The DO’s and DON’Ts of starting and growing a new transplant program

Andrew Ready
University Hospital Birmingham, UK
Transplant Links
Chronic Kidney Disease

- The incidence of CKD is growing globally by 6% to 8% per annum.
- Studies suggest that the incidence of CKD is disproportionately greater in the developing world.
  - Predisposition, Poverty, Cultural factors
  - This seems linked to socio-economic factors
    - The poorest countries are worst affected
- Estimated prevalence of pre-dialysis chronic kidney disease in Africa ~50 million
- Starts younger, presents later, more aggressive course
  - Most patients aged between 30 and 50 years at the peak of their productive life
- The magnitude of this problem is likely to increase
Renal Replacement Therapy

• Renal replacement therapy (RRT) is a triumph of modern medicine.
• In the industrialized world dialysis and transplantation have been developed on a massive scale
• Almost no-one dies directly from the effects of end-stage renal failure or for lack of appropriate treatment.
• The contrast with the developing world could not be more stark
  • Preventative and diagnostic measures are lacking
  • Dialysis is largely unavailable or prohibitively expensive ($15000 per annum)
  • Transplantation is largely unavailable or prohibitively expensive
• For most patients there is no treatment - renal failure means death and most patients die within weeks or months of the need of RRT
Managing CKD in the developing world

- Developing dialysis programs is costly
  - Significant infrastructure
  - Organization
- Transplantation may be a better alternative
  - One-off, relatively cheap treatment
  - Technically within the capability of local teams.
  - Provides an immediate solution
  - The mode of treatment is centred on the patients own family.
  - Improved quality of life
  - Extends life
- For many, it would provide the best and most cost-effective solution to their dilemma
Challenges to developing transplantation in the developing world

- Fledgling programs usually geographically distant from experience
- Local teams may have had no previous exposure to transplantation
- Absence of suitable infrastructure
- Concerns about the cost and availability of immunosuppression
- The clinical need may be unrecognized - except by an enlightened few
- Transplantation may not be on the political healthcare agenda
- There may be lack of confidence about begin
Challenges to developing transplantation in the developing world

• These factors may create a state of ‘resignation’
  
  • Complex medical interventions such as transplantation will ‘simply not happen’.
  
• This produces a ‘gridlock’

• Progress fails to occur despite clear clinical need

• The rich go abroad for treatment - exporting experience!
• How to break the gridlock?

Do some transplants!
Transplant Links

The Vision

• To support the development of sustainable living donor kidney transplantation
• Perform transplants with on-going mentoring
• De Novo development
• Further develop struggling pre-existing programs.
• To create a linked group of units sharing issues and creating solutions.
• Provide support with additional services
  • Nephrology, Nursing, Pathology, Tissue-typing, Research, etc
• To break the gridlock that inactivity often creates
Transplant Links

- Founded 2007
- Funded by charitable donations raised by TLC
- Funds raised approx £1.5m
- Finances pay for team visits
- No financial support of the costs of transplants
  - These need to be funded through local economics
  - For ‘skill transfer’
Transplant Links

- Teams composed of unpaid volunteers using annual leave
- Personnel involved in the TLC program include:
  - Renal transplant surgeons
  - Nephrologists
  - Specialist nurses
  - Operating department personnel
  - Anaesthetists
  - Paediatric nephrologists
  - Tissue typing personal
  - Pathologists and radiologists providing back-up services
TLC – Models of Assistance

Support to developing units is tailored to the needs of the individual units
Support falls into four broad categories

- **Developing programs ‘de novo’**
  - Full TLC team transplanting visits

- **Supporting the development of pre-existing services**
  - Improve surgical techniques, paediatric transplantation more complex patients

- **Providing training in the UK**
  - Educational visits and longer training fellowships.

- **Providing advice - exiting units and ‘potential units’**
  - Response to early development plans
The TLC /UHB Network
TLC - Outcome

• Confirmed the need
• Transplants performed - some lives saved
• Proven the concept – increased confidence
• Given patients individual and collective voices
• Local clinicians more secure with ‘partners’ to support development
• More likely to retain staff in developing world
• Skill transfer has occurred
• Placed transplantation on the agenda - media … and politicians
TLC

What have we learned?

Sustainability is not just about surgery!
Setting up a Transplant Program

- Progress always takes longer than expected.

- Travelling to a unit and just performing transplants will not itself produce sustainability.
  - This only constitutes surgical tourism.

- For real progress to occur, pressure needs to be applied over a longer period of time with repeated visits and clear pathways of development.
Setting up a Transplant Program

• Working across cultural differences is not always easy
• Issues need to be discussed with appropriate sensitivity.
• Most issues are manageable particularly if all parties focus on the common goal.
• Working across cultural differences can be a very rewarding experience.
Setting up a Transplant Program

- A local champion with transplant experience with whom to liaise and collaborate
  - Ideally with an understanding of CKD and basic training in dialysis and transplantation
- Receptive hospital management
- Institutional capacity
- A pool of well-informed dialysis patients
- Enthusiastic hospital staff
- Appropriate protocols
Independent Ethical Assessment Committee

• The role of the independent assessment committee is to ensure that act of donation had been done freely/ genuinely without any coercion or financial gain

• The committee reviews donor and recipient independently and then discussed together

• Ethical considerations must to be at the very centre of all developments

• An ethics committee should be set up before any transplant is performed and ethical issues discussed at every occurrence thereafter.
Setting up a Transplant Program
Skill transfer

• The amount of surgical (and medical) skill that can be transferred during a visit is limited.

• Even with experienced surgeons!

• It must be recognised that surgical learning in particular requires considerable exposure.

• It takes several years to train transplant clinicians in the developed world so why should it be any different in the developing world?

• Visits provide exposure and opportunity to ‘recruit interest’

• Fellowships in established units are required for skills to be safely developed.
Political Underpinning

• Many aspects securing sustainability/stability depend upon the non-medical establishment – politicians!

• Politicians generally, appear suspicious of RRS - including transplantation,
  • RRS are seen as a significant financial commitment.

• This may be particularly true in developing countries
  • Intense competition for scarce resources
  • Multiple healthcare problems (that may be more acute)

• RRS become another pull on scarce resources
Political Underpinning

- It is vital to engage local politicians to ensure their on-going support of transplant development, both philosophically and financially.
- It is vital to extend education to local patients with CKD in order to give them a voice demanding that treatment should be made available to them.
- Patients voices are perhaps the most powerful.
- For similar reasons, it is important to engage with media to publicise development and support the wider aspects of public health education regarding CKD.
Economics

• Political will is required to provide economic support

• Political support will depend upon the state of the local economy

• Universal access to dialysis is not seen as a requirement in much of the developing world

• Transplantation does not constitute economic sense – there is no trade off with dialysis costs

• Transplantation becomes another healthcare component that requires funding
Economics

• The Political/Economic issues are more difficult than skill transfer.

• It is vital to recognise that unless the program is financially viable it will not survive - even if skill transfer is successful.

• Unless medical staff and other health-care personnel are able to earn a living from transplantation, programs will not survive.

• In such circumstances it is likely that trained professionals will seek employment in the developed world, which is not the philosophy of the development exercise.
Work where the odds are favourable

• A common language – English
• Political stability – recent elections
• An emerging economy – oil
• Political Support
Conclusions

• The development of transplantation cannot be pushed quicker than the overall developmental rate of a country will allow

• This should not put us off our task

• But we do need to realistically assess what we can do

• And over what timescale!

• By direct action and collaboration with clinicians and patients we should ensure transplantation is on the agenda with other developmental challenges.
Should we bother?

Of course!

- The lives of patients dying of ESRF are as valuable as any others.
- We have a duty to be their advocates.
- Economies are not static – they are developing.
- Resources Riches - Oil, minerals etc.
- Full development may have to await full economic development.
- We must ensure that it’s on the agenda now.
- Resource Riches - often badly spent!
- But we have to proceed with realistic expectations and review our achievements in this context – Assess the legacy!
- We must never forget the human factor!

Dear TLC,

I am writing you this letter with immeasurable joy and gladness for the good work that you doing on the surface of this world, extending your skills and knowledge to the saving of lives of the less-privileged countrymen and women. I happen to be one of these people who saw no hope of a dialysis-free life and was always tormented by the terror of death since my father went bankrupt hence could not pay the exorbitant dialysis bills let alone erythropoetin and other drugs to sustain my life. I inevitably resorted to the illegal once-a-week dialysis with strict renal diet check nevertheless with fear and trembling.

And so I am utterly grateful to every member of the team for allowing yourselves to be used by God Almighty as vessels of honour to reach out to the people of the developing countries. He will reward you abundantly and channel an overflow of donations for your enterprise.

My transplant was a great success and even to the whole of Ghana. A breakthrough in Ghana medical history has been achieved on the 50th of Nov 2008: the first kidney transplantation in Ghana. Currently I am well and good-looking with lots of exuberance, the same is my sister who donated for me. My body biochemistry has stabilized and all is well except the problem of drugs which I will soon tolerate.

Thank you once again and do not relent in your mission. Please send me some of my pics. Bye!

Charles Antwi
Questions!

• Should we bother?

• How should we, as a community, address the global imbalance?

• Should we be making more of a commitment?

• Instead of developing more complex and expensive procedures for the industrialised world, should we be concentrating on extending the benefits of transplantation globally?

• How can we best be advocates for ESRF patents globally?

• How do we work to break the gridlock?
Acknowledgements

Jennie Jewitt-Harris
  Nick Inston
  Jo Adu
Tim Brown Adrian Shaw Simon Nicol Daman Mullhi Ayo Shonibare David Milford Peter Townsend Shazia Shabir
  Colin Hutchison Bethan Gough Marie Walters Paulette Williams-Jones Aisha McKenzie Graham Lipkin
Paul Cockwell Richard Moore Hany Riad Gordon Evans Fleur Kelly Dale Mitchell David Briggs Steven Mellor
  Simon Ball Laura Ludman Amanda Justice Richard Ball Gill Wyatt Chris Shearman Andy Comber Peter Unsworth
James Bell Fiona Alexander Mike Sharpe Gareth Duggan Kevin Durkin Rob Jones Ann Kenny Victoria Lush
Michael Mbambiko David Rowley Huntsworth Health Drummond Paris Julia Cumberlege Elsie Owusu Mike
Asemanu Quentin Cooper David Rosser Sulley Gariba Bernard Ribeiro Yinka Shonibare David Glaser Covidien
Sinopec-Addax Petroleum Foundation Barclays Ghana Ecobank Ghana Republic Bank Trinidad and Tobago
Novartis Roche Astellas Fotwtil Motors Nepalese Doctors Association Petrotrin Rotary Ghana Bank UK Sands
Tony Jewitt Kelly Richardson Jane Clarke Tina Evans James Trouton Aimee Jewitt-Harris Belfast Marathon Team
Gary Roche and the Cross Australia Cycling Team Jenny Dale Chris Eden Best Bar Naan Dakar TLC rally team
Anthony Frost Bob Devereux Michael Foreman Michael Morgan Jess Wilde Kazi Zawad