IDENTIFYING DEMENTIA IN RURAL SOUTH AFRICA: A COLLABORATIVE VENTURE

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ABSTRACT : ADI 13-1337
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DEMENTIA SA

VISION:
A social conscience about dementia in South Africa, with respect and dignity for those affected.
DEMENTIA SA

- National organisation established in 2006 which is a registered NPO (non profit organisation) – PBO, VAT, affiliated to other international organisations ADI, IAGG, HelpAge International, IFA and part of the UN Working Group on Older Persons
- Affiliated and actively involved with other SA bodies including tertiary orgs
- Services available to all: families, people with dementia, carers, professionals and facilities caring for people living with dementia
Dementia SA

- **Core services are:**
  - **National Helpline** (0860 MEMORY / 0860 636 679)
  - **Support & Counselling** – family, groups, F2F, telephonic
  - **Education** – schools, professional groups (U3A, Rotary)
  - **Awareness** – communities, Faith-based groups, web-based
  - **Resources** – books for sale
  - **Advice & Info sheets** – hard copy & web-based – 5 languages
  - **Training** – with accreditation – two and soon three languages
  - **Advocacy** – Older Persons Act (13) 2006, SA Law Reform Comm., UN Working Group on Older Persons, DNAN campaign
  - **Research** – collaborative ventures – which forms the basis of this presentation
South Africa

- 9 provinces
- 11 official languages
- Total population 50 million
- Persons over 65
- 8 Geriatricians in SA
  - 5 in W/Cape
  - 2 in Gauteng
  - 1 in KZN
- Health budget
- Allocation to mental health
- Eastern Cape is the most dysfunctional province in health care provision & service
Facts:
In 2012 approx 58% of the 36million pwd worldwide are living in LAMIC – set to rise to 71% by 2050.

Projected increases for sub-Saharan Africa are between 70-90% (1) Alz Assoc 2012. Alz Disease Facts and Figures, Alz & Dementia, (8) 2.

10/66 Dementia Research Group in India, China, Southeast Asia, Latin America and Africa – recorded prevalence for dementia as 3.9% for persons over 60 years (2) Prince M, Acosta D, Chui H et al. Dementia diagnosis in developing countries: a cross-cultural validation study. Lancet 2003: 361 (9361):909-917

In SA extremely limited research conducted. Small Free State study investigated dementia in an urban black community – prevalence of 6% found.

According to WHO 2012 dementia report, JIV-associated dementia (HAD) = 15-30% in untreated populations, presenting neurocognitive impairments, emotional disturbances & motor dysfunction – linked to HAART (highly active antiretroviral therapy) – prevalence is 10% with annual incidence of 1%.
DEMENTIA NEEDS ACTION NOW!

WHY:
- Mental health incl. Dementia & care of OP (8 geriatricians) not recognised as priorities in SA system – limited services, no proper care, no skills development
- Dementia - Neurological or Psychiatric??
- Shrouded in myth and stigma
- Language & appropriateness of assessment tools?
- Associated in indigenous culture to be the work of ancestors
- Linked to witchcraft
- Particularly in WOMEN & “darkness” of complexion
- Killed – and many times brutally raped over a number of years
- Abuse, vulnerability and neglect

No epidemiological studies +
No figures / prevalence

= NO NEED = NO ACTION NO FUNDING
COLLABORATIVE STUDY: PILOT PHASE

Dementia SA contacted UCT who got together a specialist team
Principal investigator: Dr Celeste de Jager
Co-investigators: Profs. Marc Combrinck & John Joska
Team of six others – all leaders in their fields incl. Prof Martin Prince of 10/66
“Dementia Prevalence, assessments tools and care needs in LAMIC – isiXhosa speaking elders in rural SA

1. Essential to test the Isi-Xhosa translations of the assessment tools
2. Collaborated with partner org – Ikamva Labantu – Senior clubs in communities of Western Cape where 100 seniors participated
3. Challenges identified – transport and time
4. Changed so that social worker went to groups
5. Parallel to this, DSA ran awareness talks to other members of the community about dementia and memory screening
Ikamva Labantu: Khayelitsha & Gugulethu Cape Town
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Madwaleni, Eastern Cape (in the former Transkei) Sample group will come from this area – very rural & remote. Impoverished, high unemployment, high rate of HIV infections. One hospital and 10 community clinics. Collaborating with an NGO that has provided services for many years – essential when working in rural communities, trust and buy-in “Health in Every Hut” Lapbook with customised software which will log GPS co-ordinates of every hut in entire geographical area & data on 6 health care domains and other vital info. e.g. age etc. DSA involved in the second phase of project – we will train Community Field Worker to do the data collection with questions pertaining to the study on the lapbook
Outcomes:
- Prevalence and figures!
- Advocacy! Making dementia care a public health priority in South Africa
- Advocate for better policies and a National Dementia Care Strategy
- Better understanding of dementia – screening, care & management of a pwd
- Educate and re-educate on issues like abuse of older persons
- Expose the vulnerability and marginalisation of OP and those with cognitive impairment
- Capacity building
- Skills development on all levels including the use of standardised screening measures
- Investigate associated health problems including HIV and nutritional status
- Development of a model that can be rolled out into other rural areas of South Africa
THANK YOU!
DANKIE!
‘NKOSI!