

TRAUMATIC BRAIN INJURIES IN SOUTH AFRICA – A REVIEW

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1. The aim of this document is to consolidate and summarize research results on brain injuries in South Africa. It is by no means conclusive and is not an academic document. The Brain Injury Group (BIG) is planning projects to better the lives of the brain-injured community. To obtain this goal, BIG needs to know how many people in South Africa are living with a brain-injury, their demographic profile and their social-socio-economic, vocational and employment needs.

DEFINITION

2. BIG defines an acquired brain-injury as the acute impairment of normal brain function that causes altered cognitive functioning. This includes open or closed head injury (traumatic brain injury or TBI; neurological incidents such as strokes, (because of brain hemorrhage or thrombosis) and hypoxia.

3. People that live with disabilities that are caused by a brain-injury (focal or diffused) can become members of BIG. This definition includes changes in motor ability, arousal, personality, social style and thinking capability.

4. BIG recognises that medical conditions such as Multiple Sclerosis, Alzheimer's, Parkinson's Disease and dementia, caused by substance abuse, bulimia and full blown AIDS also causes an altered mental state, but are excluded in this definition of a traumatic brain injury.

5. The brain is a complex organ, and a person that is diagnosed with brain injury does not experience all physical and mental impairments associated with such an injury. Depending on where the brain insult occurred, the person demonstrates a altered mental state such as emotional disturbances and/or personality changes in addition to physical and/or mental disabilities. This differentiates the brain-injured person from the broader spectrum of disabled persons. Each brain-injured person's disability is unique and should be treated as such

PREVALENCE OF BRAIN-INJURIES

6. South African Population census of 2001 was used for the purpose of this document, as reported in the document based on this census entitled *Prevalence of disability in South Africa*⁵. The latest Statistics South Africa mid-term report⁴ (released on 01 August 2006) indicated a population of 47 million in South Africa.

7. South African Population:

- a. Forty percent of South Africa's population lives in Kwa-Zulu Natal and Gauteng and it is therefore assumed that the prevalence of brain-injuries would be the highest in these two provinces. This figure is also consistent with the *Community Agency for Social Enquiry (C A S E)* survey for the Department of Health undertaken in 1998 by *Schneider et al*³. The highest proportion of disabled people live in the Eastern Cape, Kwa-Zulu Natal and Gauteng (C A S E study).
- b. The document on *Prevalence of disability in South Africa*⁵ for the 2001 census indicates that 5 % out of a population of 44, 8 million (2 240 000 people) are disabled.

- i. The question asked in this survey was “*does the person have any serious disability that prevents his/her full participation in life activities (page 8)*” in terms of sight, hearing, communication, physical, intellectual and emotional disabilities.
- ii. It should be noted that in terms of these disabilities a brain-injured person may/will answer “yes” to more than one of these factors. Brain-injured people will, most probably demonstrate **intellectual** and **emotional** disabilities. In addition, depending where the brain insult occurred they might demonstrate sight, hearing, communication and physical disabilities. BIG would urge Statistics South Africa to add a category for brain-injuries in follow-up surveys.

8. Epidemiology of Traumatic Brain Injury in Johannesburg (Nell, Ormond-Brown 1991²):

- a. Research done by *Nell and Ormond-Brown (1991)* reported an average of 316 per 100 000 incidents of brain-injuries per year.
- b. If the above-mentioned figure is used, an estimated 141 568 (out of a population of 44,8 million⁵) incidents are reported.
- c. It is important to note that the number of incidents does not demonstrate the number of people living with brain-injuries.

DEMOGRAPHIC PROFILE

9. The *Nell and Ormond-Brown (1991)*² study was used to compile the demographic profile. Note that this study was done in Johannesburg only, and therefore the *Schneider et al (1999 C A S E)*³ study was used, to add to the *Nell and Ormond-Brown* study. It is acknowledged that this study did not focus on brain-injuries, but on disability in general.

- a. **African and coloured men** are the demographic group of people most at risk to brain-injuries. This trend is confirmed with the *C A S E study* (page 15) that “*Africans have a significantly higher prevalence rate than other races*”. It is also notable that all sources that were consulted, indicated African men as the main demographic group of disabled people.
- b. In terms of age distribution the African males in the age group **25 – 44 years** were the most at risk to suffer brain-injuries. This demographic group would then also indicate the highest number of brain-injuries. The White and Coloured population were mostly at risk between the ages of 15 – 25 years. The Indian population group indicated a very low risk.
- c. In the *Nell and Ormond-Brown* study, Males with brain-injuries outnumbered the Females with brain-injuries 5:1.
- d. In terms of **fatal brain-injuries** the White population group indicated the highest rate of fatalities followed by Africans, Asians and Coloureds.
- e. *Schneider et al (1999)*³ also indicated that “*African respondents who live in urban areas are more likely to be disabled than their rural counterparts*”.

- f. In the Nell and Ormond-Brown study, personal violence with blunt objects and unarmed brawls played a role in the brain-injury as did Alcohol. Motor vehicle accidents accounted for nearly 70 % of White non-fatal brain-injuries, 66,6,% among Asians, 48,8 % among the Coloured population and only 26,6 % among the African population.
- g. It should be noted that this study was done in 1991 and the political field changed dramatically since 1994. Democracy in South Africa should have influenced this picture as it is assumed that more people should have access to health services and that it would influence the non-fatal brain-injury statistics.

NEEDS

10. The needs of people living with brain-injuries do not differ from disabled people in general. They want to be accepted, treated equally in terms of work opportunities, have access to services and to be considered active members of society.

11. The brain injured survivor and his/her family often faces financial difficulties because of increased medical expenses and loss of income. The person's financial status may change. The brain-injured person's financial income often depends on a disability grant from government or payment from the Road Accident Fund. The disability results in the inability to return to either a previous work place and/or other employment. In many cases new vocational skills may have to be developed, this is often found to be difficult due to the presence of the brain injury.

12. In *Schneider et al (1999)*³ the "*intolerance of society in which we live towards people with disabilities*" is highlighted. They experience difficulties such as access to social welfare services, education, transport and most of all employment. Brain-injury can often lead to poverty because of loss of income as well as additional costs incurred because of the injury. This has an impact on the number and quality of services they can buy. A simple example is transport. A brain-injured person, who cannot drive, also doesn't have sufficient financial resources to buy public transport services. *Schneider et al (1999)*³ stated that "*only 6 % of people with three or more disabilities are employed and 87 % are economically inactive*". People with a brain injury often have more than one disability.

CHALLENGES

13. BIG needs to determine a conclusive prevalence rate of brain-injured people in South-Africa. The mortality rate and the recovery rate as a percentage of the incident rate needs to be determined. This data will enable BIG to focus support functions more effectively in terms of socio-economic, rehabilitation and vocational needs.

14. It would be beneficial to determine how many brain-injured people receive disability grants from the Department of Social Development. In order to successfully re-integrate brain-injured people into society, they need to live economically sound lives. This means that they need to work and financially sustain themselves.

15. At the moment, no distinction between accidents and medical causes for the brain-injury are made and should be investigated.

16. Should the assumption of 141 000 be correct, the annual rate of new cases and the mortality rate needs to be determined. It is mentioned that, for every one (1) fatal motor-vehicle accident; four (4) people suffer from brain-injuries. The Department of

Transport recorded 7 342 fatalities in 1999 ¹ (1999 is used to compare this figure with that of the C A S E study ³). It is assumed that 29 368 new cases of brain-injuries occurred in 1999. This figure cannot simply be added to the 141 000, as the mortality rate is not determined and, most importantly, causes such as medical and violence for brain-injuries are not included in this total.

CONCLUSION

17. Since the inception of BIG in 2000, the organisation has supported this community on a social and emotional level. It is now necessary to develop the brain-injured person with vocational and other skills that will enable him/her to lead a meaningful, productive and financially sound life.

18. With the publications that were reviewed, no conclusive prevalence of brain-injuries could be established. The only brain-injury focussed study that was reviewed, was that of *Nell and Ormond-Brown (1991)* ²; and that data was collected pre-1994. The study was only done in Johannesburg.

19. With that in mind, the picture of a brain-injured person is often that of a Black male, between the ages of 25 and 44, living in an urban area. He is economically inactive, and has the desire to work or at least lead a fulfilling life. He has a need for social welfare services, accessible buildings and adequate public transport. He also has the need to be treated as any person without a disability.

REFERENCES

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