

CHAPTER 5

SUMMARY, CONCLUSIONS,

RECOMMENDATIONS AND LIMITATIONS OF THE STUDY.

5.1. INTRODUCTION

This chapter presents the summary, limitations, conclusions and recommendations of the study based on the data analysed in chapter 4.

5.2. SUMMARY

A review of the literature suggests that the assessment of needs in terms of the expressed needs of individuals who require health services in the community is one of the most neglected areas in health care services. This could be due to a lack of sensitivity to those needs.

Being insensitive to the expressed needs of the mentally retarded was identified as being one of the problems in the community of District 22 (sub-district 222), KwaZulu – Natal. The major aim of this research was to assess the needs of persons with mental retardation and the services and facilities available in the community of District 22 (sub-district 222). KwaZulu - Natal. The physical, spiritual, financial, psychological, social, educational, spiritual and cultural needs were assessed together with the support systems and the community resources that were available for meeting the needs of the mentally retarded in the community of District 22 (sub-district 222), KwaZulu – Natal.

Information on needs assessment, as was portrayed in the literature, was outlined in chapter 2. In terms of the needs and information associated with the mentally retarded, the theory of wholism was described. A needs assessment done in other developed and underdeveloped countries was described and compared with the situation in the Republic of South Africa.

In chapter 3, a detailed research methodology was outlined. The study design and the sample population used in the study were described. The sampling technique used was the purposive sampling of persons who were mentally retarded, collecting their disability grants at the designated pay points in the community of District 22 (sub-district 222), KwaZulu-Natal.

A quantitative, exploratory, descriptive design was used in this study because it was viewed to be the most appropriate for this research. Data was collected by using an interview schedule that focused on the health needs of the mentally retarded as outlined in the research objectives. The interview schedule was considered to be an appropriate instrument for obtaining data relevant to problem statement, the objectives and the research questions of this study.

In chapter 4, findings of the research were presented from the statistical analysis done after the completion of the interview schedule by the respondents, who were mostly the parents/guardian of the mentally retarded, through the main frame computer system at the Department of Health, KwaZulu-Natal, using the "Epi info version 6"

This chapter will present the summary of the research, conclusions, recommendations,

limited and challenges to the health care providers. The summary based on the results of the research will be discussed according to the research objectives presented in chapter 1 of this dissertation.

5.3 CONCLUSIONS

The conclusions are based on the findings of the study and discussed in accordance with the conceptual framework used and the research questions guiding this investigation.

5.3.1. Section A: Demographic data

- All the respondents could speak Zulu.
- There were more males (55%) than females (44,9%) who took part in the research.
- The majority of the respondent's fell equally into the age category of 0 – 20 years and 21 – 40 years of age.
- The majority of the respondents (99.4%) were never married due to their dependence on others to take care of them.
- The respondents were affiliated to different churches. There were some respondents also who were not affiliated to any church (4,19%).
- All the respondents were South African citizens and lived either in town, villages, farms or townships.

- The majority of the respondents had no education at all (60,4%).
- The majority of the mentally retarded had no dependents (95,2%) due to the fact that they themselves were dependent on families, relatives and friends to take care of them.
- The majority of the respondents indicated that their income sources were from disability grants (61%) and the majority of the respondents fell within the income category of R501 – R1000 per month (65,8%). Disability grants were the only income in most of the households. Therefore the rest of the family members relied on the disability grants of the mentally retarded person.
- The majority of the respondents (94,6%) were unemployed, had no previous occupation (94,0%) had no previous employers (94,0%) and were homebound (95,8%).
- Approximately ninety six percent (95,8%) of the respondents used public transport.

5. 3. 2 Section B: Needs of the mentally retarded

5.3.2.1 Physical needs

- The findings of this research indicated that besides being mentally retarded, there were other health problems that prevented the mentally retarded from having an excellent health status such as epilepsy, recurrent chest infections and flu symptoms. They therefore required medical care which was ranked the second

highest in the prioritization of physical needs from the respondents point of view.

- Their skills on feeding, bathing, dressing, oral hygiene, differed from independent to fully dependant individuals depending on their level of intellectual functioning.
- The results of the study also indicated that approximately fifty percent (49.7%) were continent and had complete control of their bowel and urinary systems. The mentally retarded who did not have complete control of their bowel and urinary systems need to be put on toilet training programmes.
- Elimination is considered to be a basic and strong need, as it is a physiological need. If these needs are not met, then they override all other needs.

5.3.2.2 Social needs

The findings of this research indicated that the majority of the respondents needed social skills development and opportunities for socializing. This is in line with Jordaan & Jordaan (1990:655), who indicate that the need for love is generally characterized by striving to establish and maintain loving relationships with other people and involves both giving and receiving love.

- Approximately eighty percent (80,2%) of the respondents were unable to read and write which is in line with the findings of their level of education where (60,4%) had no education at all. Most of the respondents did not find this to be a problem,

as they loved having their mentally retarded family member at home. This was also due to the fact that there were no schools available for the mentally retarded in the community of District 22 (sub-district 222), KwaZulu-Natal.

- Most of the respondents, approximately ninety six percent (95,8%) were home bound. This could be due to the fact that there were no job opportunities for the mentally retarded and only a few, approximately six percent (5,9%) were employed previously as laborers.
- In addition to their mental retardation that interfered with social relationships, the respondents had to also contend with the stigma attached to mental retardation (41,9%). The majority of the respondents, approximately fifty eight percent (58,1%) did not find stigma to be a problem of daily living because they received love and affection from family and friends and could also express love and affection to others.
- The services and facilities needed by the mentally retarded, to be taught skills such as reading, writing, needle/wood work, are not available. These services and facilities should be made available so that the mentally retarded can be taught skills and learn to function more independently, thereby boosting their self esteem.

5.3.2.3 Emotional needs

- Everybody needs friendship, including the mentally retarded. The barrier to meet

this need could be aggravated by their inability to communicate and have meaningful conversation and also behavior problems associated with the inability to cope with stress.

5.3.2.4 Psychological needs

- The majority of the mentally retarded (59,8%) people's memory and comprehension needed reminding/repeating or support or interpretation so as to ensure that they understand properly.
- The mentally retarded therefore, would need relatives or guardians who would continuously remind them. The family members or guardians, need to be told and encouraged to do so.
- There were others (13,1%) who could not comprehend anything and therefore could not fulfill any instructions given to them.
- The mentally retarded who cannot fulfill any instructions also need stimulation as there are some who can comprehend, but cannot fulfill any instructions given to them, such as the mildly and moderately mentally retarded who are spastic. They will however still need to be spoken to, and encouraged when things are being done for them, such as feeding and bathing.

5.3.2.5 *Cultural needs*

- Most of the mentally retarded (70,1%) were satisfied with family and traditional activities they participated in.
- Even though there were traditional healers (100%) in their communities, only (3,0%) indicated that they consulted the traditional healer when they were sick. The caregivers had accepted that having a mentally retarded person was a gift from god/ancestors and the traditional healers could not make them better.
- This is in line with Giger & Davidhizar (1995:3), who state that for many, culture determines the causes for illness such as mental retardation.
- Smeltzer and Bare (2000: 103) states that culture involves “learned and transmitted knowledge about values, beliefs, rules of behaviour, and lifestyle practices that guide a designated group in their thinking and actions in patterned ways. Therefore the mentally retarded gain knowledge from their family members or guardians about cultural practices.

5.3.2.6 *Spiritual needs*

- The majority of the respondents (95,8%) were affiliated to various churches. Only a minority (4,19%) was not affiliated to a church.
- It is clear from this study that religion played an important and supportive role in meeting the needs of the mentally retarded, their families, relatives/guardian’s needs to relate to a god or a philosophical world-view as discussed in the

literature review, allowing them to place themselves and their lives within a larger context.

Apparently these needs could be met in the areas that were investigated.

5.3.2.7 Financial needs

- The main source of income, for 61 % of the respondents, both male and female was from disability grants. The disability grant was from government sources
- The majority of the respondents (65,8%) fell into the income category of (R501 – R1000 per month, and again mainly from the governments disability/child maintenance grant.
- Formal employment opportunities for the mentally retarded were non-existent as (94,6%) were unemployed.
- Persons with mental retardation have no or poor skills for employment due to their low intellectual functioning, behavior problems and lack of vocational training.
- There are no services/facilities in the community for sheltered employment for the mentally retarded who could be taught skills required for sheltered employment, which could help generate an extra income from the sale of their completed work, and would help boost their self image and morale. These needs can be met if the human resources and services/facilities are made available to the mentally retarded in the community of District 22 (sub-district 222), KwaZulu-Natal.

5.3.2.8 Educational needs

- Most of the respondents (97,0%) indicated a need for vocational training and employment opportunities, which would promote the normalization of the mentally retarded people.
- With regard to educational qualifications approximately 35 percent (35,3%) of the mentally retarded fell into the category of grade 1-5. The majority, 60,4% had no education at all, therefore limiting their chances of gainful employment and of meaningful recreational activities.
- The mentally retarded, therefore need formal and informal education so that they can be able to live a much more productive life.

5.3.2.9 Support systems

- The mentally retarded found it difficult to support themselves as they were mostly dependent on family members for care and support (see table 4.7).
- The mentally retarded received support from family members, friends and professional teams.
- The majority of the mentally retarded shared the same accommodation as the rest of the family members. They were therefore regarded as valuable members of the family as some of them were helpful in doing daily chores such as housekeeping and grazing the herd in the fields.

- The mentally retarded therefore need their family members, friends, guardians and professionals as support systems, at all times so as not to feel left out and to try to lead a “normal” life as best as possible.

5.3.2.10 *Resources available*

- The results of this study indicated that the majority of the mentally retarded relied on public transport when visiting the hospital or clinic for treatment.
- There were no services for alcohol and drug abuse. The study indicated that approximately five percent (4,19%; n = 7) of the mentally retarded abused alcohol and drugs. This problem should justify further investigation, as it was discovered while collecting data, at the pay points, alcohol was sold freely to anybody who wanted it, ranging from spirits, beers and Zulu beer.
- There were no educational/vocational training facilities in the community.
- There were no employment programmes and training centers for the mentally retarded.
- The mentally retarded therefore need services for alcohol and drug abuse, vocational training opportunities, employment programmes and training centers.

5.4 **RECOMMENDATIONS**

The results of the study support the following recommendations based on the conclusions and findings of this study.

5.4.1 Physical needs

- As there are no services and facilities that provide therapeutic programmes for people with mental retardation, therapeutic programmes are recommended that show a balance between stimulation, support and protection. These programmes could teach them self-help skills such as personal hygiene, oral hygiene, grooming, dressing and also toilet training, so as to make them more independent, thereby boosting their self esteem.
- The mentally retarded also had physical ailments such as recurrent chest infections, which needed medical treatment. For this reason priority should be given when medical resources are allocated.
- It is recommended that primary health care be made more assessable and available more frequently to the mentally retarded in the community of District 22 (sub-district 222), KwaZulu-Natal, as opposed to once or twice a month as is the case in some communities.

5.4.2 Social needs

- Social support is vital for the mentally retarded as it provides them with friendship, encouragement and practical advice. There are no services and facilities in the community to help with the social needs of the mentally retarded, such as vocational counseling, training and education. Community resources to develop a more active social life, vocational counseling and support to family

members and the mentally retarded are highly recommended, so that the person's life-style can improve. This would also help reduce the stigma that is attached to mental retardation.

5.4.3 Emotional needs

- The care of the mentally retarded demands and needs group effort and needs the participation of all available multi-disciplinary team members.
- The mentally retarded with behaviour problems, such as aggression, need to be put onto behaviour modification programmes. This can become a success if the parents/relatives/guardians are taught these skills and have the resources and the facilities for the programmes.
- The present primary health care systems in the communities cannot provide adequately for the mentally retarded, due to scarce human resources resulting in primary health care being available in some communities, once or twice a month.
- Good and proper rehabilitation, treatment of acute episodes of epilepsy, behavior problems and medical conditions, appropriate medication, maintaining of nutrition and general health, provision for safe and proper accommodation and provision of crisis support need to be considered and recommended. It is also recommended that family members, relatives and community members be contacted when planning for their future care, as they were actively involved with the mentally retarded and can thus give first hand information.

5.4.4 Psychological needs

- An effort should be made towards organizing awareness campaigns and mental health promotions and making rehabilitation services available to the mentally retarded people and families, relatives or guardians as these are not available in the community of District 22 (sub-district 222), KwaZulu-Natal.

- The psychosocial rehabilitation programme is of utmost importance to people with mental retardation as it is aimed at addressing physical, psychological, emotional, social and spiritual needs with the following objectives in mind:
 - Improved mental state, for example, an improvement in the number of unacceptable and inappropriate behaviours.

 - Improved life skills focusing on the self-image, communication, relationships, motivation as well as caring for and teaching in basic human skills such as personal appearance and hygiene, nutrition and an ability to prepare meals.

 - Improved vocational adjustment, focusing on motivation and preparation for employment

As these are not available for the mentally handicapped in the community, these services are recommended so that the mentally retarded can live a productive life as far as possible.

5.4.5 Spiritual needs

Support from significant others is vital in the care of the mentally retarded.

Religious leaders in the community should play a vital role, by being supportive to the family and the people with mental retardation.

5.4.6 Cultural needs

- Even though most of the respondents indicated that they were satisfied with family and traditional activities they participated in, it could be possible that the mentally retarded are not consulted, and may be forced into participating in cultural activities. Some of the mentally retarded may be so low functioning that they may not be able to comprehend the need or reasons for such cultural activities.
- Ethnotherapy (family therapy and ethnicity) need to be explored by the nurses, working with the mentally retarded depending with the level of mental retardation and behavior of the client. The family unit of various ethnic groups may be the cornerstone to individual behavior. Restoring a greater sense of identity may require resolutions of cultural conflicts within the family, between the family and the outside community, or in the larger society in which the following exists (Beck, Rawlins & Williams 1988: 196).

5.5 RECOMMENDATIONS FOR FURTHER RESEARCH

- To determine the reason for the shortage of qualified psychiatric nurses, other health care professionals and paraprofessionals, who work with the mentally retarded.
- The curriculum for the training of psychiatric care to nurses and medical students should be reviewed to increase the emphasis on community psychiatric care.
- To determine how community care can be expanded, and day centers and other community services can be developed to include the mentally retarded.
- To determine how primary health care can be expanded to attain the needs of the mentally retarded.
- To determine to what extent policy principles are translated into the effective delivery of mental health services.
- Departments of Health and Welfare should get together and devise a programme of care for people inhabiting the rural areas, such as the Health Department having a mobile clinic crew available at the pay points to help with assessments, mental health promotions and basic care of individuals.

5.6 LIMITATIONS

During the course of the research, there were certain limitations that were identified. Apart from the limitations which call for further research, the most

prominent were the following:

- There was no information on the assessed needs of persons with mental retardation in South Africa, therefore many overseas literature was used to compile the interview schedule.
- The literature on mental retardation was outdated.
- The research focused only on the respondents who were present at the pay points.
- People who were not present at the pay points were not included in the research. More information might have been obtained from those excluded.
- Despite the pre-testing of the instrument, some of the questions were still not easily understood, and had to be explained over and over in simple terms.
- The interview schedule was too long as respondents displayed impatience as they needed to collect their grants.
- The research proved to be very broad in scope. The community resources and support systems could be studied in more depth separately.
- It is doubtful whether the 5-point (*never, hardly ever, sometimes, often and almost all the time*) scale yielded more information than did the 3-point (*never, sometimes and almost all the time*) scale would have done. The use of open ended questions could have elicited more information.

5.7 A CHALLENGE FOR US ALL

The psychiatric and scientific fields frankly admit that it knows comparatively little about the causes of mental retardation, as some of the causes are unknown. There is no cure for mental retardation and some of them have to take high dosages of medication to control other issues such as epilepsy and behavior problems. This in turn requires close monitoring of the patient and regular blood pressure and blood level checks.

The system of care for the mentally retarded is poor and the community at large openly appears to be afraid of the mentally retarded and also categorize them with the mentally ill. Health professionals are obliged to educate the community about mental retardation.

More and better research is urgently needed on mental retardation. Mental health services requires funds so as to enlighten the public to understand mental retardation through education and the provision of resources to counter the negative images of mental retardation persisting in many societies.

A concerted programme of public education and enhanced awareness, coupled with increases of resources for clinical research and practical care will suffice to guarantee the care of the mentally retarded in the community.

5.8 CONCLUSION

A strong commitment must be made to provide for a hopeful outcome and improved quality of life for this, vulnerable and neglected group of people who are required to continue living in the communities. The health care professionals, with the forward move with health reform need to play urgent attention to the needs, the services and facilities available in the community with no or limited resources.