Guidelines on Psychosocial Support for Adults living with HIV and AIDS and other Chronic Conditions

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social development

Department:
Social Development
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FOREWORD

The mandate of the Department of Social Development is to provide psychosocial support to people made vulnerable by HIV and AIDS and chronic conditions and their families. The availability of treatment is crucial in prolonging the lives of individuals living with HIV and AIDS and/or chronic conditions and is often hindered by unattended psychosocial issues. Unattended psychosocial issues contribute to high levels of non-disclosure of health status and non-adherence to treatment.

The Department has developed these guidelines on psychosocial support for adults living with HIV and AIDS and chronic conditions to guide implementers on the provision of psychosocial support, to equip individuals and families with the necessary skills to prevent, provide care and support, and to disclose health status to their children, partners and other family members. Parents are guided and equipped on how to take good care of themselves and still nurture and show love to their children. These guidelines seek to protect the rights of people that are made vulnerable by HIV and AIDS and other chronic conditions, to ensure that their psychosocial needs are adequately met and also to address stigma and discrimination associated with HIV and AIDS.

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DEFINITION OF TERMS

Adherence	This refers to the degree to which the client (child and caregiver and/or adult) follows the treatment plan, specifically the requirements for taking medication, e.g. The recommended dose, at the recommended time, in the recommended way. Adherence means the client never misses taking the recommended dose of medication at the recommended time.
Antiretroviral Treatment (ART)	Antiretroviral Therapy (ART) is a drug treatment that is given to HIV infected people to prevent HIV infected cells from replicating, therefore limiting the number of HIV virus copies in the body and damage to the immune system.
Chronic Conditions/Illnesses	Chronic conditions refer to a persistent and long-lasting medical condition that lasts for more than three months. The most common chronic conditions are high blood pressure, asthma, arthritis, diabetes, rheumatic fever, cancer, depression, obesity, respiratory diseases like emphysema, high cholesterol, etc. HIV can now be managed as a chronic disease.
Disability	Disability means a moderate to severe limitation in a person's ability to function or perform daily life activities as a result of a physical, sensory, communication, intellectual or mental impairment.
Disability Grant (DG)	This is allocated to individuals between the ages of 18 to 59 years who cannot support or maintain themselves financially due to a disability, with either permanent psychological and physical disability, or for temporal ailments that render them unable to work.
Nutrition	Nutrition refers to how food is consumed, digested, absorbed and utilised by the body for growth, reproduction and maintenance of health. Food contains different nutrients that include water, carbohydrates, proteins (amino acids), lipids, vitamins and minerals.
Nutritional Support	This is the support given to people who are in need of nutrition that contains nutrients that are needed by the body for growth and maintenance of good health.
Opportunistic Infections (OI's)	This refers to diseases that affect people with immune deficiency due to long-term illness or chronic condition.

Psychosocial Support	The word "psychosocial" can be used to describe the unique internal processes that occur within an individual that are influenced by psychological and social factors. Psychosocial support is the support aimed at restoring the normal functioning of individuals and families, taking into account the psychosocial factors.
Tuberculosis (TB)	Tuberculosis (TB) is a potentially fatal contagious disease that can affect almost any part of the body, but is mainly an infection of the lungs.

ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy/Treatment
CBOs	Community-based Organisations
CCG	Community Caregiver
DG	Disability Grant
DSD	Department of Social Development
HIV	Human Immunodeficiency Virus
HCBC	Home Community-based Care
M&E	Monitoring and Evaluation
NSP	National HIV & AIDS and STI Strategic Plan for South Africa
NGOs	Non-Government Organisations
OIs	Opportunistic Infections
PMTCT	Prevention of Mother to Child Transmission
PLHIV	People Living with HIV and AIDS
STIs	Sexually Transmitted Infections
TB	Tuberculosis
VCT	Voluntary HIV Counselling and Testing

INTRODUCTION, PURPOSE, OBJECTIVES, BENEFICIARIES, GUIDING PRINCIPLES, APPROACHES AND POLICY FRAMEWORKS

CHAPTER 1

1.1 Introduction

Chronic conditions have been identified as key challenges that affect a significant proportion of the population, not only in South Africa, but also around the world. In addition to HIV and AIDS, South Africa faces a high burden of other diseases, such as diabetes and hypertension. HIV infection can now be managed as a chronic disease.

There are three categories of chronic illnesses namely, a life-long chronic condition with no hope of being able to work again and complex to manage medically (e.g. Severe arthritis, cardiac problems, epilepsy); curable and/or controllable with medication and require health care for a specified period to regain health and ability to function fully (e.g. TB, hypertension, diabetes, mild to moderate asthma, epilepsy); and life-long but manageable (e.g. Moderate epilepsy, arthritis, Asthma, HIV and AIDS etc). The most common chronic conditions are cardiovascular disease, cancer, chronic respiratory disease, diabetes, HIV and AIDS.

The biggest challenge facing communities today is that not all chronic diseases are detected early. Often they are not detected until they are in advanced stages. Most people who are eligible for treatment of HIV and AIDS and other chronic conditions are not on treatment.

This is due to many reasons which are ranging from lack of information, lack of access to treatment centres for clinical assessments and early detection, late detection of those who have chronic illnesses and those who need treatment, and the stigma that is often associated with HIV and AIDS. As of 2009, the national antiretroviral rollout reached only about 22% of those diagnosed as having AIDS illness (Aarif Adam & Johnson, 2009), leaving millions of adults untreated and with chronic and worsening opportunistic infections.

The availability of medication is crucial in prolonging the lives of people with HIV and AIDS and other chronic conditions and is often hindered by unattended psychosocial issues, inability to afford nutrition, inability to afford extra medication and other necessities.

Self-management is an essential component of early treatment, as it includes equipping individuals with skills and resources that they need to make changes in their behaviour and lifestyle and health decisions that can delay disease progression and maximise quality of life. Support for self-management should be put in place at the earliest possible opportunity. The early detection and access to treatment for those eligible for treatment needs a co-ordinated strategy that involves all relevant stakeholders and making use of community-based organisation and community caregivers.

Strategies need to be developed to ensure early identification, detection, access to appropriate psychosocial services, nutritional support, and access to treatment of all those who are eligible for treatment. The advantages of early detection and early treatment can include reductions in mortality. Effective early treatment can improve quality of life.

Access to a balanced diet is crucial for people living with chronic illnesses, including HIV and AIDS, and while undergoing treatment, healthy nutrition is essential in order to comply with medication requirements. Some chronic illnesses have dietary requirements for management purposes. People living with HIV and AIDS and other chronic conditions need food from both a prevention and a treatment point of view. From a prevention perspective, a healthy diet may delay the progression and initiation of treatment by helping to maintain the immune system's resistance against infections.

From a treatment perspective, a person with good nutritional status who starts any treatment is much more likely to be successful with the treatment response than someone who begins therapy in a state of hunger or malnutrition. The nutrients facilitate the absorption of any treatment into the body and enable maximum response. In an environment of high unemployment and poverty there are people who have no guarantee of one meal per day, let alone several meals. In most instances medication would be taken on an empty stomach, which might complicate the illness or lead to other illnesses.

Often medication is not taken according to instructions due to the unavailability of food. Generally medication cannot be taken on an empty stomach. Noncompliance with dosages of medication leads to complications of varying degrees. These may include fast progression of the disease, onset of other illnesses, disability and even death. The Department has a mandate to address the vulnerability of individuals due to poverty and other psychosocial factors. The South African Government adopted a comprehensive social protection approach, where people generally access social security provisions in the form of social assistance or social insurance.

With regard to social insurance, people with chronic illnesses are accommodated, whilst with social assistance they are included in disability grants by default, due to a number of reasons that ranges from misinterpretation or misunderstanding of what disability is, the high unemployment rate, high poverty rates in South Africa and the high incidence of HIV and AIDS. This grant does not aim to relieve poverty for the general population, only for those with a disability, which means that people with chronic illnesses that are living in poverty need food assistance.

1.2. The purpose of the guidelines

The guidelines seek to guide the service providers to ensure that people living with HIV and AIDS and other chronic conditions are informed, identified early, receive appropriate interventions such as psychosocial support, linked to HIV counselling and testing (HCT), linked to Prevention of Mother to Child Transmission (PMTCT), linked to treatment sites for appropriate assessments and early treatment to reduce risks for disease progression in order to prolong and improve quality of lives.

1.3. Objectives of the guidelines

The Guidelines are designed:

- To promote early identification and early access to treatment;
- To guide the service providers on how to support and meet the needs of people living with HIV and AIDS and other chronic conditions;
- To guide the service providers on provision and promotion of psychosocial care and support;
- To facilitate provision of comprehensive services to people living with HIV and AIDS and other chronic conditions; and
- To empower beneficiaries with knowledge and skills to promote their wellbeing and to prolong their lives.

1.4. Beneficiaries

These guidelines are developed to guide the responses of community caregivers, Community Based Organisations and other service providers at implementation level who are delivering services to people living with HIV and AIDS and chronic conditions.

1.5. Guiding Principles

The following relevant sets of principles were adopted in the development of Guidelines:

- HIV infection can now be managed as a chronic disease
- HIV and other chronic conditions if identified early can be managed
- There are interventions which can significantly prolong and improve quality of life and survival of people living with HIV and AIDS and chronic conditions
- Promotion and protection of rights of people living with HIV and AIDS and chronic condition

1.6. Approach

The approach adopted in compiling these guidelines was to take into account:

- Policies, legislations, and programmes related to HIV and AIDS, and other chronic conditions
- Research that exist
- Recommendations of earlier initiatives and
- Approaches listed below:

The guidelines adopted the following approaches:

- **Developmental Approach** - based on the strengths of the individual, groups or communities and promoting their capacity for growth and development

- **Needs Approach** (Maslow's hierarchy of needs) recognises that people have needs on different levels of the hierarchy that needs gratification. The physiological needs on the lower level of hierarchy are basic needs such as hunger, thirst, shelter needs to be met, and if those needs are not regularly gratified they dominate other needs on other higher levels. People living with HIV and AIDS and other chronic conditions also have needs and those needs must be met especially the need to obtain food so that they don't take medication on an empty stomach.

- **Psychosocial Model** recognises the interaction and relationship between psychological and social environment. Psychosocial can be used to describe the unique internal processes that occur within an individual that are influenced by psychological and social factors. This model encourages the provision of psychosocial care and support services that are aimed at restoring the normal functioning of individuals and families.

- **Systems Approach** recognizes the importance of the family to function as a system, whereby if one member of the family (sub-system) is sick or suffering from HIV or other chronic conditions, then the whole system is affected. The family needs to respond as a whole, support each other, and help each other to cope and deal with the challenges such as accessing treatment, psychosocial support and adherence. A family centered approach recognizes the crucial role of the family in the treatment, care and support of children and adults and that the family needs to be strengthened to deal with HIV and other chronic conditions.

A **family centered approach** is interlinked with **strength based approach**, as it involves:

- Identifying the strengths of a family and using them to compensate for any weaknesses in its capacity to provide effective care and support,
- Build on and extend the capacity of the family to care for its members, and
- Help the family to deal with challenges that may affect their ability to care for each other.

1.7 Legal and Policy Framework

The Guidelines are set within the following legal and policy frameworks:

A. International obligations/strategies

Policies/Legislations/Strategies	Purpose/Description
Millennium Development Goals	The Millennium Development Goals (MDGs), endorsed by governments at the United Nations in September 2000, aim to reducing poverty, hunger, child and maternal mortality, ensuring education for all, controlling and managing diseases: **Goal 1:** Eradicate extreme poverty and hunger by 2015 **Goal 4:** Reduce child mortality by 2015 **Goal 6:**Combat HIV and AIDS, malaria and other diseases by 2015

B. National obligations/strategies

Policies/Legislations/Strategies	Purpose/Description
1. The Constitution of the Republic of South Africa (Act 108 of 19996)	Highlight values of human dignity, achievement of equality, advancement of human rights and freedom. Section 28 of the South African Constitution provides for human rights in South Africa.
2. The HIV & AIDS and STI Strategic Plan for South Africa 2007-2011 (NSP)	Seeks to reduce the number of new HIV infections by 50% and reduce the impact of HIV and AIDS on individuals, families, communities and society by expanding access to appropriate treatment, care and support to 80% to all people diagnosed with HIV and AIDS.

	Goal 6: Enable PLHIV to lead healthy and productive lives **Goal 7:** Address the special needs of pregnant women and children
3. National Antiretroviral Treatment Guidelines, National Department of Health, 2004	Set standards as the basis for the use of ART drugs in South Africa.
4. Prevention and management of side effects and drug interactions (ART), National Department of Health, 2006	Gives an outline of side effects, dosage regimen and treatment for adverse drug reactions in algorithms that are easy to follow.
5. Guidelines for the management of HIV in adults, National Department of Health, 2010	Provides for the comprehensive management of HIV infected adults. The new regimens are described as well as laboratory and clinical monitoring at diagnosis, initiation of antiretroviral treatment and whilst on treatment.
6. South African National Guidelines on Nutrition for People Living with TB, HIV, AIDS and Other Chronic Debilitating Conditions	Provides with more information on nutritional management of HIV-infected children.
7. National Tuberculosis strategic plan for South Africa 2007 – 2011; and National TB infection control guidelines , June 2007	Based on WHO Stop TB strategic objectives are to strengthen the implementation of DOTS strategy, to address TB, HIV, MDR and XDR-TB, to work collaboratively with all care providers, to empower people with TB as well as communities and to coordinate and implement TB research.
8. The Social Assistance Act, 13 of 2004	Makes provision for social assistance benefits. Provides for the right of access to appropriate social assistance to those who are unable to support themselves and their dependants.
9. HIV Counseling and Testing (HCT) Policy Guidelines	To provide national framework that will direct the provision of HIV counseling and testing for children, youth and adults in public and private sectors in South Africa. To ensure better quality and consistency of the delivery of many elements of HCT.

CASE MANAGEMENT APPROACH

CHAPTER 2

The primary goal of case management is to optimize clients functioning by providing quality services in the most efficient and effective manner to people living with HIV and AIDS and chronic conditions with multiple and complex needs.

2.1 What is Case Management?

- Case Management is a method of providing services whereby a service provider assesses the needs of the client and family, when appropriate, arranges, coordinates, monitors, evaluates, and advocates for a package of multiple services to meet the specific clients complex needs.

2.2 Process of Case Management

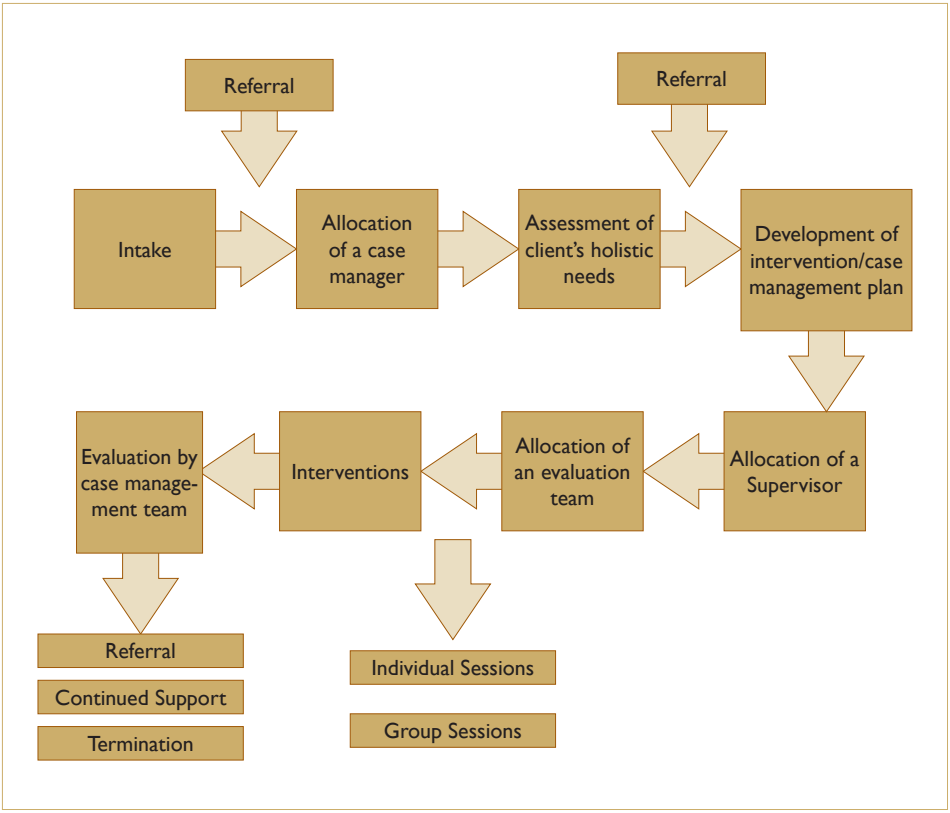
- Follow the stages of case management
- Appointment and allocation of a case manager, case supervisor and case management team
- A case manager shall carry a reasonable case load that allows effectively planning, providing and evaluating case management tasks
- A supervisor is someone with more experience than the case manager, to monitor and evaluate processes followed and services rendered
- Appointment of case management team. Case management team sits after 90 days to evaluate the case and the progress made. A case manager also forms part of the case management team.

Case Manager must be:

- Knowledgeable about available resources and services, cost and budget parameters
- Knowledgeable about external resources and how to access them

2.3 Stages of Case Management

- Intake stage
- Allocation of a case manager
- Assessment of clients holistic needs
- Development of an intervention plan/case management plan
- Allocation of supervisor
- Allocation of case management team
- Intervention/interventions
- Evaluation



2.3.1 Intake Stage

It is the stage at which the client make contact with the service provider (Community Caregiver etc). It is the responsibility of the service provider to know and understand the service delivery system, services, policies and legislation. This stage should promote and protect human rights, and Batho Pele Principles. The intake stage involves completing an intake form and giving immediate, urgent assistance.

The service provider conducts an intake interview to assess needs of the client and whether the client can benefit from the services rendered. The intake form covers the following:

- Identification details
- Individuals circumstances

- Family composition (who lives at home with the client?)
- Economic situation
- Relationships and support systems (How does the client get along with other family members, who does the client prefer to go to when he/she needs help or has a problem)

- Presenting problem
- Plan of assistance
- Evaluation and Recommendation

The service required by the client must be determined at this stage. An immediate assessment and evaluation of the presenting problem or situation must be undertaken. **A file must be opened.** An action plan for the intervention must be developed during the intake interview. The client can be referred to the case manager for further assistance, or if there is a need to refer to other service provider then the client can be referred, all referrals must commence with an intake. A follow up on the progress made on all cases referred to other service providers must be done.

2.3.2 Allocation of a Case Manager

A case Manager is allocated to handle the case. The case load of the case manager must be monitored to ensure that it does not exceed the prescribed ratio. (In the case of HCBC programme, the case manager would be the community Caregiver; in social welfare services, the case manager would be the Social Worker, etc).

2.3.3 Assessment of clients holistic needs

The rational of assessment is to **identify strengths, needs, risks that may impact on the well-being of the clients and their families.**

Confidentiality must be ensured during the assessment. The case manager assesses the clients **holistic needs** by looking at the following:

- **Social Aspects** – Home circumstances, who the client is residing with, adequate space for all members, relationships within the household etc
- **Education** – Assessing the clients education level.
- **Economic Aspects** – Family/household income and expenditure. These aspect also covers issues of nutrition (availability of food on a regular basis, quality of food, preparation of food and storage, etc)

- **Medical/Health Aspect** – Whether the client got any disability, illness, have ever tested for or diagnosed with any illness. Whether client is healthy or not. How often does the client get sick?
- **Psychological Aspects** – Level of maturity, ability to understand what is going on in his or her life, ability to process information given and to take rational decision. Ability to cope with his/her situation.
- **Emotional Aspects** – Clients understanding of his/her emotions, and ability to express emotions appropriately.
- **Conclusions and Recommendations** – The case manager makes conclusion about his/her assessment, observations and make recommendations in terms of what need to be done to equip the Client and the family to achieve optimum functioning and minimize the impact of dysfunction.

The assessment findings need to be discussed with the client and be documented into the clients file.

2.3.4 Development of an intervention plan/case management plan

Once the assessment has been done, results discussed with the Client an Individual Development Plan is developed, prioritised and implemented with the client and family. The client and family must takes full responsibility of the plan. The proposed interventions be discussed with the client and family (both Short, long term and Permanency plans – Skills building, succession planning etc). The roles and responsibilities of all relevant parties be clarified, duration of the intervention be agreed upon. The permanency plan must indicate which continued support the client and family will receive and how often will it be provided.

2.3.5 Allocation of Supervisor

The Allocated Supervisor is more responsible for quality checks, to ensure that there is no stone left unturned and that the conclusions reached and recommendations made and plans made are appropriate.

Further checks the individual plans to ensure that the short and long term plans are realistic and achievable. All services rendered to the beneficiaries must be subjected to Supervision. The case manager must be supervised at least once per month. This is done for the purpose of support. All crisis interventions must be closely monitored.

2.3.6 Benefits of having a Supervisor:

- Help the case manager to deal with emotions that are interfering with the helping process
- Making sure that the case manager is right on track and is delivering according to the client's needs and the developed IDP
- Provides the case manager with new techniques and strategies
- This helps especially when the case manager gets stuck with the client
- Provide support
- Provides expert information
- Provides answers to questions that the case manager has no or limited knowledge of.

2.3.7 Who is the Supervisor?

The Supervisor is a person who is more experienced, highly skilled person than the case manager, who serves as an advisor, quality assurer, confidant and a support system to the case manager who assists with challenges and issues that may arise during individual or family sessions.

2.3.8 Allocation of Case Management Team

The case management team includes the case manager, supervisor and another team of experienced people and experts. The case management team is more concerned about ensuring that the client needs are met, rights are protected and the resources are used effectively and efficiently. The case management team sits quarterly to evaluate the work done and is playing more of a supportive role.

2.3.9 Intervention/interventions

It is important to consider the type of programme needed, its duration and an exit strategy. The needs of the client living with HIV and other chronic conditions and those already on treatments vary depending on socio-economic circumstances.

2.3.9.1 Individual Sessions

Individual sessions can be arranged, to meet the special needs of the client.

2.3.9.2 Group Sessions

If needs cannot be met on an individual basis, group sessions can be used with family members and that is referred to as family therapy or a group session with other clients

who are going through similar circumstances and those are called support groups. Methods of selecting group members vary from group to group. Support group members can be identified and recruited from current caseload.

The case manager as an intervention strategy identifies and recruits clients who can benefit from support groups. The National guidelines on establishment and management of support groups for children and adults, DSD, 2010 provides a clear step by step process on how to establish and run support groups.

2.3.10 Evaluation

An evaluation needs to be done to check if the goals set and plans made at the beginning have been reached. Assess further areas that need further assistance and for further referral to other service providers.

2.3.10.1 Exit/Termination

A closure report which indicates achievement of objectives be prepared and presented to the case management team. If the case management team agrees then the case can be terminated.

2.3.10.2 Referral

Referral to other service providers for other services that can not be met.

2.3.10.3 Continued Support

Beneficiary that needs continued support, be linked to relevant programmes.

PSYCHOSOCIAL SUPPORT SERVICES

CHAPTER 3

Individuals who are living with HIV or chronic condition need more support to deal with their emotions as they are experiencing a variety of emotions such as sadness, feeling down, depressed, lonely, sick, and hopeless about the future.

Parents who are HIV positive and those with chronic conditions face numerous challenges in caring for their young children and need support to meet their children's needs as well as their own health and emotional needs.

3.1 Counseling

Adults living with HIV and those with chronic conditions require counseling and helps to:

- Talk and deal with diagnosis, illness, feelings (guilt, anger, hopelessness etc) and challenges that they experience
- Help to understand the circumstances surrounding the diagnosis and illness
- Strengthen coping skills and promote healthy life style and behavior
- Address issues of sexuality, family planning and prevention of HIV infection
- Address reproductive desires and decisions
- Discuss time away from work that one might take due to being ill and implications for job security and earnings need to be discussed
- Explore the way of meeting their needs including their children's needs.

3.2 Disclosure

Most people worry about other family members or public knowing their health status.

3.2.1 Benefits of disclosing the health status

- Individuals should be assisted to understand the benefits of informing specific people about their health status (e.g. Partner, family members, close relatives, friends etc).

3.2.2 Disclosing health status to a partner

- Disclosing to a partner is very important for support. In illnesses like HIV and AIDS disclosure to a partner is imperative for support, for prevention of infection or re infection, to encourage the partner to also test and know his or her status.
- Clients need to be prepared to disclose (how, when to disclose, possible reactions and how to deal with them) ,how to deal with consequences, realities and benefits of disclosing.

3.2.3 Disclosing health status to family and friends

- Willingness to disclose seems closely related to the degree of acceptance or shame associated with that illness. Disclosing one's status can lead to support and acceptance from others rather than exclusion.
- Prepare the client to disclose (how, when to disclose, possible reactions and how to deal with them)

3.2.4 Disclosing health status to children

- The biggest worry for parents and caregivers is telling their children that they are chronically ill or HIV positive. They worry that the child is not ready, will not understand, will be upset, blame parents or themselves, be frightened and start telling other children, family members, neighbours especially with diseases that have stigma attached to it like HIV and AIDS.
- Telling children about health status is the right thing to do. Children need to know what it means to live with illness, how to improve health and prolong life in an age appropriate language. When children have all information they are likely to be supportive with treatment.

3.2.5 Benefits of disclosing the health status to children:

- Help strengthen trust between parent and the child. Children are better able to deal with truth more than we can imagine. They may be sad and go through all normal feelings, afterwards they will be fine.
- Helps to prepare children about possible discrimination that they might encounter due to the parents illness especially if the parent if suffering from HIV and AIDS.

3.3 Supporting the affected children

Children are affected by their parent's health status and become anxious about illness and or death. Parents tend to forget children, become so preoccupied and absorbed with their own health. This often leads to neglect of children.

Often these children go through a variety of emotions which ranges from sad, down, depressed, lonely, unloved, loss, hopeless about the future. Most of the time they are under a lot of stress. Parents needs to be guided and equipped on how to take good care of themselves and still nurture and show love to their children.

3.4 Succession Planning

Decisions on who to take care of the children if something happens to the parent/caregiver needs to be taken early by each and every parent, irrespective of their health status. It becomes more imperative to those who are aware of their health status.

- Adults need to make plans of their lives, right to the end of life, to ensure that loved ones and children are protected e.g. Plan for education, retirement, death, etc.
- Children and young people need to be prepared for the death of a parent, to cope better with grief and loss (children can benefit from grief counseling).
- Counseling of PLHIV, and people living with chronic conditions to disclose their illness to their children may encourage succession planning.

Succession planning covers the following:

- Building memories through deliberately planned activities with children and family members
    - **Building memory boxes, books:** These books or boxes remembers and describes a person's life. This may focus on specific events, periods within person's life. Memory boxes may be used to hold important documents such as birth certificates, wills, etc.
- Documenting family experiences through diaries, albums, videos (within the family resources e.g. Memory books, quilt, etc). **Preparing for the eventuality including death:**

a) Arrangements for children

Who to take care of their children? This involves appointment of a standby guardian. This person will take on the responsibilities for children if the parent no longer able to do so.

b) Asset arrangements:

- What would happen to the property should they die?
- Who would administer their estates?

c) Documentation:

Without proper documentation loved ones and children won't be taken care of, leaving them with a burden of sorting parent's papers.

The following documents need to be kept in a safe place:

- Record of birth from Hospital and clinic card.
- Baptismal certificate.
- Birth certificates of all children
- Inheritance and or will
- Death certificate where one parent has died
- Marriage certificates or family arrangement
- Medical records
- Treatment records

Personal documents:

- Housing documents (title deed)
- Bank, policies, assets, pension and provident funds

d) Funeral arrangements:

Most people don't want to think about funeral arrangements, some with the belief that they are inviting death. Funeral arrangements can be a source of conflict between family members if no clear instruction has been made with specific details.

- Clients must be encouraged to belong to a burial society or have an agreement with the funeral parlor. If one does not have a burial arrangement and can not afford to bury the loved one, a referral can be made to the Municipality to access pauper's burial.

These are the questions need to be asked, and decisions to be made when one is making funeral arrangements:

- Documents that will be needed if one dies?
- Will they be buried or cremated?
- What type of funeral?
- Who will pay for the funeral (burial society or funeral insurance)
- Who to officiate at the funeral?
- Who to say something about you e.g. A friend, family, etc

TREATMENT AND ADHERENCE SUPPORT

CHAPTER 4

Individuals who have started with treatment need more support as they are experiencing a variety of emotions and feeling such as loneliness, fear, hopeless about the future, nervous or anxious, trouble remembering, trouble sleeping, side effects of treatment and if these feelings are left unattended may hamper coping skills, and adherence to treatment. Counseling and support groups can help the client to get in touch with these feelings and deal with them appropriately.

4.1 Community caregiver's support

Community based organisations through Community caregivers provide appropriate care and support to people living with chronic illnesses and are more able to motivate people to go for testing, provide support to the infected and affected, facilitate access to treatment, facilitate a return to treatment or improvement of adherence.

Community based organisations must be linked and develop working relationships with the health centres to facilitate referrals and easy access of clients to treatment. Many people who are on treatment appreciated the support from the community caregivers, who accompanied them to and from the clinic for an HIV test and treatment (Goudge and Ngoma, 2010).

4.2 Strategies to facilitate early identification and access to treatment

- Mobilising individuals, families and communities to go for testing for HIV and other chronic illnesses and to know their health status
- Referral to testing sites for testing for HIV and other chronic illnesses
- Referral for treatment

Facilitate early access to treatment by linking and referring to the treatment centres for clinical assessment and treatment. *NB: TB/HIV clients and HIV positive pregnant women are eligible for treatment with CD4 350 or less (DOH guidelines)*

4.3 Strategies to support adults on treatment

4.3.1 Self Management

Is an essential component of early treatment, as it includes equipping individuals with skills and resources that they need to make changes in their behaviour, lifestyle, health decisions that can delay disease progression and maximize quality of life. Support for self management should be put in place at the earliest possible opportunity. Exposure to self-management strategies is crucial.

4.3.2 Positive Living

Means keeping up hope, feeling good and live the best way possible. Clients need to be helped to live positively with any disease by taking care of their mind, soul and body.

ABC of positive living for people living with chronic conditions:

- Have positive attitude towards life (stay hopeful and positive).
- Expel negative thoughts from your life. Surround yourself with people who have qualities that you want to develop in yourself
- Express your emotions (cry when sad, etc)
- Laugh a lot – laughter has been known to reduce stress (buy a book of funny jokes and read them when feeling low)
- Pleasure seeking activities to avoid stress and burnout
- Recognize that you are special and unique
- Be proactive in dealing with the illness and the future
- Normalising the illness and carrying on with normal life activities, such as continuing with roles in life and in family e.g. Being a wife, husband, mother, father, grandmother, grandfather, brother, sister, etc.
- Integration of the illness into everyday life
- Involvement in illness related activities
- Get up and keep moving – When you fall, move, do not stay down, no matter how difficult it may seem
- Make a habit to encourage yourself and others especially when things aren't going well
- Surround yourself with people who are motivating and inspiring – the chances are it will rub off on you
- Do often what makes one feel better and relaxed. If not sure what makes one feel relaxed ask these questions, make a list of things that make one feel relaxed and check it from time to time:

    - Do you like listening to music, what is your favourite music?
    - Do you like listening to radio, what is your favourite programme?
    - Do you like watching TV, what is the favourite programme?
    - Do you like gardening?

- Do you like going to church?
- Do you like singing; is there a choir you can join?
- Do you like out door activities?
- Do you like cooking, what is your favourite meal?
- Do you like helping other people? Etc.

4.3.3 Coping during the episodes of illness

The family struggles when one family member is sick. **Family support services must be rendered to the family to prepare the family for the episodes of illness and help them cope and support each other.**

4.3.4 Support groups

Encourage adults to join a support groups (refer to the National guidelines on establishment and management of support groups, DSD, 2010). In Goudge and Ngoma, 2010 community caregivers reported that "People who attend support groups are different to those who don't, they are positive, they don't mind being known as HIV positive people, they are free and they don't live in fear".

4.3.5 Adherence support

Treatment to chronic conditions requires adherence. Antiretroviral treatment requires high levels of adherence for the medication to be effective, and to prevent development of drug resistance.

Understanding the reasons for poor adherence and discontinuation of treatment:

4.3.5.1 Individuals decision to adhere to treatment

The decision to comply and adhere to treatment depends on:

- Understanding of health status, what it means
- Understanding how to self manage the illness
- Understanding how to live positively
- Acceptance of health status. Denial can hinder an individuals ability to deal with reality
- The acceptance can be achieved only if the client has been given an opportunity to deal with emotions that are associated with the health status through counseling and support
- Willingness to face the reality, to deal with health status and to do something about it.

How to help the client to face reality:

a) Assess psychological functioning and mental state of the client to fully understand what is going on and the consequences thereof.

b) Provide counseling to help the client to express and deal with emotions and the reality.

4.3.5.2 Side effects of treatment

Most people are scared to start treatment due to the fear of dealing with side effects, and some discontinue treatment because they find the side effects to be unbearable, most cases are reported in ARV treatment.

How to help a client to deal with side effects of treatment:

a) Prepare the client about the possibility of experiencing side effects

b) Provide information on the possible side effects that one might experience

c) Prepare the client on what to do to deal with those side effects

d) Link the client with the support groups, where the client will learn more skills and learn from other peoples experiences.

4.3.5.3 Combination or multi chronic illnesses

Most people who are suffering from more than one illness find it difficult to handle the burden of huge amounts of treatment, in most cases they end up discontinuing treatment e.g. HIV and AIDS and TB (number of pills to swallow, etc).

How to help a client to deal with combination treatment:

1) Prepare the client or refer the client to the treatment sites for guidance

2) Help the client to find possible ways of taking medication, ways that suite clients lifestyle

3) Link the client with the support groups, where the client will learn more ways and learn from other peoples experiences.

4.3.5.4 Family relations and stability

- Assess family relations and family support.
- Unhealthy, unstable family relations, conflicts contribute to failure to adherence
- Support the family to re-establish, re-connect and support each other through counseling, family therapy and life skills to build skills in dealing with family conflict resolution strategies or refer for these services to other service providers.

4.3.5.5 Support Systems

- Explore with the client available support system and assist the client to establish or revive support systems.
- The presence of support systems especially family support encourages individual's acceptance of health status and coming into terms with the illness.

4.3.5.6 Transport and finances to travel to appointment and to collect treatment.

- Most clients are unemployed, have no money to pay for transport costs to honor appointments.
- Most clients because they don't have transport and money for transport, they don't collect treatment and they end up missing their treatment and that impacts on adherence.
- Explore mode of transport used to travel to appointments and to collect treatment (walk, taxi, bus, car, etc).

a) If the form of transport is by feet (walking) – assess the distance needs to be travelled

b) If the form of transport is by taxi, bus, train – assess sources of income, whether the client can afford transport

c) If the form of transport is by car – Assess whether the client owns the car or not, who does the vehicle belong to, can the client afford to put fuel in the car when there is a need to collect treatment.

4.3.5.7 Gender

- Males are associated with being strong, providers and most males find it difficult to seek help and be seen as vulnerable or helpless, as a result access to treatment and adherence to treatment becomes a big challenge. In most cases the social networks of man do not provide the necessary and required support

- Develop strategies to support man provide with appropriate social support

i. Recruiting more male community caregivers

ii. Establishing men's support groups

4.3.5.8 Stigma and Discrimination

- Discriminatory behaviour by friends, family members and community is linked to the possibility of discontinuation of treatment
- Develop a range of strategies to fight stigma and discrimination
- Openness or disclosure diffuse the possibility of stigma, discrimination and associated tension

MATERIAL SUPPORT

CHAPTER 5

It is estimated that 61% of children in South Africa live in poverty (Smart, 2000). It is these families whose conditions will deteriorate with the impact of HIV and AIDS and chronic conditions. Chronic illness as well as caring for orphans and vulnerable children adversely affected food consumption as well as production (SADC, 2003).

Malnutrition is a significant cause of morbidity among children less than five years of age in Africa and is more likely to be present in people living with HIV and other chronic diseases, due to lack of access to food, poor appetite and poor preparation of food.

- Malnutrition is well known to predispose people to develop active TB. Malnutrition and wasting are particular issues for clients co-infected with HIV and TB. The census on Orphaned and Vulnerable children in SA communities revealed that 43% of households had one day of the week where they would not eat any food, mean household income is R1 081.00 of which 60 % of households have an average monthly income of less than R851.00 (HSRC, 2006).
- **Step by step process to help individuals and families to address nutrition needs:**

Nutritional assessment:

- Assessment and identification of nutrition needs with the client
  - Check household meal patterns, and food frequency
  - Explore available foods at home
  - Available foods near home
  - What foods are bought
  - What food are grown
  - Is there access to land for growing food
  - Assess constraints on food preparing
  - Intake of energy and key nutrients
  - Intake of dietary supplements (might include food supplements, vitamin/mineral supplements)
  - Emergency coping strategies
  - Nutrition needs
  - Ability and the extent of meeting those needs.

Developing a nutritional plan

a) Prioritise the nutrition needs with the client
b) Develop a short and long term food support plan
c) Design exit strategy

5.1 Nutritional Counseling

Nutritional counseling refers to an interactive process between the service provider and the client to assess nutritional status, needs, understand client preferences, constraints and plan a feasible course of action that supports healthy nutritional practices. Community Caregivers and other service providers should be trained and encouraged to provide nutrition counseling:

- Give basic information on nutrition (Some clients needs nutrition education to help them select a nutritionally balanced diet from food stuffs available, rather than consuming soft drinks)
- Food handling, preparation and storage (education on food handling, preparation and storage are important in protecting against food borne diseases
- Refer for dietary counseling to the Dietician
- If the client can not meet the nutrition needs, the necessary support needs to be rendered, which might include, but not limited to:

5.2 Food Support

Food security is an essential pre-requisite for adherence to treatment

- Identify those whom food insecurity is a problem and who are in need of food support.
    - Provide food support to all the unemployed and those without grants (food parcels, vouchers, etc).

Over half (15/23) of the respondents reported that they struggled to take the medication due to insufficient food. The pills result in an increased appetite, or hunger if little food is available, and if taken without food, result in nausea or vomiting. One participant described the dilemma of her own increased hunger as compromising the food security of her family ; and another express the depth of hunger created by the pills: 'If I take them on an empty stomach I would be hungry as if I would go mad.' (Goudge and Ngoma, 2010).

Food support can be in the form of food vouchers, food parcels, etc; and is designed for clients:

- Who lack economic means for basic food
- Requires better quality and quantity of food in resource limited settings
- Have been rejected from social grant applications

Advantages of food support programme:

- Improve nutritional status and quality of life
- Improves adherence to treatment
- Encourages TB patients to complete the full duration of their treatment

Challenges associated with food nutrition support programmes:

Clients may fail to collect food due to stigma.

- Alternative arrangements of collecting food should be made.
- Transportation of food to beneficiaries
- Beneficiaries lack money to collect food

5.3 Facilitate access to Social Grants

Those who are eligible to social grant must be assisted by:

- Ensuring that the clients have necessary documentation, if not be referred to Home Affairs
- Refer to SASSA to apply for social grant.
- Those whose social grant application was not approved be linked to food support programme, sustainable livelihoods programmes
- Those on temporary grants be linked to sustainable livelihoods programmes

5.4 Shelter, water, electricity, sanitation

Most of the poorest, vulnerable and marginalized groups in South Africa have no proper housing. These groups are affected by poverty, unemployment; the situation becomes worse when the head of the household or any member of the household is living with HIV or chronic conditions.

- Necessary partnerships with Municipality must be established
- Inclusion of the needs of people made vulnerable by HIV and AIDS and other chronic conditions in the IDP's
- Facilitate prioritisation of allocation of houses, access to services like water, electricity and sanitation.

5.4.1 Transport Costs

Money vouchers or the proposed chronic illness grant could assist in covering the transport costs. Individual living with HIV and or chronic conditions needs financial support to travel to appointment with Service providers, to buy vitamins and healthy food. Most clients are unemployed, have no money to pay for transport costs to honor appointment. Because most clients don't have transport money, they don't collect treatment and end up missing their treatment which impacts on adherence.

5.4.2 Food Production

Participants consume some of their produce to improve their diet and sell any surplus.

Requirement:

- Training of family members (to also act as substitute if the participating member cannot continue with food production or is ill)
- Organise knowledge and skills transfer from older to younger generation in the community
- Provision of micro credit, seed and tools

Examples:

- Home and community gardens (plant variety of vegetables etc)

5.4.3 Income Generating Activities (IGA)

- Aim is to produce food and generate income.

Requirement:

- Training in Income Generating Activities and running of small businesses

IMPLEMENTATION OF THE GUIDELINES

CHAPTER 6

6.1 Institutional Arrangements

Implementing the guidelines requires the involvement of all sectors in rendering holistic and comprehensive psychosocial support services to people living with HIV and AIDS and other chronic conditions. There is a need to ensure that financial resources and technical skills are available to implement the guidelines on psychosocial support for adults living with HIV and other chronic conditions.

6.2 Communication Strategy

The successful implementation of the guidelines on psychosocial support for people living with HIV and other chronic conditions will be facilitated by a well-defined social mobilisation and communication strategy.

The specific aims of this communication strategy are to ensure that all relevant stakeholders, implementing agencies, people living with HIV and other chronic conditions, families and communities are knowledgeable about all of the key provisions. Outreach programmes must include components that strengthen communities to support people living with HIV and AIDS and chronic conditions.

6.3 Resource Mobilisation

Financial resources for the implementation of the guidelines will be mobilised through current and future budget processes of the Department, agencies that provide support and services to people living with HIV and AIDS and other chronic conditions.

6.4 Monitoring and Evaluation

The implementation of the guidelines requires effective monitoring and evaluation with appropriate feedback mechanisms. Implementation of the guidelines will follow a Result Based Model (RBM) outlining programme inputs, process, outputs, outcomes and impact indicators. Monitoring is the routine, daily assessment of ongoing activities and progress.

In contrast, evaluation is the episodic assessment of overall achievements. Thus monitoring looks at what is being done, whereas evaluation examines what has been achieved or what impact has been made.

The Monitoring and Evaluation functions shall be undertaken at all levels to enhance accountability and effectiveness:

- The National together with provincial Departments of Social Development, Partners and other agencies will develop and define indicators consistent with the delivery of the guidelines
- National will oversee the implementation of the guidelines
- Provinces facilitate and monitor the implementation and report on the progress made.
- District coordinate and monitor the implementation and report on progress made
- Local implement and monitor the implementation and report on progress made
- Evaluation of the implementation of guidelines will be undertaken at agreed upon intervals of three to five years from commencement of the implementation of the guidelines.

It will be essential to ensure that there are adequately trained personnel at all levels to manage the M&E function.

6.5 Conclusion

The involvement of all sectors in rendering holistic and comprehensive psychosocial support services to people living with HIV and AIDS and other chronic conditions is crucial. Training of community caregivers should be implemented to ensure that appropriate psychosocial support services and proper referrals are rendered. NGOs, FBOs, CBOs be capacitated on the implementation of the guidelines on psychosocial support for adults living with HIV and AIDS and on other relevant programmes.

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