

MODULE 4

SESSION 1

Compassion, Care and Support: Working With People in Need

Purpose

For participants to learn how to create a compassionate and supporting environment for those in need within their congregations including but not limited to those infected and affected by HIV and AIDS. Once this has been established in the congregation, then participants will learn to extend (scale-up) similar services to the entire community.

Objectives

By the end of the session, participants will have:

- Viewed and discussed examples of congregations responding to HIV/AIDS needs.
- Identified members of the community and congregation currently served.
- Discussed ways they can expand to serve others currently not served (elderly, children, PLWHA)
- Identified ways to reach other community people with need (outreach visits, prayer visits, and congregation families).

Time: 90 minutes

TOPIC	TIMING	METHODS	MATERIALS
“Springs of Life” Video	25 minutes	Video, Viewing & Discussion	“Springs of Life” video, VCR, TV
What can the church/mosque do?	15 minutes	Plenary discussion & Brainstorming	Uniting Reformed Church of S.A.
Who do mosque/church-serve now and How?	15 minutes	Plenary discussion & Brainstorming	Flip charts and markers
Changing policies & priorities; Getting others on board?	15 minutes	Plenary discussion & Brainstorming	Flip charts and markers
Case study “Kofi Addo”	20 minutes	Case Study, Group Work & Plenary discussion	Flip Chart, Markers, Handouts

PARTICIPANT TRAINING MANUAL

CONTEXT

This session is designed to stimulate participants to clearly and distinctly identify their current roles first within their congregations and then scale it up to extend to the entire community. In addition, the participants are given the opportunity to understand that their mandate is larger than their current efforts and begin to see how they fit into the larger community.

ACTIVITIES

“SPRINGS OF LIFE” VIDEO

“A Church Friendly to People Living with AIDS”

List of possible benefits:

- To come to terms with the reality of HIV/AIDS
- Recognise that "everyone" is at risk for infection, including children
- Recognise HIV/AIDS as having disastrous effects, including on people of faith of all denominations.
- Mobilise the churches, Mosques and all people of faith
- "Stand where God stands" - for compassion for the sick and those in need.
- Create a conducive environment for people living with HIV and AIDS to enable them get tested as well as disclose their status so they can get the support and care they need.
- To assure PLWHAs that they will have their support and attend to their needs

THE CHURCH/MOSQUE: WHO ARE WE SERVING NOW?

Who Are We Serving?

- The sick
- The elderly
- The mentally ill
- The widows
- The children
- The bereaved
- The poor
- The orphaned
- The general public
- Those preparing to marry
- People with spiritual problems
- People with marital problems

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How Do We Serve?

- Through the welfare committee – visits, organises financial support
- By giving funeral assistance
- By prayer groups/prayer warriors that pray for the distressed
- Through classes for children (Sunday School)
- Through pre & post marital counselling
- Through youth training programmes
- By developing policies and issues of social concern
- By giving financial support
- By establishing schools
- Through spiritual support
- Counselling services
- Through communal labour
- Through social activities
- By establishing literacy programmes

Many mosques and churches are doing a lot for those in their congregation with all kinds of need. However, when it comes to HIV and AIDS infection, many people of faith begin to moralize, judge and condemn. They tend to forget their values of not judging (an activity reserved for God). They also forget all kinds of teachings on compassion for people of faith.

- The problem is that these services are often restricted to the people **within** the church/mosque and there is a need to extend these services to the whole community.
- Dragons: things that inhibit progress
Some of the dragons in church/mosque include:
 - Policies
 - Changing Church/Mosque priorities
 - A desire to win souls (not a holistic approach) as the mission of the church

The Salvation Army uses a Soap, Soup, Salvation approach as their mission, believing that until they meet/minister to the physical needs of people, they will not be ready to have his/her spiritual needs met. The Salvation Army uses a holistic approach to winning souls.

- In general, churches/mosques do not lack resources. Within most congregations are experts and professionals from all walks of life. The human and materials resources are available to congregations willing to mobilise them to benefit their member as well as their communities. They simply have in place “DRAGONS” (things that stand in the way of getting things done) and must learn to deal with these dragons and get them out of the way.

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CHANGING POLICIES & PRIORITIES; GETTING OTHERS ON BOARD

Possible Ways to Begin to Change Priorities:

- Through the “power of one”. Change is a cascading event that begins gradually then spreads, sometimes fast, other times slow. However, it usually begins with one person who is committed and willing to make the sacrifice to bring about change.
- Often when one decides to change an individual or social norm, that person is viewed as "abnormal" and unpopular. Driven by strong internal convictions, a strong belief and commitment in the rightness of one's cause, others will follow suit. This again can happen slowly (Nelson Mandela versus Apartheid, Mahatma Ghandi versus the British Empire) or very fast (Chinese students protest on Tienamen Square).
- To create such changes, one has to be ready to pay or make necessary sacrifices (sometimes with their lives). No change is easy and all changes take time.

Example: At one time, at the death of a loved, Ghanaians in general all had wake-keeping services. They continued that way for years until one person decided not to do it. Then others decided not to do it. Now, some churches (Presbyterian and Methodist) have policies in place that there will be no wake-keeping as part of their funeral rites.

You may have to stand-alone initially when promoting the need for HIV/AIDS compassion, care and support, etc. However, over time, as support increases and the cause becomes popular more people will come on board.

Ways to Get Others On-Board:

A single individual or a small core group of individuals can certainly initiate the work of changing social, cultural and religious norms. However, there is strength in large numbers. It is effective to seek as many supporters for a cause as possible. So, those who believe in the cause will have to become spokespersons or advocates for the cause. They have to go around and convince others that there are better ways of viewing the issues, or better ways of getting things done. Such people who believe and wish to convince others will need to:

- Let people in the church know that you are available as a person of faith to help, serve, care for and support those in need, including those living with HIV and AIDS.
- Reinforce that God/Allah receives and does not reject those in need no matter what the source or cause of the need. God does not discriminate, and people of God should not discriminate. God shows compassion to all in need and people of God should do the same.
- Provide an enabling environment for those in need to come for prayers, fellowship, compassion, support and care.

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- Associate with the PLWHAs. Do things with them. Treat them like you would treat your family, friends and colleagues.
- Gain the trust of the people in the larger community and the PLWHAs
- Identify with the PLWHAs, accept and welcome them
- Do not judge nor condemn PLWHAs. Do not moralise their predicament. All PLWHAs are loved ones and should not be treated differently.

The church/mosque should make it clear that their role is to bring souls back to God/Allah by providing a comfortable and nurturing environment. It is not the church/mosque's role to judge and condemn.

CASE STUDY: "KOFI ADDO"

Questions for group discussion:

1. What will happen to Kofi Addo?
2. What will happen to his job?
3. What will happen to Kofi's family?
4. Who are affected by Kofi's HIV status?
5. What support roles are available to Kofi, his family, and his parents?

CASE STUDY

Kofi Addo is a 35 year old married man with two daughters and a son. He works for a shipping company in Accra and has been promoted to a supervisory position. He and his wife plan to have a fourth child – with hopes that it will be a boy.

Mr. Addo is also supporting his parents who live in the village. Kofi considers himself lucky, because while his parents are elderly, they are healthy. But with his new promotion, he is planning to get a young girl to live with his parents in the village to help them with daily chores.

Kofi is also active in his church. He contributed a large sum of money for the new church expansion that was recently completed. Kofi is also a trained mason and during the church expansion, he spent his weekends helping the carpenters and bricklayers. His wife Anna sings in the choir, so the Addo household attends church regularly.

Kofi has just completed his annual medical examination and is excited to begin his new role as supervisor. What Kofi does not know, is that he has tested positive for HIV.

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DOCUMENT FROM <http://www.rca.org/mission/africa/south/aids.php>

Uniting Reformed Church of South Africa Declares Itself "A Church Friendly to People Living with AIDS"

As AIDS continues to ravage sub-Saharan Africa, the Reformed Church's partners there are making a difference and taking a stand in solidarity with people who have HIV/AIDS.

Though some in the churches and many in society have tended to ignore or downplay the seriousness of the pandemic, the leadership of the RCA's partner churches in Malawi, Ethiopia, and South Africa continue to courageously confront the disease and call the church to minister to those with HIV/AIDS in Christ's name.

The Uniting Reformed Church of South Africa recently passed the following statement on HIV/AIDS:

URCSA statement on HIV/AIDS

The Church of Jesus Christ must come to terms with the HIV/AIDS pandemic. As a church we have no choice. No community that claims to be founded on the principles of the ministry of Jesus Christ has a choice. In obedience to our Lord, the head of the Church, we will follow Him where He will lead us in the fight against HIV/AIDS.

The URCSA ACKNOWLEDGES

- That the HIV/AIDS pandemic is having a disastrous impact on thousands of individuals and families in Southern Africa and in the URCSA. What pain, suffering, loneliness, rejection, and prejudice people living with HIV/AIDS must endure!
- That HIV/AIDS is not only somebody else's problem; it is also ours.
- That we, the body of Christ, also have HIV/AIDS.

The URCSA BELIEVES

- That Christ came that all may have life in abundance.
- That Christ calls his church to be the Light and the Salt of the world.
- That Christ calls us His Church to be a caring and compassionate community.

The URCSA CONFESSES

- That we have not always showed support and love for people living with HIV/AIDS as we should have. We ask for forgiveness for our lack of love and understanding.
- That the church as God's possession must stand where God stands with those who are living with HIV/AIDS and against discrimination, rejection, and prejudice against people living with HIV/AIDS (Belhar Confession).

The URCSA therefore declare ourselves a Church friendly to people living with HIV/AIDS.

The URCSA CALLS upon church leaders and congregations to:

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- Create an environment in each congregation and institution of the URCSA conducive for members living with HIV/AIDS to, freely and without condemnation, declare their HIV/AIDS status.
- Empower themselves to deal effectively and compassionately with people with HIV/AIDS, by doing the following:
 - Speak openly about the HIV/AIDS pandemic.
 - Set up support groups and home-based care.
 - Arrange training sessions on HIV/AIDS, especially on counseling.
 - Address the issue of AIDS orphans.
 - Encourage voluntary testing.
 - Pray regularly for people living with HIV/AIDS and those who are affected.
 - Cooperate with relevant stakeholders in the fight against HIV/AIDS.

As a matter of prevention the URCSA CALLS on church leaders and members to

- Abstain from irresponsible sexual activities.
- Respect the Christian view of marriage and be faithful to their (marriage) partners.
- Follow safer sexual practices.

The URCSA ASSURES all people living with HIV/AIDS that we will

- Support and love them with sincere Christian compassion.
- Provide counseling.
- Attend to their physical needs.

The URCSA is making this statement, conscious of the fact that the example of Christ's caring and compassionate ministry, calls us to stand, in the midst of the HIV/AIDS pandemic, where He stands: with those who are living with HIV/AIDS.

As the Uniting Reformed Church in South Africa and other RCA partners in sub-Saharan Africa commit to minister to the physical, emotional, and spiritual needs of people with HIV/AIDS, they need our help. Their commitment is great, but their resources very limited.

If you would like to support these churches in this ministry, please send your contribution, made out to the Reformed Church in America and designated for "Battling AIDS in Africa," to:

Reformed Church in America
PO Box 19381
Newark, NJ 07195-1938
or

Reformed Church Centre
RR #4
Cambridge, ON N1R 5S5

MODULE 4

SESSION 2

Compassion, Care and Support: Creating a Compassionate Congregation

Purpose

Participants discuss ways to create a compassionate and supporting congregation to support those in need.

Objectives

By the end of the session, participants will have:

- Described the make up of their congregation
- Identified opportunities for support within their congregation.
- Identified barriers to establishing support within their congregation.
- Discussed ways to bridge the gaps between the opportunities and the barriers.

Time: 90 minutes

TOPIC	TIMING	METHODS	MATERIALS
Who is in our congregations	15 minutes	Plenary discussion	Flip charts and markers
What opportunities exist (funds, committees, youth and women's groups, etc.)	20 minutes	Plenary discussion	Flip chart and markers,
What barriers exist (conservative wing, moralists, rich and powerful individual)	25 minutes	Group Work, Plenary discussion	Flip charts and markers
Closing the gaps (how to bridge the divide between opportunities and barriers).	30 minutes	Plenary discussion	Flip Chart, Markers,

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CONTEXT

This session is designed to enable the religious leaders to examine their church/mosque membership. This session will also help them identify members of their congregations who could serve as resources as well as those who present barriers towards achieving their goals of providing a compassionate, supporting and caring roles for community members in need.

ACTIVITIES

WHO IS IN OUR CONGREGATIONS?

- Healthcare providers (Physicians, Nurses, Social workers, etc.)
- Legal practitioners (Judges, Lawyers, etc.)
- Community Elders (cultural leaders, community stakeholders).
- Artists
- Business people
- Traders
- Construction workers
- Labourers, etc.

WHAT OPPORTUNITIES EXIST?

Internal Opportunities

Identify those within the congregation who may be considered positive role models and pillars of the church/mosque. These are the major stakeholders whom the clergy depends on to carry out much of the church/mosque programmes. These members are not only financially active but provide both moral and social leadership in the church.

External Opportunities

Identify individuals as well as organisations outside the church/mosque that support programmes. These are traditional partners that may include a range of people and institutions from traditional rulers to bookstores and schools.

WHAT BARRIERS EXIST?

Types of barriers could include:

1. Church Policy
2. Church Priorities
3. Insufficient knowledge about HIV/AIDS
4. Attitudes towards PLWHAs
5. Resistance to condom use and other safe sex methods
6. Misinterpretation of the Bible and Qur'an teaching relative to HIV
7. Moralistic view of faith based organisations towards HIV
8. Tendency to separate evangelical from social issues

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Internal Barriers:

While many members of the congregation are supportive of the church/mosque itself, they may be opposed to new programs that they consider inappropriate for the church/mosque to undertake. This is especially so for programs that deal with HIV and AIDS. These individuals in the congregation may take the view that this disease affects only the immoral or they may not accept the new role that the church/mosque must play to help stop the spread of the disease.

Their opinions are powerful and influential with the congregation and their concerns must be addressed fully in order for the church or mosque to have success in its new undertaking. One way to address this is to provide them a forum through which to express their views, ask questions and hear them out. This will also provide an opportunity for clergy and his/her allies and supporters to educate these members. Often people oppose church associations with HIV because of the myths of the disease, whereas, if they understand that many people are at risk and that God accepts all people without judgement they may understand better the role that the church/mosque must play.

External Barriers:

Clergy might examine individuals as well as organisations outside the church/mosque congregation that may oppose their associations with people in need, especially those infected or affected by HIV. These may include the more conservative members of their congregation or church affiliates.

CLOSING THE GAPS

a) Approach/Strategies

1. Education at all levels
2. Advocacy
3. Giving a human face to the problem
4. Effective use of suggestion boxes
5. Strengthen existing structures
6. Openly embrace PLWHAs
7. Praise families who acknowledge their loved ones are infected
8. Open Dialogue
9. Experience-sharing by PLWHAs and PABAS
10. Developing a policy document on HIV/AIDS
11. Establish HIV/AIDS Fund (Be aware of issues surrounding:
 - a) disbursement of these funds
 - b) question of sustainability
 - c) families left behind after the death of a PLWHA)
12. Contemporary interpretation of Scriptures (Bible and Qur'an) and use of commentaries
13. Group and individual Bible/Qur'an studies
14. Encourage functional literacy in church /mosque

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b) Allies

1. Health personnel
2. Social workers
3. People infected with HIV/AIDS (PLWHAs) and People Affected By AIDS (PABAS)
4. Agencies already working in HIV/AIDS field – NGOs
5. Others who understand the issues
6. Clergy
7. Lay-leaders
8. Congregation
9. Local small businesses who might have a positive policy re-HIV/AIDS
10. Auxiliaries (functional groups in congregation – youth, women etc)
11. Religious scholars

c) Adversaries

1. People who lack knowledge
2. People who uphold culture and tradition
3. People Living with HIV and AIDS (PLWAs)
4. Immediate family of PLWHAs (PABAS)
5. Co-workers
6. Those who control the church/mosque resources/funds

The role of religious leaders in the community is to serve the people of God/Allah in their need. These include those who are suffering, those who are in pain, those who have experienced losses.

The people of God/Allah are one and all. They do not necessarily have to belong to a specific church or mosque to have these needs or to have these needs met by those who are pledged to the service of God/Allah and his people.

Our communities are diverse, with different people who have different needs. While we are directly pledged to serve our church/mosque members, we are also pledged to serve our communities and all within it.

HIV and AIDS is a disease that knows no religious boundaries. Many people in the communities are affected in different ways. For example, a man who is infected with the disease places his wife at risk of infection, if they continue to have marital sex (without protection). If the man becomes sick, the family income and financial support is diminished. The children may be withdrawn from school as a result. And more money is needed to spend on his medical treatment. The family may stop attending religious services. Their tithing to the church/mosque will also be affected. The parents of the man may be forced into helping out financially or with childcare or even with farm work to generate more food for the family.

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With this single-family example, we have shown that while one person is infected by HIV many people in the family, the community and church/mosque are also affected. All of these people and structures need support and help.

So, as religious leaders, we must expand our scope of the community and congregation.

MODULE 4

SESSION 3

Compassion, Care and Support: Identifying needs and resources in the community

Purpose

For participants to identify the needs of community and the resources that exist within the community. The resources include church-related and non-church related resources. Some of the non-church related resources could include local organizations, NGO, government entities, etc.

Objectives

By the end of the session, participants will have:

- Discussed ways to identify those with needs in their community.
- Discussed ways to identify resources in the community.
- Discussed the differences between church-related and non-church related resources and how to avail themselves of these resources.
- Identified ways to connect those with needs and the resources that exist in the community.

Time: 60 minutes

TOPIC	TIMING	METHODS	MATERIALS
Needs existing the community	20 minutes	Group discussion	Flip charts and markers
Resources found in the community	20 minutes	Group discussion	Flip chart and markers,
Connecting community needs with community resources	20 minutes	Group discussion	Flip charts and markers

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CONTEXT

This session is designed to stimulate participants to think about the needs of their congregations, congregation families and social networks. Participants are also expected to examine the resources that exist within their congregations and their communities. Finally, participants are expected to identify some of the best mechanisms for bringing need and resources together for greater community good.

ACTIVITIES

COMMUNITY NEEDS

“Who in our congregation and in our community has a need?”

- The elderly
- Those who are sick
- The poor
- The widow, etc.

Congregational need:

In this case, the religious leader is compelled to work from inside (the congregation) to outside (the community). Often, many members of a church/mosque confide their needs to religious leaders. Sometimes, these are done mostly in confidence and can range from the physical to the spiritual.

Congregational needs are not always readily apparent or brought to the attention of the religious leaders. For example, the reasons a member stops coming to church may not be clear to church members or the religious leaders. While some people may stop coming because they are sick or busy, others who are sick may stop coming because they do not feel welcome in the church. If the Church doctrine has condemned those who have HIV in the past and has regarded them as immoral, a member who becomes HIV positive may choose to stop coming, feeling that he is no longer accepted in the church/mosque.

Community need:

We have discussed the idea that churches and mosques are part of a larger community, and as a result must be responsive to the needs of the community outside of its congregational membership. This means that a church/mosque has a larger role to play, much like a school, in providing for the needs of the community. It must be the church/mosque role to reach out to the greater community and provide care (e.g. physical), support (e.g. emotional) and compassion (e.g. spiritual) for those who are sick, and in need.

How this aspect of the church/mosque responsibility is carried out depends on the resources and communities, which they find themselves. But the broad notion

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is one where the church must look beyond its membership to provide services to those in need, regardless of their affiliation with the church/mosque.

AVAILABLE RESOURCES

For churches and mosques in urban areas, their list of resources, organisations and partners might be more extensive than churches and mosques in rural communities. However, the fact is that there are many organisations that would be happy to collaborate with and are natural partners to churches and mosques. These partners would be happy to collaborate with churches and mosques in their efforts to provide services for those in need.

Discussion Points

Within many communities, there are resources that religious leaders can use to achieve their goals of providing compassion, care and support for those in need. Some of these resources include local schools and teachers, local hospitals, clinics and providers who work in those settings. In both rural and urban settings, one cannot overlook the powers of traditional leaders in mobilising the communities and helping build consensus. Because diseases like HIV affects young people disproportionately, traditional leaders see a need to save their constituents in the prime of their productive years as well as the future of their communities. The same applies to religious leaders who must view the community as the future of the church. If HIV/AIDS is unchecked in our communities, the numbers of people who attend churches/mosques and help build these institutions will be greatly diminished over time.

CONNECTING NEEDS WITH RESOURCES

Within the church/mosque membership are all types of skilled and unskilled resources and people whose interests include the preservation of their communities. Within the churches/mosques are doctors, nurses, lawyers, teachers, engineers, scientists, etc.

More often than not, the organisations, institutions, businesses, hospitals and schools that these people work in are not too far from the churches and mosques. There are also government agencies as well as non-government organisations which are capable of providing material and non-material support to churches and mosques that choose to undertake these caring, compassionate and supportive programs for community members in need.

It is the responsibility of the religious leaders to outline the needs to church members and encourage them to identify and utilise whatever skills and resources they have to assure the success of the programs that the church/mosque undertakes. It is also the responsibility of the religious leaders to ascertain that community and cultural leaders support these programs.

MODULE 4

SESSION 4

Compassion, Care and Support: Getting and Maintaining Community Support

Purpose

For participants to learn how to create partnerships with their communities in order to provide compassion and support for those in need.

Objectives

By the end of the session, participants will have:

- Identified ways of generating community support.
- Discussed ways of maintaining community support.
- Identified appropriate community and cultural partners who can support church/mosque-based programs.

Time: 60 minutes

TOPIC	TIMING	METHODS	MATERIALS
Generating the support of the community.	10 minutes	Group work, brainstorming, Plenary discussion	Flip charts and markers
Maintaining the support of the community.	10 minutes	Group discussion	Flip chart and markers
Networking with community and cultural leaders	15 minutes	Group discussion	Flip charts and markers
Experience sharing by participants	25 minutes	Group discussion	Flip Chart, Markers

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CONTEXT

This session is designed to enable the religious leaders to examine ways of generating and maintaining the support of community as well as the support of cultural leaders. The session will explore advocacy roles of religious leaders to both community and cultural leaders who may not always be in agreement with the new role of the church.

ACTIVITIES

GENERATING COMMUNITY SUPPORT (FOR CHURCHES AND MOSQUES PROGRAMS)

Participants are expected to take the discussion lead for this session. Many religious leaders negotiate relationships with community leaders on a regular basis. While each community may be different, the ways of building these connections with communities are very much the same.

The experiences of religious leaders in each of their various communities will be unique and informative. Hence, it will be helpful for all participants to share their views and experiences.

MAINTAINING COMMUNITY SUPPORT

There are several competing issues within a community. HIV and AIDS is only the latest of these issues. These issues are pressing right now because it is affecting so many people within the communities. However, HIV and AIDS compete with issues of poverty, hunger and malnutrition, lack of medical services, lack of infrastructures, etc. All of these issues are inter-related. An effort focused on one does not necessarily detract from the other. So, it is necessary that cadres of competent advocates are available to focus community attention to the emerging issues of HIV and AIDS that is affecting diverse groups within the community.

Advocacy leads to partnership. Perhaps, religious leaders should invite community partners to meetings in their churches and mosques to show publicly that these partners are committed to the causes of providing support for those in need.

These partners should be publicly recognised and appreciated and rewarded with token gifts (certificates, plaques, etc). Religious leaders must share credit generously for any registered successes.

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(The experiences of the religious leaders are instructive and helpful here. As their roles include gaining the support and trust of their parishioners, they have to network with community and religious leaders.)

As times change, there may be shifts in the alliances. HIV and AIDS has caused a big shift in religious, community and cultural norms. The impact and consequences of HIV and AIDS infections have forced community norms to be changed. In an effort to respond to these changing norms, some stakeholders may feel threatened or unhappy with the changes.

This whole shift calls for new thinking, new solutions and perhaps new alliances. With this effort, religious leaders are undertaking yet another leadership role in providing for the needs of their congregations and communities. Again lessons learned from those who have successfully navigated these shifting times will be instructive and welcome.

NETWORKING

“Who are community and cultural partners for churches and mosques?”

Community partners:

School teachers

Healthcare providers (doctors, nurses, social workers, chemical sellers)

Business persons

Lawyers

Non-governmental organisations (NGO)

Cultural partners:

Chiefs and their council

Community elders

Women leaders

Youth leaders or youth serving organisation

EXAMPLES OF ONGOING PARTNERSHIPS

Many communities have the ability to partner with existing organisations that share their goals and vision. If it is two churches or a church and a mosque, they represent unique entities that will attract the attention of other individuals or associations within the communities.

Each community is unique, but they have certain characteristics in common. Each community has a person living with or affected by HIV and AIDS, a central faith (Christian, Muslim, or traditional religion), community stakeholders and decision-makers, etc. When one person is affected with HIV and AIDS, many others related to that individual are similarly affected.

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Hence, the cascading relationships that HIV and AIDS engenders mandates the need to maintain a broad view of issues regarding HIV and AIDS, and to seek partnership in changing behaviours, and assure that prevention and risk reduction programs are effective, particularly for young people.

MODULE 4

SESSION 5

Home Based Care

Purpose

The main objective of this session is to provide participants with basic information on Home-Based Care.

Objectives

By the end of the session, participants will have:

- Discussed Home Based Care
- Examined practical ways of providing Home Based Care
- Discussed ways that Home Based Care providers can protect themselves from HIV
- Outlined ways of integrating Home Base Care into Religious Institutions

Time: 90 minutes

TOPIC	TIMING	METHODS	MATERIALS
Overview of Home Based Care	15 minutes	Presentation Discussion	Flip charts and markers
Practical Ways to Provide HBC	25 minutes	Plenary discussion & Brainstorming	Flip charts and markers
Self Protection and HBC Provider	20 minutes	Plenary discussion & Brainstorming	Flip charts and markers
Integrating HBC into Church/Mosque	20 minutes	Plenary discussion & Brainstorming	Flip charts and markers
Summary	10 minutes	Highlight main points	Flip Chart, Markers,

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CONTEXT

Increasingly as health care costs rise and the public health system is overloaded, more families must care for family members and loved ones living with AIDS. This session introduces participants to some basic principles and practices needed for effective Home Based Care.

ACTIVITIES

HOME BASED CARE

The aim of this session is to provide participants basic information about Home Based Care (HBC) and to discuss its aim, principles and practices. If possible, invite a person who has been involved and has experience in Home Based Care to provide information and insight to participants.

Home-Based Care is the care of a sick person at home. This care is provided by family members or volunteers, in collaboration with professional health care providers. Home-Based Care is becoming much more common throughout Africa, both because hospitals cannot meet the high demand for care of AIDS patients, and also because many AIDS patients cannot afford hospital care.

Aims of Home-Based Care

- (1) To ensure that people receive basic nursing care as well as social and emotional support. HBC is a holistic approach to health care.
- (2) To promote acceptance of people with HIV.
- (3) To reduce the demand for AIDS care in hospitals.
- (4) To integrate care with HIV education.
- (5) To mobilise more people to provide support.
- (6) To reach sick people who are not using health services
- (7) To enable health workers to make home visits
- (8) To train volunteers, families and communities (including PLWHAs) in basic nursing care and infection control

Most of the time, AIDS patients do not need to be in a hospital. However, Home-Based Care given to a person with AIDS is not the only care that the person will need. It is part of a continuum of care, which includes clinics, hospitals and other health professionals.

Family members and volunteers cannot provide the same level of care as trained health professionals, but they can be taught to provide good nutrition and to help with hygiene and personal care. If possible, the volunteers should receive some basic training before beginning to care for a person living with AIDS (PLWHA).

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PRACTICAL HOME BASED CARE

The aim of this activity is to explore ways that Home-Based Care can be administered by caregivers.

Types of Care:

Personal care

Home-Based Care providers can help with a patient's personal care in the following ways:

Physical:

- Giving medications
- Changing bed sheets
- Bathing patients and helping them to go to the bathroom
- Feeding patients
- Preventing stiff joints and bedsores by helping bed-ridden patients to change positions frequently and by adjusting their pillows and blankets
- Helping patients to do simple arm, leg, hand and foot exercises. These help to prevent stiff, sore joints and improve blood circulation
- Treating basic ailments, such as diarrhoea, sore throat, headaches, skin sores and coughing
- Maintaining a hygienic environment to prevent the spread of infections
- Obtaining professional medical help when needed

Psychosocial:

- Providing emotional support
- Counselling
- Companionship
- Stress Relief
- Promoting positive living and health behaviour
- Inspirational songs
- Entertainment

Spiritual:

- Prayer
- Reading
- Songs of Praise
- Visiting
- Memory boxes (stories, thoughts, what they want to leave behind for their children, photographs, letters to friends, family, objects of value they want to pass on). If the person is illiterate, they can dictate to someone or be taped (audio/video).

Palliative Care – defined as relief of pain to make one to feel better and more comfortable (by providing drugs, by singing or praying, etc.); temporary relief for the sick.

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Economic Care – Income Generating Activities

The Home-Based Care family provider must remember that s/he is not alone in this care. S/he must be in contact with the doctor, nurse, social worker and other health care workers who are also providing care. The medical team should give clear, written information about the medications. The family health care providers should also be helped to understand the changes expected in the condition of the PLWHA. For example, the beginning of a cough, diarrhoea, or confusion may mean an infection or problem that needs a new medicine or hospital care.

The **Goal of HBC** is to provide holistic care.

When does it start?

Day of diagnosis whether or not the case is being managed at the hospital. One should remember that it is not just for the terminally ill, but for the person who has just been diagnosed as HIV positive also.

Who should provide HB Care?

- Immediate family
- Extended family
- Friends
- Community
- Church members

Skills Needed:

Treatment of pressure areas, bed-making, changing dressings, etc.

Diet: It is important to prepare high calorie diets including nutritious foods (fruits, vegetables, etc.)

Personal Hygiene: It is important for the caregiver to protect him/herself and to use plastic bags or gloves

Medication & Referral:

Look at the size, shape, colour and markings of drugs to be sure to identify them well. Be sure to identify any medications or indications on the medication that requires a call for referral.

SELF PROTECTION OF THE HOME BASED CARE PROVIDER

The aim of this activity is to explore ways that Home-Based Care providers can protect themselves using locally available supplies.

Providing care to PLWHA means **guarding against infections**, both for the PLWHA and for the caretaker. As mentioned above, it is unlikely that a caregiver will contract HIV, as long as s/he is following universal precautions. It is possible to get other infections, however.

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Home-Based Care providers should make sure that their *immunisations* are up-to-date. This is not only to avoid contracting an illness from an AIDS patient, but also to prevent spreading illness to the person with AIDS. Children or adults who live with someone with AIDS and who need to get vaccinated against polio should get an injection with the “inactivated virus” vaccine. The regular oral polio vaccine contains the live poliovirus, which can spread from the person who got the vaccine to the person with AIDS.

Everyone living with a person with AIDS should also be checked for tuberculosis (TB) every year.

Gloves and hand washing play an important role in protecting caregivers from both transmitting and receiving infections. Rubber gloves should be worn in the following scenarios (in the absence of these, use plastic bags over the hands):

- Whenever the caregiver is exposed to body fluids of a PLWHA, including blood, urine, saliva and sexual fluids.
- Whenever caring for a PLWHA with diarrhoea
- Whenever the PLWHA has blisters or sores around the nose, mouth or genitals.
- When the caregiver has a skin rash, such as eczema or ananse

Many persons with or without AIDS are infected with a virus called cytomegalovirus (**CMV**), which can be spread in urine or saliva. Washing hands or wearing gloves is extremely important after touching urine or saliva from a person with AIDS. This is crucial for a pregnant woman because a pregnant woman infected with CMV can also infect her unborn child. CMV causes birth defects such as deafness.

Needles and syringes need to be disposed of safely in puncture-proof containers. This will prevent accidental needle sticks, which could infect the caregiver with HIV or other diseases. Needles and syringes should be used only once. Caps should not be put back on needles, and needles should not be taken off syringes. If a needle falls off a syringe, tweezers, pliers or another similar instrument should be used to pick it up. The sharp end of a syringe should always be held away from the caregiver's body. All of these materials should be kept out of the reach of children.

Any **liquid waste** containing blood (such as urine or vomit) must be flushed down the toilet or thrown down a latrine. Items that cannot be flushed down the toilet should be put in plastic bags or wrapped in enough newspaper to stop any leaks (i.e. paper towels, sanitary pads and tampons, wound dressings, bandages and diapers). They should then be thrown away in a container where other people cannot easily come into contact with them, and/or burnt.

If the Home-Based Care provider is also a **sexual partner** of the PLWHA, s/he should be tested for HIV, and the couple should always use condoms when having sex.

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Useful Supplies

Following are some supplies that are helpful to have in the home when caring for an HIV-positive person who is very sick and bedridden¹.

- Plastic sheeting for the bed
- Rubber gloves
- Walking Aid
- Face mask for colds (for the provider to wear)
- Radio
- Bedpan or bedside commode (chamber pot)
- Plastic urinal made from an old container

INTEGRATING HBC INTO THE CHURCH/MOSQUE

The aim of this activity is to explore ways that Home-Based Care can be integrated into the normal/daily activities of the church/mosque.

HOW TO INTEGRATE HBC INTO THE CHURCH/MOSQUE?

- Train group to undertake HBC regularly
- There should be sensitisation and education about HBC
- Encourage volunteers to participate and receive skills training
- Churches and mosques should set aside funds
- Contributions in-kind to support HBC
- HBC should be made one of the responsibilities of the church/mosque welfare committee
- Strengthen the visitation groups of the church/mosque who already have a mandate to visit the sick and shut-in
- Set up income generating activities to support HBC

Emotional Support

AIDS causes stress for both the patients and their caretakers. Taking care of someone who is sick can be hard emotionally as well as physically. It is often helpful for caretakers to talk with other caretakers, either informally or through religious organisations or support groups.

Care of the Caregiver:

The caregiver/s will be under stress, especially after prolonged care giving. It is important to give this person relief if they are to continue to give care or they may get burnt out.

Care for the Dying:

The church/mosque and the family should discuss this thoroughly.

¹ Granich, R. 1999. *HIV, Health & Your Community : A Guide for Action*. Stanford, CA (USA) : Stanford University Press.

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Bereavement & Grief Counselling:

Starting life again.... Continuation of care for those left behind.

Care of Orphans and other vulnerable children:

In cases where parents are too ill to care for the children, they may need alternative arrangements to be made for care. Sometimes, a member of the extended family (grandparent, etc) may be needed to provide care and support.

Testimonials to examples of HBC/support

In Kenya, the Methodist Church has a guesthouse and at the guesthouse they have a box at the receptionist area for contributions in any amount. Anglicans have the same thing in Kenya. Some churches have the "charity box" designated for contributions. Some churches take up a special offering for "welfare" whenever communion is given.

Muslims have established giving programmes, but what must be done now is for lobbying for specific monies to be set-aside for HBC to be done. The Catholic priests are very responsive to any calls for assistance in this area without regard to the person's religious beliefs or affiliation. One Catholic sister would take clients to a home in Ashaiman and provide holistic care (feeding, clothing, medicine, etc.) but now the home is too full to add additional persons. Also, the Centre of Hope and Catholic Relief Services provide similar services but there are challenges in regard to food rationing, etc. In Catholic hospitals, they provide care free of charge but they receive no government support and some of the hospitals are threatening closure because the work and the needs are overwhelming, putting undue stress and strain on human, financial, in-kind and other resources (many centres are being made to respond to thousands of people/needs each week).