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Evaluation of the implementation of the model for empowerment of a family with a mentally handicapped child

J.C. KGOLE¹ AND T.R. MAVUNDLA²

¹Department of Nursing Science, University of Limpopo, Private Bag X1106, Sovenga, 0727, South Africa. E-mail: jermina.kgole@ul.ac.za

²Department of Health Studies, University of South Africa, P.O. Box 320, Pretoria, 0001, South Africa.

Abstract

A model that was developed for empowerment of families with mentally handicapped children was applied to three families, but only one family will be reported in this article. The model revealed positive achievement of aims and objectives after mobilization of resources. The purpose of the study was to evaluate the implementation of the empowerment model for the family of a mentally handicapped child in Moletši centre for the mentally handicapped children. The population was all families of mentally handicapped children at Moletši centre. Non-probability, purposive sampling was used. A case study approach using semi-structured interviews and assessment guides were adopted in the application of the model of empowerment for families with mentally handicapped children to evaluate its effectiveness in practice. The data were analysed and synthesised from the semi-structured interviews and assessment guides. The results are discussed according to the phases of the model, namely creation of awareness of needs; formulation of plan; mobilisation of resources; monitoring and evaluation, and self-efficacy. The evaluation proved that the family achieved the objectives as formulated and attained self-efficacy.

Keywords: Evaluation, implementation, model, family, empowerment.

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Introduction

This article focuses on the evaluation of the implementation of the model for empowerment of a family with a mentally handicapped child. In the original study the theory-generative approach was used (Chinn & Kramer 2003). The empowerment model was developed, described and guidelines for the operationalization of the model for empowerment of families were formulated. In this article this model for empowerment of families with mentally handicapped children is evaluated to find out whether it was effective or not, using the following phases of the model: assessment of needs, plan of action, mobilization of resources and evaluation of the implementation of the model to determine the efficacy of the model.

Fieldwork

Appointments were made with the participants, the family to conduct the interviews with them at the clinic with the assistance of the registered nurses. The case studies were implemented using semi-structured interviews, lasting between 45 and 60 minutes, and assessment guides. The data were collected on alternate Fridays over a period of three months. It was found challenging and enlightening to listen to the participants' experiences in caring for, treating and rehabilitating their mentally handicapped children.

Preparation and training for the case studies was done in order to establish whether the empowerment model was effective. Pre-morbid functioning and quality of the empowerment of families with mentally handicapped children was provided before the theory (model) was used; that is, how the nurses assisted and treated the families and the children (Chinn & Kramer, 2003). Yin (2003) emphasises that good preparation of case studies should start with good listening, adaptability and flexibility, a grasp of the issues being studied, and lack of bias. Rapport was established with the parents and the nurses at the clinic in order to explain the nature, purpose and effects of the model on the care, treatment and rehabilitation of mentally handicapped children.

Preparation of nurses at the clinic

An appointment was made to see the professional nurses at Moletši Clinic in order to arrange dates and times for the orientation and training in applying the model of empowerment. The nurses at the clinic agreed to meet the researcher on Friday afternoons, when the clinic was not busy

Letters of permission from the Department of Health and Social Development and the University of South Africa, Health Studies Research Ethics Committee (HSREC) were shown to prove that permission to conduct research was given (Mouton & Marais, 2008).

An enlarged copy of the model that was clear and coloured to make it easy to understand was used. The purpose, context, phases and structure of the model were explained, and that it would be applied to the families of mentally handicapped children to determine its effectiveness in producing independence and self-efficacy to the families of mentally handicapped children. The psychiatric nurse and the professional nurses at the clinic were allowed to make additions and suggestions for the model. Moletši clinic staff were given a one-day seminar on the care, treatment and rehabilitation of mentally handicapped children and support of their families

Pre-morbid functioning of the clinic on empowerment

When asked how they empowered the families with mentally handicapped children, the nurses said they were short-staffed, catered for over eighteen villages, and did not have transport to do follow-ups of their families. Moreover, the families did not bring their children monthly as expected, but only for minor ailments. They had no opportunity outside of those times to educate the families about their mentally handicapped children and refer children with problems to the psychiatrist in hospital, especially children suffering from epilepsy.

The objectives of the case studies were to:

- identify the needs, problems, weaknesses and shortcomings
- formulate a plan of action to meet the needs
- mobilise and gain access to resources, support and information to meet the needs
- evaluate and monitor the effectiveness of the plan and whether the needs were met
- determine whether the model was effective and self-efficacy was met

Establishing a relationship

Rapport was established and a relationship was also built with the family through primary (parents, friends and siblings) and secondary (colleagues, friends, and relations) members and the nurses (Becker, 2005). Communication was open, a sharing relationship established, and allowed the family to identify and express their needs with regard to their mentally handicapped children. The model promotes a power-sharing relationship and so the parties displayed a relationship of mutual sharing and respected the families of mentally handicapped children (Baumann, 2007; Sadock, 2003). Accordingly, an enabling environment was created by listening carefully, showing empathy, and communicating with the families of the mentally handicapped children (Baumann, 2007; Margo, (2003). The family was encouraged to freely express and identify problems.

Preparation and training of the family

The researchers and the clinic nurse established good interpersonal relationships with the family members in order to eliminate mistrust. The two parties introduced themselves, explained the nature, purpose and significance of the study, and the family was informed that participation was voluntary. The family members were assured that all information (data) would remain confidential and anonymous, they would not be subjected to harassment, and they were free to ask any questions or to decline to participate. The participants were also

informed that a small portion of the population was needed for the study, and that the researchers wished to apply the model to determine its effectiveness in empowering parents to care for, treat and rehabilitate their mentally handicapped children. Their permission was sought to use a tape recorder in the interviews to ensure that the data were accurately reflected. The family members were enabled to express their anxieties openly (Mouton & Marais, 2008). The family members then read and signed the informed consent to take part in the study. Appointments were scheduled for the process to start and subsequent appointments to go through the process of the model. The families were given incentives in the form of food packages as tokens of appreciation for being participants in evaluation of implementation of the model.

Methodology

The design of the research study was theory-generative, qualitative, explorative, descriptive and contextual (Chinn & Kramer, 2003). The following stages of theory development were followed: Concept analysis, which consists of concept identification, concept definition and concept classification. The second step was description of model structure and process, consisting of model description and model evaluation. The third stage was description of guidelines to operationalize the model in practice and the last and the fourth stage was evaluation on the implementation of the model in practice of psychiatric –mental health nurse in a specified clinical area. The method of data collection was semi-structured, using case study method (Yin, 2002).

Population and sampling

The sample of this research was drawn from the population of all families with mentally handicapped children who attended and collected their monthly medication at Moletši Clinic. Purposive sampling was used to deliberately identify and include families with mentally handicapped children for participation (Babbie & Mouton, 2009). The inclusion criterion was the families who stay with their children daily. The sample consisted of three families, who cared for, treated and rehabilitated their mentally handicapped children, but only one family is discussed in this article.

PHASE 1: Creating awareness of needs

The model of empowerment of families with mentally handicapped children is a two-way, sharing process, in which the mental health professionals work together with the families to identify the family's basic health needs (Gaines, Jenkins & Ashe, 2005). The family provided information about their knowledge and skills, beliefs, norms, values, family support groups, and influential persons. The family started realising that they had a crisis and needed help. Available and

generated data were gathered, including problems and capabilities encompassing physical, social, psychological and cultural dimensions of Neuman's systems model (George, 2003).

Characteristics of the mentally handicapped child's family (Sample description)

The family under discussion was a single parent family, at child-bearing and child-rearing stage, with five members, children aged 14, 12 and 7 and belonging to Zion Christian Church. The family resided in Moletši area in Capricorn district, belongs to a middle class citizens, has good housing, can afford basic needs. The family is traditional and use traditional medicines, get social support from Zion Christian Church, aunt and Moletši clinic nurses, has good, educated and supportive neighbours, religious people, including a priest living opposite the family house. The child was delivered in hospital, has slow milestones and listens to music and radio, watches television during leisure. The child sings and dances "mokhukhu" in Zion Christian Church.

Results and Discussion

Data were collected from the family through case study approach, using semi-structured interview and assessment guide. The data were analysed using Tesch's method (Cresswell, 2003) and the following themes and subthemes emerged during the creation of needs:

Table 1: Themes and subthemes

Themes	Sub-themes
1 Little knowledge and information on mental handicap by families	 Definition of concept of "mental handicap" Medications, storage and follow-up after discharge Conditions associated with mental handicap, and existing health services Rights of the mentally handicapped
2 Failure to protect children physically, from abuse and infection3 Poor support	 Proper clothing Failure to prepare, cook and serve meals Financial support Academic support Emotional support
4 Poor self-management, motor development and speech development	 Self-help skills: feeding, toilet training and dressing Fine and gross motor skills development Speech development
5 Rejection by health professionals and neighbours	 Doctors Social workers Neighbours
6 Lack of socialization skills	• Basic socialization skills; inability to use leisure time and recreation

Theme 1: Little knowledge and information on mental handicap

The family did not have knowledge and information on mental handicap, causes, manifestations, and care, treatment and rehabilitation of mentally handicapped children. The family members presented with little knowledge, ignorance, and cultural beliefs (Townsend, 2003) and they expressed the causes and treatment of mental handicap as follows:

Sub-Theme1.1: Definition of concept of "mental handicap".

The family had little knowledge on the definition of mental handicap, what causes it and what needed to be done to assist the child. The mother said:

This child is a present from God. Her mother saw a cripple when she was pregnant.

We took the child to the traditional healer, with no improvement, thereafter the child was taken to the Apostolic and Zion Christian Church for strong prayers and for religious prescriptions ("ditaelo"). They also sang and danced for the child.

Heese and Steenkamp (2006) and Blacher, Shapiro, Lopez, Diaz and Fusco (2006) emphasise that families only recognize the strange behaviour that the children display during early childhood.

Sub-Theme 1.2: Medication, storage and follow-up after discharge

The family was unaware of medication and follow-up after discharge and did not know the names of the medications and methods of safe-keeping and storage, and the health services that they should consult. The family said:

I stopped the treatment and never went back to the hospital and clinic and I had no reason for not going there. I just did not go since I did not believe in the hospital treatment, I strongly believed in the traditional medicine. I keep the medicine safe in the display cabinet.

Buntix (2008) stressed that medication should be kept in a cool place and out of reach of children as the children may take it and become poisoned or overdosed.

Sub-Theme 1.3: Conditions associated with mental handicap and existing mental health services

The family did not know about the conditions associated with mental handicap, such as Down syndrome, hydrocephalus and epilepsy. Other conditions include

autism, hyperactivity, microcephalus, temper tantrums, adjustment problems, speech problems and muscle weakness (Busman, 2010; Heese & Steenkamp, (2006). The mother said:

My child was taken to the traditional healer for the big head and after consultation with the traditional healer, the head became bigger and bigger, and I then took the child to the hospital where they said that my child had a condition named hydrocephalus.

Davis (2010) emphasises and encourages family support in the form of parent groups and community involvement in helping families to care for, treat and rehabilitate the mentally handicapped children. Families should be referred for medical and psychiatric problems.

Sub-Theme 1.4: Rights of the mentally handicapped

Mentally handicapped children have the right to protection and should not be abused (Cartwright, 2006). The families with mentally handicapped children in the Moletši district do not know about the rights of their children. The children are harassed, ridiculed and beaten by other children at home and at school, and beaten by relatives and neighbours. Protection from infection is another important element ignored by most families in Moletši district. The researcher found the toilet facilities poor and unhygienic. According to the participants:

What can I say if my child gets beaten by his brother? It is a form of punishment, the child is very silly. Peer group members playing in the street also beat him; he will wake up and fight for himself one day.

The children and visitors go to the bushes for the toilet. I do not have money to build a toilet. It is very expensive.

Clarke and McGraw (2007) supports that families do not have the right to beat, harass or abuse mentally handicapped children. In applying the empowerment model, the researcher educated the families on the rights of the mentally handicapped children to be listened to, respected, educated, protected and cared for. Mentally handicapped children have the right to respect and dignity, not to be discriminated, the right to information, and the right to participate in treatment decisions and confidentiality (Heese & Steenkamp, 2006;

Theme 2: Poor support

Generally there is little support for families of mentally handicapped children from relatives, friends, neighbours, colleagues and support services in the community, including other parents with mentally handicapped children Heese and Steenkamp (2006) found that the church provided the strongest support for mentally handicapped children in the community. In their study of stress and coping abilities of parents with mentally handicapped children, Burack and Zigler (2006) found that groups outside the community supported the parents of mentally handicapped children emotionally and formed family support groups.

Sub-Theme 2.1: Financial support

The family had problems with applications for social financial security funds (*motente*). This prevented them from purchasing clothing, food and other basic needs for the mentally handicapped children. The family complained:

I was suffering and asked for financial security 'motente' until I got tired. The gentlemen told me that financial security is only given to children who have physical disability, like cripples.

Dryden (2011) and Fletcher (2003) stress that mentally handicapped children have the right to financial security and this right should be respected and cherished.

Sub-Theme 2.2: Poor academic support

The family was not taught how to capacitate their children with academic skills. According to the father:

At the school the mistress said that my child cannot even write his name, but just draws a straight line. This is the fifth year and I wonder who is going to help this child of mine.

Mentally handicapped children learn by repetition and reinforcement when they do something well (Kraus & Singer 2003).

Sub-Theme 2.3: Poor emotional support

The families of mentally handicapped children undergo a series of reactions before they can accept that there is a mentally handicapped child in their family. Reactions include emotional shock, numbness, denial, blaming, guilt feelings and depression. Grieving takes time, depending on strengths and weaknesses. One of the participants said:

I did not know what I had done wrong to deserve this punishment of having a mentally handicapped child. Nobody seems to be sensitive to the problems that my family experience.

The families complained that nobody seemed to care or be sensitive to the emotional problems of the families of mentally handicapped children. Boyd (2007) and Busman (2010) emphasise the formation of support groups in the form of parent groups, mutual support groups where families come together and discuss the same problems and advise one another on how to solve individual problems of their mentally handicapped children. Mental health care workers should accept, empathise, listen attentively, and be non-judgmental when supporting the families of mentally handicapped children emotionally. The mother reported being rejected by a doctor as follows:

Mummy, I am very busy and will not be able to examine your child. I am going somewhere, I cannot help. I am sending you to the sister in the clinic to help you.

Nurse, Rohde and Farmer (2003) refer to this doctor's attitude as an "unhelpful encounter" between the doctors and parents. Many parents are dissatisfied with the amount of information, the language and the lack of interest shown by doctors (Nurse et al., 2003).

Theme 3: Poor motor development

Poor motor development refers to poor development of fine and gross muscles. Fine muscles are developed by exercises such picking up of beads, tying shoe laces and picking up of small stones from a sandpit. Gross muscles are developed by exercises such as running and walking. Development of motor skills also assists in the maintenance of balance and posture. The families experienced problems with their mentally handicapped children because the children could not hold objects well and could not walk and run well due to poor muscle tone.

Gross muscles are developed by exercises such as running, walking, pushing a wheelbarrow, jumping, hopping, skipping, tumbling and gymnastics, games and other back and abdominal exercises (Heese & Steenkamp, 2006).

The mother referred to her child's weak back muscles as follows:

My child gets tired easily and sits down while playing with other children. His back gets tired easily.

Theme 4: Rejection by other health professionals and neighbours

Health professionals rejected the mother by ignoring her, because immediately after birth the registered nurse at the clinic told the mother that she has given birth to a mongol. The mother was frightened and she wanted to know what a mongol is. The mother proceeded to the regional hospital where the doctor and

the social worker had little time to attend the family with mentally handicapped child but said to the mother:

My diagnosis of the patient, she is still small. I think you should go home and wait and see. Mummy, I cannot make out the diagnosis of the child, you better go home to observe your baby.

Chen and Tang (2003) found lack of acceptance/rejection of parents of mentally handicapped children by the community at large and health services. According to Heese and Steenkamp (2006), medical practitioners often adopt a "wait and see" approach, making vague statements, not telling the truth or leaving the mother until she is prepared for the shock and disappointment.

Mavundla, Toth and Mphelane (2009) found that the caregivers in a rural community in South Africa were rejected not only by the community, but by nurses and social workers. The caregivers complained that nurses did not assist them when their relatives with mental illness were admitted to hospital and did not give them any health education. The social workers were of little assistance in supporting them with regard to their mentally ill relatives. The caregivers complained that they were not given health education on mental illness and this frustrated them as they wanted to support their relatives. The caregivers had only heard on the streets that mental illness could be caused by dagga and environmental problems, but they wanted to know the actual causes of mental illness.

The participants referred to rejection by neighbours. According to one participant:

I felt bad when the community and the neighbours rejected my child, even children in the street did not want to play with my child. Neighbours do not care.

Dunn (2006) emphasises establishing good relationships between clients/families and their neighbours.

Theme 5: Inadequate socialisation skills

Socialisation is a basic skill necessary for individuals to interact with the family and become responsible members of their society. Socialisation is important in introducing the child to the world such as teaching the child how to greet, how to play and how to share with other children.

During basic socialisation in the family children should be taught how to greet, to say "thank you", to say "sorry", to say "goodbye", and be able to share whatever is being eaten (Heese & Steenkamp, 2006). The mentally handicapped

child was not able to display basic socialisation skills. The mentally handicapped children in case studies 1 and 2 were able to greet and two children demonstrated happiness on their faces.

Sub-theme 5.1: Inability to use leisure time and recreation

Recreational activities, use of leisure time, socialisation of children in basic aspects, outings, visiting of support groups, and occupational skills are generally not done in Moletši district for the mentally handicapped children.

According to the mother of the mentally handicapped child in the first case study:

The only recreation that my child gets, is from the ZCC Church. My child sings and dances with other children in church and the church arranges trips for our children.

Cartwright (2006) found that the church is an institution of socialisation in the case of children with mental disability.

PHASE TWO: Plan of action for families with mentally handicapped children

Mental health care professionals, the researcher and the family of mentally handicapped child planned how and who should tackle the needs identified. Short- and long-term goals were formulated according to the needs and plans made for the expertise and specific groups required (Stanhope & Click, 2009). Maslow's hierarchy of needs was used as the basis to facilitate planning for needs of mentally handicapped children and their families (Antai-Otong, 2008)

The family had inadequate basic needs, especially physiological needs, safety, love and belonging and esteem. A plan of action was drawn for each family with specific objectives.

The objectives of the plan were to:

- educate the family members on the causes, manifestation, care, treatment and rehabilitation of mentally handicapped children
- teach the family how to prepare, cook and serve meals
- support the family academically, financially, and physically
- improve socialisation and recreation skills
- improve poor self-help skills

PHASE THREE: Mobilisation of resources, support and information

The families started to participate in problem solving and to access information, resources and support. The family started to realise that they had to take charge of their needs and become responsible and accountable for achieving autonomy and self-efficacy and become experts in the care, treatment and rehabilitation of their children (Ross & Deverell, 2004; Antai-Otong, 2008).

The researchers and clinic nurses gave health education lectures on mental handicap, epilepsy and hydrocephalus, which are some of the conditions associated with mental handicap, the clinical features, the care, treatment and rehabilitation of the Epileptic and Hydrocephalus child. Family members were shown a film of Epilepsy and Hydrocephalus at home and given handouts. The family was referred to the Psychiatrist for treatment and the family members showed appreciation for all the information.

The family attended the workshop for the parents of mentally handicapped children at the Moletši Centre, which included lectures and demonstrations of how to care for, treat and rehabilitate their mentally handicapped children. Families, relatives, friends, neighbours and interested people were invited to the workshop.

The family was educated about preparing, cooking and serving a well-balanced diet. Women from the Zion Christian Church were invited to come and assist the family. The women prepared, cooked and served meals in the family home and used the family's utensils.

Improving academic performance and financial problem

Voluntary Moletši Centre teachers were taught to be patient and try to teach the mentally handicapped child to write his name. Volunteers at the centre were encouraged to be patient, kind and loving, and repeat what they teach because mentally handicapped children learn by repetition and reinforcement for doing something well (Heese & Steenkamp, 2006). An application for financial assistance was made to the Department of Social Development at Seshego township.

Improving socialisation and recreation

The mentally handicapped boy was poorly socialised at home. The researcher and the clinic nurse encouraged family members to take him along when they go to church so that he could participate in 'mokhukhu' dancing on Sundays after church.

For socialisation, Moletši social workers obtained different toys for the mentally handicapped children, and the boy was also given one to take home.

On the "fun day" the nursing students hired a "jumping castle" from Polokwane and all the mentally handicapped children who attended enjoyed the day together and made friends (Holloway & Freshwaters, 2007). This was one of the ways in which the researchers and the psychiatric nurse together with the nursing students socialised the mentally handicapped children. Both parties referred and showed the family the support groups in the community like families with children with epilepsy and hydrocephalus. The boy also took part in family excursions, songs in church and music competitions in church to improve socialisation and concentration.

PHASE FOUR: Monitoring and evaluation of the family

Monitoring and evaluation should start during the planning stage to determine whether the goals go hand in hand with the problems identified, and whether implementation takes place according to the set objectives throughout the empowerment process (Stanhope & Click 2009).

The mental health professional and the clinic nurse who assisted the researchers in the implementation of the model evaluated the empowerment process to establish whether the empowerment process was successful or not. Colleagues who were observers evaluated the impact of the empowerment model in the care, treatment and rehabilitation of the families of the mentally handicapped children. The family of the mentally handicapped child was involved in monitoring and evaluation as the model for empowering families involves power sharing, and is a two-way process in which both the family members and the mental health professionals share.

Feedback on rights of mentally handicapped child

The clinic staff, staff in the nearby clinics, the researchers and mental health professionals discussed the rights of the mentally handicapped children. It was discovered that the family members understood the rights of their mentally handicapped child, and knew that their child had the right to be protected, to a name and surname, happiness, education, respect, dignity, to be loved and cherished, and the right to live like any other child.

Feedback on academic performance

The family reported that they were invited to the Moletši parents group on mental handicap where they discussed their children's problems including their failure to progress at school. The family found that the other families had the same problems and they consoled and supported one another. The family gave feedback on their child's improved academic performance and they were referred to Grace and Hope school for mentally handicapped children where remedial teaching was done.

Feedback on preparing, cooking and serving meals

The researchers and the clinic nurse visited the family at home and observed improvement in the preparation, cooking and serving of meals. The mother wanted to be alone when she prepared the meals. The meals were prepared in a clean environment, utensils were clean, and the meals were well cooked and served attractively. The family thanked the researchers and the clinic nurse and the voluntary organisations for their assistance.

Monitoring of care, treatment and rehabilitation

The family members and the child were observed in care for the mentally handicapped child to find out whether improvement is marked or not. The family was able to clean their mentally handicapped child with little support from organisations and neighbours. The mentally handicapped child and the family were found to be clean. The family took the boy for treatment regularly and the family assisted each other to rehabilitate him. The researchers and the clinic nurse were pleased with the improvement in the family.

Monitoring financial support

Regarding the application for financial assistance, it was found that mentally handicapped child was on the waiting list and within 3 months he will be getting the financial assistance.

Monitoring of knowledge of mental handicap

The family members opened up and were observed discussing the concept of mental handicap, the causes such as heredity and non-prescribed drugs, conditions associated with mental handicap like Epilepsy and Hydrocephalus, the services available, and the care, treatment and rehabilitation of mentally handicapped children with other families. The family could explain how community facilities are utilised, including the social worker and mental health professionals.

Self-efficacy was observed and the family members could care, treat and rehabilitate their mentally handicapped children.

Recommendations

Based on the findings it was recommended that the model of empowerment of families with mentally handicapped children should be implemented in psychiatric wards, occupational health setting, health centres and psychiatric community clinics to encourage trained psychiatric nurses and students to work together with families of mentally handicapped children.

Psychiatric nursing tutors should undergo training on the model so that they can teach the students the scientific approach of caring, treating and rehabilitating the mentally handicapped children and empowering families to care for their children. The model can also be utilized to plan the community psychiatric services.

Further research should be conducted on the attitudes of the community towards mental handicap to enable mental health workers can determine community perceptions of mental handicap and provide relevant assistance to the needy.

Conclusion

The results revealed that the family members could be independent and can reach self-efficacy in the care, treatment and rehabilitation of their mentally handicapped children. The model was beneficial to the family.

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