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Kidney Health Australia: Response to the 'Factors Contributing to the Decline in Living Organ Donations' Report.

Introduction

Kidney Health Australia is responding to the Australian Healthcare Associates' (AHA) report *Factors Contributing to the Decline in Living Organ* Donations. AHA was engaged in 2013 by the Department of Health and Ageing (DoHA) to undertake an investigation into the decline of living organ donations.

Kidney Health Australia has previously made a submission on this topic directly to AHA also had the opportunity to meet face to face to discuss.

Transplantation is the most cost-effective treatment for end-stage kidney disease (ESKD). There has been a substantial increase in recent years in the number of deceased donors for kidney transplantation, however this change has not been accompanied by an increase in the total number of kidney transplant operations due to a co-incident 33% fall in the number of live kidney donors in the same time period. The reasons for the fall in the live donor numbers are not evident and were subject to investigation by the AHA. Some key issues identified included: Financial barriers to donation, and transplant capacity and the variation in uptake of live kidney transplantation at the Unit level.

Policy Recommendations

Many of the policy recommendations from the AHA report coincide with points made in our submission, and face to face consultation with the AHA. Live donor kidney transplantation has existed in Australia from the earliest days of transplantation in the 1960's and has contributed a significant component of kidney transplant numbers. The availability of a live donor allows "pre-emptive" transplantation to occur without the requirement to go onto dialysis. This pre-emptive pathway is associated with the best clinical outcome and is the most cost-effective approach in the renal replacement pathway. Living donation is associated with an increase in patient survival of 27% at 20 years (over that observed with deceased donors).

The rate of uptake of live donor kidney transplantation varies significantly between units, regions and states in Australia. The reason for this variation (documented to vary tenfold between units) is not well studied but is believed to likely reflect the attitude of health professionals to live donor transplantation and the variable resourcing of units with staff. Living donor transplantation is based on the belief that it can be performed without affecting the quality and length of life of the donor. Long term follow-up studies of living

donation are reassuring in this regard but are based on overseas data. The strong concern and the need for certainty in this area has led to the establishment of an Australian long term follow-up registry (through ANZDATA) but this initiative has not been successful in recording follow-up over time in the majority of donors.

The decisions around living donation are all taken at the individual unit level with no national or state based guidance in place. No performance indicators have been established in contrast with the effective and successful Australian Organ and Tissue Authority (AOTA) driven deceased donor program. Even reporting the numbers of live donation through ANZOD/ANZDATA has been given no priority and may lag fifteen months behind the event.

With these issues in mind we have ranked the findings from the AHA in terms of priority for Kidney Health Australia, and outcomes we believe will best assist in understanding the rates and issues surrounding living organ donation.

1. ***AHA FINDING**: "Conducting a more granular analysis of LDKTx at the level of jurisdictions/transplant centres to identify variations in funding, policies and clinical practice that may impact on rates of living organ donation"*

It is important that for patient equity that variation in funding, policies and clinical practice impacting on rates of living organ donation at each level of jurisdictions/transplant centres is identified. There is a marked regional variation across Australia in the incidences of donation, and any attempt to address this should be based on an understanding of the differences that potentially underpin and drive such variation. These differences can also be compounded due to geographical differences (rural and remote areas), access to health services, and clinical barriers such as hospital wait times and theatre availability.

Detailed information is lacking that would allow a full assessment of this variability in health service delivery. It is evident that economic factors impact on would be donors and further analysis of this issue is also required.

Although comprehensive data is collected through ANZDATA, a more granular analysis at the individual unit level is required.

It is likely that this analysis would lead to a requirement (if change is to be accomplished) for strong policy leadership at both the state and federal level, increased funding and sufficient flexibility for state governments to motivate and overcome jurisdictional barriers.

Kidney Health Australia therefore recommends and agrees with the AHA report that an in-depth analysis be conducted to identify variations in funding, policies and clinical practice that have an ongoing impact on rates of living organ donation. This analysis also will benefit further recommendations within the AHA report, such as investigating variations in socioeconomically disadvantaged groups which is a high priority. Furthermore Kidney Health Australia would request involvement in such review.

2. ***AHA FINDING:*** ***"Closer scrutiny of the data available through the ANZDATA Registry would enable a more granular analysis of the changes in rates of LDKTx within jurisdictions and within individual transplanting centres"***

The ANZDATA (together with its "sister" registry the Australian and New Zealand Organ Donor Registry (ANZOD)) have the responsibility for reporting on the number and characteristics of live donor kidney operations. In contrast to the remit for ANZDATA/ANZOD to report on deceased donor activity on a monthly basis by the 2nd Monday of each month thereby ensuring that all stakeholders can monitor performance effectively, there are no such requirements in the live donor arena.

The AHA report clearly identifies (p25) that there is no system in place to allow ANZDATA to report live donors on a frequent (e.g. monthly) basis.

As a consequence, it is usually many months after the annual close of the database before any report is issued. This means that it is often 18 months behind in documenting activity. This delay seriously impairs any timely analysis and the opportunity to address problems impacting live donation. To correct this situation would require AOTA (the funding body for ANZDATA/ANZOD) to be given the responsibility for creating and monitoring reporting timelines. A modest increase in resources for these Registries would be required to allow additional staff time to be allocated to this process, and this would need to be supported by developing national reporting standards – the supply of data to ANZDATA remains a significant cause of the delay.

We acknowledge that existing ANZDATA / ANZOD data could be interrogated in more detail to understanding the variation in uptake (the age of the donor, seasonal variation) but would not provide enough information to understand the issue with any full clarity. It is for this reason we agree that a new survey of all transplant units, which investigates resourcing and structural barriers (theatre times, surgery availability) is necessary.

3. ***AHA FINDING:*** ***"Ensuring that living donors are not financially penalised by their decision to donate, by expanding financial reimbursement and support (the Supporting Leave for Living Organ Donors Scheme was viewed as a positive first step in this regard)"***

Kidney Health Australia has identified that inequity in financial assistance is a hurdle to live donation. Currently donors travelling from Tasmania to Victoria are covered for reimbursement, but it is by no means universal, as outlined in the report. Kidney Health Australia has called for a national approach to interstate travel for donation would ensure all donors are equally assisted, and would strongly support such an initiative that also covered out of pocket medical costs.

There is also inequity in the time frame in which reimbursement takes place. A national approach to reimbursement would ensure donors out of pocket expenses are reimbursed within a standardised time frame regardless of state/region of residence.

Due to the costs involved in living kidney donation, families often incur financial strain due to lost income from time off work, accommodation and travel costs. Kidney transplants are

done in city based hospitals which means rural and regional families have no choice but to travel to the city for the operation and treatment. Kidney Health Australia currently operates a Family Accommodation Initiative Transplant Housing (FAITH) house in one State. This initiative provides furnished accommodation for families who need to travel to Perth for living kidney transplants. The model works effectively as the costs are charged (to the full amount claimable) to the Patient Assisted Travel Scheme (PATS) to cover the entire cost of the stay, making it a cost neutral option. FAITH is currently running at full capacity all year round (2 houses in WA), but currently does not operate in other states and territories. Kidney Health Australia pays for rent and ongoing payments such as electricity and water so the program is run at no cost to the patient.

The ability or inability for a live donor to have adequate leave in order to donate and recover has been an issue Kidney Health Australia has successfully raised in multiple levels of government. The Supporting Leave for Live Organ Donors Scheme (the Scheme) is the first major policy step forward for live donation policy in some time. However, it is heavily dependent upon employers voluntarily supporting the scheme.

Furthermore, noting the limited education and communication in place for the 1 July 2013 launch, it is the view of Kidney Health Australia that the scheme should be extended beyond the first two years to allow the opportunity for the scheme to become well known, and ingrained in the minds of both employers and employees. Furthermore, without data collection around the people who have not proceeded with the scheme, it is not possible within the short time frame of two years to assess the full merits of the Scheme.

Furthermore, to assist in this process a voluntary 'Employer Charter' (Kidney Health Australia has developed such a charter) should be developed to outline the principles behind the Scheme, including the agreement to allow the employee to take short leave breaks to undertake the tests to confirm the ability to donate, support the policy principles of live organ donation more broadly, and increase the awareness of live donor opportunities within their organisations. Currently, many employers are hesitant in both the public and private sectors to list live donation as a formal entitlement under leave arrangements. Many of those who become live donors currently are required to take unpaid leave, adding further strain to an already stressful situation.

Many couples who own and manage a small business don't have the option to donate to each other as there is currently no assistance offered to allow them to both leave their business at the same time - i.e. the new live donor scheme will only cover the donor, at minimum wage for a 6 week period, meaning that the time off work for the recipient is not covered.

Recently reported US experience indicates that income is strongly and positively related to live donor rates and that in times of economic stress the lower income groups fall off most markedly in live donation rate. This highlights the need to have an equitable arrangement in place that ensures live donation is possible without undue financial stress in the lower socio-economic quintiles in Australia.

4. ***<u>AHA FINDING</u>: "Developing and ensuring consistent delivery of education and awareness-raising strategies around living donation, targeting: the general public, potential donors and recipients (including having access to 'mentors' who are past kidney donors or recipients), and health professionals (including nephrologists, GPs and dialysis nurses)"***

The AHA report has identified that future policy development for living donation should be based around developing and ensuring consistent delivery of education and awareness-raising strategies around living donation, targeting: the general public, potential donors and recipients (including having access to 'mentors' who are past kidney donors or recipients) and health professionals (including nephrologists, GPs and dialysis nurses).

Kidney Health Australia has previously identified that the variation in the rate of live donation is in part driven by the absence of high quality patient education material that informs new or existing dialysis patients about LDKT in a positive, yet balanced manner. There is considerable variation in enthusiasm for living donation by nephrologists and surgeons resulting in patients being given markedly different accounts about the suitability of this pathway for themselves.

Kidney Health Australia is currently developing high quality patient education material in the area of dialysis (with a $1 million Australian Government grant) and a similar initiative is needed in the area of living donation. Such a model could be adopted in this space, and Kidney Health Australia would welcome the opportunity to demonstrate the materials and concept to the Department.

To supplement the proposed live donor leave charter, and noting the strong focus from the AOTA on improved education, marketing and awareness activities for organ donation, such as strategy could start with a Communications, Education and Awareness Strategy for the live donor leave scheme. Such a strategy could develop and disseminate communication aimed at key target markets, and do so through existing networks (such as Kidney Health Australia's established network with patients, carers, medical professionals, renal networks and clinics, and the broader kidney community). It is the view of Kidney Health Australia that medical professionals, employers and potential donors will need education and support for this scheme to realise its full potential – indeed through our networks we are aware there is already a very strong demand for further communication and information regarding this scheme, particularly noting the approaching start date. Such networks already exist under AOTA.

Such a strategy could also incorporate a significant presence at key organ donation and kidney related events (such as Kidney Health Week and DonateLife Week), and be supported by a social media campaigns in order to raise awareness, understanding and to generate an increased uptake.

Furthermore, the development of a 'Ambassador' or 'Champions' program to support, reward and publicise those who have chosen to become a live donor, and selected employers, would not only provide a form of support and recognition, but also assist to further publicise the initiative to the wider public. Kidney Health Australia is very well placed to assist in providing, in partnership with AOTA, the necessary communication, events,

marketing and patient support elements, and could for minimal cost draw upon existing events and already established networks with the target audience.

5. ***AHA FINDING**: "Increasing health system capacity to undertake LDKTx by addressing funding, staffing and theatre access issues where they exist"*

AHA has identified that health system capacity shortages may be impacting on the ability for live donations to occur. This widely refers to general funding streams in the health care system, staffing levels and fluctuations, and theatre access issues. Increasing strains on the health care system and an aging population have contributed to longer waiting lists in the health system more generally and this has an effect on the ability to secure adequate theatre time. Some responses to the AHA report have indicated that having a donor coordinator in some jurisdictions had facilitated the organ donation process in general - and increased awareness. This donor facilitator could potentially add a great deal in streamlining improving ease of access within the health system for living donation to occur.

Kidney Health Australia has previously identified that the issues surrounding surgical shortages and mismatched resources– stemming in part from the Federal / State divide between organ donation and transplantation – are a barrier to increased numbers.

The absence of a timely information flow about the number of live donor kidney transplants performed and their location makes it impossible to properly document this issue. However KHA has direct reports from Units that the following are current issues and impact on the ability to deliver live donor kidney transplants to patients in a safe and timely manner:

- A shortage of surgeons resulting in the need for the interstate short term recruitment in order to "clear the backlog". This fly in/fly out arrangement is considered highly undesirable.
- A shortfall in theatre allocation to living donation resulting in gating the maximum number of operations performed in any time period.
- A lack of dedicated nurses resulting in delays and inefficiencies in processing that has resulted in patients needing to start dialysis (unnecessarily) with its attendant morbidity and increased cost.

Kidney Health Australia agrees that increasing health system capacity needs to be a priority. This priority refers to the improvements in resources, skills, culture and technology that are needed to support transformation to an integrated live organ donation system. Strengthening the system's infrastructure and capabilities also means building a commitment to donation amongst health care administrators and professional associations. It may also involve removing barriers to accessing intensive care beds, theatre rooms and follow-up care, and considering learning from the rollout of the DonateLife staff in hospitals. It may also involve providing staff with the technologies to increase efficiency and deliver the data needed to drive performance improvements.

6. ***AHA FINDING: "At a national level, improving governance and leadership in relation to living organ donation"***

AHA has identified that on a national level, there is an issue that needs to be addressed in relation to developing standardised clinical protocols in donation; improving communication through the donation process and facilitating a consistent national approach. This includes developing standardised clinical protocols and guidelines; improving communication and collaboration between transplant units; and standardising funding arrangements. Kidney Health Australia agrees with these recommendations.

However one area that needs to be explicitly stated, which could be considered related to this, is making live donation a responsibility of AOTA.

Kidney Health Australia strongly believes that live donation policy should be the sole responsibility of the (AOTA), and furthermore considers this to be a high priority.

The establishment of AOTA in 2009 and the consequent changes to deceased donor procurement centring on the organisation's engagement with hospitals, the establishment of the DonateLife network, public communication, education, awareness, activities, events and engagement with civil society, including through the Advisory Council, has led to significant increases in the deceased donation rate.

In addition, AOTA are responsible for the Australia paired Kidney exchange Program 'an initiative of the Organ and Tissue Authority to increase the options for living kidney donation' –a scheme which is clearly a living donor policy in action. By placing this aspect of organ donation under the AOTA it would better align it with existing activities and therefore create an economical and efficient mechanism for moving this issue forward, by leveraging off all the work and structures already in place. It is envisaged that AOTA would be charged with establishing standard clinical protocols (including guidance about clinical suitability of would be live donors), minimum performance criteria, education material for staff and patients and the responsibility for reporting the rate of, and the long term follow-up of, live donors.

7. ***AHA FINDING: "Sociological and social biology research into the reasons why people consider living kidney donation (from both the donor and recipient perspectives), and the short- and longer-term psychosocial impacts of these choices"***

The AHA has identified that further research needs to be conducted into why people consider living kidney donation (from both the recipient and donor perspective) and the short and longer term consequences of those choices.

Kidney Health Australia believes there is a clear shortage of information about the psychosocial influences that impact family decision making for a living related donor kidney transplant. This may be related to potential recipient's decisions about the kidney donor, and families' roles and expectations. Furthermore, there are sociological implications of organ donation being seen as a "gift". Experiences revealed to Kidney Health Australia show

that families make decisions about kidney donation in different ways. Emotional responses of potential kidney recipients can include a spectrum of gratitude to ambivalence, and even a denial of the severity of their illness. Emotional responses of potential family donors range from unrestrained willingness to uncertainty and concerns of obligation. Within the Australian landscape there is a need for improved accuracy of health assessment and awareness of the importance of sociological perspectives. This could be investigated through assessments in addressing the fears and concerns of both potential recipients and donors.

8. ***AHA FINDING: "Understanding local public opinion regarding altruistic non-directed donation (ANDD), which may be useful in determining whether consideration of strategies to increase this potential donor pool is warranted"***

Kidney Health Australia agrees with AHA's recommendation that local public opinion regarding living donation may be useful in determining whether consideration of strategies to increase this potential donor pool is warranted. It is recognised that potential altruistic (non-directed) donation needs the most careful clinical and psychological assessment and that this source of donors is never going to be a significant component of the live donation. Directed live donation where there is a connection between donor and recipient has accounted for about 2% of live kidney donation in Australia in recent years and is likely to remain at this level.

Kidney Health Australia recommends that an ongoing, sustainable public-awareness strategy be developed to increase the likelihood that all would be recipients are aware of this pathway and how to access it. This is particularly important in Units where there is little or no live transplant activity and patients are potentially severely disadvantaged. Such a strategy would focus on increased discussion with families, and will promote and improve action to support decisions surrounding live organ donation. It is also recommended that a robust national communications plan be developed to support the strategy.

9. ***Continuing to support and develop the AKX program***

Kidney Health Australia agrees with this recommendation and would support the ongoing operation and potential increased resourcing of the AKX.

10. ***Further investigating variations in access to and rates of LDKTx between population subgroups (particularly Aboriginal and Torres Strait Islander people and socioeconomically disadvantaged groups).***

Kidney Health Australia again agrees with this recommendation and would support further investigation of this area – understanding there are significant differences between population subgroups stemming not just from cultural constraints, but existing health outcomes, socio-economic constraints as well as distance and travel barriers.

Conclusion

Kidney Health Australia broadly agrees with the findings and recommendations of the AHA report and would ask that you consider our recommendations as above. Kidney disease is a serious public health concern and increasing pressures on governments for budgetary savings mean the pressures on the health system will only increase with an ageing population.

Living organ donation is a complex ethical concept that can change lives and reduce long term financial burdens to the health system and governments. However, better results are being hampered by the lack of governance structure and continuity, an absence of significant granular analysis to assess and address the variation in live kidney transplantation between transplant units. The disconnect between support for donation and action results from the absence of a clear action plan, the absence of system mechanisms to support any plan, and the many inconsistent practices operating within the current system.

Kidney Health Australia seeks to see resourcing constraints overcome that may impact on any surgery taking place in a timely manner. Support for donors through education and raising awareness within the healthcare system must be seen as a main concern. The measurement and accountability mechanisms must be in place to drive consistent and system wide improvements. Furthermore, placing live donation on the national agenda through the incorporation of it as a responsibility of AOTA would naturally prompt consideration of further areas for action.

It is imperative that a stronger commitment for follow-up of donors is made to strengthen the ability to monitor long term outcomes. Furthermore, post-operative support for both donors and recipients must be made a priority.