Pre-dialysis Education – A National Australian Survey

Pre-dialysis education – A National Australian Survey (Jan 2012)

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Introduction:

Pre-dialysis education is a critical component of the patient journey leading to the selection of home dialysis or a centre-based dialysis modality. The KHA survey of consumer perspectives revealed that 49% of consumers perceived they did not have a choice in their modality option.\(^1\) Anecdotally the provision of education services varies widely across Australia, and is predominantly the domain of nursing staff. Pre-dialysis educators discuss having large databases of patients, late referrals, inadequate resources, cultural challenges, non-supportive unit policy and insufficient time as factors that limit the ability to provide comprehensive education. The newer role of CKD (healthy lifestyle) education by nurses is also increasing. This survey aimed to establish data about the delivery of renal consumer’s education, focusing on the relationship of education to the uptake of home dialysis.

Hypothesis:

Pre-dialysis education staffing, use of teaching resources and programme content will demonstrate wide variance throughout Australia. This will affect the uptake of home dialysis.

Method:

A 26 question survey was developed on survey monkey, with input from Kidney Health Australia staff.\(^2\) The questions focused on staffing levels, content of education programmes, barriers to education and the resources that may be required to improve education. The survey was piloted by renal experts. The link to the survey was distributed to an established email network of pre-dialysis educators operating in collaboration within the 43 renal units previously identified as managing home dialysis programmes. Some units offer training to more than one catchment of patients meaning there were potentially 48 education services. Stand alone satellite haemodialysis units were not targeted. Data was consolidated by survey monkey and further analysis was completed by KHA staff. Home dialysis rates were sourced from ANZDATA 2010.\(^3\)

Results:

All identified 43 Australian home training units, and associated education services were sent the survey link. 34 units participated, representing all States with both metro and country represented equally. 7342 (70%) of Australian patients are managed by the responding units.

<table>
<thead>
<tr>
<th>State</th>
<th>Education</th>
<th>Survey</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>NT</td>
<td>3</td>
<td>2</td>
<td>67</td>
</tr>
<tr>
<td>NSW</td>
<td>12</td>
<td>7</td>
<td>58</td>
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<tr>
<td>Vic</td>
<td>11</td>
<td>6</td>
<td>55</td>
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<tr>
<td>QLD</td>
<td>11</td>
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<td>55</td>
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<tr>
<td>SA</td>
<td>2</td>
<td>2</td>
<td>100</td>
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<tr>
<td>WA</td>
<td>5</td>
<td>5</td>
<td>100</td>
</tr>
<tr>
<td>Tas</td>
<td>3</td>
<td>3</td>
<td>100</td>
</tr>
<tr>
<td>ACT</td>
<td>1</td>
<td>1</td>
<td>100</td>
</tr>
<tr>
<td>Total</td>
<td>48</td>
<td>34</td>
<td>71</td>
</tr>
</tbody>
</table>
Staffing and Patient Numbers:

Three units had no specific nursing education staff employed, but the renal unit nurses provided the education. Nine units had only a pre-dialysis educator and 11 had separate pre-dialysis and CKD educators. In 10 units, one person covered both positions. Treatment option education remains the dominant type of patient education by nurses.

The hours of employed educators was cross-referenced with the numbers of patients on each database. A calculation was made of the number of patients for each hour that an educator was employed. The ratio by unit, varied from 2 patients to 31 patients per hour that a specific educator was employed. The mean was 12. On average for every one fulltime equivalent (FTE) educator employed there are 456 stage 4-5 CKD pre-dialysis patients on the unit database.

State-wide SA has the highest ratio overall at 1 hour per 20 patients, ACT is 1:17 and Victoria is 1:16. NSW, QLD, Tas NT and WA have the best average ratios at 1:7-10. 79% of units had over 150 patients CKD stage 4-5 patients on their databases with 35% of these having over 300 patients.
Less than 10 hours of pre-dialysis educator was linked with lower home dialysis rates.

10 pre-dialysis educators were also managing the stage 2-3 database of CKD patients. 7 units had over 200 stage 2-3 patients on their databases, with 11 units having between 100-199 patients.

Nurse CKD specialist roles are now being utilised in 72% of units. QLD had the highest number of CKD specialist nurses with 1-2 FTE in the major units. Only five specific CKD specialists are employed in other States. 11 units however have a shared role of CKD mixed with either pre-dialysis or the anaemia management role.

A nurse practitioner (NP) is employed as the pre-dialysis educator in three units, with 4 planned for the future. Seven CKD NP’s are currently employed within the 34 units with four more planned. QLD has 65% of current NP positions.

Quantifying of both pre-dialysis and CKD hours was difficult because of the combined roles. The survey did not adequately anticipate assessing the breakdown of those shared roles.
Rates of comprehensive education pre-dialysis:

Only 37% of units estimated that 91-100% of patients received comprehensive education, prior to starting dialysis. The mean receiving comprehensive education was estimated at 82% of patients.

Approximately what percentage of patients receive at least one comprehensive education session regarding treatment options prior to starting dialysis?

This rate was similar in the 16 units with the highest number of education staff hours.

Two units that only had a pre-dialysis educator for 1-10 hours reported delivery of comprehensive education to 91-100% of patients. These 2 small units offered bimonthly group education. Units calculated at 31 patients per educator hour reported that 91-100% of patients received comprehensive education.

Hours an educator employed compared to % of patients receiving comprehensive education.
The extreme variance in the comprehensive education rate compared to the ratio of patients per hour of educator indicated that other factors contribute to completion of education. However staffing ratios has some impact. 70% of the units achieving over 75% educated, had less than 12 patients per educator hour. If less than 75% of patients were educated only 40% of units had less than 12 patients per hour.

Overall in units achieving maximum pre-dialysis comprehensive education, 32% are on home dialysis compared to 22% of the group with less than 50% provided with comprehensive education. The positive correlation is for the uptake of PD with 22% uptake for those reporting 91-100% of early education and 11% for those reporting low rates. There is no significant correlation for HHD. This supports comprehensive education before dialysis commencement to enhance PD uptake.
Timing of Referrals

Referrals for CKD (healthy lifestyle) are earlier than treatment option referrals. Earliest referrals were in QLD, reflecting the CKD education nurses.

Which answer best describes the stage of kidney disease when the majority of your referrals for CKD (healthy lifestyle) education occur?

- Stage 1-2: 3%
- Stage 3: 17%
- Stage 3 and 4: 30%
- Stage 4: 47%
- Stage 5: 3%
- Not available: 0%

Treatment option education referral is dominated by stage 4 and 5, with 20% stage 3-4 referral preference.

Which answer best describes the stage of kidney disease when the majority of your referrals for treatment options education occur?

- Stage 3 and 4: 53%
- Stage 4: 27%
- Stage 4 and 5: 17%
- Stage 5: 3%

Two NSW units reported that most referrals for dialysis modality education were during CKD stage 5. Victoria reported more early referrals.

CKD stage when treatment option education most likely to occur by State

- NSW: Stage 4
- NT: Stage 5
- Vic: Stage 3 and 4
- QLD: Stage 4
- SA: Stage 4 and 5
- WA: Stage 5
- Tas: Stage 5
- ACT: Stage 5
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Education referrals once on dialysis:

97% of units reported that either by using a formal process (dominated by QLD) or via an informal process late referrals would receive comprehensive education.

Once patients are established at satellite dialysis 66% of units then continue to target and assess them for home dialysis with 43% doing this routinely. The units routinely assessing and referring for education average 11% on HHD compared to 7% HHD in the units that do not.

Victoria, ACT, WA and Tasmania have the lowest rates of re-evaluation and referral to home from satellite haemodialysis. NSW and QLD have the highest rates of home dialysis.

<table>
<thead>
<tr>
<th>State</th>
<th>Respondents</th>
<th>Yes - Referral</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>NT</td>
<td>2</td>
<td>2</td>
<td>100</td>
</tr>
<tr>
<td>NSW</td>
<td>6</td>
<td>5</td>
<td>83</td>
</tr>
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</tr>
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Delivery of Education:

13% of units spent on average less than one hour providing education. These 4 units were all in different States. 13 units were educating for 1-2 hours and 13 units over 2 hours.

The rate of home dialysis is 36% in the units offering the longest education hours compared to 20% in the units averaging less than 1 hour’s education. HHD is most affected.

Use of group education sessions varied widely. The units that reported holding more group sessions, with the exception of QLD units, reported more hours of education regarding treatment options.
The use of groups sessions or one-on-one sessions was analysed by State:
- NSW were most likely to use group, but also used one-on-one education
- QLD used more one-on-one education with quarterly group sessions
- SA have monthly group sessions at one unit, other education is one-on-one
- NT and ACT have no group sessions, and focus is on one-on-one education
- Tasmania hold quarterly group sessions, plus one-on-one
- WA have three State group sessions per year, plus one-on-one
- Victoria units were very variable with between 0-12 group sessions per year.

Six units provided one-on-one education only, and one provided no education. Overall most units combined one-on-one sessions with group education but the variance was so wide in how this was structured that it is not possible to quantify the results. Referral timing can impact which education option, group or solo, comes first.

Overall staffing levels did not correlate with the ability to run group sessions. The reasons for choosing to run group sessions or not, was not determined.

The number of group sessions did correlate with the rate of home dialysis. If monthly group education sessions were available 38% of patients were at home, compared to 20% if there were none. It affected both HHD and PD rates.

![Number of group education sessions related to home dialysis rates %](chart.png)
Barriers to Education:

Untimely referrals affected 82% of units in delivering education. Patient factors; including reluctance to attend education and difficulty in doing so, affected 82% and 78% of units respectively. Staffing numbers had an impact in 9 units and this was more likely to be in the country areas. The interpreter issues were in the States recognised for having multicultural populations, and were prevalent at small units.

The units reporting the highest rate of barriers had an average of 6% HHD compared to those reporting the least having 10% HHD. There was no correlation with PD rates.

Significant others

Having a significant other to attend education was supported by 100% of nurse educators as being at least very important, and usually encouraged at every opportunity (80%). Despite this only 53% of units reported that over 75% attended with that significant other.

There was no dominant State pattern to attendance rates, nor did it correlate with the frequency of group sessions. There was no demonstrated correlation with the presence of significant others and home dialysis rates.
Methods of Education:

A wide combination of education methods are used, incorporating many members of the health care team. PD is more widely promoted than HHD overall, with involvement of the PD team and demonstrations more likely to occur. Dieticians (79%) and social workers (69%) participate widely.

The dialysis options that are covered during these education sessions include HHD and PD being presented to over 95% of patients. Satellite nocturnal HD and self-care options are not being discussed widely and this may reflect local practice regarding these modalities.
Although HHD is presented to 97% of patients variations in HHD regimes such as enhanced hours and nocturnal are only discussed in 65% and 80% respectively. The units who did not use a member of the HHD team for education averaged only a 3% rate of HHD, compared to an average 10% on HHD overall.

It is important to note only those who attend can gain this widespread education and only 82% are comprehensively educated prior to commencement.

Use of formal Assessment tools:

Formal assessment tools are not standard practice for pre-dialysis education in Australia. Only 20% report significant use of tools. Only one unit in each of WA, QLD and NT unit use a formal tool at all times. One Tasmania unit is contemplating the use of match D and a number of NSW units use an unspecified tool. There were not enough units using a tool to draw any conclusions about the outcome of tools.

Despite only 20% use of tools 70% of units support possible future use of an assessment tool.

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**Does the team use a formal tool to evaluate the most appropriate treatment option for each patient?**

- 52%: Always
- 14%: Usually
- 14%: Sometimes
- 14%: Rarely
- 10%: Never

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**Do you think a formal tool should be used in your unit to support the process of choosing the best treatment options?**

- 30%: Yes
- 40%: Maybe
- 20%: No
- 10%: Unsure
Home first policy

Home first is a recognised policy for 77% of dialysis programmes. Comments related to this included physician resistance and awareness of the social circumstances of the patients.

The team policy for home treatment option first does impact on the rate of home dialysis, particularly PD. Units reporting always having a home first treatment option policy achieved on average 34% at home compared to 26% for units who usually had a home first policy. The 7 units that sometimes, rarely or never had a home first policy had 21% on average at home.
Language and Culture:

The 26 units completing this question have a dominance of English speaking Europeans, but only 11 units have over 75% of this population.

- 19 (73%) of units reported having non-English speaking Europeans
- 20 (77%) of units had non-English speaking Asians
- 21 (81%) of units are managing indigenous patients
- 7 (27%) of units had less than 50% Europeans English speaking

The languages spoken were varied with a wide reporting of Cantonese, Mandarin, Italian, Vietnamese, Greek, Arabic and Indian. Occasional culture reporting included Malaysian, Malta, Phillipino, Russian, Maori, Pacific Islanders and Indonesian.

Written materials that cover the topics from chronic kidney disease, to all treatment modalities were requested by 30-45% of units in all suggested languages. Indigenous tools were acknowledged to be well developed in the NT, but assumedly not widely distributed.

The following resources were identified as requiring development or updating to further enhance education programmes.

<table>
<thead>
<tr>
<th>Education Tool</th>
<th>% of units that would like tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Dialysis Website</td>
<td>66%</td>
</tr>
<tr>
<td>Personal stories on DVD</td>
<td>46% (non-American)</td>
</tr>
<tr>
<td>Staff Education Packages</td>
<td>70%</td>
</tr>
<tr>
<td>Pre-developed Power-point</td>
<td>50% (incorporate short videos)</td>
</tr>
<tr>
<td>Patient Network</td>
<td>63%</td>
</tr>
</tbody>
</table>
Limitations:

Use of electronic surveys allowed more than one respondent per unit. In some units there was confusion as to whether they had completed the survey resulting in 2 or 0 being completed on 3 occasions. The most relevant and complete surveys were kept in the analysis.

The definition and allocation of time for the role of nurse educators between pre-dialysis and CKD nurses is often blurred with seven nurses filling both roles. This limited the ability to interpret the ratio of CKD nurses and also may have underestimated the workload of some pre-dialysis educators.

The small number of Australian units allows extreme answers to sway results, especially when analysing each State. Analysis was only completed by spread-sheeting data, and graphs.

ANZDATA reporting for NSW includes home patients by the unit who trains them rather than the parent hospital or education service, which may have skewed the percentage results for 3 country units. Respondents without detailed databases would have estimated some answers although it is suggested that most units would have to be maintaining a database in order to successfully remain in control of their patient load.

Barriers to education were identified but there were no questions to explore the underpinning reasons for this further. It would be useful to consider for example if timing of education, location or other factors contributed to difficulties in attending sessions.

The effectiveness of education and whether the content is delivered utilising adult learning principles, patient centred approaches or focusing on life-style considerations was not assessed. It did not define the characteristics or beliefs of the nurse educators.

Survey fatigue resulted in a number of respondents failing to complete the latter sections of the survey especially those questions regarding culture and resources.

Summary/Discussion:

This survey provides staff opinions and data regarding the provision of education services and the uptake of these services. Analysis considers how factors related to each other and was also cross-referenced against known home dialysis rates. The survey confirmed factors determined by PINOT and established information that was not previously known. 71% of units, representing 70% of Australian patients responded allowing reasonable conclusions to be drawn about the whole population.

Results demonstrate that provision of pre-dialysis education is varied across all States of Australia, and further within each jurisdiction in many States. The greatest variance is in the staffing; specifically the staff to patient ratios. There is an estimated 456 patients for every 1 FTE of pre-dialysis educator, with a ratio from 2-31 patients (mean 12) for every hour that a pre-dialysis nurse is employed. The fact that most units have only one educator suggests that each individual will heavily influence the focus of the programmes. The educator qualification level varies with nurse practitioners becoming more widely used, predominantly in earlier CKD, and in QLD. Having less than 10 hours of a pre-dialysis educator correlated with lower home dialysis rates.
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The delivery for education varied widely with options being; group, one-on-one education or a combination of both. Variations in programme delivery could not be related to the hours an educator is employed. Over 90% of units report that they provide information about all relevant modalities within their programmes. Enhanced hours options for HHD remains a limited option even within units that do offer HHD. There was a bias towards PD over HD with higher use of training staff and demonstrations for PD. Low rates of information pertaining to modified HHD regimes and limited use of HHD staff suggests patients are not made aware of all options and benefits. Use of HHD staff as part of the education programme was linked with twice the rate of HHD.

On average 82% received early education which is comparable to the PINOT survey which found that 84% received information prior to treatment, but only 75% received information about home dialysis. 33% of units however reported that less than 75% of patients received comprehensive education prior to commencing dialysis. Significantly attendance did correlate with home dialysis rates, with an average 32% at home in those units who indicated that 91-100% received early education, decreasing by percentage groups down to only 22% in those units that determined that <50% had early comprehensive education. The difference was principally in the PD rates.

The units that reported being the most affected by late referrals and the patient factors of reluctance and difficulty attending education, had the lowest education rates. Timing of referral to treatment option education overall was estimated to be predominantly between stage 4-5. The PINOT trial found the average education delivery to be at late stage 4, at 13.3mmol/l. Systems are in place to increase the comprehensive education rate once patients start dialysis and 97% of units had a referral system, even if it was informal, for late referrals. Of concern is the fact that only 43% of satellite units regularly re-evaluate patients. This implies that some patients, who quickly transfer to a satellite unit can get through the system without comprehensive education about home modalities. The units with formal re-evaluation and referral for further education had on average twice the rate of HHD.

Units are using a wide range of methods to deliver education, and are covering a wide range of topics. If patients attend education it appears that the system would provide information regarding home. PINOT found 72% of patients were documented to have received PD, and 52% HHD, education.

Education times vary from 30 minutes to over 3 hours. The hours of education delivered do correlate with home dialysis rates, and the longer the education hours the higher the home dialysis rate, particularly the HHD rate. This suggests that time is needed to come to terms with the prospect of performing HHD. Group sessions use demonstrated wide variance. Use of group sessions correlated with more hours of education. The use of group sessions also correlated with higher rates of home dialysis, especially HHD.

All units identified that significant others were important within the education process and yet in 53% of units less than 75% chose to attend education about a decision that will impact on their lives. PINOT found that only 20% of patients started on home dialysis, but 80% of these had a carer present at education compared to only 56% of those who started at a centre. In this survey when comparing the reported rates of attendance of significant others against home dialysis rates there
was no correlation. Determining reasons for non-attendance of patients and families and converting this information into strategies to bridge this gap could be an important factor to enhance the uptake of home.

Home dialysis first as a policy was also positively correlated with the rate of home dialysis. An average 34% of patients were at home in the units always advocating home first compared to 21% in the units that sometimes, rarely or never had this policy.

Use of a modality selection tool is rare. Despite this 70% would consider use of an available tool. The American Match D tool has been available for three years and is included in the WA and Victoria dialysis reports. This would suggest either poor marketing or reluctance to use the existing tool and therefore there is a need a relevant tool for the Australian market. 75% reported using websites to support education but 66% report that an improved site is needed.

The provision of culturally specific education should be mandatory to comply with informed decision making. Limited materials are available currently. 100% of units provide written material but most acknowledge significant percentages of non-English speaking Asians and Europeans, and up to 45% of units acknowledge requiring materials for each of six dominant cultural groups. Interpreters are used, where available, but this is unlikely for group education and therefore it can be assumed that most non-English speaking patients would receive limited one-on-one education in their own languages with limited back up materials that they could read.

As future recommendations units also identified pre-developed power-point presentations, and staff education packages as areas for improvement in education provision, and a national approach to this would be prudent.

**Future recommendations:**

Obtaining information about the education programmes is only part of the picture in determining how well the consumer is educated. Education delivery may only result in minimal understanding. With the knowledge that perceived and objective knowledge can be very different, even if the consumer reports having enough knowledge to make informed choices do they really? Receiving of information is marred by numerous blocks that will all impact on understanding. PINOT used documentation of education about a particular modality to reflect that the patient was educated, and this survey used the opinions of the educators to determine who was comprehensively educated. It is suggested that future assessment of reflective discussion or even objective questions could reveal more objectively the level of understanding reached by the individuals.

Considering the lack of correlation between home rates and the nature of each education programme it is hypothesised that the characteristics and the opinions of pre-dialysis educators, or the unit culture they operate in may reveal some interesting data. Alternatively analysis of whether programmes prioritise life-style issues or modality options, with a cross-analysis of home dialysis uptake would also shed more light into the best method of home dialysis promotion.

Further research is also needed that focuses on reasons why significant others choose not to attend education. The impact of their opinion on choice of modality would also be of interest.
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Conclusion:

Pre-dialysis education and the use of CKD nurse education remains a very unit driven process, with no formula for the average programme. There is a high but variable ratio of patients to be educated and supported, and this is by less than one educator in 90% of units. Units with highly active programmes that are well staffed, using a wide variance of educational modalities, succeed in early education and operate within a home first policy achieve the highest rates at home. Occasional units without these qualities also succeed, which may reflect the qualities of the pre-dialysis educator.

Most education programmes do aim to deliver information about most relevant modalities of dialysis. However HHD rates are lower where HHD is not being marketed to the maximum. Objective tools for modality choice are rarely being utilised. Alternative cultures and non-English speaking individuals are not adequately catered for in a very multicultural country. Relatives do not choose to engage in the education process at the rate nurses would like them to. Too many patients, either by choice, related to personal barriers or lack of timely referral, do not attend education prior to the commencement of dialysis.

External provision of resources could maximise the time available for direct education, and would be accepted by many units. A home first policy, early comprehensive education, increased education hours, referral from satellite units, use of group sessions, and use of HHD staff were all positively correlated with home dialysis rates. All are factors that can be implemented for any programme.

References: