain a flexible, empathetic and non-directive approach. Continuity of care is of paramount importance to instil trust and develop an equal partnership between patient and clinician to optimise adherence. Simplified once daily drug regimens and tools such as mobile phone reminders help to improve clinical management.

The benefit of peer support amongst young adult patients as a means of patient education, support and enhanced self belief cannot be underestimated. **JRN**

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