

Facilitating Familial Support of Saudi Arabians Living with HIV/AIDS

Noor Attar

Abstract—This paper provides an overview of the current situation of HIV/AIDS patients in the Kingdom of Saudi Arabia (KSA) and a literature review of the concepts of stigma communication, communication of social support. These concepts provide the basis for the proposed methods, which will include conducting a textual analysis of materials that are currently distributed to family members of people living with HIV/AIDS (PLWHIV/A) in KSA and creating an educational brochure. The brochure will aim to help families of PLWHIV/A in KSA (1) understand how stigma shapes the experience of PLWHIV/A, (2) realize the role of positive communication as a helpful social support, and (3) develop the ability to provide positive social support for their loved ones.

Keywords—HIV/AIDS, Saudi Arabia, social support, stigma communication.

I. INTRODUCTION

THERE is significant stigma related to HIV/AIDS in the KSA and it affects both the patients and their nuclear families. HIV/AIDS related stigma can have negative physical and psychological effects including depression, hypertension, coronary heart disease, and stroke [16]. Research also shows that stigmatized individuals may not seek medical treatment [12]. There is also research that indicates that stigma affects individuals who have close connections with the stigmatized and is called vicarious shame [11]. Lickel et al. [11] state that vicarious shame and guilt reactions are stronger in collectivistic cultures such as KSA rather than individualistic cultures. Therefore, family members of PLWHIV/A in KSA are also likely to experience stigma and this can impact how they treat the PLWHIV/A. Because of this stigma, information about how to understand and manage communication stigma and how to provide social support would provide helpful guidance for Saudi families of PLWHIV/A. This paper argues for the importance of creating an educational brochure about positive communication between HIV/AIDS patients and their nuclear families. After providing background information about HIV/AIDS in KSA, we will justify the paper based on the high amount of misinformation and stigma about HIV/AIDS in KSA. Next, we will turn to the communication research on stigma and social support to understand how communication between patients and their families can reduce stigma and provide social support. Finally, we will discuss the proposed methods, which seek to develop the text of a brochure for the nuclear families of HIV/AIDS patients in KSA to address this need.

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II. HIV/AIDS IN SAUDI ARABIA

The number of PLWHIV/A is a problem worldwide [23]. The UNAIDS organization indicates in 2012 there were 35.3 million PLWHIV/A. According to the Saudi government and the UN statistics, the rate of PLWHIV/A is low in KSA; however, this may be due to a problem of underreporting [3]. In 2011, the rate of AIDS in Saudi adults from the ages of 15 to 49 was 0.4% [1]. Seventy-seven percent of HIV-positive Saudis were males, and most HIV/AIDS patients are from the three major Saudi cities [4].

Although the prevalence of HIV/AIDS in Saudi Arabia is low, there is a serious problem due to a lack of knowledge about the disease and a high degree of stigma associated with it. This is despite the fact that Islamic doctrine prohibits stigmatization of the ill. Half of the general public surveyed did not have much knowledge about HIV/AIDS [2]. Even more concerning, many have misinformed views of the disease, especially related to its transmission; for example, some believe that it can be transmitted by mosquito bites, sharing food utensils, shaking hands, coughing or sneezing, and sharing toilet seats [2]. Badahdah's research [4] about college-age Saudi males indicated that more than half believed they could recognize PLWHIV/A from their appearance and that kissing on the cheek could transmit it. Abolfotouh et al.'s research [1] about knowledge of Saudi nursing students also revealed many misconceptions about the transmission of HIV. For example, the nursing students believe that the disease could be transmitted through use of the same toilets and bathrooms or washing clothes together, swimming, or coughing and sneezing.

The misinformation about how HIV/AIDS is transmitted leads to stigmatization of PLWHIV/A in KSA [4]. AIDS-related stigma refers to negative feelings toward and negative treatment of those with HIV/AIDS. Such feelings frequently result in discrimination or mistreatment of PLWHIV/A and their nuclear families. Mistreatment may include insults, avoidance, and isolation [4] and results in emotional and physical problems for patients and their nuclear families [2].

Badahdah [4] found that Saudi college students who knew less about HIV/AIDS were more likely to stigmatize PLWHIV/A than those who knew more. Also, more than half of Al-Ghanim's respondents indicated that they would end their friendship with persons infected with HIV/AIDS [2]. In addition, more than a quarter of the respondents agreed with the statement that PLWHIV/A should be kept away from public places such as schools and workplaces.

Badahdah [4] shows that shame is a significant emotion for Arabs and that it affects their perspectives about PLWHIV/A.

Saudi students connect AIDS with shame and believe that AIDS is a moral-religious issue not a health condition. Results of [1] with Saudi nursing students indicated that while they had an average level of knowledge about HIV/AIDS, they believed PLWHIV/A deserve what has happened to them. More than half of the students in the study indicated that PLWHIV/A were responsible for their infection, and 75% believed that AIDS is a punishment from God.

Family members of PLWHIV/A have significant stigma that can negatively impact how they treat their family members. Badahdah [4] indicated that 72.3% of the students said that they would be ashamed if a relative was diagnosed with HIV. Also, 68.4% of participants agreed that having PLWHIV/A in KSA is shameful.

The official religion of KSA is Islam. Approximately 95% of the population identify as Muslims [23]. Therefore, discussion of and solutions to the problem of stigmatization of PLWHIV/A must take into account the Islamic principles and beliefs. Gray [9] explains that Islamic sexual codes are significantly different than Western sexual codes. In Islam, both males and females are prohibited from having sex outside marriage including homosexual practices. In addition, [1] explains that many Muslims believe that following Islamic rules will protect them from AIDS. As a result, practicing Muslims may not be aware of the possibility that they could contract the disease through blood transfusions or other behaviors that are not related to sex outside of marriage. These factors likely underlie the stigmatization of PLWHIV/A in KSA since others see the disease as a mark of sin.

In summary, despite a low prevalence of HIV/AIDS in Saudi Arabia, there is a problem related to a lack of knowledge and significant stigma connected to this disease. This leads to poor treatment of PLWHIV/A. PLWHIV/A and their families often suffer from shame due to Islamic sexual codes and the stigma surrounding the disease.

III. CONCEPTUAL FOUNDATIONS

Communication can be instrumental in both challenging stigma and supporting those dealing with significant illness. In the literature review, we will discuss the concepts of stigma management communication and social support to provide an understanding of the types of communication that can be helpful to manage the stigma facing PLWHIV/A and their families. As we will argue, these literatures justify the importance of creating educational materials for family members of PLWHIV/A so that they can be equipped to better support their loved ones.

IV. STIGMA AND COMMUNICATION

From a communication perspective, [20] defines stigma as a social construction or a shared concept of community members about how to react to individuals who are seen as threatening. Misinformation about how HIV/AIDS is transmitted can facilitate stigmatizing communication about PLWHIV/A. This reaction can affect the stigmatized person's quality of health and even length of life. Social constructions

necessarily involve communication and therefore change in communication about the stigma of HIV/AIDS in KSA is one way to assist HIV/AIDS patients and their nuclear families dealing with the stigma.

Smith [18] defines stigma as the disgrace of a person or groups of persons that is fostered by a community. She proposes four types of content cues used to differentiate the stigmatized: (a) marks (cues that make stigmatized individuals quickly recognized), (b) group labels (names for a group of persons that draws attention to and differentiates them from others), (c) ascribed responsibility (content cues that imply that the stigmatized have chosen their condition), and (d) ascribed peril (content cues magnify the dangers of the stigmatized to others). These four ways of communicating (labeling, marking, ascribing responsibility, and ascribing peril) are how stigma is constructed through communication. By attaching labels to the stigmatized, it makes it possible for the community to easily differentiate the person from the non-stigmatized. Thus, understanding how labels reflect stigma is important to be able to avoid stigmatizing communication between family members and PLWHIV/A. For example, ascribing responsibility for the stigmatizing situation changes the reaction to the stigmatized person. Communities will judge the stigmatized more harshly, if they believe they are responsible for their situation, than those who are not responsible for their situation. Thus, misinformation about transmission of HIV in KSA will lead to stigmatization. Additionally, [21] indicated that perceived dangerousness of a stigmatizing disease is a strong predictor of interpersonal stigmatization. This indicates the importance of educating family members and the general public in KSA about HIV transmission so they are less likely to stigmatize PLWHIV/A.

It is important to understand how labels can increase or decrease stigmatization. How we refer to those with HIV/AIDS, for example, can impact the extent to which they are stigmatized. Labels for PLWHIV that are to be avoided—because they would likely lead to greater stigmatization—include referring to PLWHIV/A as patients (as opposed to persons), infected (as opposed to living with), and as having AIDS (without mentioning HIV). One significant example of the change in labeling persons with HIV has happened since the mid-1990s. At that time, these persons were referred to as persons with AIDS (PWA) in academic literature [5]. After that time, effective medical treatment makes it possible to *live* with HIV. As a result, academic literature now refers to these people as PLWHIV/A. Because this new label implies that HIV is no longer certain cause of death, the new label is less stigmatizing. As a result, we have chosen to use the label PLWHIV/A instead of PWA in this proposal. It will be important to incorporate into the educational brochure understanding the concept of labeling PLWHIV/A and how it can reduce or further stigmatization.

Meisenbach [13] describes stigma as a discrediting mark based on a physical, social, or moral situation. Stigma communication implies that the stigmatized persons may be responsible for being part of this separate group. Stigma communication includes emotional reactions to the

stigmatized person such as disgust, anger, and fear. The social construction of stigma can motivate discrimination against the stigmatized.

A. Stigma Management Communication Theory

Meisenbach [13] proposes a Stigma Management Communication Theory (SMC) to assist individuals to manage the result of stigmatization. She describes stigma communication as the behavior of both the stigmatizer and the stigmatized. The stigmatizer will label, mark, and assign responsibility to the stigmatized. The stigmatized person's response to the communication depends on two factors: First, possible acceptance or resistance of the public's belief that the stigma is real, and second, possible acceptance or resistance of the application of the stigma to self. Meisenbach [13] proposes a typology of different ways the stigmatized respond to—or manage the stigma—based on these two factors. These management strategies are summarized in Table I and will be explained in the following paragraph.

TABLE I
SMC STRATEGIES

	Accept stigma applies to self	Challenge stigma applies to self
Accept public understanding of stigma	Accepting	Avoiding
Challenge public understanding	Evading and Transcending	Denying

Adapted from [13]

The resulting stigma management strategies are accepting, avoiding, denying, evading, and transcending. Meisenbach [13] proposes that those who manage stigma by *accepting*; behave in the following ways: passive acceptance such as not commenting on the stigma; disclosing the stigma or engaging in the stigmatized behavior; apologizing or asking for forgiveness; using self-deprecating humor such as telling jokes that focus on the stigma; isolating self or limiting communication with others; or blaming the stigma for all other personal problems. Meisenbach [13] proposes that those who manage stigma by *avoiding* behave in the following ways: hiding the stigma or keeping it secret, avoiding stigmatized situations in which the public could attribute stigma to them; stopping behavior that may be associated with the stigma; distancing self from stigma in order to separate identity; or making favorable comparisons of self to other stigmatized by indicating that the others are inferior. Third, those who manage by *denying* behave in the following ways: simply or logically denying the existence of the stigma—for example, by stating that there is no stigma or providing logical reasons that there is no stigma—or ignoring the stigma and continuing to display it. Finally, those who manage by *evading* behave in the following ways: acting in a provocative way such as blaming others; accepting defeat; or attempting to reduce offensiveness of stigma. Or, they may respond by *transcending* the stigma, which means identifying it with a positive outcome and by reframing the stigma in a way that challenges the public understanding. This means the person

attempts to confront the current public understanding of the stigma and create a new understanding.

In summary, [13] proposes that whether a stigmatized person accepts or challenges the public's understanding of the stigma and that the stigma applies to him or herself will determine which communicative strategy he or she will choose. Meisenbach [13] believes that this typology can be taught to individuals who encounter stigma communication. For example, education about SMC can be provided to those diagnosed with HIV and their families by practitioners that assist stigmatized individuals in finding new ways of managing stigma based on this typology. Due to the low level of knowledge about the HIV/AIDS and the high prevalence of stigma related to it in KSA, PLWHIV/A may find it difficult to challenge the public's understanding of this stigma. In order to change the current social construction of HIV/AIDS in KSA, it will be necessary for patients and their families to learn to challenge it by choosing the communicative strategy of *transcending* and *reframing* the stigma. *Transcending* and *reframing* represent the best ways of managing this stigma because patients and their families can then challenge the current public understanding and feel empowered to identify it with a positive outcome. In other words, in responding to stigma communication the hope is that families can transcend the stigma by learning about social construction and truly understanding its role in stigma communication and learning how to reframe discussion about this disease.

B. Stigma and Communicating Social Support

Social support in the context of HIV/AIDS is especially important because of the stigma and discrimination associated with this disease [15]. A significant amount of research shows that social support helps people successfully cope with HIV/AIDS [7], [8]. Social support is defined as interpersonal interactions that manage emotional concerns or provide aid and information [8]. Goldsmith [7] defines social support as "... the things people say and do for one another that can buffer individuals from the negative effects of stress by facilitating coping" (p. 3). From a communicative point of view, social support can be viewed as the observable features of talk that happen within a close relationship [17]. The success of social support is determined by the recipient's evaluation of that support [7]. Smith [21] proposes that stigmatization occurs in interpersonal encounters such as those that happen in supportive communication. Thus, helpful social support can provide opportunities to reduce stigmatization [19].

Features of social support used for a wide variety of illnesses have been analyzed to differentiate those that are helpful from those that are unhelpful [19]. Goldsmith [7] compiled 23 studies to define specific social support behaviors as either helpful or unhelpful. See Table II for a complete listing of these findings.

There is also specific research about social support for PLWHIV/A. Pakenham [15] found similar helpful behaviors. Nurturing—expressing love and concern through physical, verbal, or behavioral acts—was the most frequently way to

show positive social support. Both researchers also described listening or being a confidant as helpful. In other words, having someone who listens empathically is very helpful for PLWHIV/A. Another helpful behavior is being encouraging, which means having an optimistic attitude about the possibility of returning to a normal life. Accepting or interacting naturally—not treating the person differently than before he or she received the diagnosis of HIV/AIDS—was also determined to be helpful. Finally, both studies found that companionship—simply spending time with the person—was very helpful. On the other hand, [15] found that some behaviors were particularly unhelpful when communicating social support to PLWHIV/A. Acting in a judgmental manner or being unaccepting was considered unhelpful because it can suggest that the person is at fault for the illness. Being over protective—by doing things like controlling the patient's finances or medical care or forcefully offering advice—was also found to be unhelpful. Finally, disclosing patient information—such as the patient's HIV status—to others without permission was considered unhelpful.

TABLE II
HELPFUL AND UNHELPFUL FORMS OF SOCIAL SUPPORT

Helpful Forms	Unhelpful Forms
Mere presence, increased attentiveness	Avoided contact, too little concern, wouldn't communicate or listen
Companionship, involved in social activities, did special things	Minimized, questioned severity of condition, didn't recognize difficulty
Opportunity to talk and vent, listened	Encouraged recovery, told about others' positive experiences
Expressed love, concern, empathy, affection	Gave care without emotion or incompetent care, lack of assistance
Showed loyalty	Rude, insensitive remarks
Understood, calmly accepted condition, made accommodations or allowances	Criticism, verbal attacks, hostile acts
Pleasant, kind	Blamed other for condition, lack of acceptance
Reassured, encouraged, praised abilities	Said "I know how you feel"
Respected autonomy	Unhelpful emotional support
Showed honesty	Overly concerned, overprotective, catastrophized consequences, expressed fear, underestimated knowledge or competence
Information, advice	Competence
Contact with similar other, positive role model	Tried to control situation, manipulate, had divided loyalties
Provided philosophical or religious perspective	Unwanted tangible support, interferences
Optimistic prognosis	Unwanted discussions of problem or prognosis
Provided practical assistance, competent care, financial support	Patronized, pitied
Engaged in coping, problem solving	Information, advice
Treated normally	Provided too little information
Talked about other topics	Poor role model
Encouraged distance and self-restraint	Negative attitude or beliefs about condition, disagreed with action
	Seemed uncomfortable
	Provided philosophical perspective

Excerpted from [7].

One way of communicating social support to PLWHIV/A is through compassionate communication. Miller [14] defines compassionate communication as ways of focusing on others in order to help them overcome adversity. She proposes a model of compassionate communication that includes three steps. The first step is noticing, which is not only paying attention to the person but also actively gathering information to understand the person's situation. The second step is feeling

or connecting, which involves making a relational connection to the person. The final step is responding in both verbal and nonverbal ways that communicate compassion. Similarly, [24] and [22] proposed a model of communicating compassionately with three sub-processes: 1) recognizing, 2) relating, and 3) re (acting). First, recognizing means noticing what is said and what is not said and understanding the meaning behind the communication. That is, the person who wants to communicate compassionately may have to actively attempt to elicit information and be sensitive to its meaning. Second, relating involves experientially connecting to the person's pain and suffering. Finally, the core component of compassionate communication is reacting, which means behaving or communicating in compassionate ways. Thus, one important way for families to offer social support to their loved ones is to understand and use compassionate communication processes.

In summary, research indicates that social support is especially important for PLWHIV/A and from a communicative perspective it happens through observable features of interpersonal talk. Certain behaviors that were identified as helpful for PLWHIV/A include: nurturing, listening, encouraging, accepting, and providing companionship. Unhelpful behaviors have been identified as: judging, failing to accept, overprotecting, and disclosing information without the patient's permission. Several Islamic principles for caring for the ill are similar to the helpful behaviors identified by research and are useful for helping families of PLWHIV/A in KSA.

V. ISLAMIC PRINCIPLE FOR CARING THE ILL

In addition to Western research about social support, Islamic doctrine also provides information about treatment of illness. Because of the social context of KSA and its deep ties with the Islamic religion, PLWHIV/A and their nuclear families will be most receptive to information that comes from Islamic doctrine. In other words, advice from the Islamic perspective may be more comprehensible to Saudi Arabians and can be used to frame the information about social support above.

Esack [6] has produced a workshop manual for educating Muslim communities about the relationship between Islam and HIV/AIDS. There are Islamic concepts related to treatment of and communication with the sick that are especially helpful for discussing the issue in a way that reduces the stigma surrounding it. It is significant that Islamic doctrine prohibits stigmatizing people through actions or speech and prohibits ascribing reasons for the causes of others' illness. In addition, Islamic doctrine requires care for those who are ill by praying for them and asking them to pray for you. Moreover, Muslims are required to visit the ill.

Esack [6] also describes sections of the *Sayings of the Prophet* (a book used by Muslims as a source of Islamic laws and tradition) related to helping Muslims communicate with PLWHIV/A and introduces six concepts that can be applied. The first concept is "Compassion not scorn." This means that Muslims should not mistreat any person even if he or she is

poor, sick, hungry, or homeless. The second concept is "Patience not judgment." This means that Muslims should not discriminate against PLWHIV/A. The third concept is "Humility not self-righteousness." This means that Muslims should not feel superior to PLWHIV/A. The fourth concept is "Justice not injustice". This means that Muslims should not treat PLWHIV/A unfairly or stigmatize them. The fifth concept is "Acceptance not looking down on others". This means that, communication can be used to hurt or help those who are different and should be used in a helpful way. Finally, the sixth concept is "Knowledge not ignorance". This means that Muslims should educate themselves about PLWHIV/A. These Islamic doctrines can be related to some of the helpful social support behaviors described in the academic research above. Academic research encourages acceptance rather than stigmatization of PLWHIV/A [15], which is similar to the Islamic doctrines of avoiding stigmatization, showing patience not judgment, and being compassionate not scornful. The Islamic doctrine of visiting the sick aligns with the importance of providing companionship in facilitating helpful social support: The other helpful support behaviors can provide useful guidance for Islamic families of how to best support their loved one during such visits. The Islamic doctrine of praying for the person who is ill and allowing him or her to pray for the visitor includes elements of the helpful behaviors of both listening and providing religious perspective. In order to best influence a Saudi audience, advice from this Islamic perspective will be the best ways to frame the information about social support for PLWHIV/A.

VI. PURPOSE AND PLAN

Based on the high prevalence of stigma of PLWHIV/A in KSA, the negative effect that stigma has on PLWHIV/A, and the positive impact that social support can have for PLWHIV/A, the best hope for managing the stigma related to HIV/AIDS in KSA is to encourage family members of PLWHIV/A to communicate in ways that reduce and reframe the stigma around HIV/AIDS and that provide helpful social support to their loved one. Therefore, families of PLWHIV/A in KSA would benefit from information about how to reframe the stigma around HIV/AIDS and enact social support for their loved ones. The purpose of this paper is to develop an educational brochure for the families of PLWHIV/A in KSA. The brochure will draw upon communication research on stigma and social support as well as the Islamic principles mentioned above for the treatment of the ill.

A. Beneficiaries

The primary beneficiaries of this research will be family members (spouses, parents, children, and siblings) of PLWHIV/A in KSA for whom the brochure will be designed. Family members are often primary caretakers for PLWHIV/A and will have the biggest possibility to help them understand and manage stigma and to provide helpful social support. Secondary beneficiaries will be the PLWHIV/A as well as health-care providers, who benefit from having educational materials to distribute to patients' families. Such materials

may prompt discussions between care providers and family members as well as introduce sensitive topics during medical encounters. The goals of the brochure are to enable family members of PLWHIV/A in KSA to: (1) acknowledge how to reframe stigma surrounding HIV, (2) recognize the role of positive communication in facilitating useful social support, and (3) improve the positive attitude of families to support their loved ones living with HIV.

B. Methodology

The previously reviewed research literature that discusses the types of communication that facilitate and undermine stigma and social support will provide one foundation for the development of the educational brochure. The material about Muslim principles related to responding to the sick will also be central. Another important basis for the development of the brochure will be a review of the materials that are currently being distributed by health-care providers and governmental agencies in KSA to PLWHIV/A and their family members. The following brochures will be translated and analyzed:

- Arabic-English Translation for HIV/AIDS brochure from King Saud Hospital containing information about counseling and social support for PLWHIV/A distributed in 2008 (Appendix A)
- Arabic-English Translation for HIV/AIDS brochure from KSA Ministry of Health containing basic information about HIV/AIDS distributed in 2008 (Appendix B-1)
- Arabic-English Translation for HIV/AIDS brochure from Saudi Charity Association for AIDS Patients distributed in 2014 (Appendix B-2)
- Arabic-English Translation for HIV/AIDS brochure from KSA Ministry of Health containing basic information about HIV/AIDS distributed in 2008 (Appendix C)
- Brochure from Saddiqa Maternity & Children Hospital containing basic information about AIDS transmission distributed in 2008 (Appendix D)
- Brochure from Khalid Idress Hospital containing information about Occupational strategy to HIV distributed in 2008 (Appendix E)
- Arabic-English Translation for HIV/AIDS brochure from Saudi Charity Association for AIDS Patients distributed in 2014 (Appendix F)
- Arabic-English Translation for HIV/AIDS brochure from Saudi Charity Association for AIDS Patients for media producers distributed in 2014 (Appendix G)

We will conduct a qualitative textual analysis of these brochures that are currently distributed to determine the audience, content, and tone. These brochures will provide an understanding of current communication in KSA with PLWHIV/A and their families. The goal is to evaluate what materials would complement what is already available. As we analyze the brochures, we will ask the following questions:

1. Who are the audiences for the brochures?
2. What types of material are included in the brochures?
3. What is the tone of the brochures?
 - a. How do the brochures reduce stigma of PLWHIV/A?
 - b. How do the brochures further stigmatize PLWHIV/A?

In order to complete the textual analysis of these brochures we will first immerse ourselves in the data and will then conduct inductive line-by-line, first level coding with the purpose of identifying codes that reflect: the intended audience, the content covered, and the tone of that content. After this first level of coding, we will then conduct secondary coding to categorize and synthesize the data and compare it to the academic concepts explained in the literature review of SMC theory and helpful social support to determine whether the brochures reduce or further stigmatization of PLWHIV/A and reflect helpful social support behaviors [10], [22]. This information will provide possible examples of helpful content and messaging that can be replicated in the brochure, as well as possible examples of unhelpful content and messaging to avoid in the brochure. More importantly, it will help us determine what material is missing, especially related to communicating stigma and social support.

C. Outcomes

This research has two outcomes:

1. Written report of the results of the textual analysis: As a result of the textual analysis of the current material distributed to PLWHIV/A and their family members in KSA, we will prepare a brief report describing the results. That report will not only report on the findings related to the research questions above, but will also articulate what findings suggest in terms of the content and tone of the brochure we will develop for family members of PLWHIV/A in KSA.
2. Textual content of the new brochure: We will also create the textual content of the new brochure. For the purposes of this professional project the content will be in English. This content will be later translated into Arabic.
3. Guidelines for distribution of brochure to families of PLWHIV/A: We will provide recommendations about the most appropriate situation for distributing the brochure. The brochure should be given to family members by a medical professional at a medical encounter after family members have been tested negative for HIV/AIDS.

VII. TEXTUAL ANALYSIS OF BROCHURES DISTRIBUTED TO PLWHIV/A AND THEIR FAMILIES IN KSA

Because of the high prevalence of stigma, its negative effects, and the possible positive impact of social support, one way to manage the stigma for PLWHIV/A in KSA is to provide educational brochures to family members about communicating in ways that reduce and reframe the stigma and that provide helpful social support. An important basis for the development of brochure is a textual analysis of the educational materials that have been distributed in the past by health-care providers and governmental agencies in KSA to PLWHIV/A and their family members. This analysis will discuss: 1) the audiences for the brochures; 2) the types of material included in the brochures; and 3) the tone of the brochures; specifically, how the brochures potentially reduce stigma of PLWHIV/A as well as further stigmatize PLWHIV/A.

We have analyzed brochures that were distributed to PLWHIV/A and their families by health care providers and governmental agencies in KSA in 2008 and in 2014 and looked for themes that emerged inductively. The goal was to compare these themes to the academic concepts of SMC and helpful social support to determine whether the brochures reduce or further stigmatize PLWHIV/A and if they reflect helpful social support behaviors. We will discuss brochures from 2008 separately from those distributed in 2014 because of differences in how the sets of brochures furthered or reduced stigma: Brochures distributed in 2014 provided more information related to social support and themes encouraging reduction of stigma towards PLWHIV/A. Significant social changes in KSA between 2008 and 2014 may account for these positive changes in these brochures. In 2006 the new Monarch initiated several liberalizing reforms such as holding elections for municipal leaders for the first time. In 2010 women were included for the first time as members of the Consultative Assembly of Saudi Arabia that is the organization of citizens that advise the King [25]. Also the King encouraged education and exposure to foreign countries to modernize the country. As a result of scholarship programs 130,000 Saudis are studying around the world, we believe that these liberalizing reforms account for the changes that we observed in the 2014 brochures [26].

A. Analysis of 2008 Brochures

The brochures distributed in 2008 were made for the target audiences of possible HIV/AIDS patients, families, and co-workers. The content of these brochures included explanations of counseling, testing, how AIDS is and is not transmitted, how to recognize a person with AIDS, and the idea that PLWHIV/A might not admit their status.

The 2008 brochures contain the theme of "stigmatization" including the ideas of confidentiality and stigmatizing vocabulary and pictures. We interpret confidentiality as stigmatization of HIV/AIDS because it indicates that the people seeking information about HIV/AIDS will need to keep their search secret. For example, brochures at this time included phrases about those being tested for or searching for information about HIV/AIDS such as: "strictly confidential", "not necessary to provide identification", "voluntary" and "you do not have to be examined unless you want to". All brochures in 2008 included stigmatizing language referring to PLWHIV/A such as: "infection", "rejection", "contaminated", "risky behaviors", and "drug addicts". Some of the 2008 brochures also contained stigmatizing pictures such as a young boy covering his face with his hand, babies crying, and a picture of a hypodermic needle. The picture of a young boy covering his face symbolizes shame. A baby crying symbolizes possible illness or pain and a hypodermic needle symbolizes drug addiction or a need for medical help. All these images contribute to stigma being related to HIV/AIDS. Importantly, none of the pictures of people in the 2008 brochures wore typical Saudi clothing (an abaya for women and thawb and ghutra for men). In other words, the people shown in these brochures do not look like Saudis, which

implies that Saudis do not have this disease and that non-Saudis bring it into KSA. This theme demonstrates the stigmatization of HIV/AIDS for Saudis and supports [4] finding that 72.3% of respondents said that they would be ashamed if a relative was diagnosed with HIV and 68.4% agreed that having PLWHIV/A in KSA is shameful. In summary, the content of the 2008 brochures furthered the stigma of HIV/AIDS and did not provide any information about understanding stigma or managing it or any example of positive social support.

B. Analysis of 2014 Brochures

In contrast to the 2008 brochures, the 2014 brochures did include some social support suggestions as well as themes of awareness of the international movement to reduce stigma and include PLWHIV/A in decision-making about disease treatment and policies. Some of the brochures distributed in 2014 were also made for the target audiences of patients and family but also included some specifically targeted at medical caregivers, and media producers. The 2014 brochures included content about how to respond to PLWHIV/A in a humane way and encouraged open discussion of the topic of HIV/AIDS. For example, the brochure that targeted media producers requested that media cover the topic of HIV/AIDS in ways that encouraged sympathy from readers. Specifically, the media brochure requested that media producers write about treatment of PLWHIV/A and respecting human rights as well as highlighting the fact that PLWHIV/A can live. An example of the theme of social support in the 2014 brochures included suggestions to support PLWHIV/A “psychologically, socially, and financially”. By stating this overtly the brochures promote PLWHIV/A as deserving of sympathy rather than stigma. Importantly, one brochure indicated that the Saudi Charity for AIDS Association had adopted the GIPA (Greater Involvement of PLWHIV/A) principle in order to respond to PLWHIV/A in a humane way. The GIPA principle advocates encouraging involvement of PLWHIV/A in making decisions about their political, social, and legal treatment that portrays them as deserving of sympathy rather than stigma. There are also significant phrases that encouraged reduction of stigma of PLWHIV/A such as: “avoid stereotyping PLWHIV/A as: low economic status, specific racial group, specific cultural group, specific religious group, drug users, or bad Muslims.” This type of comment encourages readers not to see PLWHIV/A as different or dangerous and, as a result, deserving social support and sympathy.

In terms of pictures of the 2014 brochures, one brochure contained a picture of a male wearing Saudi clothing, not showing his face (the fact that the male’s face is not shown indicates that there is a need for confidentiality) and with his back toward a female. The female was wearing Saudi dress that is worn outside of the home and not showing her face (this is typical for Saudi women in public). Both male and female have clenched fists, which indicates possible stress, fear, or anxiety. Unlike the 2008 brochures these new brochures used pictures of Saudis that indicates more

acceptance of the possibility that Saudis could have HIV/AIDS.

By analyzing the 2008 and 2014 brochures distributed in KSA, we conclude that there has been a reduction in the stigmatization of PLWHIV/A and some inclusion of material about the importance of social support. However, none of the brochures provide any concrete, practical suggestions about ways to encourage supportive communication about the disease between PLWHIV/A and their family members or how to assist family members in understanding and mitigating the stigma of HIV/AIDS and PLWHIV/A. It is encouraging that newer brochures show awareness that PLWHIV/A deserve social support and sympathy; however, there is still a need to provide specific information about how to communicate in concrete, practical ways. That is the goal of the brochure that we will develop for professional project.

VIII. TEXTUAL CONTENT OF THE EDUCATIONAL BROCHURE “HOW CAN YOU SUPPORT YOUR LOVED ONE WITH HIV/AIDS?”

This brochure is for loved ones of PLWHIV/A in the KSA in order to help them (1) learn about positive communication and helpful social support, (2) understand how stigma shapes the experience of PLWHIV/A, and (3) learn how to provide positive social support and deal with stigma related to HIV/AIDS. The social context of KSA and the Islamic religion require that the brochure use the Islamic perspective to frame the contents and give it credibility. Islamic and Saudi customs used in the brochure include: 1) references to Muslims use the pronoun “we” and references to the audience use the pronoun “you” and 2) quotations from the Quran are written between double parentheses.

The brochure should be distributed directly to the loved ones of PLWHIV/A by a health care professional in a private setting once the family member has tested negative for HIV. After the professional project has been approved, the author will translate the brochure into Arabic and collaborate with professional graphic designers in KSA to develop the layout. Visuals may include photos of males and females wearing typical Saudi dress to reflect the intended audience. The author will contact the Health Ministry of KSA to secure funding to produce and distribute the brochure.

Overview of the content of the six-panel tri-fold brochure:

- 1) Panel one engages the reader and explains the purpose of the brochure.
- 2) Panel two acknowledges the feelings of the loved ones (such as fear, mixed feelings, and being overwhelmed), the need to be tested for HIV/AIDS, and further engages the reader.
- 3) Panel three informs the reader of the Islamic call to care for those who are ill and seek to support a loved one with HIV/AIDS.
- 4) Panel four informs the reader how to provide positive social support and describes three steps for communicating compassionately.

- 5) Panel five helps loved ones understand and mitigate the stigma of HIV/AIDS and PLWHIV/A by using Islamic principles and SMC.
- 6) Panel six reiterates the central concepts and provides information about sources of confidential and reliable assistance related to HIV/AIDS in KSA.

– Panel 1 –Cover Panel

Goal: The goal of text on panel one is to engage the reader by showing a male and female in typical Saudi dress communicating and by posing the question that the brochure will answer as shown in Fig. 1.

How can you support your loved one with HIV/AIDS?



Fig. 1 Example of Support

– Panel 2 – Acknowledging Loved One's Feelings

Goal: The goal of text on panel two is to acknowledge the feelings of the loved ones, which may include fear, mixed feelings, and being overwhelmed, and to acknowledge the need to be tested for HIV/AIDS. This panel also seeks to engage the reader and motivate them to read the rest of the brochure.

If your loved one has recently been diagnosed with HIV/AIDS, then you likely recognize the feelings of fear, betrayal, and uncertainty reflected above. While it is very important that you be tested for HIV and learn how HIV is transmitted, family members also need guidance in how to best love and respond to their loved one given the ways that HIV/AIDS is often misunderstood and stigmatized. This brochure explains how you can support your loved one by interacting with him or her in ways that help them feel loved and that will reduce the stigma associated with HIV/AIDS.

– Panel 3 –Islamic Principles for Care for the Ill as shown in Table III

Goal: The goal of text on panel three is to inform the reader of the Islamic call to care for those who are ill and persuade the reader to seek to support their loved one with HIV/AIDS.

How should we as Muslims respond to people who are ill?

The Prophet Mohammed (sallallahu `alayhi wa sallam) says:

"Visit the sick and follow the funeral, for these will keep you mindful of the Hereafter."

"Whoever visits a sick person immerses himself in mercy, and when he sits there he sinks down into it."

➤ Does Islam encourage us to support our loved one with HIV/AIDS?

Islamic doctrines encourage us to support those in need. Accept rather than stigmatize your loved one; show compassion not scorn. Keep in mind what Islam teaches about visiting the sick to provide companionship. Always include your loved one in your prayers. Ask your loved one to include you in his/her prayers.

TABLE III
ISLAMIC PRINCIPLES FROM THE QURAN AND THE HADITH FOR TREATING THE ILL

Islamic Principle	How this principle is related to treatment of PLWHIV/A
Compassion not scorn	Muslims should treat the sick, including PLWHIV/A kindly
Patience not judgment	Muslims should not discriminate against persons living with HIV/AIDS
Humility not self-righteousness	Muslims should not feel superior PLWHIV/A
Justice not injustice	Muslims should treat persons living with HIV/AIDS fairly
Acceptance not looking down on others	Muslims should communicate supportively to PLWHIV/A
Knowledge not ignorance	Muslims should educate themselves about HIV/AIDS

– Panel 4 – Social Support and Compassionate Communication

Goal: The goal of text on panel four is to inform the reader about how to provide positive social support and describe the three steps of communicating compassionately. This will also be connected to the Islamic principles on panel 2.

➤ How can you communicate compassionately with your loved one?

After you learn about a HIV/AIDS diagnosis it might be difficult to communicate with your loved one. You can easily learn how to communicate in a way that will support your loved one: first, listen; then, understand; and finally, respond. See Table IV.

1. **Listen:** Start by listening to and looking at your loved one. Think about your body language: make eye contact, sit close to the person, show respect with your face, and make physical contact in a way that is comfortable to you and your loved one. Try to read your loved one's feeling at that moment from his or her face and ask questions that will help you understand your loved one's feelings. You might simply ask "How are you today?" If you realize that your loved one does not feel like talking at that time, wait for a better time.
2. **Understand:** If your loved one is ready to talk, first you need to actively listen. You can do this by nodding and avoiding judgmental expressions. Ask what your loved one is experiencing. Try to connect to your loved one's feelings. Imagine yourself in your loved one's place.
3. **Respond:** When your loved one pauses, you should respond with compassion by letting your loved one know that you will be supportive. You can express your compassion and support by simply being there, listening, and making physical contact in a way that is comfortable to you and your loved one

Always keep in mind what our prophet teaches us about the ways to respond to the sick: pray for them and visit them. When you follow the prophet's teaching you will be helping your loved one manage his or her situation in a positive way.

TABLE IV
SOCIAL SUPPORT AND COMPASSIONATE COMMUNICATION

Supportive Behaviors	Unsupportive Behavior
Nurturing	Being judgmental
Express love through your words and actions	Only God can judge, stay away from blaming
Listening	Being over-protective
Be a confidant: try to put yourself in your loved one's place	Encourage your loved one to help him or herself as much as possible
Encouraging	Disclosing information about your loved one
Be optimistic about returning to normal.	Only speak about your loved one's diagnosis with professional caregivers or people whom your loved one has decided to tell
Accepting	
Treat your loved one the same as before the diagnosis	
Being a companion	
Spend time with your loved one	

– Panel 5 – Managing Stigma

Goal: The goal of text on panel five is to help loved ones understand and mitigate the stigma of HIV/AIDS and PLWHIV/A by using Islamic principles and stigma management communication.

((Men and women who are good Muslims must not stigmatize or ridicule others. In the sight of God, a person's faith and actions make that person honorable or dishonorable and God will judge them based on their faith and actions. Those who stigmatize or ridicule others are the dishonorable))
Surah 49. Al-Hujurat, Ayah 11

➤ What is stigma?

When people stigmatize others they might mark or label them as different or blame them and say they are dangerous. Your loved one is not dangerous. You can hug, share a meal with, or use the same facilities as your loved one. Further, given the treatments available for HIV, those with HIV/AIDS will continue to live normally. Stigmatization of others is not acceptable in our religion and if your loved one is stigmatized, it can affect his or her health. Talk to a professional caregiver to learn the facts about HIV/AIDS.

➤ How can you avoid stigmatizing your loved one?

The prophet encourages us to accept and not stigmatize others. You must accept your loved one; your acceptance will help others to accept him or her. How you talk about your loved one is key for avoiding stigmatization. You should avoid language that labels your loved one as dangerous; for example, do not call your loved one a patient or refer to him or her as infected. Most of the time you should refer to your loved one without referencing the illness; when you do refer to your loved one or others with HIV/AIDS, you should use the phrase "person living with HIV/AIDS" to avoid further stigmatization and reiterate that people with HIV/AIDS continue to live normal lives. When you talk with your loved one, communicate compassionately by listening, understanding, and responding. This may be difficult to do at first, but it will become easier, if you remember the prophet's teaching: "Patience not judgment."

➤ How can you deal with stigma?

The first way to deal with stigmatization is to keep information confidential. It is not necessary to speak about your loved one's HIV status with anyone who is not a professional caregiver. If you or your loved one encounters stigmatization, remember that no one but God can judge. God will only judge faith and actions. You and your loved one can deal with stigma by rising above other people's comments and knowing that God does not accept stigma and ridicule of others. You and your loved one can deal with stigma by staying calm, responding positively, and offering more information, if possible.

1. Stay calm: If someone insults you or your loved one, control and deescalate your emotions before you respond. Since you know that your loved one is not dangerous, it will be easier to stay calm because you understand and do not accept the stigma. Actively listen and put yourself in the other person's place. Remember, that people stigmatize others because they feel there is danger.
2. Respond positively: Wait until the other person pauses; speak slowly, calmly, and with confidence. Acknowledge the other person's fear and uncertainty. For example, you can say: "HIV is scary and confusing and it is important to learn more about it. My loved one is not dangerous to be close to and will continue to live normally". You can remind the person of the Quranic teaching *((Men and women who are good Muslims must not stigmatize or ridicule others))*
3. Offer more information, if possible: if the person is not calm, you can leave the conversation. If the person is calm and you feel safe, you can offer more information about HIV; for example, you can tell him or her about the Saudi Charity Association for AIDS Patients and explain that there is accurate information about HIV at its website.

– Panel 6 – Central Concepts and Information Sources

Goal: The goal of panel six is to reiterate the most important concepts of the brochure and provide information about additional sources for confidential and reliable assistance related to HIV/AIDS in KSA

Although you may feel fear and confusion when you learn that your loved one has HIV/AIDS, you can support him or her by responding lovingly. Remember:

To respond to HIV/AIDS by following the Islamic principles

- Compassion not scorn
- Patience not judgment
- Humility not self-righteousness
- Justice not injustice
- Acceptance not looking down on others
- Knowledge not ignorance

To communicate compassionately with your loved one:

- Listen
- Understand
- Respond

To support your loved one by:

- Nurturing
- Listening

- Encouraging
- Accepting
- Being a companion

To avoid unsporting behaviors such as:

- Being judgmental
- Being over-protective
- Disclosing information about your loved one

To deal with stigma from others by:

- Staying calm
- Responding positively
- Offering more information, if possible

To find reliable and confidential sources to support your loved one visit:

- Saudi Charity Association for AIDS Patients
<http://www.saca.org.sa> [27].

HIV, AIDS, and Islam: A Workshop Manual Based on Compassion, Responsibility and Justice.

IX. CONCLUSION

In conclusion, significant stigma related to HIV/AIDS in KSA has negative physical and psychological effects for both the patients and their nuclear families. This project seeks to encourage supportive communication about the disease between PLWHIV/A and their family members and assist family members in understanding and mitigating the stigma of HIV and PLWHIV/A. Professional project will develop an educational brochure to encourage socially supportive communication between patients and their nuclear families. By introducing the concepts of SMC and strategies for encouraging positive social support communication, the beneficiaries will have resources to help them cope with difficulties of their situation.

APPENDIX A

Arabic-English Translation for HIV/AIDS brochure from King Saud Hospital containing information about counseling - distributed in 2008.



Fig. 2 Arabic HIV/AIDS brochure from King Saud Hospital containing information about counseling - distributed in 2008

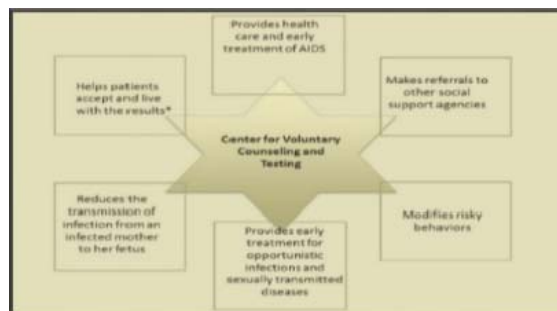


Fig. 3 English HIV/AIDS brochure from King Saud Hospital containing information about counseling - distributed in 2008

Voluntary Counseling and Testing: An Important Entry Point for HIV Prevention and Necessary Care.

Counseling and Voluntary Testing for AIDS as shown in Figs. 2 and 3.

- The Center for Voluntary Counseling and Testing does not only provide the possibility of laboratory test work for AIDS, but also focuses on counseling before and after the examination.
- When you visit, if you do not want to have the laboratory test, you can return again whenever you want.
- You can receive only advice and information; you don't have to be examined, unless you want to.
- We offer free information and the results of the test are strictly confidential. It is not necessary to provide any personal identification.
- We accept couples who desire to come together or individually:
 - Learn about AIDS: how it is transmitted and how to be protected from it
 - Learn about your current health status or your partner's
 - Learn to modify risky behaviors
 - Identify infection in pregnant women
 - Receive the necessary treatment

APPENDIX B

Arabic-English Translation for HIV/AIDS brochure from KSA Ministry of Health containing basic information about HIV/AIDS distributed in 2008.



Fig. 4 Arabic HIV/AIDS brochure from KSA Ministry of Health containing basic information about HIV/AIDS distributed in 2008

AIDS is transmitted to a healthy person in the following ways as shown in Fig. 4.

- Through unprotected sexual contact with a person with AIDS
- Through the use of sharp tools infected with HIV-contaminated blood, such as needles, tattoo tools, ear piercing tools, or through cupping tools (traditional Arabic therapeutic procedure where blood is drawn by vacuum from a cut in the skin)
- Through a mother infected with HIV to her child during pregnancy, childbirth, or breast-feeding.
- Through organ transplants contaminated by a person with AIDS to a healthy person

AIDS virus is NOT transmitted in the following ways:

- Through living together daily with an infected person with HIV at work, at school or through taking care of him
- Through the use of public facilities or transportation
- Through the use of toilets and swimming pools
- Through a person living with aids: by sharing a meal, visiting a hospital, or interacting socially
- Through insect bites or through pets
- Through the saliva from coughing or sneezing

How to recognize a person living with the AIDS virus?

- ❖ It is not possible to identify a person living with the AIDS virus by sight.
- ❖ In a number of cases, the patient does not know that he is living with the AIDS virus and it cannot be detected by sight but only by a test for Aids.
- ❖ A person can live with the AIDS virus for many years, and during that time, he can transmit the disease to others without showing any symptoms. He also could function normally in his work.
- ❖ At a certain stage of the AIDS virus, only when it breaks down the immune system, different types of symptoms appear on the patient.

Do not expect your partner to tell you that he is living with the AIDS virus!

- ❖ Most people living with the HIV virus are afraid of rejection, avoidance, anger, and stigma.
- ❖ Sometimes people living with the AIDS virus do not realize it at all.



Fig. 5 Arabic HIV/AIDS brochure from KSA Ministry of Health containing basic information about HIV/AIDS distributed in 2008

Protection from HIV infection is in your hands as shown in Fig. 6.



Fig. 6 Arabic-English Translation for HIV/AIDS brochure from Saudi Charity Association for AIDS Patients distributed in 2014

APPENDIX C



Fig. 7 Arabic-English Translation for HIV/AIDS brochure from KSA Ministry of Health containing basic information about HIV/AIDS distributed in 2008

From Fig. 7, Center for Voluntary Counseling and Testing Counseling is:

- A meaningful interaction focusing on a central issue in which the counselor offers the visitor time, care, and respect in order to discover and facilitate a better life.
- A confidential dialogue between the visitor and the counselor, in order to help him cope with the pressures and make personal decisions related to living with the HIV virus.
- A dialogue that leads to several options to make decisions and change your behavior for a better life.



Fig. 8 Brochure from New Jeddah Clinic Hospital about AIDS in the Workplace

AIDS in the Workplace (See Fig. 8).

Is it possible to safely share the workplace with an AIDS patient?

- YES! There is NO danger of transmission of the HIV virus from the majority of the work related tasks, and people living with HIV do not represent a danger to their co-workers or their social acquaintances.
- The AIDS virus is transmitted to adults mainly through contaminated blood or bodily fluids and secretions of the infected person's body to the non-infected person.
- Do not worry about being near to a person living with the HIV virus in the same office, factory, or even using the same phone or other workplace equipment.

APPENDIX D



Fig. 9 Brochure from Saddiqa Maternity & Children Hospital containing basic information about AIDS transmission-translated by hospital distributed in 2008

APPENDIX E

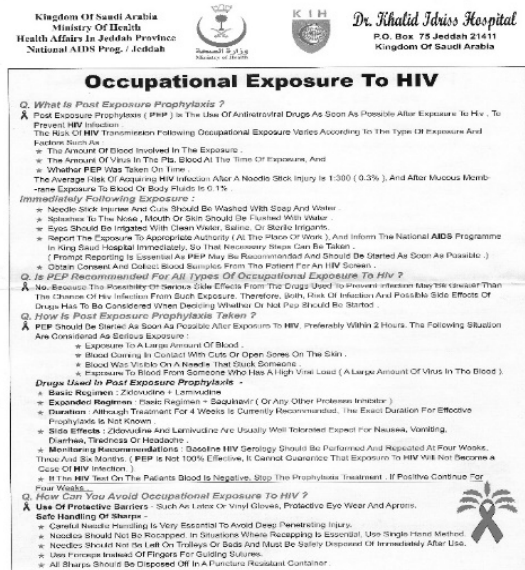


Fig. 10 Brochure from Khalid Idress Hospital containing information about Occupational strategy to HIV -translated by hospital distributed in 2008

APPENDIX F

Arabic-English Translation for HIV/AIDS brochure from Saudi Charity Association for Health Care Providers distributed in 2014.



Fig. 11 (a) Arabic HIV/AIDS brochure from Saudi Charity Association for Health Care Providers distributed in 2014



Fig. 11 (b) English HIV/AIDS brochure from Saudi Charity Association for Health Care Providers distributed in 2014

APPENDIX G

Arabic-English Translation for HIV/AIDS brochure from Saudi Charity Association for Media Producer -distributed in 2014.



Fig. 12 Arabic for HIV/AIDS brochure from Saudi Charity Association for Media Producer -distributed in 2014

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