

The Northern Territory's Remote and Community-based Haemodialysis Program: Interesting Times.

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Abstract

The Northern Territory has the highest incidence and prevalence rates of kidney disease in Australia and the majority of people receiving renal replacement therapy are Aboriginal Australians and originate from a remote community. Providing community-based dialysis would seem a more practical option than relocation. However establishing remote community home haemodialysis is potentially an expensive and high support activity. Challenges include inadequate and overcrowded housing, unreliable power and water supply, limited community infrastructure, seasonal access to most communities and high transport and maintenance costs. Developing a system that addresses cultural issues, promotes flexibility and encourages community participation and cross agency support has been the aim of the NT Renal Services (NTRS) remote home and community-based dialysis program. Integral to the program is the reintegration of clients into the community and the promotion of community-based dialysis as a treatment for well people. In order to successfully achieve reintegration NTRS promotes the view that clients should be seen as community members who require a specific health treatment, rather than health department clients living in the community. This program has been supported with significant funding and although operational for less than twelve months, is already seeing encouraging results.

Key Words

remote, community-based, haemodialysis, dialysis, Aboriginal Territorians

Inadequate and overcrowded housing, unreliable power and water supply and the expense of capital expenditure limit the ability to provide remote home haemodialysis. In addition, the difficulties associated with delivering supplies and ongoing maintenance outside of the metropolitan area contributes to the increase in costs and further hinders processes. The issues surrounding the establishment of remote and community-based dialysis are multi-factorial and must be viewed in their entirety to understand and appreciate the challenges facing renal service providers in Western Australia, Queensland and now the Northern Territory.

“May You Live in Interesting Times”

(A Chinese proverb thought to be a curse but seen as good fortune for those able to overcome the interesting times!)

Introduction

Home haemodialysis is now readily available in most developed countries including Australia. As a treatment for kidney failure this option has improved clinical outcomes and is far cheaper than institutional dialysis due to reduced overheads and staffing requirements (De Vecchi et al, 1999). In the Northern Territory (NT), which has the highest incidence and prevalence rates of kidney disease in Australia, the majority of people receiving renal replacement therapy are of Aboriginal descent and

originate from a remote community. Providing community-based dialysis would seem a more practical long-term option than relocation to the city. However, establishing remote community home haemodialysis is potentially an expensive and high support activity, which has in the past reduced the clinical impetus and political will to promote and fund an appropriate service. To date, provision of remote dialysis services has been achieved in a limited number of settings around the world (Villarba & Warr, 2004).

A History of NT Renal Services

To appreciate the “Interesting Times” NT Renal Services have experienced, it is necessary to briefly discuss the history. The first acute dialysis treatments in the NT occurred in 1970 with the first self-care patient dialysing in their home in 1976 (Gorham, 2001). Initially all people offered replacement therapy were sent more than 1500km south to Adelaide for assessment work up and treatment. People were able to return to the NT if they were able to undertake the treatment themselves. Home haemodialysis was not readily available, satellite haemodialysis was not offered and many people declined the offer of treatment interstate. These obstacles

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caused premature death for many people in the NT (Pugsley, 1993).

Staffed dialysis facilities were not available in the NT until 1984 when a two-station facility was established in Darwin. The NT was serviced by The Queen Elizabeth Hospital in Adelaide who provided a nephrologist on quarterly visits. In 1987 a 10-station satellite facility was established in Alice Springs and a nephrologist was appointed to direct the service. However, it was not until 1996 that Darwin was able to attract a full-time nephrologist. By that time the two station facility had expanded three times to twelve (12) stations, home dialysis was no longer available and the Tiwi Island community had successfully lobbied the Commonwealth Government for their own satellite service on Bathurst Island, 80 km off the NT coast. The new nephrologist for Darwin took control of a rapidly expanding service, dominated by "crisis and ministerial interventions" (Dunje, 1994).

The Northern Territory has the highest incidence of end stage kidney disease (ESKD) in Australia while the incidence rate in Aboriginal Territorians at that time was nearly 10 times the national rate (ANZDATA, 1998). The majority of people on dialysis were and still are Aboriginal Territorians who have been relocated from their remote communities. The issues of relocation were well documented by then and not limited to the NT or Australia (Wilson et al, 1994). The term "social price of renal disease" coined by Mahoney (1995) to describe this concept did not adequately reflect the injustice, community fracturing and family dislocation suffered by clients receiving treatment in the urban centres.

Home dialysis, or at least treatment closer to home, was known to improve clinical and quality of life outcomes (Goeree et al, 1995). Yet despite this, home haemodialysis was still not offered, as the perceived expense associated with capital equipment requirements were

felt to be too high. Communities across the NT, alarmed by the number of community members disappearing to the urban centres, increased public agitation for services. Some communities went to extreme lengths to secure services. The Jawoyn people of Katherine exchanged land rights for dialysis services in 1998 (Loff & Cordner, 1998). The Tennant Creek community had been lobbying for many years for services and in 1999 commissioned the Cooperative Research Centre for Aboriginal Health to write a report on the incidence of ESKD in their community and possible treatment options (Gorham, 2001). Kintore Community held a national art auction at Sotheby and raised over a million dollars for community-based services in 2000 (Western Desert Dialysis Appeal, 2002).

The appointment of a second nephrologist in the NT foreshadowed the expansion of renal services. The satellite units in Darwin and Alice Springs expanded in 1997 to offer 23 and 26 stations respectively, the Tiwi Dialysis Centre on Bathurst Island became operational in 1999 followed shortly after by the Katherine Dialysis unit in 2000.

Only Tiwi and Katherine offered services closer to home and the desire to establish home or community-based haemodialysis was now considered a necessity if client outcomes were to improve. However, concerted lobbying by individual clients, community groups, remote communities and service providers had little effect. The Tiwi Dialysis Centre evaluation (Gorham, 2000) provided a local perspective on potential outcomes for community-based dialysis. Conducted in 2000, the report suggested improved client clinical outcomes; reduction in missed treatments, admission rates and community evacuations and decreased recurrent expenditure. It also noted that clients were happier and reported improved quality of life, more disposable income and greater physical activity.

In October 2000, the Northern Territory's Department of Health and Community Services (DHCS) policy was relaxed slightly. However, the requirement for a client contract, policy restrictions that effectively confined the service to the urban area and limited funding meant that only two clients living in Darwin were able to access the program. The most contentious restriction was the client contract, which required a letter from the community outlining how home haemodialysis would increase the client's productivity.

In 2002, a significant policy change by the DHCS called "Building Healthier Communities" promoted greater access to services and treatment closer to home. Substantial recurrent operational and capital works funding was provided to facilitate the establishment of remote and community-based dialysis. Accompanying this policy change, renal services across the NT were restructured into one service – NT Renal Services with the appointment of a nephrologist as Director of Renal Services.

Current Situation

The opportunity to provide remote haemodialysis to the largely scattered communities in the NT raised an important question – how do we do it? With little experience, guidance was sought from other units around the world with particular attention paid to issues that other service providers felt could have been done better – such as regular on-site visits, funded respite and community involvement and support. The ability to design our own service has led to a flexible approach to service delivery and resource development but has also enabled us to put in place comprehensive monitoring and evaluation mechanisms.

Developing a system that addresses cultural issues, promotes flexibility and encourages community participation and cross agency support has been the

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philosophy of the NTRS remote home and community-based dialysis program.

The current aim of NTRS is to promote community-based dialysis as a treatment for well people, demonstrate the client's independence in managing their treatment through the lack of impact on the health service and encourage a cross organisational approach to client support in the community. NTRS believe the outcome will be clients who are reintegrated into the community as members who require a specific health treatment, rather than health department clients living in the community.

However, the tyranny of distance has far ranging repercussions. Many coastal communities in the Top End of the Territory are only conveniently accessible by air and serviced by freight barge fortnightly, while access to those in the lower or Central Australian region is often seasonal. Moreover, operational expenses limit regular passenger flights; usually involve multiple community visits by the flight operator and often a change between air services. Consequently travelling in and out of most remote communities is difficult, time consuming and expensive. Charters are expensive but eliminate overnight stays and are the most time efficient mode when more than three people need to travel.

Supply lines are dependent on outside services and the prevailing weather. Communities can be isolated for weeks or months at a time. Design and construction is a lengthy and expensive process; community infrastructure is limited and health services are stretched. Staff turnover in all areas (health, education and council) is high, impacting on the ability to develop long-term relationships with community members, which is necessary for program development.

Community consultation has also highlighted anxieties amongst some local primary health service providers, of the impact of returning haemodialysis clients and their families. The potential to increase not only workloads with

additional community members but also the complexity of presenting conditions, coupled with the fear of needing to understand the dialysis process and perhaps deliver the treatment, creates resistance from some primary health care practitioners.

First steps - Understanding Roles and Responsibilities

The establishment of community-based haemodialysis commences with a number of site visits to the remote community. The intention is to discuss with community elders, traditional owners, council and clinic staff their views on community-based dialysis, potential sites for treatment location and determine what support can be offered. Operational aspects such as removal of biohazard waste, transport of consumables to and from the barge or delivery point, early notification of power or water interruptions to clients and assistance from essential services to establish the connections is necessary. NTRS covers expenditure associated with establishment costs plus recurrent costs such as telephone, electricity, deliveries and consumables including medications. Ongoing clinical and technical support is also managed through the installation of a direct telephone line and regular onsite visits, which are initially monthly. The meetings allow clarification and assurances to be given by both the service provider and client regarding the client's ability and willingness to retain independence. The last visit concludes with all parties agreeing to and signing a Memorandum of Understanding, which outlines the roles and responsibilities for each party including the client. The intention of these agreements is to ensure the client is able to successfully manage their treatment, equipment and supplies and preserve the safety and integrity of the program for future users.

Cultural Issues

The use of interpreters to facilitate the communication process has been an important step in the development of this program. Interpreters have been integral to the client's understanding of what the

training program entails, the attendance frequency necessary and the requirement to be independent. Interpreters have also worked closely with clinicians and researchers on developing appropriate translated resources in a variety of media, to facilitate the understanding of western biomedical concepts of health, renal disease and the haemodialysis process (Coulehan et al, 2005).

Clients and 'buddies' entering training are asked to sign contracts. Cultural issues surrounding "blame, responsibility and payback" have been topical in several Top End coastal communities, which has necessitated the change to have clients completely responsible for and independent in their treatment. Therefore the 'buddy' role is primarily accompaniment during treatment, with basic skills in re-needling and administering saline. The cultural requirement in some communities to apportion blame for untoward events has necessitated this change. Further, it is important in this cultural environment, that the marital or community status of the client doesn't override this process and potentially place the buddy in an unsafe position.

Procedures have been developed with clients and community elders regarding the process for evaluation of clients whose activity jeopardises their health and safety and therefore the program. This "Process for Home Haemodialysis Placement Review" is designed to determine causes for clients becoming unwell and provides opportunities for community elders, families and the service to work together. Community elders provide guidance on how rectifiable situations maybe addressed, what additional client support maybe necessary or in extreme cases facilitate the client's return to the urban centre if that is the only solution available.

Program flexibility

Community visits have identified the need to remain flexible when establishing



Fig. 2. Relocating self-care facility

service points. It has also been clear that installing simple systems that can be safely contained and easily maintained by the client and buddy are preferable. Self-contained portable filtration systems that sit beside the dialysis machine and chair require more room but eliminate the need to build protection for external services.

To meet the need to be flexible, relocatable dialysis facilities have been developed, specifically designed to cope with remote community life. It provides a clean, dry place for clients to store their consumables and attend their treatment. The facilities are replicas of the dialysis-training unit at the Nightcliff Renal Unit in Darwin and therefore provide some comfort and continuity for those returning to communities to use them. They are transportable units and will be relocated as needed and therefore eliminate the potential for under-utilised services (Fig. 1). A change in locations has already been tested (Fig 2). The Nightcliff training facility also provides a testing area for other initiatives such as recycling reverse osmosis rejection water.

NT Renal Services has now installed dialysis systems in a number of different remote community based locations. These have included a client's home, a respite centre, a dedicated relocatable facility to cater for more than one client and soon two stations will be established in a community-controlled health clinic. A partnership pilot program has also been running since September 2004 with a non-government Aboriginal organisation. This program aims to provide opportunities for renal clients to return to their community for short bursts (up to three weeks) and receive dialysis in the local clinic from trained staff. Evaluation of this pilot program continues and will be reported in future publications.

Trials and Tribulations: The Practicalities

Even with the best of intentions, it would have been particularly optimistic

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to believe this new initiative would run smoothly. Ensuring work is completed in communities, such as installation of surge protectors, telephone lines, pumps and changing locks has been a frustrating and time consuming process with most requests taking 10 to 12 months to action. In addition, communication with remote communities is often erratic with unreliable telephone and email access. This hinders the communication and coordination processes especially where support procedures require robust coordination, communication and understanding between the health service, client, community council and non-government services in the urban area. As we have discovered it doesn't always go to plan and limited access by air, road or sea has meant delays for some deliveries. Despite the planning and processes that have been undertaken for this initiative a great deal is dependent on factors not under our control. An example of this was the cancellation of a fortnightly barge by a storekeeper who was in the middle of a stock take.

Despite the challenges, the ability to be involved in the facilitation of clients receiving treatment in their own communities has been very rewarding. Witnessing the welcome clients receive on their return to their community or how they proudly demonstrate their knowledge and technical expertise to the apparent awe of the community is difficult to describe. The most pleasing part has been the change in the client's demeanour as they return to the social and community activities of hunting, meetings and story telling.

Making it Work

NT Renal Services home and community-based dialysis program has been developed to meet the needs of the clients and the community. The training program itself has been adjusted to address the educational and literacy requirements of the client. Interpreters facilitate client understanding of the

treatment and training requirements and assist with the development of educational resources. Cleaning and trouble shooting guides are in pictorial formats and simple checklists have been designed to prompt the client to attend monthly bloods, stores orders, medications and water samples.

Memorandum of Understanding has been developed with community input to identify roles (including those of the client) and promote shared responsibility to ensure client support and safety. This has included a procedure to utilise community elders to help manage the review process of clients whose activity or health is of concern. Funding to bring buddies in from communities for training, regular respite opportunities and frequent on-site visits have been built into the program for each community to support clients and buddies. Community Development Employment Programs (CDEP) have been accessible to date for buddy time back in the community.

Treatment locations have been flexible and implementation programs have been aimed at developing partnerships with communities. Trials to recycle reverse osmosis reject water to conserve community resources are being developed. Performance indicators have been established to evaluate training, clinical and operational support and funding required to support people in remote locations. These indicators will be reported in future publications.

The Costs and Benefits

To date the establishment costs for community-based haemodialysis have been higher than home haemodialysis in the urban area. On-site visits, capital expenditure and community costs for refurbishment and technical services have been considerable. Recurrent costs are also expected to be higher than home haemodialysis in the urban area as a result of freight costs and support mechanisms embedded in the program such as ongoing site visits and client respite.

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Nevertheless, the anticipated recurrent costs are still expected to be less than providing institutional haemodialysis in the urban centre but as the program has been running for just on 12 months the cost benefits are yet to be delivered.

In addition the true costs of treating people distant from their communities, families and support networks and the resulting impact on the urban centre (housing, support services and reduced opportunities for family to find employment) are difficult to determine. Importantly, the benefits to the client and the community must be considered. Certainly clients claim reduced expenditure, increased disposable income, improved quality of life including in one case a reduction in domestic violence and alcohol and drug abuse as a result of being back in the community. Although it is early days for our program, there have not been any adverse events requiring community or NTRS intervention for the two clients living on Elcho Island and Groote Eylandt, respectively 600km north-east and 800 km south-east of Darwin. They have proven to be reliable, independent people taking care of their own health requirements.

This new initiative for the NT has been supported with significant funding and

although operational for only twelve months, is already seeing encouraging results. The program will potentially reduce the need for clients in the long term to relocate permanently to the urban centre for treatment and as such the benefits to the client and community should not be underestimated.

Conclusion

Setting up a community-based, home haemodialysis program within the Northern Territory has provided us with quite interesting times. The practicalities of the communities have forced us to develop a new form of dialysis facility, one that is fully relocatable. We have successfully established a number of people on this form of haemodialysis within their own communities. Although the costs in initial establishment are greater than traditional home haemodialysis, we hope to be able to demonstrate numerous other benefits that are priceless.

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