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BC KIDNEY DAYS



**Transcending Bollywood:
Renal Care and South Asian Populations**

Presenters

- Sarb Basra, Renal Social Worker Fraser Health
- Dr. Anurag Singh, Nephrologist, Northern Health
- Dr. Mohamud Karim, Nephrologist, Fraser Health
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Objectives

- Diversity of South Asian Populations
- Interface of Culture and Health
- Medical and Social Experiences across continuum of Care (CKD to EOL care)
- Discussions, Decisions, and Clinical Refocus
- Strengths, Successes, and Opportunities



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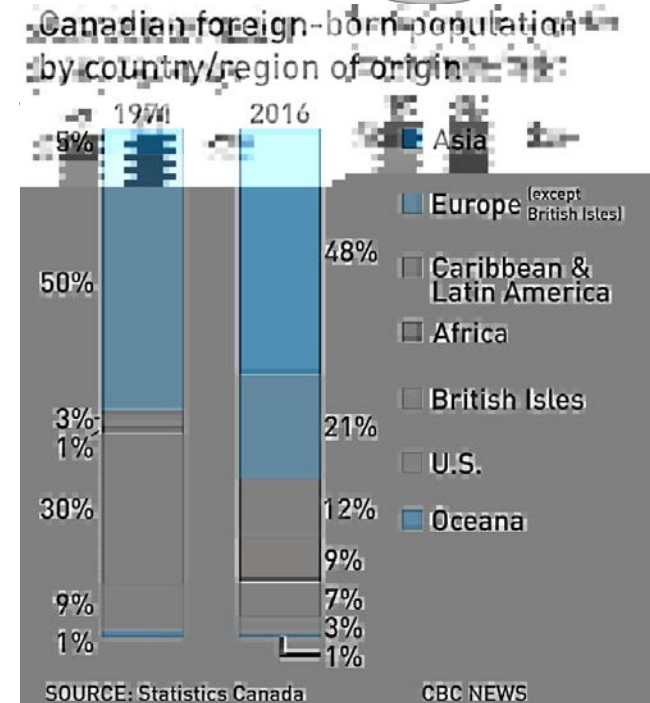
IN CINEMAS
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Who are South Asians?



- Migrants from India, Pakistan, Bangladesh, Sri Lanka, Nepal, Afghanistan, Bhutan and Maldives
- Secondary Immigrants from UK, East Africa, South Africa, Caribbean, Middle east, Fiji..
- Religions: Hindu, Sikh, Islam, Christians, Buddhist, Parsee, Jain, Humanist values
- Rising proportion SA of the population in big Canadian cities



Diversity within SA populations

- Immigration and Settlement Histories
- Education
- Languages
- Religion



Diversity within SA populations

- Culture
- Values and Beliefs
- Generational Change
- Rural vs. Urban

South Asian secularists counter religious power

DOUGLAS TODD Updated: May 11, 2013

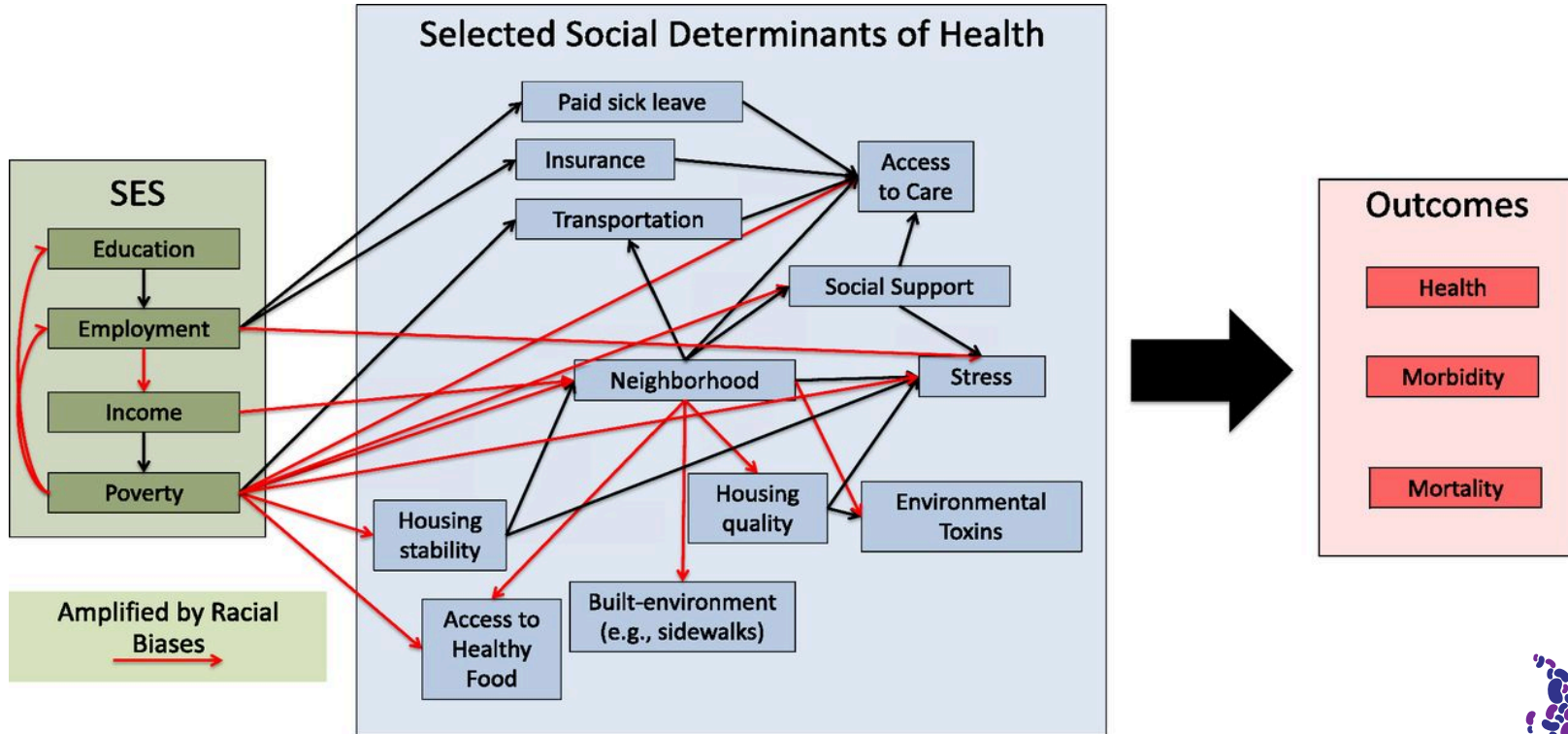


SHARE

All may not be what it appears when more than 150,000 people with South Asian roots flood the streets of Metro Vancouver for springtime's annual Vaisakhi parade - creating a sea of mobile altars, women in saris and men in orange turbans.



Why is this socially relevant?



Type 2 diabetes in migrant south Asians: mechanisms, mitigation, and management

*Naveed Sattar, *Jason M R Gill

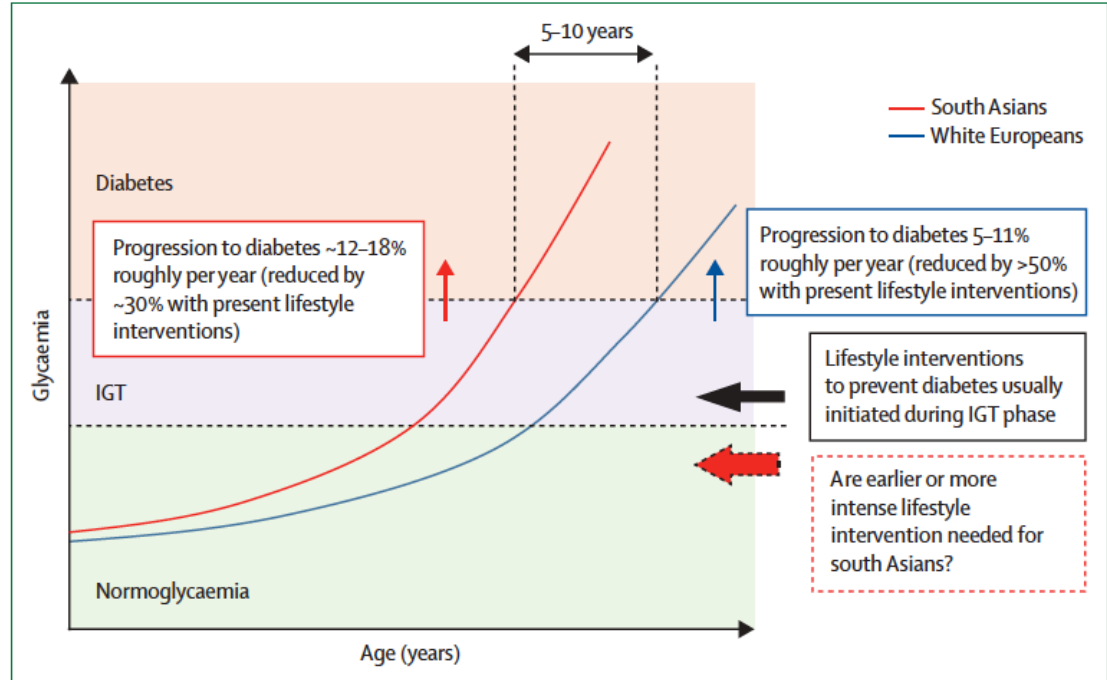


Figure 2: Glycaemia over the life course and the effect of lifestyle intervention on diabetes progression in south Asians and white Europeans

South Asians develop diabetes about 5–10 years earlier than do Europeans and have more rapid progression from impaired glucose tolerance to overt diabetes. IGT=impaired glucose tolerance.

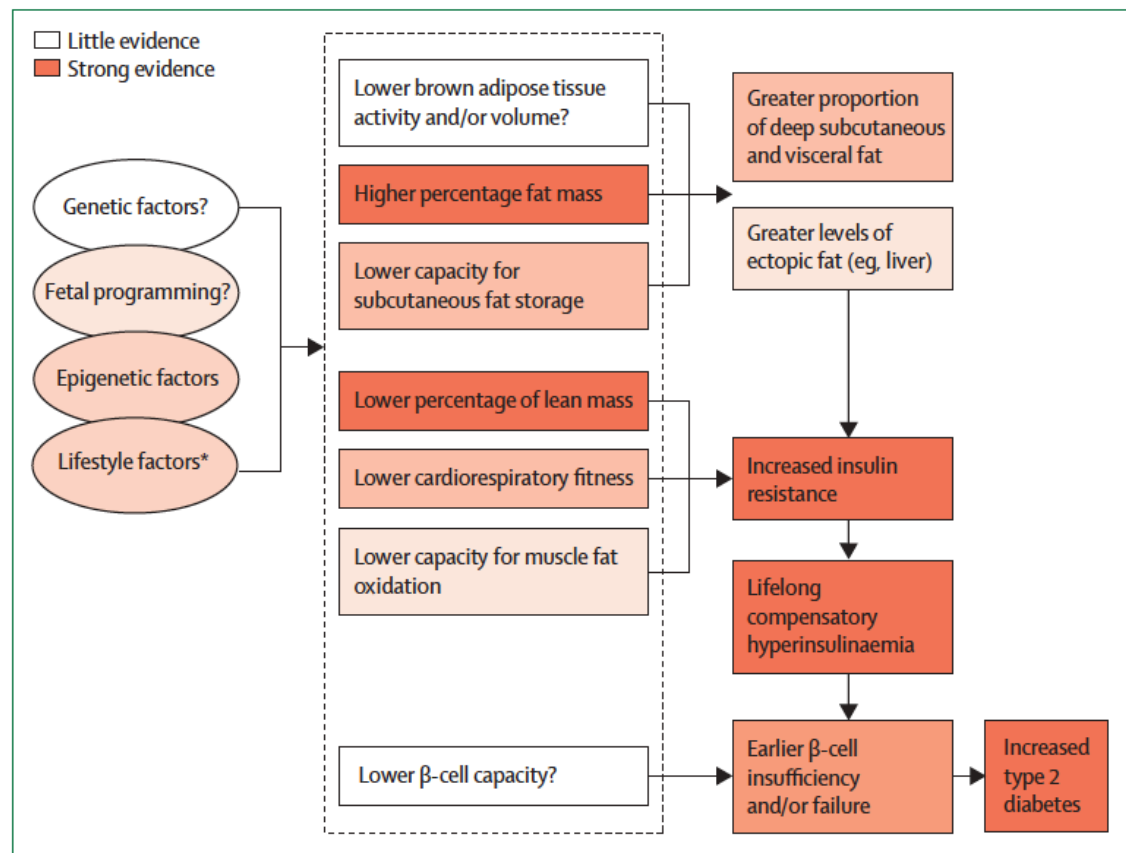


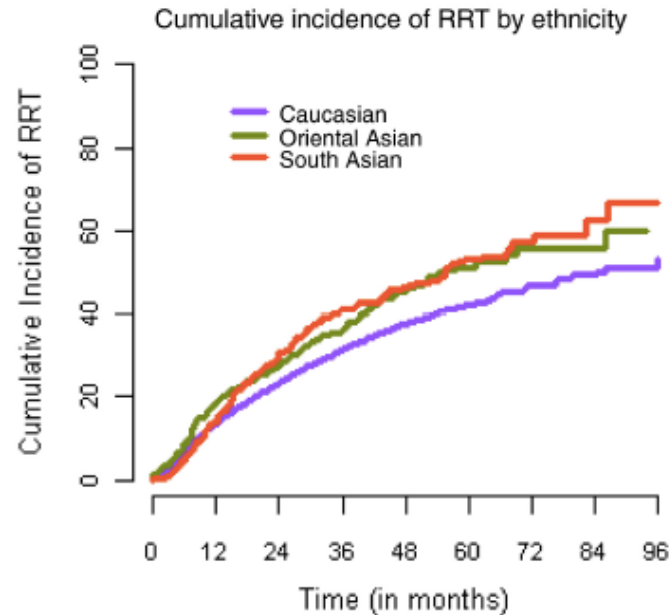
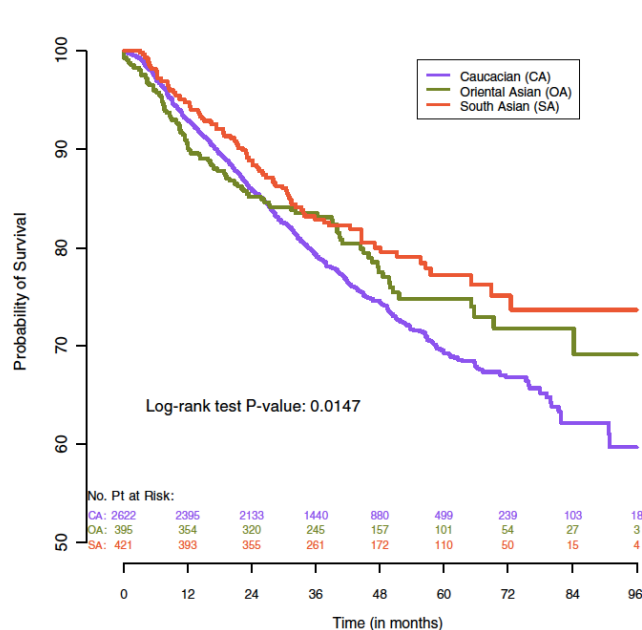
Figure 3: Hypothesised mechanisms for increased type 2 diabetes risk in south Asian people

A combination of innate and environmental factors interact to accelerate diabetes risk in south Asian people compared with individuals of white European descent, through the potential mechanisms outlined. Intensity of colour in the boxes suggests the amount of supporting evidence for each factor. *Such as urbanisation, diet, physical activity.

Differences in progression of CKD and mortality amongst Caucasian, Oriental Asian and South Asian CKD patients




Sean J. Barbour¹, Lee Er^{2,3}, Ognjenka Djurdjev^{2,3}, Mohamud Karim^{4,5} and Adeera Levin^{1,2,3,4}

Nephrol Dial Transplant (2010) 25: 3663–3672



Choice of Modality SA (UK data)

Total number of patients and their percentage on different modes of treatment at start of RRT, 3 months and 12 months by ethnicity ^a

Time	Mode	Caucasian	South Asians	Black	
Start RRT		N = 26 815	N = 2493	N = 1218	
	Haemodialysis	71.2	75.2	74.5	<i>P</i> < 0.0001
	Peritoneal dialysis	26.3	22.2	23.2	
	Transplant	2.5	2.6	2.3	
Day 90		N = 23 337	N = 2273	N = 1118	
	Haemodialysis	65.4	71.1	70.8	<i>P</i> < 0.0001
	Peritoneal dialysis	31.1	26.3	26.8	
	Transplant	3.5	2.6	2.4	
1 year		N = 17 905	N = 1771	N = 904	
	Haemodialysis	61.6	68.5	69.2	<i>P</i> < 0.0001
	Peritoneal dialysis	29.6	26.0	26.4	
	Transplant	8.8	5.5	4.4	

If not otherwise indicated, numbers are percentages of column totals.

Nephrology Dialysis Transplantation, Volume 24, Issue 12, December 2009, Pages 3774–3782, <https://doi.org/10.1093/ndt/gfp348>

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How do patients from South Asian backgrounds experience life on haemodialysis in the UK? A multicentre qualitative study

Shivani Sharma,¹ Madeline King,¹ Roisin Mooney,¹ Andrew Davenport,² Clara Day,³ Neill Duncan,⁴ Kirit Modi,⁵ Maria Da Silva-Gane,⁶ David Wellsted,⁷ Ken Farrington⁸



Social Deprivation in SA patients

Baseline socio-demographic and clinical characteristics by ethnic group ($n = 30\,561$)

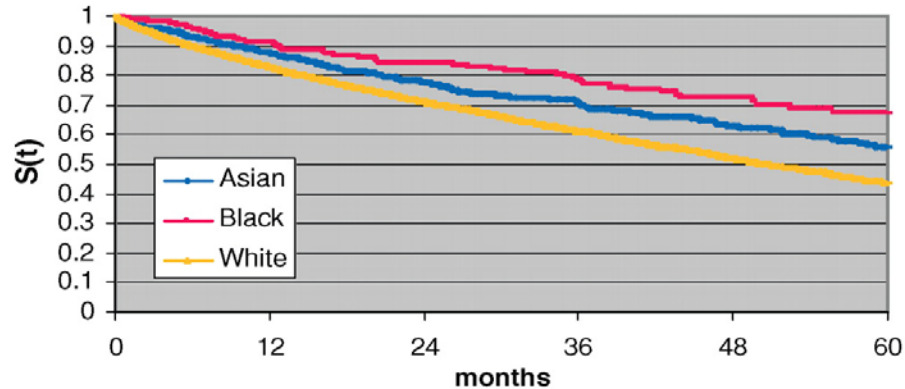
Caucasian ($N = 26\,848$) South Asian ($N = 2495$) Black ($N = 1218$)

Townsend deprivation index

% in population quintiles	$N = 26\,144$	$N = 2432$	$N = 1183$	
1 (least deprived)	19.4	6.5	4.2	
2	21.0	7.7	4.9	
3	20.1	13.7	9.3	
4	20.9	29.9	21.8	$P < 0.0001$
5 (most deprived)	18.6	42.3	59.8	

SA patients Survival on HD (UKRR data)

KM survival for non-diabetic patients from 90 days after starting RRT (as HD), age adjusted



Numbers alive over time by ethnic group

Month	0	6	12	24	36	48	60
South Asian	921	788	672	466	322	218	156
Black	455	391	321	216	150	88	48
White	11758	9597	7924	5413	3601	2299	1384
Total	13134	10776	8917	6095	4073	2605	1588

Transplantation

Access to Renal Transplantation for Minority Patients With ESRD in Canada

Karen E. Yeates, MD, Douglas E. Schaubel, PhD, Alan Cass, MD, PhD, Thomas D. Sequist, MD, and John Z. Ayanian, MD

American Journal of Kidney Diseases, Vol 44, No 6 (December), 2004: pp 1083-1089

1086

YEATES ET AL

Table 3. Covariate-Adjusted Cadaveric and Living Donor Transplantation RRs by Race

	White	Aboriginal	Black	South Asian	East Indian	Other
Cadaveric transplantations	Reference	0.56 (0.46-0.68)	0.64 (0.53-0.79)	0.86 (0.75-0.99)	0.74 (0.61-0.89)	0.78 (0.68-0.90)
Living transplantations	Reference	0.48 (0.35-0.67)	0.31 (0.19-0.48)	0.25 (0.17-0.38)	0.46 (0.31-0.66)	0.50 (0.38-0.66)
Total transplantations	Reference	0.54 (0.45-0.63)	0.55 (0.46-0.66)	0.69 (0.61-0.79)	0.66 (0.56-0.78)	0.71 (0.62-0.80)

NOTE. Values expressed as relative rate (95% confidence interval).

South Asian Ethnicity as a Risk Factor for Major Adverse Cardiovascular Events after Renal Transplantation

G. V. Ramesh Prasad,** Sai K. Vangala,* Samuel A. Silver,† Steven C.W. Wong,† Michael Huang,* Lindita Rapi,* Michelle M. Nash,* and Jeffrey S. Zaltzman**

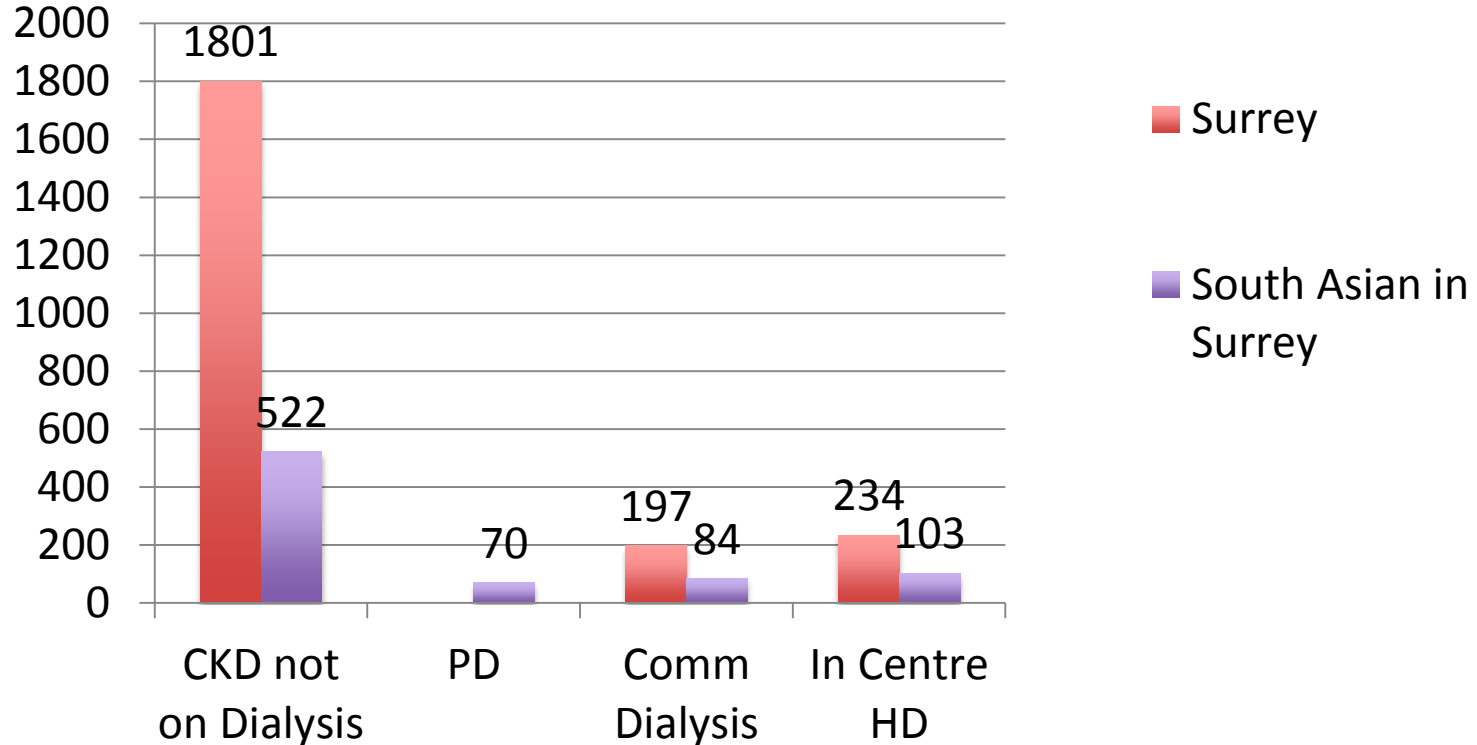
Summary

*R
D-

Table 4. Final multivariate Cox regression model for major cardiac events beyond 3 months after transplant

Variable	Parameter Estimate	SE	χ^2	P	Hazard Ratio	95% Hazard Ratio Confidence Limits	
						Lower	Upper
Age (per 10 years)	0.492	0.103	22.47	<0.0001	1.63	1.33	2.00
Gender (male)	0.789	0.308	6.54	0.010	2.20	1.20	4.03
SA ethnicity (<i>versus</i> white)	1.239	0.251	24.26	<0.0001	3.45	2.10	5.65
Diabetes	0.482	0.244	3.91	0.048	1.62	1.00	2.61
Systolic BP (per 10 mmHg)	0.216	0.063	11.82	0.0006	1.24	1.09	1.40
Previous cardiac disease	0.788	0.245	10.34	0.0013	2.20	1.36	3.55

SA patients in Surrey (Data from 2017)



Evidence in SA Renal patients

- Higher incidence of Diabetic Nephropathy
- Faster progression to ESKD
- Better Survival on Dialysis
- Lower uptake of Home or independent Dialysis
- Low rates of Cadaveric and LKD transplants
- Higher risk of CV complications after Tx
- Poor experience of Healthcare

What are our challenges?

Late presentation:

- New Immigrants, Awareness,
- Access,
- Psycho-social factors
- Racism



Adjustment to chronic disease:

- Engagement (language/culture/beliefs)
- Faster progression of disease
- Undiagnosed depression
- Family/community pressures



Participation in key decision making:

- Modality,
- Advanced Care Planning,
- Access to Cadaveric Tx (Blood Type matching)
- Living Donor Transplant

Patient experience of Renal Care SA (Semi-Structured Interviews)

- **Acceptable care:** *“When I said no to PD, the nurse started questioning why? OK I did not understand about PD first but, then she was so upset with me? PD was the best thing for me...” “I wish they let me talk to somebody in the same situation”*
- **On Dialysis modality:** *“I want my doctors to still tell me what is best option for me...How will I know?” I don’t understand why they put such a big decision on me, I have never made decisions”*
- **Lack of relationship with HCP:** *“I feel they brush me off sometimes...I see nurses giggling and talking to other people” Everyone is very nice but I feel I get treated differently...I have accepted this now” “Language matters but its not the only thing, I have English speaking friends”*
- **Communication:** *“I don’t always understand why they make changes to my medication?...They never stop, just add more...I just say OK because I don’t want to look stupid in front of my doctor!!”*
- **Cultural Sensitivity:** *“They don’t realize that I am just different...they think my cultural practices are backward and behind times.. One time a nurse told me that Arab people have more body pain...she told me its in my culture to complain of pain and that it was nothing serious” “One time a dietician said to me after my transplant, Oh I thought your people have to be vegetarian”*

What currently works? (from Literature)

- Role Models
- Family support model
- Community Engagement
- Cultural Sensitivity: Trust building and relationship with clinical care providers
- Social Media: You Tube, Social media to inform, educate communities
- Culturally Appropriate education

What should be our approach?

- Understand risk profile of SA patients
- Raise awareness of specific needs of SA patients
- Engage and involve SA patients and community leaders
- Collect and examine ethnicity Data
- Research on gaps, inequities in healthcare of SA patients

Discussion point:

Is it time to create a strategic framework to address “system level” factors to reduce ethnic and racial health disparities?



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Transcending Bollywood: ACP in South Asian Populations

What's the Problem ?

- ACP Principles rooted in Western Ethical models
 - Patient autonomy
 - Informed decision making
 - Truth Telling
 - Control over the dying process
 - Non Maleficence
- Heterogeneity across Cultures, generations and outlooks
- Language
- Cultural Norms
- Beliefs
- Limited Literature

Scant Literature

ORIGINAL RESEARCH PAPER

WILEY

Understanding advance care planning within the South Asian community

Patricia D. Biondo PhD¹ | Rashika Kalia MDCS² | Rooh-Afza Khan MD² |
Nadia Asghar MD, MDCS² | Cyrene Banerjee² | Debbie Boulton² |
Nancy Marlett PhD^{2,3} | Svetlana Shklarov MD, PhD, RSW^{2,3} |
Jessica E. Simon MB ChB, FRCPC^{1,4}

Health Expectations. 2017;20:911-919.

wileyonlinelibrary.com/journal/hex | 911

ETHICS

Ethical Issues in the Care of Vulnerable Chronic Kidney Disease Patients: The Elderly, Cognitively Impaired, and Those From Different Cultural Backgrounds

Sara N. Davison and Jean L. Holley

Numerous ethical issues such as the appropriate initiation or withdrawal of dialysis are inherent when one cares for patients with chronic kidney disease (CKD). Conflicts concerning decisions to withhold or withdraw dialysis often involve particularly vulnerable CKD patients such as the elderly, those with cognitive impairment, or those who come from different cultural backgrounds. Issues related to renal replacement therapy in vulnerable or special CKD populations will be explored within an ethical framework based on the principles of autonomy (self-determination), beneficence (to maximize good), nonmaleficence (to not cause harm), and justice (what is due or owed).

© 2008 by the National Kidney Foundation, Inc.

Index Words: Ethics; Chronic kidney disease; Decision making; Withdrawal from dialysis; Cross-cultural

BMJ

RESEARCH

Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study

Cross-Cultural Considerations in Promoting Advance Care Planning in Canada

Andrea Con, Ph.D
Research Investigator

CIHR Cross-Cultural Palliative NET



BC Cancer Agency

CARE & RESEARCH

An agency of the Provincial Health Services Authority

Biondo et al (Calgary)

- Objective:
 - Explore perspectives of SA community members towards ACP
 - Gain a better understanding of barriers and facilitators to participating in ACP from the perspective of individuals who identify themselves as SA
 - Determine ways in which members of that community would want to engage in ACP
- Design:
 - U of C PaCER program (Patient and Community Engagement)
 - Focus group interviews in Calgary - 57 self identified members of the SA community, followed by family interviews, then play back to community

Biondo et al - Design



FIGURE 1 Patient and Community Engagement Research methodological framework¹².

Sharing of stories

- Tell us about a time when a loved one was unable to make his/her own medical decisions.
- Was there anybody to help?
- What helped you get through this?
- What would you have liked to happen?
- Who would initiate or start a conversation about health plans in your family? How and when?

Focus Group Learnings

- Importance of Language
 - No literal translation of ACP
 - Difficult time understanding the meaning of ACP
 - Notion of planning ahead for future decision making foreign
 - Little shared historical or health service contexts familiar to participants to draw on
 - The importance of story telling
- Different understandings of ACP

Focus Group Learnings

- Power differentials
 - Oldest male
 - Naturally understood, and a cultural norm
 - Doctors authority
 - Community social status

Advance care planning

Language

"Old and sick"

ACP is associated with older, ill individuals who **require support from the family**

"Pulling the plug"

Difficult decisions (e.g. 'pulling the plug') are made by the family, but **spouse or oldest child has final say**

"Organ donation"

ACP relates to organ donation, with many different individual views **based on religion and beliefs**

"Doctors"

Doctors are viewed with **high regard and have authority** when making end-of-life care decisions

"Wealth/wills"

ACP is associated with wills: securing assets is understood to be a key component of **end-of-life care planning**

Themes from Interviews with families

- Introduction of foreign ideas
- Cultural Norms
 - “ When anyone in the family is faced with a difficult situation, everyone intuitively knows what their role is and what to do, and then right decisions are just made without planning ahead”
 - Planning as not being necessary because of close family ties, predefined roles within the family and trust in shared decision making as a family.

Avoidance

Cultural Norm and Protection

- Don't talk about that

We cannot speak of bad things or else we shall make them happen.

*We don't plan for death and it is not discussed in our family.
We are brought up in such a way that death is not discussed.*

We don't like to think that anything will happen to us and, therefore, fail to plan our health decisions.

- Avoidances as a cultural norm
- Avoidance as protection

God's will

Attitudes towards health-care planning tended to be fatalistic, believing that “one has to surrender to the higher wills of God”:

We don't plan about death and severe health conditions as we believe it is not in our control. Discussing and preparing for it puts us in control rather than God and the higher power.

God is the one who makes the final decision as to when it's time to go.

Themes more evident in SA

- Faith and coping
 - Illness and suffering viewed as gods will and a test of faith
 - Struggle to reconcile present suffering with the promise of a good afterlife
 - God's approval sought through positive thinking and actions
 - Despair and anger seen as spiritual deficits and emotional problems difficult to acknowledge openly

Too busy with life

Dealing with the many challenges associated with emigrating from South Asia to Canada emerged as a barrier to becoming informed about and participating in ACP. Finding affordable housing, securing employment, sometimes learning a new language and enrolling children in schools (among other pressures), all while adapting to a new culture, left little time for ACP:

There are so many challenges here, that sometimes I forget my name.

I wake up at 5 am and come home tired, have to cook, eat, etc.

How will we have this thought in our mind when we are having this life stress?

We are too busy to think about ACP.

Wealth vs Health

Planning for the end of life was more often associated with wealth distribution than with health-care planning. Participants were much more likely to have prepared a will and/or thought about the allocation of their assets than to have thought about their preferences for future health care:

What would happen if something happens to me, do we have to write a will? What will happen to my bank account?

Many people don't include their health decisions in their will, it's all about who gets what.

Wealth decisions are more important than health decisions.

Learnings from Community fora

- “Got it”
- Consolidation around sharing of experiences
- Community Capacity

Community Recommendations

- Recognize and build on community capacity
- Inform the community through forums and seminars
- Involve religious leaders in ACP discussions
- Include family members in conversations
- Respect cultural norms
 - An Asset and facilitator rather than a liability and barrier
- Encourage MDs to initiate discussions
- Translation of Material

Recommendations from BC Cancer

4.2.2.5. South Asian

1. South Asian people viewed terminal illness as “God’s wish”. For that reason, ACP was a foreign concept to them and they did not discuss or plan for their death:

You can't plan to die before it is God's time to take you.

You go to death as it happens and as the route unfolds in front of you.

2. South Asian key informants believed that anticipating one’s future and end, would bring it closer. Therefore in order to conduct ACP, culturally sensitive questions must be asked without telling them that ACP is being done.

3. Like the Chinese key informants, South Asian key informants reported that besides their spouse and children, the extended family played an important role in their EOL care.
4. Key informants said that at the EOL, South Asian people found prayer and connection with God very important.
5. Several of the interviewees reported that South Asian men would not name their spouse as their proxy. South Asian males would name a male relative or male friend whereas South Asian women always named their husband as their proxy.

- Avoidances as a cultural norm
- Avoidance as protection



Thank You

Discussion